

Individual Budgets for Families with Disabled Children

Scoping Study

Meera Prabhakar, Graham Thom, Jennifer Hurstfield
and Urvashi Parashar

SQW Consulting



Research Report No
DCSF-RR057

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The views expressed in this report are the authors' and do not necessarily reflect those of the Department for Children, Schools and Families.

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ISBN 978 1 84775 257 4

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Acknowledgements

The authors would like to thank Carol Lynagh and Chris Bestwick from the Department for Children, Schools and Families, who acted as the project manager and advisor respectively. We would also like to thank Christine Lenehan, Director of the Council for Disabled Children and Lynne James-Jenkinson, the Director of the North West Training and Development Team, for their support throughout the research. Finally we extend our thanks to all the Local Authorities and stakeholders who took part in the research and in doing so, provided a wealth of information on their experiences of existing IB provision and interventions of a similar nature (please refer to Annex G for a complete list of consultees).

Authors

Graham Thom, an Associate Director at SQW Consulting, acted as the Project Director of the Scoping Study.

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Gerry Zarb from the Equalities and Human Rights Commission acted as an expert advisor to the SQW research team.

Executive Summary

Introduction

1. As part of Aiming High for Disabled Children (AHDC), the Department for Children, Schools and Families (DCSF) has commissioned SQW Consulting (SQW), supported by Gerry Zarb from the Equalities and Human Rights Commission (EHRC), to undertake a scoping study prior to the piloting of Individual Budgets (IB) for families with disabled children. The primary purpose of the scoping study was to inform the development of the IB pilot programme.
2. A multi-method, iterative approach was adopted to ensure we built a comprehensive understanding of existing evidence on the effectiveness of IB and interventions of a similar nature for families with disabled children. The approach included a review of literature, and consultation with a range of stakeholders, local authorities and families with disabled children. This resulted in the research team consulting a total of 102 individuals. The evidence gathered was used to answer a series of questions highlighted in the analytical framework developed for the study.

Approaches to delivery

Direct Payments

3. 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. 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.
4. Evidence from the local authorities consulted indicates that the take-up by children and families of direct payments has been increasing, albeit from a low base. This upswing has been in part stimulated by additional support offered by councils.
5. The consultation exercise identified that the main factor deterring people from taking up a direct payment was that individuals did not want the monetary responsibility associated with managing and holding their own budget or the additional responsibility of becoming an employer. Consultees also stated that staff often failed to sufficiently promote the advantages of direct payments and therefore while not restricting take-up were not seeking to maximise it.

in Control pilots

6. in Control initially supported six pilot local authorities and focused on 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.

7. Step one of the in Control system has been facilitated by the 'Resource Allocation System' (RAS). 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, produces the individual's allocation.

DH Adult Individual Budget Pilot Programme

8. Thirteen local authorities took part in the IB Pilot Programme, which ended on the 31st of December 2007. Indicative findings show that 16-18 year olds formed a successful part of the pilots. One local authority stated this was due to the breadth of the outcome assessments which allowed young people to think about what they wanted to achieve and the different options enabling them to do this.
9. The majority of pilot sites used some form of the in Control RAS with two notable exceptions. One local authority found that the RAS did not work well for them as it produced large variations in the price point scoring between different client groups. They therefore modified the RAS to extend its coverage to include a focus on both assessment and outcomes. The second exception was a local authority which initially trialled the RAS but found great variations between the value of an individual's current care package and the RAS assessment and also found no consistent pattern in variations. The local authority therefore chose to create and implement an Outcomes Focussed Assessment (OFA) as an alternative to the RAS.
10. 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 Equipment Services fund. However, the allocation of budgets differed between the pilot sites.

Dynamite and Taking Control pilots

11. 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. Dynamite sought to provide IBs for disabled children at transition stage (14-25yrs). 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 20 local authority sites, albeit at a relatively limited scale.
12. Both programmes are run in largely the same fashion as the in Control adult model, with all the local authorities consulted using the adapted RAS. It was clear that a RAS which was aligned with the five ECM outcomes provided useful linkages to the Government's over-arching agenda for children. However, this approach was often felt to lack sufficient detail on the potential issues faced by disabled children and their families.
13. The pilot sites which provided a limited choice of both the management of IB funds and support brokerage have tended to attract families with disabled children from

middle-class and well educated backgrounds. This was felt to be largely the result of these families being better informed and feeling more confident in taking up the IB approach.

14. It was apparent that capacity to take on additional work was an issue for some of the staff who were implementing Taking Control and Dynamite. The consultations also highlighted the need for significant cultural change for local authority staff.

Budget Holding Lead Professional pilots

15. The Budget Holding Lead Professional (BHLP) pilots ran from June 2006 until the end of March 2008 and was delivered in 16 DCSF funded Local Authorities and in one additional self-funded local authority. 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.
16. The pilots highlighted a number of issues of relevance to IBs including that there was a lack of people able to complete the Common Assessment Framework, as insufficient individuals were trained and those who were trained felt they did not know enough about the target group. This indicates a need to provide skills training to all delivery staff.

Early Support Programme

17. The Early Support Programme (ESP) was established in 2003 and is funded by the DCSF through the Sure Start Unit. There were 45 Early Support Pathfinder areas which ran over the course of two years, from 2004-2006. ESP provides a range of support products to families with young disabled children. For instance, the provision of information through the 'family pack.' Consultees noted that a key difference between ESP and other self directed support interventions was the role of the 'key worker' who coordinates the multi-agency support planning process. Consultees thought that this role could form a valuable part of the IB approach.

Barriers and success factors to the effective delivery of individual budgets

18. For an IB type approach to be successful the study identified a range of factors. These include general issues such as the commitment of senior management and resources to making any initiative work, and more specific to this initiative the need to build an allocation framework and market demand.
19. There is, however, a range of barriers at local authority level. These include issues of capacity and experience, such as commissioning of support services being relatively underdeveloped in many local authorities and the lack of existing infrastructure available to develop appropriate support brokerage. Barriers also include uncertainties about how to deal with safeguarding and a lack of data on unit costs. There is also considerable uncertainty and variation in the funding streams that are deemed to be in scope.

20. Beyond this there are also issues in terms of the provider base being able to respond and indeed in the level of demand from possible budget recipients, who appear uncertain as to what is involved and the potential risks and benefits.

Demand and added value

21. There is relatively little evidence in the literature on demand from which to draw firm conclusions. One recent study suggests that for some services – particularly short break schemes - 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.
22. The local authorities and other stakeholders were generally not able to provide an estimate of the potential numbers within the target group who would be interested in taking up an IB approach. However, there was a widely held view that many service users would welcome the notion of greater choice in type of services and how they were delivered. Some stakeholders felt that there might be a significant number of potential beneficiaries who would not wish to have the responsibility for managing a budget or employing a carer.
23. The views of local authorities, other stakeholders and parents supported the findings in the literature review about the added value of the IB approach. Most of the focus was on qualitative changes in: improved user choice and control over services; better partnership working between professionals and families in a user-led approach; greater consistency in service delivery; and greater transparency of costs.

Funding

24. Consultation evidence indicated that the majority of local authorities which were offering an IB to disabled adults were heavily reliant on the social care budget. Small amounts of additional funding have been drawn in from additional sources, such as the Integrated Community Equipment Services (ICES), the Independent Living Fund and the Disabilities Facilities Grant (DFG). However, difficulties have been experienced with both the ILF and DFG as a result of incompatible eligibility criteria and separate assessment, monitoring and audit requirements.
25. Looking specifically at the integration/alignment of health budgets within an IB package, little progress appears to have been made in this area. However, we identified two local authorities which had used health funding within an IB/DP package. Encouragingly, one consultee also stated that although it was not currently possible to directly allocate health monies into the IB pot, there was potential to pool health budgets on the premise that they pass Section 75 of the National Health Service Act 2006 (which is essentially the same as Section 31 of the Health Act 1999).

26. Local authorities which have piloted IB provision to families with disabled children have encountered a similar set of difficulties to that of adult provision. The main barrier was again cited as a lack of coherent policy/legal structure detailing which funding sources could form part of an IB package.
27. Although a number of the local authorities were still considering which funding streams to include within their IB pot, those local authorities which had completed their funding alignment process were using the Social Care budget, Short Breaks funding, pooled health budgets, Education based transport funding and the Integrated Community Equipment Service Fund. However, use of some of these funds relied on isolated examples, with other authorities reporting not being able to attract similar funding in their own work.
28. All consultees wanted to go further. In terms of health they identified Continuing care funding and Community health budget/funding for therapy services as potentially very useful. Discussions around the integration of education budgets also revealed a desire to include particular forms of education funding. These included the Extended Schools, Sure Start and Children's Centre budgets, which could all be used to meet the current demand from families with disabled children for intensive childcare support. However, many local authorities are currently unclear whether childcare provision can form part of IB service provision.

