

Individual Budgets for Families with Disabled Children - Scoping Study

Literature Review Report

Meera Prabhakar, Graham Thom, Jennifer Hurstfield
and Urvashi Parashar

SQW Consulting



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1: Introduction

Introduction to the literature review

- 1.1 The aim of the literature review was to draw together the existing national and international evidence on the effectiveness of Direct Payment and Individual Budget approaches for families with disabled children. The process of conducting the literature review comprised the following elements: establishing the analytical framework for the review; defining the key concepts and search terms; identifying the key sources for the literature search; deriving a template for reviewing the documents; and analysing the findings from the literature.
- 1.2 The analytical framework was derived from the key objectives and aims of the scoping study. We then took the key objectives and research questions and reviewed the literature under the following headings:
- Approaches and barriers to delivery
 - Funding
 - Demand
 - Added value.
- 1.3 Our sources included evaluations from the evaluations of Direct Payments, Budget Holding Lead Professional pilots, in Control pilots and the adult IB pilots. We also reviewed a wide range of other documents in academic journals, government-funded research in the UK and in other countries, and research published by independent research and policy organisations. This resulted in a review of over 100 UK documents and an additional 15 documents containing international evidence.

Report structure

- 1.4 The following report details the findings of the literature review which was carried out at the beginning of the scoping study. This report acts as a supporting document to the main scoping study report and is set out as follows:
- **Chapters 2-6: National literature review** – details the key findings from the national literature review and draws out implications for the research. The review is supplemented with information from the scoping consultations, where information was lacking.
 - **Chapter 7: International literature review** – sets out the findings from the short international literature review.

2: Literature review: Approaches to delivery

Approaches used to deliver IB and similar interventions at national or local level

- 2.1 The following chapter provides a brief description of the existing approaches being used to deliver IB and interventions of a similar nature. We have considered the following approaches: Direct Payments (DP), in Control pilot work, Dynamite and Taking Control pilots, Budget Holding Lead Professional pilots (BHLP) and the Early Support Programme (ESP).

Direct Payments

- 2.2 The Community Care (Direct Payments) Act 1996 established the right for people aged 18-65 assessed as requiring community care to receive direct payments in the form of cash payments in lieu of services provided directly by the local authorities. This initially provided access to direct payments for adults with physical disabilities, adult mental health service users, and adults with learning difficulties. The intention was that disabled people could arrange their own services, choose the type of support they wanted, and how it was to be delivered. The Carers and Disabled Children's Act 2000 extended direct payments to carers over 16, parents with responsibility for disabled children, and disabled young people aged 16 and 17. In 2003, following implementation of the Health and Social Care Act 2001 in England, Scotland and Northern Ireland (2004 in Wales), it became mandatory to make direct payments available to people with parental responsibility for disabled children, young people aged 16-17 years and older people.
- 2.3 Take up of direct payments has been slow particularly for mental health service users compared with people with a physical disability or sensory impairments. Take up rates are presented as the proportion of total numbers of community care service users receiving direct payments. In 2004-5, 6.2% of those with a physical disability received direct payments, compared with 4.7% with a sensory impairment, 3.6% with a learning disability, 0.7% of older people (65+), and 0.6% of mental health service users (Davey et al, 2007). However, as the PSSRU report on a UK-wide survey of direct payments pointed out, England has led the way in the promotion of direct payments compared with the other UK countries. Chapter three examines some of the ongoing barriers affecting take up of the direct payments scheme.

in-Control pilots

- 2.4 in Control was set up in 2003 as a partnership between central and local Government and the voluntary sector. It was formed to "help social care service departments fundamentally change their social care systems to increase the citizenship of disabled people through a system of Self-Directed Support (SDS)" (Poll C et al, 2006). The organisation initially supported six pilot local authorities¹ and focused on

¹ Essex, Gateshead, Redcar & Cleveland, South Gloucestershire, West Sussex and Wigan LAs.

the provision of personal budgets to small numbers of adults with complex cognitive disabilities. Personal budgets (PB) in this context were similar to the concept of individual budgets (IB) but were limited to the provision of social care services only.

- 2.5 The pilots sought to replace the existing care management arrangements with a 7-step process as set out in table 2-1:

Table 2-1: in Control 7-step process

In Control System	Description	Additional details
1. Set Personalised Budget	The person can find out how much money they are likely to be able to receive in a personalised budget	
2. Plan Support	The person can work out how they should use that money to meet their needs in a way that suits them best	Whenever possible, planning done by the individual and close allies, but where not possible, in Control suggests four additional kinds of help: Support brokers – independent source not involved in commissioned/providing support Support providers Care managers People in the community – individuals, family members and community organisations
3. Agree Plan	The person checks out their Assessment and Support Plan with the local authority or any other funding provider	For those individuals who require assistance, in Control advocates the use of an Agent to support them in managing their own plan – use of Agents is a vital part of SDS
4. Manage Personalised Budget	The person decides on the best way to manage their Personalised Budget	Identified the following ways to manage the budget: Through the user i.e. managed directly by the disabled person Representative – manages on person's behalf Trust – trust set up to act for the disabled person. Social services dept then contracts directly with the Trust and transfers funding into the Trust's bank account Broker – pay an individual or organisation to act as their broker, who controls the money on their behalf and can organise and coordinate services they want Service Provider – PB paid directly to the service provider who can manage their money through an Individual Service Fund – funding is restricted and must be spent on behalf of the disabled person. Any management fees must be set out and agreed in advance Care manager – acts for the person by planning and organising services for the individual in the same way that they act in the current system
5. Organise Support	The person organises the housing, help, equipment or other kinds of things they want	
6. Live life	The person uses support to live a full life with family and friends in their community	Some of the support arrangements available: personal assistance, community support, live-in support, community inclusion, housing, work, equipment and skills
7. Review and learn	The person along with the Care Manager checks how things are going and makes changes if	

In Control System	Description	Additional details
	needed	

Source: *in Control*, 2006

- 2.6 Step one of the in Control system has been facilitated by the 'Resource Allocation System' (RAS) which has been developed by the organisation. This system allocates each individual an indicative budget at the beginning of the process and is based on establishing a 'price-point', an amount which, when multiplied by the points scored on a self-assessment questionnaire, produce the individual's allocation.
- 2.7 The value per point is calculated on an area basis, where approximately 50-100 individuals who are currently accessing traditional services are identified and the current price of their existing care packages calculated. Each individual then completes an assessment, all answers are amalgamated to produce the total number of points and this total is divided by the total current price of the existing care packages of the group.
- 2.8 The in Control 7-step system has since been applied more widely to additional local authorities and to support the social care needs of all disabled adults, regardless of the type of disability. More in-depth information on the outcomes and results of the pilots are set out in the subsequent chapters.

Department of Health Individual Budget Pilot Programme

- 2.9 The IB Pilot Programme was set up by a partnership between the Department of Health, Communities and Local Government, The Department for Work and Pensions and the Office for Disability Issues following the Government's commitment to pilot the IB approach for older people and disabled adults (PM Strategy Unit, 2005).
- 2.10 Thirteen local authorities² took part in the Programme, which began in April 2006 and ended on the 31st of December 2007. A formal evaluation of the pilots has been carried out which had not been released at the time of drafting this report. However, interim information from the Care Services Improvement Partnership (CSIP), who supported the delivery of the pilots, was available and forms the basis of the following summary.
- 2.11 The basic model used by all 13 pilot sites was similar in nature to that of the in Control approach illustrated above. That is, it included a self-assessment which resulted in the provision of an indicative budget and an associated support plan, which was subject to review by the LA, following which the appropriate services were provided. The support plan was then reviewed periodically after completion.
- 2.12 The majority of pilot sites used some form of the in Control RAS, which they adapted to meet the needs of the relevant area, with the exception of one of the local authorities, who adapted an existing system.

² Pilot sites – Barking and Dagenham, Barnsley, Bath and North East Somerset, Coventry, Essex, Gateshead, Kingston and Chelsea, Leicester, Lincolnshire, Manchester, Norfolk, Oldham, West Sussex LAs

- 2.13 Funding allocations were mainly derived from social care budgets, with additional aligned monies sourced from the Access to Work Fund, Supporting People funding, Independent Living Fund, Disabled Facilities Grant and Integrated Community Services Equipment Services fund. However, it is important to note that the allocation of budgets differed between the pilot sites' as a result of the differing charging regimes enforced in each local authority. This aspect of the pilots is described in more detail in Chapter 5.

Dynamite and Taking Control pilots

- 2.14 The Dynamite and Taking Control pilots both form part of the suite of in Control activities which are specifically aimed at children and young people, where each programme is delivered as follows:
- **Dynamite** - sought to provide IBs for disabled children at transition stage (14-25yrs) to facilitate a seamless move from child-based to adult-based services. The Programme is being piloted to support eight or more young people and those closest to them in 12 local authorities³, has been set up to run for two years and is led by Paradigm⁴.
 - **Taking Control** - focuses on the provision of IBs to children with disabilities who are 0-18 yrs. This Programme of work was established in July 2007 and currently involves 15 local authority sites⁵, each of which are at differing stages of development.
- 2.15 Both programmes are run in largely the same fashion as the in Control adult model. However, the in Control RAS has been adapted from its original adult-based use to reflect the needs of families with disabled children, by basing it around the five Every Child Matters (ECM) outcomes. This adapted RAS has been used in all Taking Control pilots and a number of the Dynamite pilot sites and has meant that each family assesses itself against a set of questions associated with each of the five outcomes. Each question asks the family/child to assign itself to a category, where each category relates to a certain no of points. This assessment is conducted both on the basis of the child's needs – to give child points – and family needs – to give family points. Both sets of points are aggregated and the total assigned a monetary value (where one point=certain amount of money), giving the budget.
- 2.16 Anecdotal evidence indicates that the Dynamite pilots have had a significant impact on beneficiaries. For example, one of the pilots has been particularly successful at targeting young people from Black, Asian and Minority Ethnic (BAME) communities, who have found the IB approach more culturally sensitive. We were unable to source evaluation based evidence for the Programme for this report, but consulted a small

³ Dynamite sites include – Bradford, Ealing, Newcastle, Norfolk, North Tyneside, Northumberland, Redbridge Stoke-on-Trent, Surrey, Wandsworth LAs.

⁴ Paradigm is a consultancy which has primarily focused on providing supporting to individuals with learning difficulties. It was one of the founding members of the in-Control partnership, where originally, Simon Duffy (formerly Director of Paradigm) was seconded from Paradigm to in-Control.

⁵ Gloucestershire, Halton, Middlesborough, Northumberland, Sandwell, Staffordshire, Redbridge, Barnet, Newham, Leeds, Hull, Wakefield, Sheffield, Kirklees and Norfolk – where Gloucestershire was the first Taking Control site, which was set up in July 2007.

number of the pilot sites to gain an understanding of the workings and outcomes of the pilots. The results of this process are reported in the main scoping report.

- 2.17 The Taking Control pilots have not been subject to review or evaluation, as most of the pilots have not yet produced outcome results as they have not progressed beyond their developmental phase.