Recommended features of a common delivery model

29. Evidence from the research suggests a need for a set of clear and flexible guidance to underpin the delivery of the forthcoming pilots. The information gathered also suggests that thinking and evidence are sufficiently advanced to promote a general model at this point in time. The common delivery model proposed provides recommendations on ten essential requirements for the forthcoming pilots covering:
 - The involvement of many different staff
 - Provision of a change management programme for all staff involved
 - Facilitation of awareness raising and information dissemination for potential beneficiaries
 - Provision of advocacy and support brokerage for IB users
 - Facilitation of peer support mechanisms for IB users
 - Development of appropriate IT systems
 - Development and implementation of a resource and funding allocation system
 - Provision of a spectrum of choice for the management of IB funds
 - Facilitation of sufficient market development
 - Engagement of all parties in development of the pilot.

Recommendations for the DCSF

30. One of the key points identified from the consultation exercise was the need for the DCSF to ensure the provision of a considerable amount of support to work alongside the pilots and a need for clear guidance on a number of issues. Some elements of this should be in place before the pilots begin (for example guidance on the alignment of funding streams and safeguarding, and monitoring and evaluation tools) while others should be developed alongside and on the basis of the lessons coming from the pilots (for example guidance on who can spend an IB and on what).

Purpose of the pilots and the pilot options

31. It is apparent that the pilots present a significant opportunity to develop the evidence base. The first question for the pilots is the most fundamental: is the provision of Individual Budgets to families with disabled children a viable alternative to traditional forms of service provision for some or all families?
32. In seeking to answer this there needs to be realism about what can be assessed in the period that will be available for the pilots. Following from this are then a series of questions around cost and demand implications, and then about process and good practice in delivery. This would include issues around:
- Changes in levels of demand as new families take up services (even at standard unit costs this would add to aggregate costs)
 - The cost implications of providing brokerage and support services set against possible savings in commissioning and management.
 - Which income streams can successfully be integrated or aligned into an Individual Budget package
 - What are the characteristics of the families who take-up the Individual Budget offer
 - Does the timing or delivery of certain elements (such as brokerage) in some ways more positively influence outcomes than others?
33. A key aim of the scoping study was to develop costed options for the forthcoming pilots to be taken forward as part of the AHDC programme. A series of costs calculations is contained in the main report. A series of possible pilot options was developed and consulted on through the study. Synthesis of the research findings suggests a strong desire to base the forthcoming IB pilots on the 'comprehensive offer' for reasons of both equity and completeness. Therefore, we recommend that the forthcoming pilots should all offer an IB to a target number of families with disabled children, regardless of their disability or age. To ensure the delivery of an equitable set of pilots, each site should also aim to engage a sample of beneficiaries that is representative of their overall population.

34. As the research also highlighted an interest in developing IB provision for particular groups of disabled children, we recommend that each pilot site should also be given the choice to develop a particular theme as part of their general pilot. The addition of a theme will facilitate a detailed understanding of the challenges and successes of delivering to the specific groups and will provide an additional depth to the pilot.
35. Discussions with local authorities and stakeholders highlighted the need to target a sufficient and realistic number of beneficiaries in each pilot site. This number should ensure that results and outcomes can be used to inform both local and national policy and should consider what can be realistically achieved within the timescales of the pilots. We recommend that each pilot site is set a target of between 30-50 beneficiaries, which is likely to be dependent on both the starting point e.g. whether the site is already piloting an IB approach, and size of the local authority.
36. Consequently, we would recommend that the pilot site selection criteria includes the following: a range of both urban and rural local authorities; a selection of local authorities who are already piloting an IB type intervention for families with disabled children (i.e. BHLIP and Taking Control/Dynamite pilot sites) and those who are not currently delivering this form of activity; and a range of sites who wish to pilot the in Control RAS and some who wish to develop their own outcomes-based assessment framework.

1: Introduction

Introduction

- 1.1 As part of Aiming High for Disabled Children (AHDC), the Department for Children, Schools and Families (DCSF) commissioned SQW Consulting (SQW), supported by Gerry Zarb from the Equalities and Human Rights Commission (EHRC), to undertake a scoping study prior to the piloting of Individual Budgets (IB) for families with disabled children. The primary purpose of the scoping study was to inform the development of the IB pilot programme, which is due to commence in late 2008/early 2009 and the evaluation completed before April 2011.
- 1.2 Improving Life Chances for Disabled People (Prime Ministers Strategy Unit, Jan 2005) recommended that the IB approach should, in principle be extended to families with disabled children. AHDC seeks to deliver on that recommendation by undertaking pilots during the next three years. However, with a range of pilot work already being undertaken in related areas, there was a need to undertake a scoping study to set out in more detail what kind of IB pilots should be taken forward, and how these could build on and add value to existing knowledge and innovation in this area.
- 1.3 The aims of the scoping study, as set out in the Terms of Reference (ToR), are as follows:
- Draw together the existing national and international evidence on the effectiveness of Direct Payments and Individuals Budgets for families with disabled children;
 - Set out what further evidence is likely to emerge from existing pilot work currently being taken forward; and
 - Develop costed options for the forthcoming pilots to be taken forward as part of the AHDC programme.

Defining 'disability' and a 'disabled child'

- 1.4 'Disability' as a concept has been defined in various ways, which has left the term open to user-interpretation. This in turn has created difficulties in identifying the number of disabled people within a defined geography and in ensuring that sufficient and appropriate service provision is delivered to the relevant people. However, attempts have been made to formalise the meaning of the term to alleviate the issues discussed, where the most commonly used definition is set out within the 1995 Disability Discrimination Act:

Meaning of “disability” and “disabled people”

(1) Subject to the provisions of Schedule 1, a person has a disability for the purposes of this Act if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities.

(2) In this Act “disabled person” means a person who has a disability.

Source: *Disability Discrimination Act 1995*

- 1.5 Disabled children, the target beneficiaries for this study, form a sub-set of the overall population of disabled people and are therefore subject to the same definitional issues. For example, official figures relating to disabled children often refer to either limiting longstanding illness or to Special Educational Needs data (PWC, 2007), both of which are collated using distinct and different definitions.
- 1.6 Consequently, in defining the potential beneficiaries for the study, we considered it important to recognise the guidance provided by the *Every Child Matters* campaign, which stipulates:

“The Disability Discrimination Act (1995) defines a person as having a disability 'if he has a physical or mental impairment which has substantial and long-term adverse effect on his ability to carry out normal day to day activities'.

The Special Educational Needs and Disability Act 2001 defines a 'disabled pupil' as a school pupil who meets the definition of disabled person under the 1995 Act.

The Children Act 1989 also includes a definition: section 17 states that a child is disabled if 'he [or she] is blind, deaf or dumb or suffers from mental disorder of any kind, or is substantially and permanently handicapped by illness, injury or congenital or other such disability as may be prescribed'.”

Source:

<http://www.everychildmatters.gov.uk/deliveringservices/multiagencyworking/glossary/?asset=glossary&id=22500>

- 1.10 We have used the DDA (1995) definition of disability as the over-arching definition for the scoping study.