Budget Holding Lead Professional pilots

- 2.18 The Budget Holding Lead Professional (BHLP) pilots were established following the publication of Support for Parents: The Best Start for Children. The report set out a commitment to support the increased personalisation of services and described the need to test whether a BHLP approach could be implemented more widely.
- 2.19 Pilot activity was established in June 2006, ran until the end of March 2008 and was delivered in 16 DCSF funded local authorities and in one additional self-funded local authority⁶. The pilots sought to assess whether better service packages for core groups of children and families could be delivered by giving lead professionals a small budget with which to commission goods and services directly from providers⁷.
- 2.20 The pilots were targeted at children with additional needs i.e. a children or young person that is unlikely to achieve one or more of the five Every Child Matters (ECM) outcomes without additional help. Therefore the budget could not be used to purchase services for the target beneficiaries of this study i.e. children with more complex needs who required statutory intervention.
- 2.21 BHLP service provision is based around the Team Around the Child (TAC) model, which brings together a range of different practitioners to help and support an individual child. Official guidance⁸ provides the following additional detail:

“The model does not imply a multi-disciplinary team that is located together or who work together all the time; rather, it suggests a group of professionals working together only when needed to help one particular child. In this sense, the team can be described as a ‘virtual’ team; in practice, practitioners will find themselves working with a range of different colleagues at different times to support different children..... Team Around the Child places the emphasis firmly on the needs of the child, rather than on organisations or service providers”.

- 2.22 The BHLPS worked as follows:

- **Assessment:** The BHLPS worked with the child and their family to assess their needs using the Common Assessment Framework (CAF)/Initial Assessment (for social care).

⁶ DCSF funded BHLP pilots: Blackpool, Bournemouth, Brighton and Hove, Derbyshire, Devon, Gateshead, Gloucestershire (is the only pilot which specifically targeted disabled children, Hertfordshire, Knowsley, Leeds, Poole, Redbridge, Telford and Wrekin, Tower Hamlets, Trafford, and West Sussex. Coventry Local Authority self-funded their own BHLP pilot.

⁷ <http://www.everychildmatters.gov.uk/leadprofessional/budgetholding/>

⁸ <http://www.everychildmatters.gov.uk/deliveringservices/multiagencyworking/glossary/?asset=glossary&iid=22520>

- **Development of support plan:** The assessment process was followed by the development of a family support plan, which set out the support required (including social care, health and education) by the child and their family and in some cases identified the need for additional funding to assist the provision of the support package.
- **Costing and purchase of services:** The BHLIP identified what needed to be purchased and the proposed cost of the services/goods required, alongside the child and family. The BHLIP also worked with colleagues from their own and other local agencies (with the family) to identify where the services should be purchased from and to ensure value for money was achieved.
- **Review:** the BHLIP was responsible for reviewing the impact of the support package and adjusting the service provision where necessary.

- 2.23 It is important to note that the budget was sourced in its entirety from the DCSF funding provided for the pilots and could only be used to purchase new services/goods or services/goods that were not available as part of an existing local authority offer. For example, if a service was available from an local authority, but was not meeting the needs of the child (and family) quickly enough, the budget could be used to facilitate more speedy support. This provision of additional support led to the development of market provision either where local authority services were absent or where they were failing for efficiency reasons.
- 2.24 In April 2007, four of the BHLIP pilots took on an additional focus and also became part of the BHLIP Look After Children pilots. Similarly, in October 2007, seven of the existing BHLIP pilots became 'enhanced BHLIPs' (EBHLIPs), which essentially allowed the pilots to tailor the total targeted services budget that was typically spent on the child. This move from BHLIP to EBHLIP signals a move towards an IB approach, which requires further exploration.
- 2.25 The formal evaluation of the BHLIP pilots is due for release in Autumn 2008 and therefore the findings detailed in this report are based on interim findings.

Early Support Programme

- 2.26 The Early Support Programme (ESP) was established in 2003 to promote the implementation of Together from the Start and to facilitate better co-ordination of services for families with a young disabled child. The Programme is funded by the DCSF through the Sure Start Unit and was initially delivered through a set of pathfinders targeted at disabled children under the age of three.
- 2.27 There were 45 Early Support Pathfinder areas which ran over the course of two years, from 2004-2006, which promoted the following⁹:
- better joint assessment and planning processes for individual children and their families

⁹ <http://www.earlysupport.org.uk/modResourcesLibrary/HtmlRenderer/AboutES5.html>

- better co-ordination of service provision to families where many different agencies are involved
- better information for families
- the introduction and development of lead professional or key worker services to improve the continuity and co-ordination of support available to families
- better exchange of information about children and families between agencies and at points of transition
- joint review of multi-agency service provision and joint planning for service improvement at strategic level
- the development of family-held, standard material to monitor children's development which can be shared across agencies.

2.28 ESP provides a range of support products to families with young disabled children. For instance, the provision of information through the 'family pack', which informs parents about services to support them, helps families know what to expect by way of good service provision and what to ask for. The pack contains a background information folder containing booklets explaining health and social services and what these services should provide i.e. childcare, financial help (for example Disability Living Allowance) and information on education.

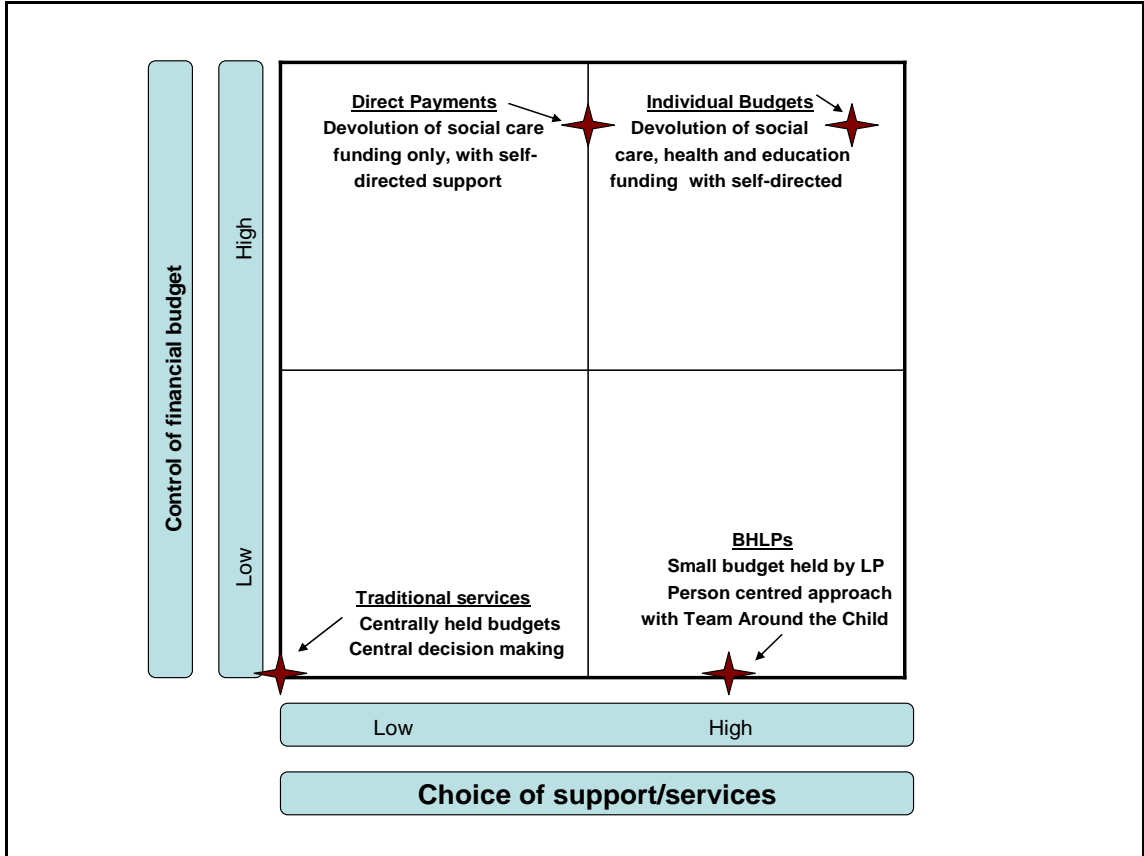
2.29 The Programme has since been extended to include all children under five, following the announcement of the Government's intention to roll-out the programme across the country.

Concluding statements

2.30 The initial review of existing approaches used to deliver IB and similar interventions at national or local level has illustrated a number of models of relevance for this study. Although the majority of these have not been targeted to support families with disabled children specifically, each approach forms a significant component of the existing choice-control spectrum of service provision and therefore is likely to provide useful insights for this study.

2.31 Figure 2-1 provides an illustration of the relative position of Direct Payments, IBs, BHLs and traditional services in relation to the levels of choice of support/services and of control of the associated financial budgets. It is clear that the move from the provision of traditional services to that of IBs will require the largest transformation, and therefore it is essential to draw on the lessons learnt from other approaches which have sought to devolve the choice and/or control of service provision.

Figure 2-1 : Choice/Control Spectrum



Source: SQW Consulting

3: Barriers to the effective delivery of individual budgets

Introduction

- 3.1 There is a growing body of evidence on the barriers to successful delivery of both Direct Payments and Individual Budgets approaches. The Direct Payments approach is longer established and there have been a number of studies seeking to identify the reasons for the low take up and the factors that impede or facilitate delivery of the scheme. Many of the factors highlighted in these studies are echoed in the emerging findings from the in Control and Individual Budgets pilots.

Direct payments

- 3.2 In 2006, the Wanless Review identified as a key barrier limiting the take up of Direct payments (DP), the administrative burden that tended to fall on users and their families. In particular the Review pointed to the lack of administrative support for older people to help them employ a care worker.
- 3.3 A detailed study of a DP Pilot targeted at families with disabled children in Swindon (Swindon Borough Council, 2006), highlighted the organisational barriers experienced by both service users and staff, particularly social workers. Although the pilot only involved eight families with disabled children who were receiving DPs, the in-depth qualitative responses are insightful. The findings are based on the responses from seven of the eight families, a questionnaire sent to social workers, and managers in the Disabled Children's team, and input from a parents' discussion group. The study identified the following barriers:
- **The assessment process** – staff found this difficult to understand. Social workers found it difficult to calculate the hourly rates, and parents were unclear how the amount of money they received was broken down.
 - **Delays in obtaining direct payments** – five families had to wait a significant amount of time before the pilot began and they were able to receive the services they needed.
 - **Lack of joined up working between agencies hindered access** – parents felt that information was not being openly shared between different agencies and this affected the extent to which they were able to manage their direct payments and arrange care.
- 3.4 Following the evaluation of the pilot, additional support for staff involved in assessments was provided in the form of guidance documents and training events. The difficulty in calculating the hourly rates led to the adoption of a new approach involving a “banding method of payment”. An audit of the current cost of directly provided services was conducted and levels of banding were set that corresponded to the cost of directly provided services for similar levels of need. The approach was discussed with the families before introduction.

3.5 Two factors were seen as facilitating successful delivery of the pilot. The first was the partnership between the Disabled Children's team and a representative from the West of England Centre for Inclusive Living (WECIL) who provided an advisory service on DPs to the recipients. The second was the involvement of service users in the planning of the service. The families met every six weeks to discuss any issues arising from the pilot and how it might be developed.

3.6 In 2007 a survey of all local authorities was carried out by PSSRU to examine the implementation of DPs. One questionnaire was sent to all local authorities in the UK and a second questionnaire to support organisations to people receiving DPs. The survey identified the three barriers that were mentioned by the highest proportion of local authority respondents as hindering progress in implementation. These were:

- Concern about managing DPs amongst service users and carers
- Staff resistance to DPs
- Difficulties regarding the supply of people to work as personal assistants.

These three factors were mentioned by around two-thirds of all local authorities in England.

3.7 The survey also identified seven factors that were mentioned by more than three-quarters of all local authority respondents in England as aiding the successful implementation of DPs:

- Effective DPs support scheme
- Training and support for front-line staff
- Leadership within the local authority
- Positive attitude to DPs staff
- National legislation, policy and guidance
- Accessible information on DPs for service users and carers
- Demand from service users and carers.

3.8 The study expressed concern about the considerable regional variation in implementation. There were differences across a range of issues, including levels of provision of one off DPs; the level of payment rates; and the involvement of support groups. Equally important was the variation in provision of DPs for different groups. The most significant level of provision was for people with a physical disability or sensory impairments, and the lowest provision was for people with a mental health problems. But this general pattern was also found to vary across local authorities. This variation, argues the report, "raises questions about the impact of devolved government on equity and social justice for people supported by social care services".

- 3.9 A small-scale study of the experiences of a particular group of users – deafblind people and their families – was published earlier this year (Sense, 2008). The research was conducted as part of Deafblind Direct, Sense’s Direct Payment’s project. Questionnaires were distributed to Sense members and their contacts, 20 users and 19 non-users to explore their views on any barriers to effective delivery.
- 3.10 One of the main barriers mentioned was that of insufficient funding to pay for specialist staff. One respondent stated that they were only given £6 per hour to pay for a carer for an epileptic deafblind child. When they complained to the manager that this hourly rate was too low, they were advised to reduce the number of carer hours if they wanted to pay more. The report points out that this conflicts with the Department of Health, DPs Guidance, which states “the Direct Payment should be sufficient to enable the recipient lawfully to secure a service of a standard that the council considers is reasonable to fulfil the needs for the service. There is no limit on the maximum or minimum amount of a direct payment either in the amount of care it is intended to purchase or on the value of the Direct Payment”.
- 3.11 According to the report, some deafblind people also required two support staff, and parents found that the DPs rate was insufficient to provide for this. However, some respondents had been successful in negotiating a higher rate by ensuring that the request was made for specialist skilled staff, e.g. BSL, or deafblind awareness training. For these staff, the going rate was around £25 per hour.
- 3.12 The ability to recruit and pay the appropriately skilled staff seemed to be one of the major barriers for respondents. In one case a respondent who had a negative experience using the Independent Living Fund, was reluctant to use DPs: “I found it very difficult to recruit suitable staff to work with my son using ILF”. This also highlights the way in which users of one scheme may be deterred from taking up other self-directed support schemes.
- 3.13 A further difficulty experienced by users was that of managing their funds when they came from more than one source. Respondents who used both DPs and ILF said that the two funding streams came from different sources and was sent to their bank accounts at different times and different intervals. This could make it hard to budget, ensure that invoices for services could be paid and that the bank account stayed in credit. Many users said that they did not feel they received enough support to help them with these problems.
- 3.14 In general, both small scale qualitative studies of users and the large scale survey of providers of DPs have highlighted many of the same issues. These include:
- A mismatch between the hourly rates used for Direct Payments, and the recruitment of suitably qualified staff to meet the needs of people with different disabilities
 - Concerns of service users about managing the financial aspects of Direct Payments
 - Variations in the level of support services for service users

- Staff difficulties in administering the system unless they received adequate training and support.

BHLP pilots

- 3.15 Given the problems managing DPs experienced by some service users, the BHLP pilots can be seen as one approach to addressing this barrier. The process by which the BHLP works with the family in the four stages of assessment, development of the support plan, costing and purchase of services and review of the support package (see Chapter 2) has the potential to overcome the difficulties associated with managing budgets for care for the first time.
- 3.16 As the full evaluation of the BHLP pilots will not be completed until Autumn 2008, the literature only presents emerging findings at this stage. Many of the studies have been conducted by the Office for Public Management (OPM), and the evaluation is being carried out by Newcastle University.
- 3.17 Much of the literature focuses on the slow process with which change can be expected. As an OPM paper (OPM, 2007i) pointed out:
- “One or two of the pilots are close to reaching the tipping point at which power effectively transfers to families and young people and the BHLP is acting as a broker for them – so that the system is beginning to be user-led rather than service-led. However this is an enormous shift in behaviour and culture and will take time to happen more widely.”*
- 3.18 Much of the reason for the slow base of change relates to the commissioning process. Where the BHLP process results in changing patterns of demand for services, this represents a challenge to existing service provision. There is some evidence that BHLP funds are being used to fund new contracts and spot purchase for new services provided through the voluntary sector and independent providers of services.
- 3.19 One of the initial limitations of the early BHLP pilots was the relatively small amount of funding available. Typically up to £3000 was allocated per child, with smaller amounts being the norm. The decision to change seven of the existing BHLP into ‘Enhanced BHLPs’ (EBHLPs) meant that they could now use the full budget that would normally be spent on targeted services for the child.
- 3.20 A report by OPM in October 2007 (OPM, 2007a), comparing BHLP with the approach involving individual budgets, states that the early BHLP pilots were characterised by interventions that were speedier and short term compared with individual budgets. The small cash budgets for BHLPs did not allow the reshaping of the total package of support. Nor did it provide the longer time span needed for service users to engage with the process and gain some control. The outcomes from the EBHLPs will explore the impact of removing the previous limit on budgets.
- 3.21 The OPM report also identified some other barriers to the effective implementation of the BHLP approach. These included:

- Some BHLPS had little experience in engaging children and families in planning and decision making. Therefore “in many cases engagement is nominal. Staff require training, supervision and continuing support to build up the necessary knowledge, skills and confidence.”
- Many BHLPS found co-ordination of the team around the child a major challenge. This points to the “need for a continuing system of management and supervision to enable effective collaborative working”.
- Some BHLPS did not make the amount of the available budget explicit to children and their families. This denied them the opportunities to consider the budget in relation to what services they were choosing. Sharing knowledge of the budget and thereby enabling greater user control is seen as a part of the EBHLP role.

3.22 Evidence from the scoping consultations indicated that the pilots had experienced difficulties in monitoring the adequacy and quality of service provision and expressed the need to develop an inspection framework to mitigate this issue.

DH Adult Individual Budgets pilots

3.23 At the time of writing, the findings from the evaluation of the DH Adult IB pilots were not published. However there are a number of studies of the in Control pilots and the early findings from the IB pilots which provide examples of the types of barriers to delivery. In addition, many of these studies point to factors which facilitate effective implementation.

3.24 A frequently cited barrier to the full implementation of the IB approach is the lack of integration of funding streams in the absence of legislative or rule changes. Alignment has been the only option for the most part. For example, it has proved difficult to integrate ILF funding into local authority Individual Budgets. ILF funding was designed to be independent and parallel to local authority funding and fully integrating this funding would involve the transfer of existing money to local authorities on the basis of current uptake (Waters and Duffy, July 2007). A major funding limitation on Individual Budgets is the DH decision that the development of Individual Budgets is to cover Social Care Services only and not be extended to NHS Services. The overlap between people who use both services is considerable: around two-fifths of those using Social Care are also using Community Health Services, and 18% are using Mental Health Services.

3.25 In June 2007, a summary of early findings from the adult IB pilots was prepared by the IBSEN team (Netten et.al, 2007) which identified other barriers to implementation:

- Some service users found the **self-assessment process confusing**, and thought there was insufficient information. Some also said they were uncertain over what they could use their Individual Budgets for.

- It was important for all service users to have easy **access to support such as free brokerage or professional advocates**. Without sufficient support it was particularly difficult for certain groups to engage with the IB process. These groups included people with complex support needs and without family support and older people who found it hard to make the change to a new process.
 - The pilots identified a **major training need for different categories of staff**. These included staff responsible for leading the assessment process; and brokers and personal assistants taking on a service co-ordination role. This required the commitment of local authorities to make the necessary level of investment in training.
 - There was **resistance to the introduction of training from some staff**, including some care managers, who saw the introduction of IBs as a potential threat to their role.
 - In some areas there was also a **problem of the supply of support staff**, including personal assistants. The availability and skills of these staff were seen as critical to the effectiveness with which the pilots were delivered. Most pilots were seeking to expand capacity by looking to the private and voluntary sectors, but that process would take time.
- 3.26 Other studies of the implementation of IBs have identified some of the same barriers. For example, the report by the Care Services Improvement Partnership (Routledge, 2007) found that pilot constraints, especially timescale constraints, had meant that it had not been feasible for pilots to fully develop brokerage support approaches. It was seen as crucial to overcome this barrier and explore a range of sources of support, including user-led organisations.
- 3.27 Two reports on in Control's second phase (Poll and Duffy eds., 2008), also identified the issue of supporting IB users to plan and arrange support. In the first report on adult IBs, the authors argue that there is potentially a conflict of roles if social workers and care managers are involved in developing the plans, and that what is required is the development of independent support brokerage to fulfil that role. They suggest that social workers and care managers should be involved in ensuring the soundness of the support plans rather than developing them. The report also questions how effective providers can be in delivering independent brokerage as there may be a conflict of interest.
- 3.28 The second report on the in Control programmes for children and young people – Dynamite and Taking Control – also highlighted the issue of access to independent support. It pointed out that within the children's sectors there were fewer support options and service providers and a large amount of in-house service provision. The report also went on to explore some of the successful support mechanisms which have been used to aid young people and their families, which included the following:

- Use of *Planning Live* – workshops to aid the support planning process which involved the young person, family and a range of paid supported who were going to help the young people and their families.
- To mitigate the risk of the support plan being directed to support the families' needs as opposed to the aspirations of the young person, each young person was given a practice budget of £200 at the outset of the process to enable the young person and their support network to work through the process of making a support plan.

Concluding statements

- 3.29 Our review of different approaches to delivering self-directed support indicates that some of the barriers associated with DPs have continued into the delivery of IB approaches. These include the difficulties facing some service users in engaging with the process and understanding, in particular, the process of financial management. All the reports stress the importance of independent support, but there continue to be an inadequate supply of trained staff to meet the demand from users. The reports highlight the need for an investment in training and support for staff to enable them to engage with approaches which radically challenge their previous ways of working with service users.
- 3.30 Table 3-1 provides a summary of emerging findings against the research questions set out in the analytical framework.

Table 3-1 Summary of emerging findings

Analytical framework question	Finding
<p>What are the legislative and organisational barriers to effective delivery of the existing approaches, which may be relevant to the target audience?</p> <p>What are the key risks to the existing approaches that may also be applicable to the target audience?</p>	<ul style="list-style-type: none"> • Commissioning of support services is relatively underdeveloped in many LAs • Shortage of Personal Assistants to provide IB services • Lack of existing infrastructure available to develop appropriate support brokerage • Safeguarding – difficulties in monitoring adequacy and quality of service provision, signalling a potential need to develop Inspection frameworks • Transformation of service provision requires significant cultural change - resistance amongst care staff to promote IB approach • Funding streams were aligned and not integrated - difficulties in aligning health monies into an IB due to legislative barriers • Legalities associated with IB are unclear and require expert advice e.g. need guidance on liability issues for individual practitioners • Training and support is required for all front-line staff • IB pilots require significant resource to set up their delivery/IT systems • Backroom support was essential e.g. provision of commissioning support role and accountants to support financial aspects <ul style="list-style-type: none"> ➢ Ensure links with finance departments • Commissioning process requires review – is block contracting appropriate? • Integrated working is a key component – team around the child • Need to recognise the differing starting points of each pilot site and the associated limitations of each area.

Analytical framework question	Finding
What potential approaches could be used to deliver IB for the target audience?	<p>It is clear that the IB for families with disabled children will include a set of options, which are likely to include the provision of notional (as in the BHLF pilots) and financial budgets to accommodate the differing needs and starting points of the individuals.</p> <p>Existing evidence is insufficient in this area – requires further exploration.</p>
Why have particular LAs chosen to adopt an IB type approach in general and for disabled children in particular?	<p>Absence of evidence to answer this question.</p>

Source: SQW Consulting

4: Literature review: Demand and added value

Demand for an individual budget type approach

- 4.1 We reviewed the literature to provide evidence on the question of the likely demand for an IB approach from families with disabled children. Some studies of the take up of direct payments (DPs) point to potential issues of unmet demand. But the most relevant data comes from the PwC review of the market for children's services (PwC, 2007).