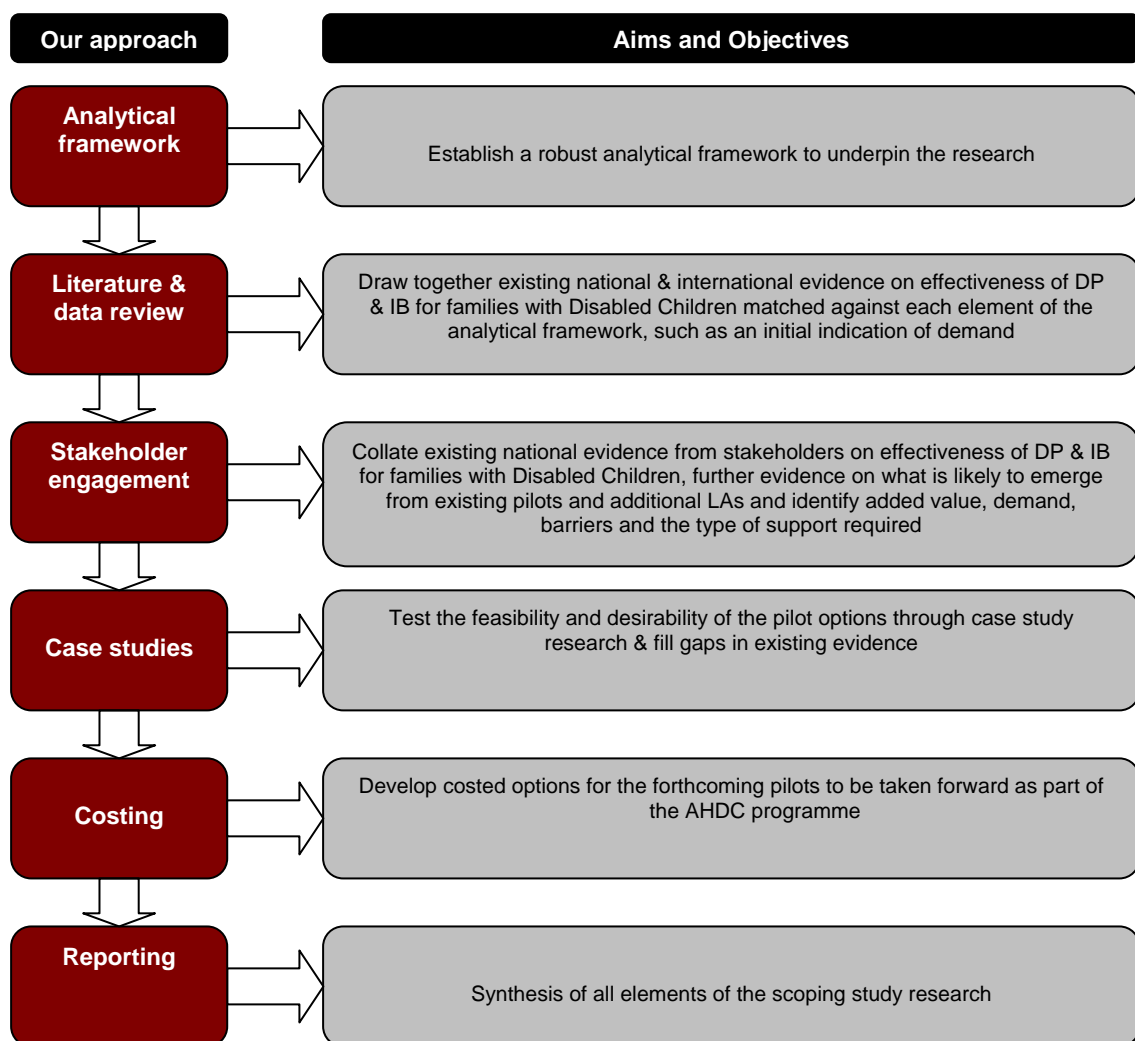
Report structure

- 1.11 The remainder of the report is structured as follows:
- **Chapter 2: Research methodology** – sets out our approach to the research and introduces the research framework upon which the scoping study is based.
 - **Chapters 3-6: Synthesis of research findings** – details the key findings from the research, which are set out under the core headings of the analytical framework i.e. approaches to delivery, barriers and success factors to the effective delivery of individual budgets, demand & added value and funding.
 - **Chapter 7: Recommended features of a common delivery model** – sets out the recommended common delivery model and accompanying information and guidance required from the DCSF for the forthcoming pilots. This guidance draws on the evidence gathered during the research.
 - **Chapter 8: Purpose of the pilots and the pilot options** – sets out the purpose of the pilots, the list of potential pilot options developed during the research, feedback gained on the feasibility and desirability of these options and a set of recommendations on which options should be taken forward as part of the forthcoming IB pilots.
 - **Chapter 9: Cost implications of the pilot options** – presents an indicative range of costs associated with setting up and running an Individual Budgets pilot for families with disabled children, based on the common delivery model.
 - **Chapter 10: Recommended evaluation criteria** – presents a set of recommended evaluation criteria, which seek to frame the pilots and facilitate the collation of process-related and outcomes material.
- 1.12 This report is also accompanied by two supplementary reports, the first of which outlines the findings from the literature review i.e. the Literature Review Report, and the second of which presents six detailed case studies i.e. the Case Study Report.

2: Research methodology

- 2.1 A multi-method approach was adopted to ensure we built a comprehensive understanding of existing evidence on the effectiveness of IB and interventions of a similar nature for families with disabled children. This approach also supported the iterative nature of the research, which involved the derivation and continual review of potential pilot options.
- 2.2 Figure 2-1 presents a summary of our approach against the aims and objectives of the research. Each element of the approach is described in more detail below.

Figure 2-1: Proposed approach and associated aims/objectives of the research



Analytical framework

- 2.3 A set of research questions were developed to form the basis of the study. These questions were developed from the study aims identified above and the associated set of objectives detailed in the ToR as a means of addressing the research aims. The approach and workplan were designed to address these questions.
- 2.4 The overall analytical framework is summarised in two diagrams, Tables 2-1 and 2-2. The first sets out each research objective and aligns these with the relevant research questions, thereby illustrating and clarifying the focus for each component of the study. The second – Table 2-2 – provides a broad indication of how each of the research methods sought to generate evidence to address each of the research questions and the type of evidence each question sought to identify, i.e. evidence which relates to the target group and/or the wider IB field.
- 2.5 The framework also facilitated the identification of gaps within the current evidence base by providing a reference point to map the knowledge found on to the key questions.

Table 2-1: Research questions

Table 2-1: Research questions			
	Core objectives (from the ITT)	Associated research questions	
Theme	Approaches and barriers to delivery	<p>Identify the legislative and organisational barriers hindering the introduction and delivery of individual budgets</p> <p>What approaches have been used to deliver IB and similar interventions at national or local level. How effective is each approach? What is the evidence on key success factors?</p> <p>What are the legislative and organisational barriers to effective delivery of the current pilots and which of these may be relevant to the target audience? E.g. Current overlaps and misalignments with existing policies.</p> <p>What potential approaches could be used to deliver IB for the target audience? E.g. notional vs. financial budgets</p> <p>Why have particular Local Authorities chosen to adopt an IB type approach in general, and to disabled children in particular? What approach have they adopted and what has helped and hindered the delivery of this specific form of service provision?</p> <p>What are the key risks to the existing approaches that may also be applicable to the target audience and how can these be minimised?</p>	
	Funding	<p>Identify and look at the financial levels of individuals budgets and the different income streams that need to come together to make most impact</p>	<p>What set of income streams are applicable to the target audience, which could form a component of the IB package? – looking specifically at health, education and social services budgets</p> <p>What service provision and spend per head is associated with each of the eligible funding streams? What are the associated costs of delivery? Do they differ by sub-group/type of disability/prior history of delivery etc?</p>
		<p>Identify the main funding streams currently used for individual budgets and the reasons why other funding streams are currently excluded</p>	<p>Which budgets did the existing pilots draw upon in their delivery? Are these applicable to the target group?</p> <p>What were the delivery and opportunity costs of the existing pilots (and of activity of a similar nature)? E.g. Direct Payments, Budget-Holding Lead Professionals)? What inferences can be made to the target audience?</p> <p>Specifically with regard to health, how and which budgets have been pooled to facilitate an IB type approach?</p> <p>What are the potential service-related implications associated with an IB approach? E.g. choice of home schooling vs. mainstream schooling</p>
	Demand	<p>Indicate the demand for individual budgets and/or direct payments within the disabled children and family community</p>	<p>How large is the potential target population of disabled children and their families?</p> <p>What is the extent and nature of unmet need for the target group?</p>
<p>Identify what support disabled children and their families want to enable them to make best use of their individual budget</p>		<p>What is the nature and extent of demand for IB by the target population that is distinct from other groups such as adults and older people?</p> <p>Is the IB approach more appropriate for specific sub-groups within the target population? E.g. age groups, type of disability, stage of development of disability etc.</p> <p>What is the demand for different IB models in general? E.g. notional vs. financial budgets, use of brokers etc. Does this differ for the target group, compared to disabled adults and older people?</p> <p>What types of services would the target audience like to access as part of the potential IB package? And are the suggestions feasible?</p>	
Added value	<p>Identify what added value individual budgets can bring to current practice</p>	<p>What does existing evidence tell us about the added value IB can bring to current practice? E.g. increased satisfaction with service provision, increased quality of life for beneficiaries</p> <p>What does the existing evidence say about cost savings and cost effectiveness?</p> <p>How could the provision of IB complement the delivery of other strands of the AHDC Strategy? E.g. Short breaks, Early Support Programme, Transition Programme</p>	