Take up of DPs

- 4.2 A guide on DPs based on the experience of 13 local authorities in implementing DPs, found that some families who had not previously used direct services requested a DP (Carline and Lenehan, 2004). Among those who requested a DP were families dissatisfied with current provision, those who had been assessed to receive services but the local authorities had been unable to meet their needs. Unmet need was considered likely to arise from families from minority ethnic groups who found that DPs could provide more culturally specific services – e.g. carers from the same culture, or who spoke the same language as the family.
- 4.3 The PSSRU survey (Davey et al, 2007) found that the take up of DPs by disabled children was generally low compared to people with a physical disability or sensory impairment, but comparable to that by people with learning disabilities. In some regions the take up rate exceeds that of people with learning disabilities. The report comments that “this was unexpected given that parents of a disabled children (and disabled children aged 16-17) have been considered to be a highly marginalised group for whom access to direct payments was thought to be poor”. Local authorities attributed the growth in uptake to disabled children to their popularity amongst children in transition (16-17), but the overall numbers for 2004-2005 were still low: 492 aged 16-17, and 265 to parents/carers of disabled children.
- 4.4 More recent evidence from the CSCI (2008) has shown an increase in the numbers of disabled children aged 16 or 17 who are accessing DPs from 492 in March 2005 to 600 in March 2006. Similarly, the number of carers who have taken up a DP have taken up a DP has also increased from 2,265 in March 2005 to 4,200 in March 2006.
- 4.5 The PSSURU report (Davey et al, 2007) highlighted the difficulties with the statistics on the numbers of disabled children and does not attempt to assess the level of unmet demand for DPs from this group. It states that “comparison of the proportional uptake for disabled children (aged 16-17) and carers of a disabled child is inhibited by a lack of a definitive number of potentially eligible clients”.

Market for disabled children's services

- 4.6 The report by PwC (2007) for DCSF on the market for disabled children's services, is the most recent estimate of the number of disabled children in the UK. According to this report, the total number in 2005 of disabled children aged between 5 and 15 was 580,000. This is based on the number of children classified as having a limiting longstanding illness or disability as self-reported in the General Household Survey. This number increases to 690,000 if children below the age of five are included.
- 4.7 The best indication of potential demand for IBs for families with disabled children comes from PwC's analysis of unmet demand for services. Despite increased funding, the report highlights evidence that:
- Parents often want additional services for their children over and above those provided
 - Many parents are unable to afford the additional services they want for their child themselves, and those who can have difficulty accessing services to purchase them
 - Waiting lists for certain services, including short breaks
 - Shortages of services such as SEN specialists (particularly for children with Autistic Spectrum Disorders (ASD)) and therapeutic care.
- 4.8 The report also makes an assessment of the extent to which the disabled children's service market is currently suitable to be considered for the introduction of individual budgets. This analysis is based on assumptions about the level of unmet demand and likely increased demand for certain services, and changes in the mix of services requested.
- 4.9 One of the services for which there is anticipated to be increased demand, is that of short break schemes to provide carers with a break from caring¹⁰. In the case studies conducted by PwC, these schemes were cited by parents and representative bodies as one of the most requested services for disabled children. The assessment of unmet demand is based on evidence that there are currently more than 3,500 children on waiting lists, according to the Shared Care Network. PwC also suggests that there may be additional families who want these services but have not been added to waiting lists yet. In 2006, around 10,000 disabled children received the service – a small proportion of the estimated 690,000 disabled children in the UK. The report argues that there will need to be improvements in the supply of short breaks and that is unlikely to come from larger providers but from small independent companies.

¹⁰ Please note that the Government has made a significant commitment to the provision of Short Breaks, through both the Aiming High for Disabled Children Strategy and the Children and Young People's Plan.

4.10 The overall conclusion is that “few markets are currently suitable for the introduction of individual budgets”. The full analysis is set out in the table below:

Table 4-1: Illustrative Market suitability for individuals budgets

Service	Structure	Proportion non public provision	Barriers to entry	Current suitability for IBs	Sources
Special schools	<ul style="list-style-type: none"> 1,105 Special Schools in England in 2006 93% of which are maintained 	Low	Med-High	Low	DfES
Provision of additional support in schools	<ul style="list-style-type: none"> 47,540 SEN support staff in maintained schools (mainstream and special) in 2006 	Low-Med	N/A	Low	DfES
Provision of additional tutoring	<ul style="list-style-type: none"> The market for private out of school tuition is highly fragmented with some providers offering services for SEN pupils. Provision is most commonly from individuals looking for additional income; often employed in the teaching profession or studying 	High	Low	High	PwC analysis
Extended school activities	<ul style="list-style-type: none"> c.2,500 schools were able to offer full hours provision of one sort or another by the end of 2006 Target for all schools to offer provision by 2010 Provision by school staff as opposed to outside providers varies by school, however for the most part, holidays and weekend activities are facilitated by a higher proportion of non school staff. 	Med	Low	Med	DfES, BMRB
Short breaks	<ul style="list-style-type: none"> Small market: 7,800 carers, 188 schemes (UK) 78% run by local authorities, 22% by Voluntary organisations 	Low-Med	Low-Med	Med	Shared Care Network
Childcare provision	<ul style="list-style-type: none"> 108,000 childcare providers offering care to both disabled and nondisabled children Wide range of providers and services available Little formal market structure for childminders Informal care is common for disabled children 	High	Low-Med	Med-High	Ofsted Quarterly Childcare Statistics
Home to school transport	<ul style="list-style-type: none"> 74% of pupils travel to and from school on contracted vehicles⁶⁹, however the relative mix of different transport methods varies between local authorities. Large and fragmented private subcontractor base 	High	Low	High	Audit Commission, DfT
Equipment	<ul style="list-style-type: none"> The market for equipment provision appears to be fully developed. Equipment for disabled children is primarily manufactured and provided by private sector companies Provided by local authorities education services / PCT / Social Services depending on type of need and equipment Parents can buy equipment directly from the providers (or through wholesale or retail channels) 	High	Med	High	Keynote, SPRU

Service	Structure	Proportion non public provision	Barriers to entry	Current suitability for IBs	Sources
Play, sports, leisure, Half term opportunities and cultural activities	<ul style="list-style-type: none"> 74,300 sports facilities (UK) c. 320 Youth Services (excluding leisure) Mix of voluntary, private and local authorities provision Third sector providers (community groups and voluntary) provided approximately 56% of services with public provision (local authorities and statutory) providing almost a 3rd. Private sector providers provide approximately 16% of the total 	High	Low-Med	Med-High	Sports England, DfES, various associations, SureStart & Regional Partnerships
Therapeutic Care Services	<ul style="list-style-type: none"> 27,000 Occupational Therapists, 40,000 Physiotherapists and 11,000 Speech and Language Therapists registered in the UK Predominantly provided by the NHS, with increased private sector therapists 	Low	Low	Med	Health Professionals Councils
Residential care homes	<ul style="list-style-type: none"> c. 4,800 beds registered for disabled children c. 640 homes split between private (50%), local authorities (36%), voluntary (13%) and other ownership 	High	Med-High	Low-Med	CSCI, Disabled Children in Residential Placements

Source: PWC (2007)

4.11 The report identifies four main barriers to future market development:

- Commissioners are not incentivised to encourage diverse provision
- Markets can be too small to be contestable
- Funding arrangements are complex
- Poor signposting of information and support for parents.

4.12 To address these barriers the report contains four recommendations:

- Encouraging diverse provision by ensuring costs are compared in a fair and transparent way across different types of providers
- Encouraging local authorities to develop more targeted commissioning, and to consider commissioning on a regional basis with other local authorities
- Simplifying funding to facilitate improved cross departmental working
- Improving information provision and ensuring key workers/lead professionals are impartial and have sufficient training and support.

Added value associated with IBs

4.13 In Chapter 3, we examined the literature on the barriers to delivering Direct Payments, BHLPS and IB pilots. In this section we examine the evidence on the added value associated with these approaches.

- 4.14 Evaluations of the in Control pilots have provided indicative evidence of positive outcomes for service users. It must be emphasised, however, that none of these studies is based on large numbers of respondents. An early study (Poll et al, 2006) was based on only 60 people with the most complex needs in six local authorities. This found improved satisfaction levels for the people who used the services increased from 48% to 100%. It also found that there was an increased use of personalised and community support, while the use of residential care was reduced by 100%. The responses also indicated that the majority had been able to make the changes they wanted over the course of one year. For example 89% had made a change in who supported them.
- 4.15 A small-scale study of early Individual Budget recipients was carried out by IBSEN team (Netten et al, 2007). In October 2006, 14 interviews were conducted in the four pilot sites. Individuals with a range of disabilities were included. However, seven of the 14 interviewees were waiting for their IBs to be signed off and were not yet in receipt of them. Insights from the interviews included positive views about the potential for IBs to improve the long-term quality of life by offering more choice and control, rather than just focussing on routine personal care. It was also found that in general IBs were seen as more flexible than other forms of support and able to meet fluctuating needs. IBs were also viewed as easier to manage than Direct Payments.
- 4.16 The most recent evidence on the experience of adults taking up self-directed support comes from the evaluation of in Control's Phase Two work (Poll and Duffy, 2008). The evaluation was based on data from 196 adults, aged 18-95 in 17 local authorities. Over half the respondents had learning difficulties and around one-fifth had physical disabilities. Over two-thirds (70%) had been using some form of social care support before taking up self-directed support.
- 4.17 The study asked people whether eight aspects of the lives had improved, stayed the same or got worse since using self-directed support. These eight aspects were:
- Better health and well-being
 - Spending time with people you like
 - Improved quality of life
 - Taking part in community life
 - Feeling safer and more secure at home
 - Choice and control
 - Personal dignity
 - Economic well-being.

- 4.18 The proportion responding positively to each aspect varied considerably. On the question of choice and control, nearly three quarters (72%) said that had more choice and control over their lives, with 27% reporting no change, and 1% stating that things had got worse. People with learning disabilities and people with physical disabilities were more likely to report improvements in choice and control than were older people. Amongst people with learning disabilities, respondents were more likely to report improvements if they were supported by a wider range of people. Within the group of older people, those who reported improvements were more likely to be supported in the planning process by a social worker.
- 4.19 More than three quarters (77%) said their quality of life had improved, with 22% reporting no change and 1% that things had got worse. Three-fifths (59%) said that they had more personal dignity since starting on self-directed support, with 41% reporting no change. On some of the other aspects including economic well-being and better health and well-being, smaller proportions reported an improvement (47% and 36% respectively). But only 5% felt that their lives had got worse in any respect.
- 4.20 Almost all (97%) reported that they had control over how their personal budgets were spent, and the vast majority (91%) said that they understood what they were supposed to be achieving with their personal budget.
- 4.21 Although these surveys cannot be seen as representative, they do indicate that the majority of users of self-directed support, experience positive outcomes to some extent. However, it is also clear that for others there may be less change, and that older people may be less likely to report improvements.

Concluding statements

- 4.22 There is relatively little evidence from which to draw firm conclusions about the potential demand for IBs from families with disabled children. However, the study by PwC suggests that for some services the current level of unmet demand for disabled children's service is high and that few markets are in a current state of readiness to meet that demand, should IBs be extended. The research on service users' responses to IBs also suggests that the positive outcomes experienced by a high proportion of users may encourage take up by the target population of families with disabled children.
- 4.23 Table 4-2 provides a summary of the emerging findings against each of the relevant research questions.

Table 4-2 Summary of emerging findings

Analytical framework question	Finding
How large is the potential target population of disabled children and their families?	<ul style="list-style-type: none"> Estimate in PwC report of 580,000 disabled children in the UK in 2005. Total of 690,000 including children below five. Inherent difficulties in estimating the target population, given the lack of consistent statistical data.
What is the extent and nature of unmet need for the target group?	No precise figures, but evidence in the PwC report of unmet demand – e.g. from interviews with parents, and waiting lists for some services
Is the IB approach more appropriate for specific sub-groups?	No evidence that it is <i>unsuitable</i> for any one group. However, in the Hatton evaluation older people were less likely to state that they had experienced improvements in their lives since using IBs, compared with other respondents.
What is the demand for different IB models in general?	Not possible to answer on basis of current evidence
What types of services would the target audience like to access as part of the potential IB package?	The PwC provides some data on areas where evidence of unmet demand by families with disabled children and likely to be requested as part of an IB package, such as short break schemes.
What does existing evidence tell us about the added value IB can bring to current practice?	The evidence from IB service users points to perceived improvements in satisfaction with services, and suggests that aspects of users' lives including choice and control and personal dignity improved for the majority.

Source: SQW Consulting

5: Literature review: Funding

Main funding streams currently used for individual budgets

- 5.1 Individual Budgets (IBs) to date have brought together a number of funding streams, largely from the local authority Social Care budget and have enabled people holding these budgets to choose from a variety of funding mechanisms including direct payments, brokerage arrangements or directly commissioned services, (Davey et al, 2007). Local Authorities currently spend approximately £19 billion on Social Care Services for children and adults in England (Waters and Duffy, 2007).
- 5.2 One of the most difficult challenges facing Social Service Departments is the successful implementation of IBs and Self-Directed Support due to their complex nature and associated change requirements i.e. cultural and process changes. For example, the 2007 in Control report states the following in relation to Social Service Departments:
- “Every aspect of the organisation and its relationship with other agencies will need to be redesigned to meet the demands of Self-Directed Support. In this context, seeking to integrate diverse funding streams at the same time, especially, where they are located in other organisations or in central government itself, is akin to taking a very difficult problem and purposefully complicating it further”.*
- 5.3 The IB Pilot Programme, operated across the full spectrum of individuals with disabilities and identified six funding streams which could be brought together to form an IB. Table 5-1 illustrates the six income streams, where each was subject to its own legal structure and policy guidance.

Table 5-1: Individual Budget Income Streams

Income Stream	Approximate Government spend per year	Coverage
Local Authority Social Care budget	£19 billion	Money which is spent by social services in areas such as: day centres; residential care; supported living; social work and meals on wheels.
Supporting People (SP)	£1.69 billion	Money spent on housing related support, assisting in improvements to independent living; developing life skills.
Independent Living Fund (ILF)	£0.22 billion	Money spent on personal care and helping disabled people live in the community
Disabled Facilities Grant (DFG)	£0.121 billion	Money spent on housing adaptations, such as: stair lifts; ramps
Access to Work (AtW)	£0.06 billion	Money spent on adaptations in the workplace and can bear up to 100% of the cost of adjustments to help disabled people take-up or retain work.
Integrated Community Equipment Service (ICES)	£0.052 billion	Money spent on the purchase of equipment e.g.: raised toilet seat; hand rails

Waters and Duffy (2007)

- 5.4 The Social Care budget is the largest in size and in comparison to all the other funding streams, can be used fairly flexibly, whilst the other streams come with more constraints. It is also important to note that the adult IB pilots were stated to have been limited in their nature as it had not been possible to integrate income streams in the absence of legislative or rule changes – therefore alignment had been largely all that was possible. (Routledge, 2007).
- 5.5 Funding streams which may be used for children and young people's IBs:
- Up to 16 yrs – Children Social Care, Child Health, Local Authority Education budget (e.g. Special Educational Needs budget).
 - 16-19 yrs – Children and Adult Social Care, Children and Adult Health, Local Authority Education and LSC 16+
 - Over 18/19 – Adult Social Care, Adult Health, LSC 19+.

Other potential funding streams for IBs

Education

- 5.6 One possibility is that Individual Budgets offer a way in which decisions about inclusive versus special education could be resolved. If statements for children led to the allocation of budgets that were to support 'Special Educational Need' then families could have more control over whether to use their budgets in Special or mainstream schools or to explore innovative forms of home-community schooling. Another example of how this budget could be used is to implement a 'buddy' system, whereby the child could take a buddy to school to support them and facilitate more effective integration in school activities.
- 5.7 Given that schools already operate a 'per pupil' funding system this would not disrupt the current funding systems for schools.

Health

- 5.8 "The Department of Health has set out clearly its decision that the development of IBs is not to be expanded directly into NHS services:

"It has been suggested that we should extend the principle of Individual Budgets and direct payments to the NHS. We do not propose to do so, since believe this would compromise the founding principle of the NHS that care should be free at the point of need. Social Care operates on a different basis and has always included means-testing and the principles of self and co-payment for services." (DH, 2006)

- 5.9 However, the overlap between people who use Social Care services and those who use the NHS is very significant. Waters and Duffy (2007) state that of those currently using Social Care, 42% are also using Community Health services and 18% are using Mental Health services. This has been seen by some advocate of IBs as

pointing to the need for change and interconnectivity between these two funding streams.

- 5.10 An IB approach could be applied to funds currently held within the NHS for groups who are not served by a Local Authority Social Care system, but who do have long term conditions leading to on-going needs. Work has been undertaken to empower patients with long-term conditions to manage their own needs. The Expert Patient Programme currently offers around 12,000 course places a year, offering a practical means of further increasing control and control and choice.

Pooling with health

- 5.11 Section 31 of the Health Act 1999 makes provision for increased flexibility of functions between the NHS and Local Authorities. It allows a range of functions from one partner to be delegated to another, allowing Local Authorities to take on duties of providing and arranging Health services, and the NHS to take on Local Authority powers in a range of areas. Partners can create a pooled budget from which to fund these functions, which is 'hosted' by one organisation. The 'host' organisation takes on management of the budget.
- 5.12 A number of local authorities have already used Health Act flexibilities to establish pooled budgets. Under such circumstances a Local Authority led Resource Allocation System would appear to offer a functional means of individualising funding, currently held within the NHS. NHS provided services for people with learning disabilities and mental health problems would be apparent areas for consideration.
- 5.13 This is a formal high level agreement which needs to be signed off at the highest levels as it transfers some of the accountabilities of partners. As noted in the DfES guidance: "*Where a package of care is funded from the pool, there would be no differentiation or isolation according to the source of usual responsibility for cost*"¹¹.
- 5.14 In addition to pooled budgets, other flexibilities provided for in the Act include:
- Lead commissioning – one partner coordinates two separate budgets to undertake commissioning that meets jointly agreed aims;
 - Integrated provisions – one partner manages services and staff on behalf of both partners.

Grant making between health and local authority

- 5.15 In addition to creating pooled funds, the NHS and Local Authorities are able to make grants to each other where it is felt that the use of funds would be of greater value than if the equivalent sum was spent on its own duties. Section 28A of the NHS Act 1977 enables PCTs to make payments to Local Authorities in respect of securing additional Local Authority services. Section 28BB of the Health Act 1999 introduced a similar power for Local Authorities to make payments to the NHS, (OPM, 2007e)

¹¹ Better outcomes through joint funding: A best practice guide, Draft, HM Government, 2007, page 18

Housing

- 5.16 Individual Budgets for housing are currently restricted to people seeking private sector rentals. A wider system would allow much more choice and control of the individual's housing. The benefit of using housing monies for individuals receiving social care would be advantageous as housing is often critical to effective support. A more flexible approach could encourage people to seek environments that make support easier and more efficient. For instance, arranging adaptations to a parent's house so that regular renal dialysis can take place at home, minimising disruption to child care; a health funded accident prevention service providing stair gates and other safety aids; and placing a homeless young person in a flat in an area in which they already have a supportive social network.

A framework for delivery of IB Funding Streams

- 5.17 In order to co-ordinate the different funding streams, it is crucial to ensure there is a clear framework in place for the development and delivery of Individual Budgets. The in Control report (2007) stated that this would be in accordance with the existing system of Self-Directed Support. The report expected successful funding integration to deliver:

- **Transparency** - Any assessment processes should be amalgamated. Information about the Individual Budget and any personal financial contribution should all be provided at the same time.
- **Flexibility** - Funds should be used flexibly, irrespective of the funding source.
- **Fairness** - Funds should be sufficient to support the needs of the individual, equitable and any means testing should be reasonable and consistent.
- **Easy to Use** - A universal and flexible framework of support which allows individuals to manage their budget as they deem appropriate.
- **Outcomes-focus** – A single monitoring system should be in place to ensure that competing systems do not exist.

Similar approaches and how they operate

- 5.18 **Taking Control** – in Control's programme for children and young people – aimed at 0-18 year olds. Exploring education, LSC and health monies funding streams used, (Poll and Duffy (eds), 2008)
- 5.19 **in Control pilots** - Valuing People Support Team and Mencap provided £60,000 each to set up pilots, and each pilot contributed £20,000 of their own funding (Poll et al, 2006)
- 5.20 **BHLP** – IBs enable the money that would be spent on the total social care package, and some other funds, to be turned into cash. Until the launching of the 'established BHLP' pilots, BHLP typically made available only small amounts of cash and did not take into account the total cost of the package of targeted care being supplied. People using IBs focus on identifying outcomes and then using the total budget to

achieve them. In the BHLF pilots the objective has been to achieve outcomes through making better and more flexible use of existing services and supplementing or replacing some of them with new services as far as the budget allows. The aim of the 'established BHLF' pilots is to extend the focus on outcomes but in the process of action planning take into account the potential to reallocate total budgets (Miller and Smyth, 2006).

- 5.21 To date, BHLF funds have mostly been used to 'top up' budgets and fill gaps in service provision. The children and young people served by BHLF currently use a combination of education and broadly defined family support and advice services, which are funded from a range of sources. Some also use additional health services (in addition to GP and acute services), mostly for mental health problems, supporting people services (for homeless young people) and YOT services (Miller and Smyth, 2006).
- 5.22 **Direct Payments** – Funding streams include the Local Authority Social Care Funding and the Independent Living Fund. Legislation introduced in 2003 required English local authorities to offer DPs to all social care users, prompting the release of a £9 million Direct Payments Development Fund (DPDF) from the Department of Health. This was intended to help increase the number of people taking up a DP offer; expand the role of the community and voluntary sector; and encourage interaction with local authorities in implementing direct payments. These funds were allocated to around 90 different partnerships of local authorities and voluntary agencies in England.