Table 2-2: Analytical Framework

	Methodology	Literature review	Data review	Consultation with existing pilots & LAs	Costing of options	Consultation with stakeholders & LAs	Case study fieldwork	Evidence relating to the target group	Evidence relating to the wider IB field
Research Questions									
Approaches and barriers to delivery	What approaches have been used to deliver IB and similar interventions at national or local level? How effective is each approach? What is the evidence on key success factors?	✓		✓		✓		✓	✓
	What are the legislative and organisational barriers to effective delivery of the current pilots and which of these may be relevant to the target audience?	✓		✓		✓	✓	✓	✓
	What potential approaches could be used to deliver IB for the target audience?	✓		✓		✓	✓	✓	
	Why have particular Local Authorities chosen to adopt an IB type approach in general, and to disabled children in particular? What approach have they adopted and what has helped and hindered the delivery of this specific form of service provision?	✓		✓		✓	✓	✓	✓
	What are the key risks to the existing approaches that may also be applicable to the target audience and how can these be minimised?	✓		✓	✓	✓	✓	✓	✓
Funding	What set of income streams are applicable to the target audience, which could form a component of the IB package? – looking specifically at health, education and social services budgets	✓	✓	✓	✓	✓	✓	✓	
	What service provision and spend per head is associated with each of the eligible funding streams? What are the associated costs of delivery? Do they differ by sub-group/type of disability etc?		✓	✓	✓	✓	✓	✓	
	Which budgets did the existing pilots draw upon in their delivery? Are these applicable to the target group?			✓	✓				✓
	What were the delivery and opportunity costs of the existing pilots (and of activity of a similar nature)?			✓	✓				✓
	How and which health budgets have been pooled to facilitate an IB type approach?	✓		✓	✓	✓	✓	✓	✓
	What are the potential service-related implications associated with an IB approach to this target group?				✓		✓		✓

	Methodology	Literature review	Data review	Consultation with existing pilots & LAs	Costing of options	Consultation with stakeholders & LAs	Case study fieldwork	Evidence relating to the target group	Evidence relating to the wider IB field
	Research Questions								
Demand	How large is the potential target population of disabled children and their families?	✓	✓		✓	✓		✓	
	What is the extent and nature of unmet need for the target group?	✓	✓					✓	
	What is the nature and extent of demand for IB by the target population that is distinct from other groups such as adults and older people?	✓	✓		✓	✓	✓	✓	
	Is the IB approach more appropriate for specific sub-groups within the target population?	✓		✓	✓	✓	✓	✓	
	What is the demand for different IB models in general? E.g. notional vs. financial budgets, use of brokers etc. Does this differ for the target group, compared to disabled adults and older people?	✓		✓	✓	✓	✓	✓	✓
	What types of services would the target audience like to access as part of the potential IB package? And are the suggestions feasible?	✓					✓	✓	
Added value	What does existing evidence tell us about the added value IB can bring to current practice?	✓		✓	✓	✓		✓	✓
	What does the existing evidence say about cost savings and cost effectiveness?	✓		✓	✓	✓		✓	✓
	How could the provision of IB complement the delivery of other strands of the AHDC Strategy?	✓		✓		✓	✓	✓	

Source: SQW Consulting

Typology of costs

- 2.6 An initial typology of the potential costs associated with the delivery of IB to families with disabled children was developed to sit alongside the analytical framework. This formed part of the foundation of the study and is illustrated in Table 2-3. This preliminary categorisation was developed from:
- SQW's previous work for the Office for Disability Issues (ODI) on the costs and benefits of Independent Living (2006)
 - Early findings from the evaluation of Individual Budgets for disabled adults and older people (2007); note that these reported set up costs only
 - An initial scan of the literature¹.
- 2.7 In developing the typology we made several assumptions; these are based on our understanding of the study brief and discussions that took place at the inception meeting for the study. A critical assumption was that options for IB would be costed at Local Authority Level and for implementation only. We also assumed that opportunity (or economic) costs needed to be accounted for, but not necessarily quantified. Many of these costs would be costs to the individual, but some would be accrued by LAs and partners (see Table below). It was agreed that exchequer and departmental costs would *not* form part of the costing process.
- 2.8 This typology is not exhaustive and was developed to serve as a guide in gathering, analysing and presenting evidence, and therefore was subject to revision throughout the research.

Table 2-3: An illustrative typology of costs

Type	Cost
Financial costs of service delivery/implementation	
Set up costs	<p>Systems development – processes for assessment, allocation, financial administration, review, including</p> <p>IT systems and development of Resource Allocation Models charging and audit arrangements,</p> <p>Systems to assess demand</p> <p>Funding stream reporting, year end arrangements, payments and monitoring systems</p> <p>Financial planning costs – planning the cost associated with individual purchasing, demographic change, unmet need, costs of in-house services</p> <p>Support planning and brokerage – leveraging funding, setting up networks and partnerships, developmental work through focus groups and awareness raising</p> <p>Workforce development – recruitment, training, information sharing</p> <p>Resource costs – salaries and other remuneration of implementation staff</p> <p>Marketing and promotion costs – promoting and marketing to families and partners</p> <p>Other administration or overhead costs</p>

¹ For example, CSIP (2007), Challenges to the Implementation of Individual Budgets and Proposals for the Acceleration of Development and Learning.

Type	Cost
Running costs	<p>Systems maintenance costs - including updating and maintaining resource allocation models</p> <p>Support planning and brokerage costs – maintaining networks and partnerships, continuing with awareness raising, liaison costs with delivery partners</p> <p>Marketing and promotion costs – costs of regular marketing and promotion activities (if any)</p> <p>Resource costs – staff support costs, salaries and other remuneration of implementation staff</p> <p>Workforce development – training of advocates and personal assistants, arranging for emergency cover, peer support</p> <p>Costs of providing referrals and information for families</p> <p>Assessment and care management costs</p> <p>Co-ordination costs of packages</p> <p>Any hidden costs – cost of providing short-term hiring of extra workers, cost of developing and promoting more appropriate responses to need than those that currently exist, increasing demand for services (emergence of unmet demand)</p>
Economic or opportunity costs	
Service delivery	<p>Costs of diverting resources to IB from mainstream services</p> <p>Cost of risk-aversion to providing alternative means of support</p> <p>Potential cost savings as indicated by the Adult IB and in Control pilot evaluations</p> <p>Costs associated with increased efficiency in the assessment processes</p>
Individual/families	<p>Responsibility for managing own personal assistance</p> <p>Process of adjustment to the new system</p> <p>Personal investment (of time and money) in developing own skills to self direct support</p> <p>Personal investment (of time and money) in developing own skills and expertise to engage with mainstream/community agencies</p> <p>Personal investment (of time and money) in managing own budget/expenditure, including providing accounts</p> <p>Costs for carers associated with foregone earnings as a result of reducing or leaving work</p> <p>Continued barriers to social participation</p> <p>Increased levels of dissatisfaction with quality of life indicators – access to services, participation in social activities, reduced flexibility etc</p> <p>Time freed up for ‘ordinary’ family life and other activities by virtue of having more individually tailored and flexible support</p> <p>Reduced reliance on statutory services and greater choice and control over how support is organised</p> <p>Potential increase in household incomes if family members are able to return to or increase paid employment</p> <p>Potential cost savings for health services if carers health and well-being improved as a result of improvements in quality and/or quantity of support</p> <p>Reductions in barriers to social participation (e.g. better educational outcomes leading to increased social capital with consequent impact on life chances)</p>

Source: SQW Consulting

Literature and data review

- 2.9 The aim of the literature review was to draw together the existing national and international evidence on the effectiveness of Direct Payments, Individual Budgets and approaches of a similar nature 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 under the following headings:
- Approaches to delivery
 - Barriers and success factors to the effective delivery of individual budgets
 - Demand and added value
 - Funding.
- 2.10 We reviewed over 100 documents in total (see Annex E for bibliography). Our sources included evaluation reports which considered Direct Payments, Budget Holding Lead Professional pilots, in Control pilots and the adult IB pilots. We also reviewed a wide range of other documents sourced from academic journals, UK and international government-funded research, and research published by independent research and policy organisations.
- 2.11 The review identified a number of potential pilot options, which were formulated into a list, which was used during the subsequent consultation exercise. The final review is presented in the Literature Review Report, which accompanies this main report. The key findings are summarised and drawn on in this document.

Stakeholder engagement

- 2.12 Having completed the initial stage of the research, we conducted an intensive set of fieldwork which included the following:
- Scoping consultations with a small number of key stakeholders
 - Consultations with Local Authorities which had or were currently piloting an IB type approach or an initiative of a similar nature e.g. BHLs, Direct Payments etc.
 - Stakeholder consultations with appropriate members of informed and interested organisations
 - Consultation with parents of disabled children and young people with disabilities.