Pooled budgets/integration/alignment/ring fenced/devolutionary budgets

Pooling with other partners

- 5.23 Section 10 of the Children Act places a duty on each Children's Services Authority to promote cooperation between the Authority and its relevant partners and enables Children's Services Authorities to establish pooled budgets with any relevant partners.
- 5.24 The pooled fund allows partners to contribute differing sums of money, which are then spent towards a commonly agreed plan.
- 5.25 The Act widens the range of partners between whom such arrangements can be made, to include: Councils (Unitary, County, District), Police Authority, Local Probation Board, Youth Offending Team, Strategic Health Authority, Primary Care Trust and Learning and Skills Council

Gaps in knowledge

- 5.26 We have reviewed some of the issues surrounding the integration of the various funding streams. At present, the IB pilots are very small and there is a real risk that the complexity of integrating money from bodies governed by very different legal and accountability structures will not be a simple process, and may not be considered to be worth the effort. The bigger picture would involve a genuine transformation of the whole system. Of course, the amount of money involved in such a scenario is both a major opportunity and a significant barrier to further progress (Glasby and Duffy, 2007).
- 5.27 Ibsen (Routledge, 2007) examined this issue and found that funding streams were more likely to be incorporated where there were good relationships between social care and other funding streams/agencies and where staff had experience of working with other agencies. Some pilots wanted to try and include all funding streams from the outset, avoiding the need to integrate them at a later stage and having to revise the RAS to reflect a revised price per point. Funding streams were also included if pilots could not see any reason for non-inclusion of them. If integration and IB is the way forward they did not feel it made sense to introduce piecemeal change (Routledge, 2007).

Concluding statements

- 5.28 The issue of funding streams for IBs is proving to be one of the most difficult in terms of implementation. As discussed above, the IB pilots have drawn on six different income streams, each with its own legal structure and regulations. Currently IBs cannot draw on health service funding streams, except to a limited extent where pooled budgets are established. The proposed extension of IBs to families with disabled children opens up the potential for other sources of funding from education to be included along with social care. The issue of integration of funds from a wide range of sources will become even more complex in the case of IBs for this group.

Table 5-2 Summary of emerging findings

Analytical framework question	Finding
What set of income streams are applicable to the target audience, which could form part of the IB package?	<ul style="list-style-type: none"> • Social care budget • Integrated Community Equipment Services budget • Disabilities Facilities Grant • Aligned or pooled health budgets – although it is unclear which health budgets have been pooled at present • Carer's Grant – short break and emergency respite care • Education budget – over and above universal provision e.g. Special Educational Needs budget
What budgets did the existing pilots draw upon in their delivery?	Social Care budget, Supporting People, Independent Living Fund, Disabled Facilities Grant, Access to Work, Integrated Community Equipment Service
Specifically with regard to health, how and which budgets have been pooled to facilitate an IB type approach?	Little evidence but might involve e.g. health funding streams being used for short breaks, equipment and wheelchairs

Analytical framework question	Finding
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What are the potential service related implications associated with an IB approach?	No current evidence
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Source: SQW Consulting

6: Literature review: Financial and other costs

The evidence base

- 6.1 SQW's review of the costs and benefits of independent living (SQW, 2007) suggested that the evidence on costs associated with personalised approaches was relatively rich, albeit a majority related to older people and disabled adults. Moreover, given that nearly 42% of the social care budget is spent on residential provision and day and domiciliary care (Leadbetter et al, 2008), with nearly 70% for adults with learning disabilities, it is perhaps not surprising that much of the economic analysis of costs is also focused on accommodation arrangements for different client groups, mainly those with learning disabilities. The evidence is mostly presented with the intent of providing a comparison between the costs of providing conventional support services and those providing personalised or self-directed support services, couched within a focus on assessing cost-effectiveness.
- 6.2 However, our review of the literature suggests that there is limited evidence on costs and evaluation of children's services, and even less for disabled children and their families. Nevertheless, there has been some recent effort at collating and analysing data on children's services, with the conduct of the first Children in Need (CiN) survey in 2001, with subsequent surveys in 2003 and 2005. The survey provides a snapshot of characteristics, service use, need and support costs of children in 144 local authorities in a typical survey week. The 2001 CiN survey has been analysed to understand the patterns and reasons for cost variations in services for children.
- 6.3 The PSSRU's Unit Costs of Health and Social Care is an annual publication that provides costings, with the most recent (2006) publication providing cost data of services for children and their families, including costings of local authority community homes, costings for children in care ranging from no additional need to those with disabilities, foster care offered by local authorities. Costs typically include unit costs of services as well as costs of health and social care staff, incorporating both overhead and capital costs.
- 6.4 The cost methodology used by PSSRU has also been adopted in developing the Cost Calculator for Children's Services (CCfCS) after research conducted to understand the relationship between costs and outcomes of looked after children. The tool is intended to assist local authorities to cost placements and all other associated support offered to looked after children.
- 6.5 More recently, the Department's own pilot comprising Budget Holding Lead Professionals (BHLP) offering services to families with children that have additional needs has begun to develop a methodology for costing BHLP services (OPM, 2007d). This comprises a five staged approach – time spent by professionals on the case on referrals, assessment and intervention, costs incurred purchasing goods and new services with BHLP funds, time spent by professionals in partner agencies co-ordinated by the BHLP, costs of other goods and services used as a result of co-

ordination by BHLF, and potential 'opportunity' costs incurred in the absence of BHLF.

- 6.6 There is very limited data and evidence on the costs associated with delivering self-directed support and interventions that come closest to comparing with individual budgets for disabled children, namely, in Control Pilots, Direct Payments and Individual Budgets for disabled adults. Some of the costs of direct payments are included in the PSSRU Unit Costs of Health and Social Care publication but they tend to be more applicable for adults and older people. The only source of evidence for costs in delivering individual budgets is an interim evaluation of the pilots published in 2007. There is some cost data that was collated with regard to the delivery of In Control Pilots but they were based on 10 local authorities and 128 individuals only.
- 6.7 Besides these, there have been some, albeit few, academic studies that were conducted with the intention of exploring the extent and nature of costs in delivering children's services, and in some cases, with particular regard to disabled children's services. The findings from such literature are summarised below, along with the evidence on cost implications in delivering interventions that share individual budget principles.

Emerging findings

- 6.8 Ibsen (Netten et al, 2007) presented emerging findings from progress made by the 13 Individual Budget Pilots and reported that the mean costs of *setting up IB* in the first year was £270,000, of which
- Average cost of systems development was £43,000
 - Average cost of workforce development was £13,000 per site
 - Av cost of support planning and brokerage was £50,000 per site
- 6.9 Salaries of the implementation team made up the bulk of the remaining costs.
- 6.10 Demos (Leadbetter et al, 2008) compared the costs and effectiveness of self-directed service models with traditional care models, and reported in-depth calculations of *costs of care packages* of 102 individuals that had moved from a traditional care plan to a personal budget. The average cost of a care package per user in a Local Authority under a personal budget amounted to £26, 621 (10 per cent less than traditional services). This was mainly due to a shift in care planning from traditional to personal budgeting. The study also indicates that a significant part of the saving could be due to reduced administrative overheads under a personal budget plan.
- 6.11 A BHLF case study (OPM, 2007d) reported that the costs of delivering an 8 month intervention could range from £6768 to £16868, depending on the complexity of need and circumstances. Note that these costs do not include any capital or set up costs.
- 6.12 In terms of *disaggregating* these financial costs further into estimating the typical costs involved in the delivery of services to disabled children, evidence points to the

importance and significance of key workers¹² and costs associated with using them in delivering services effectively. Greco et al (2005) conducted a UK wide Care Coordination Network UK (CCNUK) survey to estimate the costs of providing key worker services for disabled children and their families. Their study aimed to use data from the seven key worker services studied in depth to explore these costs further by looking at the cost implications of how children and their families use these services and any associations between costs and needs or use of other services.

- 6.13 The study adopted a twin approach to cost estimation – a *service level view* that provides data helpful to planners who may want to develop this service or who want to know about existing services, and a *user level view* that allows service managers to look at how the resources within a team are used and for example how front line workers allocate their time in response to need or whether higher costs generate greater satisfaction.
- 6.14 The CCNUK survey asked for annual expenditure for a set of standardised cost categories:
- care staff salaries and on-costs
 - manager salaries and on-costs
 - clerical/domestic salaries and on-costs
 - service costs (such as staff or user travel, expenses)
 - building costs
 - rent or capital charges
 - overhead costs or charges to the managing agency
 - charges made to the scheme for services and other costs
- 6.15 Information on service outputs were also requested to allow assessment of units of measurement and how to quantify them.

¹² A key worker is a named person whom the family can approach for advice about, and practical help with, any problem related to the disabled child. Provision of key workers or care coordinators for disabled children and their families working across health, education and social services, has often been recommended in policy guidance. Research has shown that less than a third of families with severely disabled children have a key worker, but compared to those who do not, those who do show benefits in terms of relationships with and access to services and quality of life (Greco, et al, 2005)

Table 6-1: CCNUK report costing information

Typology of costs	Description	Additional cost information/data
Service level costs – costs of providing key worker services		
Key worker	Average cost per family per year was between £1300 - £2000 for 7 teams For 5 services, they were £2300 - £3000.	Number of caseloads varied between 16 and 60. The schemes led from within the health sector tended to have higher costs per family. The final scheme was very expensive but this is likely because of a residential component, possibly respite care. Note that costs associated with the Steering Group set up to oversee each team were excluded from this estimate.
Cost of attendance at Steering Group	Additional £3000 per scheme per year	
User level costs		
Cost per working hour for each service	Ranged from £24 to £42	
Mean cost of key worker (face to face and telephone) contact (based on number of visits and number of families)	£151	Considerable variation around this mean; assuming the level of contact is constant for 12 months, the average annual costs would be £700, 38% of the average cost per family across the 12 schemes Contact to activity ration of 1:2.6 Costs varied within each service as well.

- 6.16 The largest component of the BHP costs (OPM, 2007d) was the time spent by professionals in referrals, assessment and intervention, ranging from approximately £3000 to £11,500.
- 6.17 Ward et al (2004) conducted research to explore how variations in the costs of placing children in the care of local authorities can be best understood.¹³ The study found that the process of *maintaining placement accounted for between 92-96 per cent of the costs*. Variations in costs between local authorities reflected differences in the percentage of months spent in each placement type, and in agency foster care and out of area placements. Frequent changes in placements were costly. One authority had made significant investments in process one (decision to admit and find placement) and achieved cost reductions in other processes; its children were looked after for the shortest periods, it had the lowest number of case orders, it made little use of agency or out of area placements, it had one of the highest percentages of children placed with own parents and fewer changes of placement than any other authority.

¹³ The authors conducted a retrospective longitudinal study to explore the background, needs and experiences of a population of 600 children looked after by three matched pairs of local authorities between the two CIN census dates of Feb 2000 and October 2001. The sample was restricted to children aged ten years and over and was weighted to include disproportionate numbers of children with disabilities and/or in residential units in order to provide sufficient data for meaningful analysis. Eight processes that support the case management of looked after children were costed and unit costs were calculated using this data, together with information on salary and placement fees. The evidence from the study was intended to be used to develop the Cost Calculator for Children's Services mentioned earlier in the section.

- 6.18 Table 6-2 shows the unit costs for the eight social care processes for the pilot authority compared with the standardised costs for an inner London authority and an authority outside London.

	Pilot Authority (2004-05)	Standard London (2004-05)*	Standard Outside London (2004-05)*
1. Decide to look after/find first placement	£735	£776	£597
2. Care planning	£208	£152	£112
3. Maintaining placement (per month)	£2,071	£2,392	£1,578
4. Exit from care	£287	£336	£246
5. Find later placement	£526	£250	£191
6. Review	£444	£477	£381
7. Legal (care order)	£2,852	£3,349	£2,582
8. Transition to leaving care	£851	£1,486	£1,087

Source: Ward et al (2004)

* The 2000-01 costs calculated as part of the earlier study have been inflated using PSSRU pay and prices inflators to 2003-04 (the latest year for which they are available) and the Treasury GDP deflator to 2004-05. The inflation over the period was estimated at 17.5%.