- 2.13 This resulted in the research team **consulting a total of 102 individuals**. The exercise as a whole sought to identify how, why and where existing approaches to IB/similar interventions were being delivered, how successful these approaches had been and the main barriers to effective delivery. We also gathered information on the types of services which were likely to be purchased via IB type service provision and on the funding streams which currently formed part of an IB package/those which would be desirable in the future.
- 2.14 All topic guides were based on the questions set out in the analytical framework, which were appropriately tailored to each distinct consultation group (see Annexes B, C and D).

Scoping consultations

- 2.15 The research team conducted a small number of scoping consultations with key experts in the self-directed support field and with relevant project leads at DCSF. These consultations sought to further our understanding of how IB and similar interventions were being approached on the ground, which LAs were piloting such approaches and to highlight the complexities we should seek to explore during the research. We also sought to gain feedback on the initial list of potential pilot options, during which consultees were given the opportunity to suggest additional options.
- 2.16 Evidence from this exercise informed the development of the topic guides for the subsequent LA, stakeholder and parent/young people consultations.

Consultations with Local Authorities

- 2.17 A desk based mapping exercise was undertaken to identify existing service provision in all 150 Local Authorities in England. This assessed the availability of the following:
- Adult IB pilots
 - Early Support Programme Pathfinders
 - Short Break Pathfinders
 - BHLP pilots
 - in Control pilots
 - Dynamite pilots
 - Taking Control pilots
 - Looked After Children Pilots.
- 2.18 The information from the mapping exercise was used in conjunction with recommendations made during the scoping consultations, to identify Local Authorities which have been or were delivering:
- IB work or considering it (regardless of what stage they were at)

- Similar pilot initiatives, such as the BHLP pilots and those who had been involved in supplying Direct Payments to families with disabled children (and in particular cases to adults)
- Other AHDC initiatives (such as the Short Breaks Pathfinder Programme).

2.19 Through this process, we identified approximately 20 Local Authority candidates and subsequently contacted 20 individuals from 17 Local Authorities. This resulted in 18 individual positive responses from the following 15 Local Authorities, all of which participated in the research:

Table 2-4 : Local Authorities invited to participate

• London Borough of Brent	• Newcastle City Council
• Brighton and Hove City Council	• Norfolk County Council
• Coventry City Council	• North Tyneside Council
• Essex County Council	• Northumberland County Council
• Gateshead Council	• London Borough of Redbridge
• Gloucestershire County Council	• Sheffield City Council
• Leeds City Council	• Swindon Borough Council
• Middlesbrough Council	

Source: SQW Consulting

- 2.20 Consultations focused on discussions about existing approaches, the associated implementation and delivery challenges and the costs involved in piloting such interventions. Local Authority consultees were also given the opportunity to provide their views on the list of potential pilot options.
- 2.21 The majority of Local Authority consultations involved at least two relevant members of the Local Authority and in once case included five members of staff. This resulted in the research team gaining the views of 30 Local Authority staff in total across the 15 areas.

Stakeholder consultations

- 2.22 Twenty nine stakeholder consultations were conducted in conjunction with the Local Authority consultations. This complementary activity aimed to identify the ways in which families may use IB type funds, implementation and delivery challenges and any available cost information. The list of potential pilot options was also discussed with stakeholders.
- 2.23 Candidates for the key stakeholder interviews were identified through both the literature review and the scoping consultations.

Consultation with parents and young people

- 2.24 Consultation with parents was initially facilitated through the DCSF who promoted the scoping study research on the Every Child Matter website and via the National Parents' Partnership Network. This resulted in eight parents contacting the research team, all of whom took part in a telephone consultation.
- 2.25 Parents of disabled children and young people with disabilities were later invited to express their views and experiences of individual budgets and similar interventions, via a survey which was kindly disseminated by a parent contact made during the research². Thirty one responses were received in total, seven of which were completed by young people with disabilities.

Case studies

- 2.26 Six case studies were undertaken after the consultation exercise, which sought to provide a more detailed assessment of the working of each area³, to test the feasibility and desirability of the final list of potential pilot options and to fill any gaps in the existing evidence. This involved gathering the views of a range of local authority staff from each area, e.g. staff from Children's Services, Disabled Children and Young People's Services, Social Care, Commissioning and Finance, as well as front-line staff and providers from the independent sector. This provided a more detailed assessment of how things were operationalised at a local level and of the possible pilot options in this context.
- 2.27 Case study local authorities were selected from those who took part in the consultation stage of the research. This ensured that the selection was informed by the type and depth of information available from each area and resulted in six local authorities taking part in the case study exercise.
- 2.28 Five of the six individual case studies are presented in the Case Study Report, which accompanies this main report⁴:
- Coventry City Council
 - Gloucestershire County Council
 - Newcastle City Council
 - Northumberland County Council
 - London Borough of Redbridge.
- 2.29 The key findings from all six case studies are drawn on in this document.

² Lynn James Jenkinson, the Director of the North West Training & Development Team and the parent of a disabled child supported the dissemination of the survey to a network of parents and young people with disabilities in the North West region of England.

³ The case study topic guide comprised of appropriate questions from the analytical framework.

⁴ The sixth case study has not been included due to disagreements raised within the area on the topic of Individual Budgets.

Synthesis, costing the pilot options and reporting

- 2.30 The final stages of the research involved synthesis of the research evidence and the refinement of the list potential pilot options in light of the feedback gathered during the course of the research. Feasible and desirable pilot options were then costed accordingly via the use of local authority cost data and proxy data.
- 2.31 The remainder of the report sets out the synthesis of the research under the headings set out in the analytical framework and concludes with a set of recommendations and associated evaluation criteria for the forthcoming IB pilots for families with disabled children.

3: Approaches to delivery

Introduction

- 3.1 The following chapter provides a description of the existing approaches being used to deliver IB and interventions of a similar nature. This information has been drawn from the literature review, the stakeholder and Local Authority consultations and from the case study evidence.
- 3.2 We have considered the following approaches: Direct Payments (DP), in Control pilot work, the Department of Health (DH) Adult Individual Budget Pilots, Dynamite and Taking Control pilots, Budget Holding Lead Professional pilots (BHLP) and the Early Support Programme (ESP). A number of these approaches were reviewed, as they were specified in the Terms of Reference for the study e.g. DP and BHLP. Additional approaches were chosen e.g. Dynamite and Taking Control pilots and the ESP, to ensure that the research investigated all complementary activity that has or is taking place within England.

Direct Payments

- 3.3 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.
- 3.4 Take up of direct payments has been limited 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 four examines some of the ongoing barriers affecting take up of the direct payments scheme.

Supporting evidence from the research fieldwork

- 3.5 The consultation exercise identified that the main factor deterring people from taking up a direct payment was that individuals did not want the monetary responsibility associated with managing and holding their own budget or the additional responsibility of becoming an employer. Consultees also stated that staff often failed to sufficiently promote the advantages of direct payments and therefore while not restricting take-up were not seeking to maximise it.
- 3.6 On a more positive note, consultees reported that several pieces of work have recently been undertaken to promote and raise the profile of direct payments. For example, The Children's Society was commissioned by the Department of Health's Direct Payments Development Fund to undertake a piece of work to promote the use of direct payments. They worked with three local authorities to identify the issues they faced in promoting direct payments and over an eighteen month period successfully managed to increase take-up by families and young people. For example in one local authority, a set of focus groups was held with young people to introduce and discuss DPs, which was later developed into a project which gave a small number of young people access to one to one sessions with young volunteers to discuss what they might do with a DP. This resulted in a small number of young people taking up a DP.
- 3.7 Evidence from the local authorities consulted also indicates that the take-up by children and families of direct payments has been increasing, albeit from a low base. A number of local authorities stated this increase had been supported by their own implementation of procedures to ensure eligible families were informed about direct payments at the point of referral by social workers. One local authority also stated that many of its referrals had come from word of mouth between clients who were already in receipt of direct payments.
- 3.8 A number of local authorities have commissioned the services of independent support brokers to provide assistance to families with disabled children who are in receipt of a DP. This form of support appears to have heavily drawn on the extension of services from brokers who were already providing support to adults receiving direct payments (eg through an Independent Living Centre) and were therefore asked to broaden their provision to include children and young people. Alternatively, some local authorities have chosen to deliver in-house brokerage support as opposed to commissioning out the service.
- 3.9 Both independent and in-house support brokers provided a range of services which included: information and guidance on receiving direct payments; assistance in completing application forms; advice and guidance on potential service options; recruitment, selection and training for care workers; assistance in employing personal assistants; and support to open bank accounts and set up a payroll for employees.

- 3.10 Direct payments to families with disabled children were cited as being used to purchase various services such as the employment of personal assistants to provide home and night care, and support to enable a child to take part in community based activities. The consultations also indicated an inconsistency in the provision of childcare through DPs, where some local authorities stated that they would fund childcare whilst others stated this could not form part of a direct payment. Consultations with parents also highlighted that there was confusion around whether a direct payment could be used to purchase childcare.

in Control pilots

- 3.11 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 authorities⁵ and focused on 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.
- 3.12 The pilots sought to replace the existing care management arrangements with a 7-step process as set out in table 3-1:

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

⁵ Essex, Gateshead, Redcar & Cleveland, South Gloucestershire, West Sussex and Wigan Local Authorities.

in Control System	Description	Additional details
		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 needed	

Source: *in Control*, 2006

- 3.13 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, produces the individual's allocation.
- 3.14 The value per point is calculated on an area by area basis. In each area 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.
- 3.15 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 literature review report which accompanies this main report.
- 3.16 Given the timescales of the research, we chose to only investigate in-Control's more recent work. This included visiting a number of the Taking Control and Dynamite pilot sites, which are discussed in more detail below.

DH Adult Individual Budget Pilot Programme

- 3.17 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).
- 3.18 Thirteen local authorities⁶ 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.
- 3.19 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 local authority, following which the appropriate services were provided. The support plan was then reviewed periodically after completion.

Supporting evidence from the research fieldwork

- 3.20 Indicative findings show that 16-18 year olds formed a successful part of the pilots. One local authority stated this was due to the breadth of the outcome assessments which allowed young people to think about what they wanted to achieve and the different options enabling them to do this.
- 3.21 The majority of pilot sites used some form of the in Control RAS, which they adapted to meet the needs of the relevant area. Our research identified two notable exceptions. The first involved a local authority who found that the RAS did not work well for them as it produced large variations in the price point scoring between different client groups. They therefore modified the RAS to extend its coverage to include a focus on both assessment *and* outcomes. The adapted outcomes focussed RAS was split into different categories by client need and disability.
- 3.22 The second exception was a local authority which initially trialled the RAS but found great variations between the value of an individual's current care package and the RAS assessment and also found no consistent pattern in variations. The local authority therefore chose to create and implement an Outcomes Focussed Assessment (OFA) as an alternative to the RAS.
- 3.23 The OFA was designed and developed using a pathfinder group of social workers who trialled it and revised it through a process of eight iterations. This resulted in the following process:

⁶ Pilot sites – Barking and Dagenham, Barnsley, Bath and North East Somerset, Coventry, Essex, Gateshead, Kingston and Chelsea, Leicester, Lincolnshire, Manchester, Norfolk, Oldham, West Sussex Local Authorities.

- **Identification and agreement of the individual's desired outcomes** – the outcomes based approach involves the individuals looking ahead at what they would like to achieve both now and in the future and therefore differs from a needs-led assessment which focuses on a person's *current* needs
 - **Process of support planning** - used to identify the level of support the service user requires to achieve their agreed outcomes.
 - **Development of final plan and costed package** - involved drawing up a costed package of support which formed the basis for the level of award for the IB.
- 3.24 The OFA was recognised by the local authority as marking a significant change from the traditional needs led assessments and requiring a less major cultural shift for professionals involved in the process. A training programme on the new assessment framework was put in place for social workers and detailed guidance produced.
- 3.25 Interestingly, a third local authority which used the RAS stated that having costed an indicative resource allocation, a decision was then made as to whether to allocate this indicative allocation or the value of the existing traditional support package. This local authority also chose to identify whether their IB users required ongoing brokerage support post the planning stage. This element was incorporated into the RAS, which allocated additional funds within an IB to accommodate these additional needs.
- 3.26 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 6.
- 3.27 Looking specifically at user support services, some of the local authorities consulted stated that they had commissioned independent support planning and brokerage services. Their role was to help develop support plans alongside individuals and assist them in commissioning services. Another local authority favoured a multi-disciplinary approach, which allowed users to benefit from both independent and in-house support. This support included each IB user being assigned an IB support worker, support planning workshops (provided by Helen Sanderson Associates) and peer support from a user-led social enterprise.
- 3.28 Consultees also stated the importance of ensuring that resources were developed prior to the pilot and therefore made available from the outset. This included funding resources for the local authority delivering the intervention, appropriate forms of support services for users and the availability of sufficient and relevant market provision.

Dynamite and Taking Control pilots

- 3.29 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 authorities⁷, has been set up to run for two years and is led by Paradigm⁸.
 - **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 20 local authority sites⁹, each of which are at differing stages of development.
- 3.30 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 total budget allocation.
- 3.31 We were unable to source evaluation based evidence for the Dynamite Programme for this report, but consulted a small number of the pilot sites to gain an understanding of the workings and outcomes of the pilots. Anecdotal evidence indicates that the Dynamite pilots have produced significant outcomes for 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.
- 3.32 The Taking Control pilots have not been subject to review or evaluation, as most of the pilots have not yet progressed beyond their developmental phase. Therefore, our consultation with a small number of pilots provides an insight into how development is progressing.

⁷ Dynamite sites include – Bradford, Ealing, Newcastle, Norfolk, North Tyneside, Northumberland, Redbridge Stoke-on-Trent, Surrey, Wandsworth LAs.

⁸ 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.

⁹ Gloucestershire, Lambeth, Redbridge, Barnet, Newham, Luton, Stoke-on-Trent, Sandwell, Staffordshire, Halton, Sheffield, Kirklees, Wakefield, North East Lincolnshire, Leeds, Bradford, Hull, Middlesborough, Gateshead, Northumberland– where Gloucestershire was the first Taking Control site, which was set up in July 2007.

- 3.33 Both the Taking Control and Dynamite pilots have been undertaken on a relatively small scale and the nature of our consultation limited within the scope of the study. Therefore the following discussion should be treated as indicative.

Supporting evidence from the research fieldwork

The process

- 3.34 The consultation exercise illustrated that both the Dynamite and Taking Control Pilots had or were following the seven step delivery process set out by in Control. Each pilot had recruited an average of eight families at the outset of their activity. However, there had been a tendency for families to drop out of the pilots prior to their receiving an IB, resulting in an even smaller sample during the delivery of the pilot. One local authority also indicated that approximately a quarter of their initial participants had gone on to access individual budgets post their Dynamite pilot.
- 3.35 Recruitment procedures included the local authorities approaching families who they thought might be interested in accessing an individual budget. Looking specifically at the consultations conducted with Taking Control pilot sites, it was evident that the majority of families recruited were already accessing some form of self directed support e.g. direct payments or support from a budget holding lead professional. One local authority had chosen to target two groups: one was made up of individuals who were eligible for social care and had already had a core assessment; the second comprised new referrals who did not meet the social care threshold. Another local authority decided to target children with a 'substantial and enduring disability' and whose current level of social care costs were in excess of £25,000.
- 3.36 All the local authorities consulted were using the adapted RAS. It was clear that a RAS which was aligned with the five ECM outcomes provided useful linkages to the Government's over-arching agenda for children. However, this approach was often felt to lack sufficient detail on the potential issues faced by disabled children and their families. Consultees also noted that the RAS assessment needed to be subject to continual review to ensure that periods of rapid change in the needs of a disabled child and their family were taken into account.
- 3.37 A number of local authorities also stated that they had made significant amendments to the RAS in both Dynamite and Taking Control pilot sites. For example, some local authorities felt that the RAS did not take sufficient account of the support needs of the family resulting in them making amendments to the RAS to include this factor. Another local authority chose to also review the current situation of parents and therefore recorded whether they had any personal support needs. This led to some parents being able to access other forms of support, for themselves, from the local authority.
- 3.38 Although all the pilots had followed the 7-step in Control model, variations in the delivery of support provision between the pilots was evident. These variations included:

- **Assessment process and setting of IB** – Although all local authorities included some form of assessment process, this varied from a self-assessment to a professionally supported assessment.
- **Support planning stage** – All local authorities offered support brokerage to families through the developmental stages of their support plan and in accessing services. Some local authorities opted to offer this service in-house through social workers, whilst others recruited independent facilitators. Local authorities provided all facilitators with the necessary training to be able to support, children, young people and families with their support planning.
- **Management of IB** – Families were generally provided with a choice of who controlled their IB. The options offered varied from a form of direct financial payment to the family, to a service provider holding and managing the funds, to the local authority managing the IB on behalf of the family.
- **Ongoing support** - It is interesting to note that a number of the local authorities also facilitated regular peer support and networking with other families within their pilot. This mutual support was cited as being invaluable and had created a new form of trust between the local authority and their IB users.