- 6.19 A Swindon study (Swindon Borough Council, 2006) that examined that effectiveness of piloting Direct Payments for disabled children and their families found that weekly costs varied considerably from £18.50 to over £54.00. This was partly attributable to the fact that children with a wide range of age and impairments were included. 75% of DP recipients had initially used a variety of services provided directly by the Disabled Children's Team and indirectly by voluntary agencies. These generally ceased once DP began, although parents indicated there was still a need for directly provided services, including the potential for additional respite care. It was also emphasised that alternative services should not be excluded once DP were being used to employ a personal carer.

Typology of costs	Description	Additional cost information/data
£8.50 p/h between 7am-6pm	Hourly rates funded by DPs	Amount of money provided has to cover the cost of:
£10 p/h unsociable hours eg. 6pm-7am, Sundays/Bank Hols		Recruitment; holiday pay; sick leave; insurance; training, and legal employment of a suitably qualified person. Service purchased must be of an equivalent standard to that of the Council. i.e suitably qualified and experienced people.
£15 p/h Agency		
£35 sleep in 10pm-7am		

Source: Swindon Borough Council, 2006

Drivers of cost variations

- 6.20 The SQW review for ODI (SQW, 2007) revealed that costs tended to be driven by types of settings, types of care, impairment type and extent of severity. The overall pattern of social care costs for children appears to be somewhat similar to those for adults and older people; 40% of social services expenditure is on placements for looked after children (Beecham and Sinclair, 2007). This has been a consistent trend in recent years, potentially due to the policy and delivery focus on spending significant proportions of money on relatively small numbers of looked after children, and driven by the substantial costs of residential placements. The cost data collated in the Children in Need survey (2001) suggested that:
- for children receiving support in the survey week, at a mean cost per child per week of £450, looked after children were four times as costly than those living independently or being cared for at home (£110 per week mean, £51 median)
 - these are average costs for care packages provided by social services to 50,000 looked after children and 128,000 supported children
 - around two thirds of the total social services expenditure was spent on looked after children
- 6.21 This needs to be borne in mind when costing delivery of services under individual budgets, as it is likely that a significant proportion of social care budget continues to be devoted to disabled looked after children.
- 6.22 Beecham and Sinclair (2007b) also indicated that there were specific reasons for cost variations in offering services to disabled children:
- Resource prices and fiscal pressure – this refers to amounts that social services have to pay for resources such as staffing
 - Service outputs – services on offer, such as number of places, and whether a residential home has a school attached
 - User characteristics and need – age, gender, type and severity of disability and problems faced by children and their families
 - User outcomes
 - Rate of service delivery
 - Type of sector that manages the services, i.e. public, private or voluntary sector
 - Quality of care management
 - Geographic location – cost of services in London are significantly higher than the rest of the UK, and there may be other regional variations, mainly due to resource costs.

- 6.23 The CIN (2001) analysis found that children supported in their families had higher support costs when they lived in a London authority, belonged to a low income family or had absent parents, where the children were older or babies, and if they were named in the Child Protection Register, receiving post adoption support or seeking asylum.
- 6.24 One of the studies reviewed by Beecham and Sinclair (2007b) adopted a different approach and found that cost per annum rose with increasing complexity of children's support needs. Costs rose for children with disabilities (£62,000 pa compared to children with no needs £27,000 p a) and much higher for those with complex needs.
- 6.25 Ward et al (2004) found that only a fifth of the variation in costs with regard to looked after children could be explained with higher levels of disability in the child and provision of a broader set of activities. These are logical findings as one would expect higher needs and higher quality of service to be associated with higher costs. If a service had parents involved in the Steering Group, this reduced costs.
- 6.26 They too found that costs increased with complexity of need; there were substantial differences in the average cost in each of the groups and mean costs increased as needs got more complex. Children who followed the least costly pathways had the best chances for developing and securing relationships with adults and peers. Children with costly pathways were also more likely to be moved around between placements, stay in units with high turnover of staff and stay further away from home, all contributing to a lesser probability of developing and sustaining relationships.

Table 6-4 : Pilot Authority Summary costs incurred by all children looked after during the financial year 2004-05 by needs group

Need	No of children	Total cost (£)	Total weeks	Average cost per week (£)	Weeks per child
None	66	1118732.19	2135	524.00	32.35
Disab only	13	567916.01	497	1143.67	38.20
EBD only	41	1605640.46	1710	938.81	41.71
UAS only	13	396606.87	475	834.21	36.57
Offend only	3	90454.57	103	880.64	34.24
Disab + EBD	5	310454.77	222	1398.44	44.40
Disab + offend	0	0.00	0	0.00	0.00
EBD + offend	11	763776.46	381	2004.66	34.64
EBD + UAS	2	143190.92	59	2438.77	29.36
Disab + EBD + Offend	0	0.00	0		
Disab + UAS + EBD	0	0.00	0		
All need groups	154	4996772.26	5582	895.20	36.24

Source: Ward et al (2004)

- 6.27 A rare school based study to estimate the costs and outcomes for children with moderate learning difficulties in special and mainstream schools (Crowther et al, 1998) grouped pupils according to the range of learning difficulty, from milder (Type A); to more severe (Type B). Additional criteria reflected behavioural (Type C) and sensory/medical characteristics (Type D).
- 6.28 The study found that costs of pupils of the same type can vary considerably from school to school. For instance, the cost of Type B pupils varied from £1700 to £9700, whilst for Type A+C costs varied from £2300 to £10000.
- 6.29 Special school costs were consistently higher than costs for similar pupils in mainstream schools. For Type A, in particular, average special school costs were 80% higher than average mainstream costs (£3900 to £7200). Similarly, the average costs in mainstream schools with units, though lower overall than special school costs, were higher for every type than in mainstream schools in the same phase without units.
- 6.30 In broad terms, pupils with more severe needs received more resources. However, this is not always the case. In a number of schools, for instance, Type A pupils attracted higher costs than their Type B counterparts whose learning difficulties are greater.

Opportunity costs

- 6.31 The study on the costs and benefits of independent living (SQW, 2007) highlighted the significance of acknowledging the opportunity costs of delivering as well as receiving self-directed support.
- 6.32 Indeed, Pickard (2004) points towards 'hidden costs' that relate to both public expenditure and private or individual expenditure, including costs to the NHS incurred by carers, costs to the DWP arising from increased social security benefits and pensions paid to carers, and lost income to Inland Revenue from the lower employment rates of carers. These costs include the opportunity costs of caring, that is, alternatives foregone by the carer as a result of taking on a caring role, such as employment opportunities and leisure.

Table 6-5: Opportunity and hidden costs

Typology of costs	Description
Replacement costs of informal care	<p>Institute of Actuaries (Nuttall et al, 1994) valued cost for GB in 1994 at £33.9 billion a year. This figure was based on the number of hours of informal care and an estimate of cost of providing informal care at the market rate of £7 per hour.</p> <p>Carers UK (2002) estimated this at £57 billion.</p> <p>Using a different methodology (replacing informal care with costed formal statutory care) that assumed that a client cared for by an informal carer for 20 to 40 hrs a week would be replaced by home care 15 to 20 hours of week costing £120 per week. Clients cared for more than 40 hrs would cost £250 per week. Using this method, Laing and Buisson (2000) estimated the cost to be £21 billion in 1999.</p>
Opportunity costs	<p>Joshi (1995) - £15000 a year for a woman in her fifties, amounting to £75,000 in total until retirement; for a man it would be £85,000</p>

Source: Pickard (2004)

- 6.33 Some of these costs get enhanced when they apply to families with disabled children; Meyers (Meyers et al, 1997) made a distinction between private costs of care such as deterioration in the quality of family life, reduced self esteem and psychological dependence for children, social isolation, family grief and anxiety and other financial costs that includes the direct costs of care (medical expenses, hospitalisation etc) and indirect costs of care (loss of productive output for caregiver, other opportunity costs).
- 6.34 The study, based on US evidence, found that:
- direct out of pocket expenditure for children's special needs become more frequent as the number and severity of children's conditions increased, with probability increasing from 39% of those with single, mild to moderately disabled child to 57% of those with multiple and severely disabled children
 - Indirect costs through reduced earned income also increased with extra caregiving responsibilities; unemployment was significantly higher (79 to 83% compared to 61% of mothers with no disabled children and 62% of mothers with single, mild or moderately disabled child)
 - Although families with disabled children were more likely to receive benefits from public programs, they trended to fare worse on other forms of hardship. Family income, adjusted for family size, did not differ significantly with the level of extra care giving responsibility. However, families with greater care responsibilities suffered more disadvantage on several indicators (see table below).
- 6.35 There are several studies that point to the specific needs and barriers faced by disabled children and their families (SQW, 2006) which only highlight the significance of acknowledging these costs alongside any financial costs of implementing individual budgets.
- 6.36 Kestenbaum (1999) analysed the cost and other implications of the Independent Living Fund via consultations with stakeholders, analysis of administrative data and contacts with disabled people, and found potentially higher costs of providing independent living support, related to several factors such as:
- Living alone with little or no informal care, having moved from a residential home to an adapted property
 - A worsening condition, and specific needs at home according to the impairment
 - Rural isolation that pushes up travel costs
 - The requirement for specialist/highly trained assistants for special conditions, and sometimes 24 hour supervision for those with complex behavioural problems
- 6.37 The Wanless Review (2006) also highlighted a potential shift of costs of delivering Direct Payments from services to families and individuals.

Concluding statements

- 6.38 The review of the evidence on costs involved in delivering IB and similar interventions is relatively sparse and varied. This is because research on costing children's services is limited, and this becomes more of an issue when it comes to disabled children's services.
- 6.39 Nevertheless, the evidence does suggest that service delivery models are beginning to be set up in ways that will enable robust costings to be derived; recent examples are the cost calculator for looked after children and the cost models being developed for Budget Holding Lead Professionals.
- 6.40 The evidence also indicates that delivery of IB will not necessarily entail costs that are wholly 'additional'; the principles underlying IB indicate a more effective (and sometimes cost-effective) way of delivery achieved through greater multi-agency co-ordination and closer engagement with the target group. Hence, while children's social workers may still be required, the development and use of key workers, personal assistants and lead professionals will become increasingly important. It will therefore be important to acknowledge and cost this element.
- 6.41 Other significant costs appear to be: support planning costs, costs of setting up systems, costs of co-ordination and partnerships with multiple agencies, although the evidence from the literature is limited on these types of costs.
- 6.42 The review strongly indicates that costs are far from uniform; they are driven by a number of factors such as user characteristics, complexity of need and resource costs such as costs of maintaining placement and staffing.
- 6.43 Finally, evidence suggests that costs of delivery need to be contextualised with the associated opportunity costs, i.e. opportunities foregone as a result of the intervention in question. These typically include costs to families and informal carers as well as wider exchequer costs in the form of lost tax revenue.

Table 6-6: Summary of emerging findings

Analytical framework question	Finding
What are the associated costs of delivery of the different funding streams?	Evidence mostly relates to social services expenditure and costs; Significant costs of placement and residential services, especially for looked after children
Do they differ by sub-group/type of disability etc?	Other costs include personnel costs such as key workers and lead professionals Costs tend to differ by user group – higher for those with complex needs, those cared for in placements away from families,
What were the delivery and opportunity costs of the existing pilots (and of activity of a similar nature)?	Evidence on set up costs only; Significant costs for systems development and support planning and brokerage

Source: SQW Consulting

7: International literature review

Introduction

- 7.1 The national literature review was supplemented by a brief assessment of relevant international activity. This analysis was limited to the exploration of innovative practice and did not consider approaches in detail, as it was felt that the varying policy frameworks within which the approaches were based was too far removed from that of the national context.