Challenges

- 3.39 The pilot sites which provided a limited choice of both the management of IB funds and support brokerage have tended to attract families with disabled children from middle-class and well educated backgrounds. This was felt to be largely the result of these families being better informed and feeling more confident in taking up the IB approach. For example, consultees felt that they were better equipped to manage their IB fund directly.
- 3.40 It was apparent that capacity to take on additional work was an issue for some of the staff who were implementing Taking Control and Dynamite. Consultations highlighted that in some cases, staff were allocated a small number of hours in their working week to focus on the pilot, which had proven to be insufficient. In addition, consultees stated that implementation and delivery had taken a greater number of hours than had been allocated, causing staff workload priorities to be subject to ongoing change. For example, one local authority stated that the use of IT staff resources in terms of re-scoping, testing and implementing the RAS took a great deal of time.
- 3.41 A number of consultees highlighted the division of responsibility between adult and children's services as a barrier to the effective delivery of the Dynamite pilot. They went on to explain that there often appeared to be a lack of communication between the two services and discrepancies in the levels and types of services available. This discontinuity had been difficult to communicate to young people and their families, who found it hard to understand why services suddenly became unavailable at the age of 18.

- 3.42 The consultations also highlighted the need for significant cultural change for local authority staff. For example, one local authority involved all social workers to ensure they all gained experience of the new form of working. Another local authority found that training and awareness raising workshops with staff worked effectively and had been crucial to the delivery of their pilot. Consultees also stressed the need for the effective dissemination of information to frontline staff to ensure they remain well informed.
- 3.43 The research sought to identify the main reasons why some individuals had declined the opportunity to be involved in the IB approach. Consultation evidence highlighted the following factors:
- Families felt comfortable and safe with their current provision
 - Families did not want to take on financial responsibility of the budget
 - Managing and access to staff. Becoming an employer was a daunting task to some families. Ensuring staff were paid correctly, had access to professional development and training, and isolation of personal assistants were all cited as concerns regarding employment.

Budget Holding Lead Professional pilots

- 3.44 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.
- 3.45 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 authority¹⁰. 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 providers¹¹.
- 3.46 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.
- 3.47 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 guidance¹² provides the following additional detail:

¹⁰ 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 LA self-funded their own BHLP pilot.

¹¹ <http://www.everychildmatters.gov.uk/leadprofessional/budgetholding/>

¹² <http://www.everychildmatters.gov.uk/deliveringservices/multiagencyworking/glossary/?asset=glossary&id=22520>

“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”.

3.48 The BHLF pilots worked as follows.

- **Assessment:** The BHLFs worked with the child and their family to assess their needs using the Common Assessment Framework (CAF)/Initial Assessment (for social care).
- **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 BHLF identified what needed to be purchased and the proposed cost of the services/goods required, alongside the child and family. The BHLF also worked with colleagues from their own and other local agencies (and with the family) to identify where the services should be purchased from and to ensure value for money was achieved.
- **Review:** The BHLF was responsible for reviewing the impact of the support package and adjusting the service provision where necessary.

3.49 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 a 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.

3.50 In April 2007, four of the BHLF pilots took on an additional focus and also became part of the BHLF Look After Children pilots. Similarly, in October 2007, seven of the existing BHLF pilots became 'Enhanced BHLFs' (EBHLFs), which essentially allowed the pilots to tailor the total targeted services budget that was typically spent on the child. This move from BHLF to EBHLF signals a move towards an IB approach, which requires further exploration.

3.51 The formal evaluation of the BHLF pilots is due for release in Autumn 2008 and therefore the findings detailed in this final report are based on findings from the consultation exercise and local evaluation evidence.

Supporting evidence from the research fieldwork

- 3.52 Six of the local authorities consulted were BHL P pilot sites. The number of children involved and type of pilots varied between pilot sites, however all the pilots were larger than the Dynamite and Taking Control pilots and therefore presented a greater body of evidence.
- 3.53 Social workers were heavily involved in the BHL P pilots as they were used by a number of local authorities to recruit participants. Indeed, one local authority consultee expressed concern at the increasing remit of social workers who were not necessarily equipped with the appropriate skills to commission services or administer budgets. This indicates a need to provide skills training to all delivery staff, regardless of their role in the pilot.
- 3.54 One local authority chose to deliver the pilot across 17 sites across the area and to two area-wide projects, one of which specifically targeted disabled children and young people (see the separate case study report for additional information). The targeted area-wide projects were both led by dedicated project workers, which was felt to enhance the success of the pilot.
- 3.55 The area-wide pilot ran for one year and targeted children with disabilities who did not meet the social care thresholds and were therefore deemed as having 'additional needs'. These beneficiaries were recruited through referrals made from schools, housing officers etc. The pilot later extended its remit to include children from the social services waiting list who were awaiting referral for specialist respite. This resulted in a total of 40 children and young people participated in the BHL P pilot for children with disabilities.
- 3.56 One local authority was keen to be involved in the BHL P pilot but was unsuccessful. It proceeded to set up its own pilot based on the BHL P model. They targeted 0-19 year olds with additional needs (levels 2/3) as part of the early intervention/prevention agenda. Funding could not be used to purchase services for children with more complex needs requiring statutory intervention (level 4). Young people aged 19-25 with learning difficulties or a disability were also eligible. A total of 369 families were supported through this programme involving over 414 children. The pilot is viewed by the local authority as a success and the authority is in the process of mainstreaming their model.
- 3.57 Consultees were asked about the challenges faced by the BHL P pilots. Their responses included:
- Being innovative and creative is possible but it is important to ensure the service provision is available. One local authority encouraged children and young people to suggest the services they required, but when the time came to implement services they were unable to find a service provider to meet the needs of the young people
 - There was a lack of people able to complete the CAF, as insufficient individuals were trained and those who were trained felt they did not know enough about the target group

- The financial logistics of administering a one off payment were found to be difficult and required significant amounts of time from the finance team
- Families and specialist providers often felt that specialist support was the most effective means of support and were therefore reluctant to either enable or offer more innovative forms of support.

Early Support Programme

- 3.58 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.
- 3.59 There were 45 Early Support Pathfinder areas which ran over the course of two years, from 2004-2006, which promoted the following¹³:
- better joint assessment and planning processes for individual children and their families
 - 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.
- 3.60 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.
- 3.61 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.

¹³ <http://www.earlysupport.org.uk/modResourcesLibrary/HtmlRenderer/AboutES5.html>

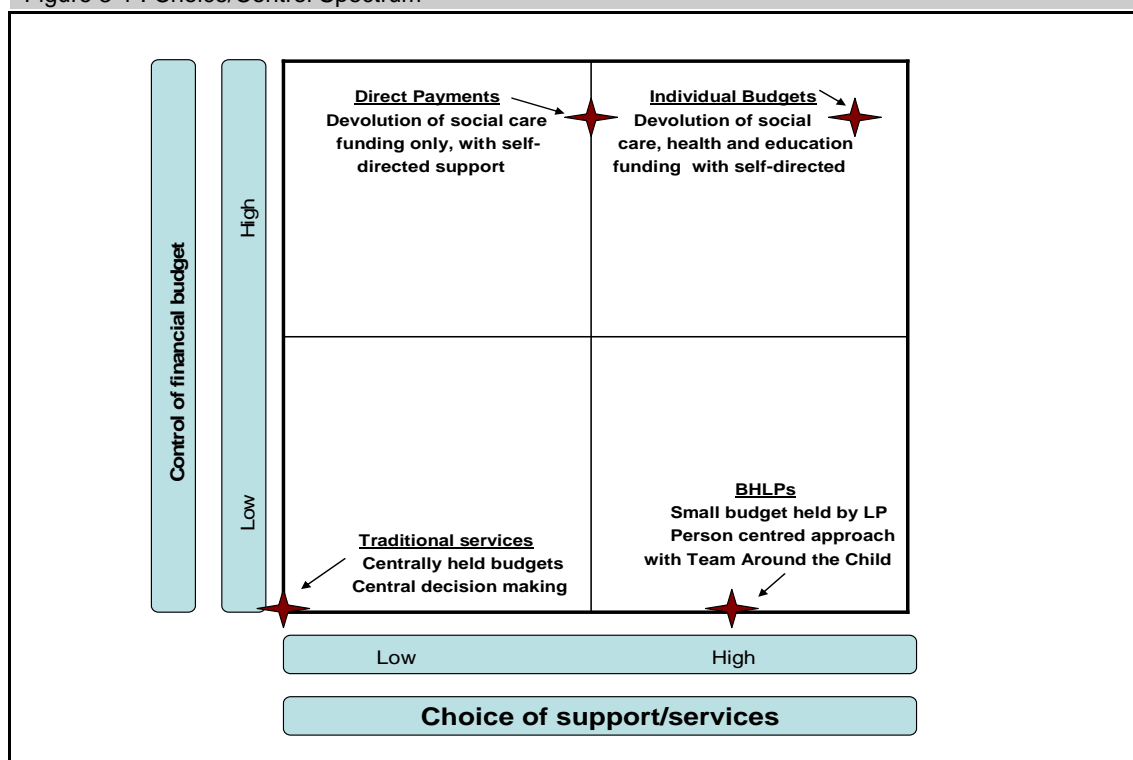
Supporting evidence from the research fieldwork

- 3.62 Consultations with stakeholders and local authorities touched upon the work of the ESP, where consultees noted that a key difference between ESP and other self directed support interventions was the role of the ‘key worker’. That is, each child is allocated a key worker, as part of the ESP. The worker coordinates the multi-agency support planning process. Consultees also noted that this role could form a valuable part of the IB approach.