Key findings

- 7.2 The international literature tends towards a positive attitude of the idea of individualised budgets, linking them to increases in consumer satisfaction, self esteem and empowerment (SCIE, 2007b). The literature contains limited information about the cost effectiveness of schemes, relative quality of services, equity (*ibid*) and the pooling of budgets at the level of the individual (SCIE, 2007a).
- 7.3 Table 7-1 outlines information on the social care systems in developed countries across the world and highlights particularly innovative and successful aspects of projects developed. Projects vary along a number of dimensions including, social welfare philosophy, funding sources, eligible group and objectives (SCIE, 2007a).

Table 7-1: Summary of key findings

Country	Current projects	Innovative ideas
Australia	<p>The Local Area Coordination and Direct Consumer Funding programme initially aimed to increase the self sufficiency of people with intellectual disabilities with the goal of eventually including people with physical disabilities. Funding was provided to users through either a tied or an untied route; “untied funding was designated for ‘one-off’ funding needs, were modest, and often used in an emergency, at the coordinators’ discretion. Tied funding was normally for larger amounts and required individuals and families to submit a detailed plan” (Lord and Hutchinson, 2003). The programme separates planning and services through the use of local area coordinators. Local coordinators assisted consumers in building support networks (<i>ibid</i>). Direct funding was the first choice when given a series of options (<i>ibid</i>).</p> <p>Spall et al (2005) found that service users were critical of individualised funding for the following reasons:</p> <ul style="list-style-type: none"> • They have experienced inadequate service supply and service cutbacks. • The personal benefits expected have not been delivered and the outcomes expected by policy makers have not been achieved. • An absence of competition between service providers undermined the provision of choice and decision making processes around service funding are likely to become increasingly fraught. • Formulas used to calculate budgets do not account for individual and local variance. • Consumers and agencies faced high transaction costs which led to cuts in service delivery and an increase in copayment. 	<p>The flexibility of schemes enabled ethnic minorities to access more culturally appropriate services (SCIE, 2007b).</p> <p>Separation of planning and services through the use of local area coordinators.</p>

Country	Current projects	Innovative ideas
Austria	The consumer directed home care programme for the elderly results in the payment of the 'Pflegegeld', a benefit paid to those in need of long term care, based on a medical needs assessment categorised seven different levels (Tilly et al, 2000, Da Roit et al, 2007). There are no restrictions on the use of the cash benefits provided and use is not monitored. The benefits are paid for all age levels without means testing and recipients can determine how they are spent (Cuellar et al, 2000). Funds can be used to co-fund residential care and in these cases allowances are paid directly to the residence management (Da Roit et al, 2007). It is possible to pay relatives and there is a high level of dependency on informal care givers (Cuellar et al, 2000), resulting in high levels of satisfaction with care and high take up of personal budgets (Ungerson, 2004). However, the use of undocumented 'grey' labour can lead to care workers feeling trapped and a focus upon experience rather than expertise (<i>ibid</i>). A recent development has been the increasing level of employment of immigrant workers (Da Roit et al, 2007).	High level of satisfaction through dependence on informal care givers.
Canada	Disability support schemes initially focussed on children and young people (SCIE, 2007a). The Individualised Quality of Life Project provided funding to individuals and assistance through 'community resource facilitators' enabling requirements to be identified on an individualised basis (Roeher Institute, 2000), adopting a person centred approach (Lord and Hutchinson, 2003). The project successfully increased the self determination of consumers, increased their level of community participation and substantially improved access to need supports (Roeher Institute, 2000). Recruitment and development of support workers was challenging, particularly as low wages resulted in high turnover (<i>ibid</i>). The introduction of a coordinator role assisted in taking the management role away from families (<i>ibid</i>).	The use of a coordinator role was useful in removing the complex staff planning requirements from family members (Roeher Institute, 2000). The separation of planning from services through a brokerage role enabled greater accountability to individuals and families (Lord and Hutchinson, 2003). Parents of young people and children with disabilities have been influential in the development of schemes (SCIE, 2007a).
France	France operates a credentialised social care system where care workers are qualified but often cannot give holistic care; care users frequently feel rushed (Ungerson, 2004). This system potentially leads to a higher quality of care (<i>ibid</i>) and is linked to the creation of jobs in the service sector (Da Roit et al, 2007). Consumer directed programmes dominate in elderly care, the majority of cash benefits must be used to pay workers but it is possible to pay relatives (Cuellar et al, 2000). The 'allocation personalisee d'autonomie' for the elderly can only be used to fund a package identified by professionals (Da Roit et al, 2007). France does not offer management support (SCIE, 2007a).	Use of tax deductions to encourage the use of registered domestic workers (Da Roit et al, 2007).
Germany	Germany operates a social insurance scheme based on the notion of citizenship; assistance is available to all and does not take into account individual circumstances (Glendinning, 2007). A single set of eligibility criteria at the national level enable extensive cost control mechanisms to ensure financial stability and ensure a high level of horizontal equity (<i>ibid</i>). Despite being lower in value, cash benefits have been more popular than in-kind options and are available to all. Private co-payments and use of social assistance are increasingly common to make up shortfalls in funding. Consumer directed programmes dominate in elderly care with no restrictions on the use of cash benefits. It is possible to pay relatives and there is a high level of dependency on informal care givers (Tilly et al, 2000).	Protection of the financial health of the scheme through the use of 'extensive cost-containment mechanisms' (SCIE, 2007a). A single set of eligibility criteria at the national level. The budget can be ring fenced and protected from pressures. Political sustainability as a result of central government's key role. (Glendinning, 2007)
Italy	The 'indennita do accompagnamento' system provides a national cash allowance that dependent elderly people with 100% disability and a requirement for continuous care can use as they wish (Da Roit et al, 2007). Problems include the differences in interpretations of eligibility criteria used by local commissions (<i>ibid</i>). The use of foreign undocumented 'grey' labour can cause communications problems and result in a focus on experience rather than expertise (Ungerson, 2004).	

Country	Current projects	Innovative ideas
The Netherlands	In the social care system, agency directed programmes dominate in elderly care and it is possible to pay relatives (Tilly et al, 2000). The role of the family is seen as important and the 'modern' way of ensuring solidarity (SCIE, 2007a).	The role of the family in care.
Sweden	Development of individual budgets initially focussed on adults with physical disabilities (SCIE, 2007a). The risk of low paid personal assistants encouraging an informal care market has been addressed by forming an interest group giving a quality stamp to those registered (SCIE, 2007b). Expenditure on personal assistance reform has increased dramatically, to the extent that they will overshadow the country's defence budget; 14 187 people are entitled to assistance at a cost of approximately 1.5 billion Euros.	Interest group to give quality stamp for qualified carers to encourage the use of registered workers. Provides a possible future source of ideas on how to reduce spending.
USA	Within the social care system, agency directed programmes dominate in elderly care (Tilly et al, 2000). The use of fiscal agents to pay workers enables users to hire and fire staff easily (<i>ibid</i>). It is possible to pay relatives, however, in California family workers were found to suffer more emotional stress than agency workers and they also undertook more unpaid work (<i>ibid</i>). The New Hampshire Self-determination Project uses an action learning stakeholder approach focussing on collaborative problem solving and communication skills (Lord and Hutchinson, 2003). Fiscal intermediaries assist people in managing their budgets (<i>ibid</i>). Analysis by the US National Council on Disability (2004) found that the type and severity of disability did not determine individual preferences for funding. It highlighted the importance of a central government coordination role and the establishment of a contact centre for programmes.	Parents of young people and children with disabilities have been influential in the development of schemes (SCIE, 2007a). The use of fiscal intermediaries to assist in budget management.

Source: Various

- 7.4 Across programmes Tilly et al (2000) found that take up of direct payments was related to personality and personal circumstances; those with assertive personalities and strong support networks were more likely to choose consumer directed options. Strong support networks and organisations of disabled people promoted take up (SCIE, 2007a). Programmes that safeguard self determination and are linked to a local support strategy and organisations of disabled people were found to be most popular (*ibid*).
- 7.5 Simple, user-friendly schemes were preferred by users and in more complex schemes the role of 'brokers' was important (SCIE, 2007a). Concern was raised around the transfer of management burden to consumers, particularly with relation to recruiting staff, and in the lack of quality assurance mechanisms (Tilly et al, 2000).
- 7.6 Da Roit et al (2007) note that the link between care and employment is important; care can be used as a mechanism to increase employment opportunities in the service industry and can also impact upon the development of a 'grey' market characterised by cheaper wages.
- 7.7 The use of relatives as care givers was found to expand the labour pool (Tilly et al, 2000). SCIE (2007a) found that personal assistants were key to the success of most schemes and therefore clarifying their role, qualifications, skills, employment conditions, training and pay was important.
- 7.8 Lord and Hutchinson (2003) identified a series of common factors across projects:
- values and principles mattered

- the policy framework was important in providing coherence and equity
- the facilitator-broker role differed from case management
- the allocation of funds was designed to be equitable and accountable to the funder and the individual
- a 'learn as you go' philosophy maximised the achievement of positive outcomes.

7.9 It is essential to note that “elements of international research cannot always inform UK policy because of differences in funding, eligibility and overall social welfare policy and philosophy” (SCIE, 2007b). For instance, there are noticeable differences in the rationale and objectives for schemes that must be taken into account (*ibid*).

Concluding statements

7.10 The international literature highlights the following relevant lessons for the scoping study:

- The increased flexibility of IB type schemes relative to the provision of traditional services has in some cases created access to more culturally appropriate services which may appeal to individuals from BAME communities.
- There is a need to separate the provision of support planning and service provision through the use of independent support brokerage.
 - Use of a co-ordinator role was useful in removing the complex staff planning requirements from family members.
- IBs must be complemented by the development and re-shaping of the provider market to ensure the adequate supply of services.
- Must ensure the provider market remains competitive competition to avoid undermining the provision of choice and decision making processes .
- Formulas used to calculate budgets must account for individual and local variance.
- Funding of informal care i.e. funding provided by informal carers like family members, has proved popular.
- Parents of young people and children with disabilities should be consulted and involved in the development of schemes.
- Eligibility criteria will need to be considered in detail if the pilots are rolled out nationally – for example, eligibility criteria in Germany is based on criteria which is applied consistently throughout the country.
 - Need to avoid confusion which may be caused by local eligibility criteria.

- Issue of emergence of low paid personal assistants can be addressed by awarding a quality stamp to those who are registered, which will also encourage the take-up of these workers.

Annex A: Glossary of acronyms

AHDC – Aiming High for Disabled Children

BAME – Black and Minority Ethnic

BHLP – Budget Holding Lead Professionals

CAF – Common Assessment Framework

CCNUK – Care Coordination Network UK

CDC – Council for Disabled Children

CiN – Children in Need

CSIP – Care Services Improvement Partnership

DCSF – Department for Children, Schools and Families

DDA – Disability Discrimination Act

DFG – Disabled Facilities Grant

DP – Direct Payment

EBHLP – Established Budget Holding Lead Professionals

ECM – Every Child Matters

EHRC – Equalities and human Rights Commission

ESP – Early Support Programme

IB – Individual Budgets

IBSEN – Individual Budgets Evaluation Network

ICES – Integrated Community Equipment Service

ILF – Independent Living Fund

LA – Local Authority

ODI – Office for Disability Issues

OPM – The Office of Public Management

PB- Personal Budgets

PCT – Primary Care Trust

PSSRU – Personal Social Services Research Unit

RAS – Resource Allocation System

RNID – Royal National Institute for Deaf People

SDS – Self-Directed Support

SEN – Special Educational Needs

SQW – SQW Consulting

TAC – Team Around the Child

ToR – Terms of Reference

YOT – Youth Offending Team

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