Concluding statements

- 3.63 The 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 some 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 provides useful insights for this study.
- 3.64 Figure 3-1 provides an illustration of the approaches we investigated and their position on the existing service provision choice-control spectrum. This indicates the relative position of Direct Payments, IBs, BHLPs 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 3-1 : Choice/Control Spectrum



Source: SQW Consulting

3.65 Table 3-2 provides a summary of the overall research findings against each of the relevant research questions.

Table 3-2 Summary of overall findings

Analytical framework question	Finding
What approaches have been used to deliver IB and similar interventions at national or local level?	<ul style="list-style-type: none"> • in Control adult pilot work • Department of Health Adult Individual Budget Pilots • Dynamite and Taking Control pilots • Budget Holding Lead Professional pilots • Early Support Programme
Why have particular local authorities chosen to adopt an IB type approach in general, and for disabled children in particular?	<p>Local authorities have stated that they wish to offer more flexibility and control to families with disabled children and that there is a need to make their services more user-led, as opposed to supply-led.</p> <p>In addition, local authorities which have piloted other forms of self-directed support interventions, such as the BHLPI pilot sites, have chosen to extend this offer to embrace the growing personalisation agenda.</p>
What potential approaches could be used to deliver IB to the target audience?	<p>It is clear that IB for families with disabled children will include a set of options, which are likely to include the provision of:</p> <ul style="list-style-type: none"> • Training and awareness raising investment for local authority staff • Awareness and information dissemination activities for potential IB users • Development of an appropriate assessment and funding allocation system • Notional, financial and managed budgets to accommodate the differing needs and starting points of individuals • Support brokerage and advocacy services, which may be supplied by the local authority, an independent provider or a mixture of both • Peer support mechanisms.

Source: SQW Consulting

4: Barriers and success factors to the effective delivery of individual budgets

Introduction

- 4.1 The literature review identified a large 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 were echoed in the emerging findings from the in Control and Individual Budgets pilots.

Findings from the literature review – Barriers to delivery

- 4.2 The review of different approaches to delivering self-directed support indicated that some of the barriers associated with DPs had continued into the delivery of IB approaches. These included 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 continued 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 challenged their previous ways of working with service users. These included care managers and social workers involved in the assessment process. There was evidence of resistance to the introduction of training from some local authority staff who saw the introduction of IBs as a threat to their traditional ways of working.
- 4.3 Table 4-1 provides a summary of the literature review findings against the research questions set out in the analytical framework.

Table 4-1 Summary of literature review findings

Analytical framework question	Finding
What are the legislative and organisational barriers to effective delivery of the existing approaches, which may be relevant to the target audience?	<ul style="list-style-type: none"> Commissioning of support services is relatively underdeveloped in many local authorities Shortage of Personal Assistants to provide IB services
What are the key risks to the existing approaches that may also be applicable to the target audience?	<ul style="list-style-type: none"> 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

Analytical framework question	Finding
	<ul style="list-style-type: none"> • 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.

Source: SQW Consulting

Findings from fieldwork – Barriers to delivery

- 4.4 Following the literature review, we conducted a series of consultations and case studies. This exercise explored the views of a wide range of informants on the barriers to the delivery of an IB approach. We also asked them about how these barriers might be addressed and what might be the key elements of a successful IB approach. We set out the findings from these consultations in the next section.
- 4.5 As indicated in the literature review, barriers to delivering an IB approach occur at different levels - local authority (including staff resources, funding, and safeguarding), provider level (market constraints) and barriers affecting service users. Each of the types of barriers is discussed in more detail below.

Local Authority barriers

Staff resistance

- 4.6 The effective delivery of an IB approach depends on the commitment of the key staff involved in the process. However, it has been acknowledged that the IB approach represents a radical change to the traditional relationship between professionals and services users. The concept of service users managing budgets and having choice over which services they receive and how they are delivered has been perceived as a challenge to existing job roles. This was a barrier mentioned by the majority of local authorities. One local authority considered that it could take from six months to a year for staff to fully understand the IB approach and the potential benefits to families. Another authority cited resistance to culture change as a significant barrier as staff had found it difficult to understand how their roles and responsibilities aligned with the new forms of service provision. The need for investment in awareness raising and training for staff was frequently cited as a key element in setting up any IB approach.

Safeguarding issues

- 4.7 Safeguarding refers to the process of protecting children from abuse or neglect and ensuring that the care provided is safe and effective. The majority of local authorities saw the issue of 'safeguarding' as creating tensions in the delivery of the IB approach. Social workers raised concerns about the risks involved in transferring

responsibility for recruiting and employing personal assistants to the families of disabled children. A major concern was that families would not necessarily carry out the CRB checks, and that they would not be able to scrutinise staff in the way that local authorities could do. Families lack of experience of the employment relationship was seen as making them potentially vulnerable to poor quality care or financial abuse.

- 4.8 While acknowledging the conflict between promoting more control for families and the duty of care, some authorities thought that there was too much focus by professionals on the risks, rather than on the ways in which the risks could be managed. One transition coordinator believed that it was important to enable young disabled people to become independent and to be able to take reasonable risks to pursue their goals, and is working with professionals to develop a risk management tool.
- 4.9 There was general agreement amongst local authority interviewees and stakeholders, that safeguarding would be an important issue in the rolling out of IB to families with disabled children. Several expressed the view that there needed to be consistent procedures across local authorities – for example on policies towards CRB checks – as at present there is no statutory obligation on a family to undertake a CRB check. Some local authorities ensured that CRB checks were carried out and that the responsibility was not left to the individual family to instigate the process. An example of the potential risks was given of where an IB client had purchased support from a residential respite provider which had been rejected for a contract from the local authority.
- 4.10 Some of the stakeholder consultations also highlighted the lack of consistent procedures across local authorities in the vetting of providers. Not all authorities have a central vetting procedure for approving voluntary and community sector providers of services.
- 4.11 The new Independent Safeguarding Authority has been established to help prevent unsuitable people from working with children and vulnerable adults. Working in partnership with the Criminal Records Bureau, the Safeguarding Authority will gather relevant information on every person who wants to work or volunteer with children and vulnerable people. This means any individual who wants to work with children and young people must be registered. However, at present this does not apply to those individuals employing people to work from their home.

Shortage of support staff

- 4.12 The evidence from the implementation of IB approaches to date indicates the importance of IB clients having access to staff qualified to support them. This support is required from the initial stage of drawing up a plan to managing a budget. It was widely accepted that the majority of families would need access to support when first moving from traditional service provision to an IB model.

- 4.13 As discussed in the chapter on IB approaches, there are many different options for delivering support following the initial assessment process and the drawing up of the support plan. Although this initial stage is usually carried out by social workers, it could also be carried out by independent advisers or brokers. Many local authorities believed that once the IB had been awarded it was preferable for support in managing the budget to be provided by a source independent of the authority, such as a broker, or an agency specialising in providing advice to service users. This meant that the role of advice and support was separated from the funding and provision of services and might be more likely to be perceived as 'independent'. However, there were concerns that the infrastructure for providing this support was under-developed and some authorities might need time to build up the scale of resources that might be required.
- 4.14 This view was supported by some of the stakeholder consultations. The National Brokerage Network, for example, indicated that there were not sufficient numbers of trained brokers to meet demand as the majority of IB users would need support. It was therefore important that a range of support options were available and that those who provided support had received some training in the IB approach.

Cost and funding issues

- 4.15 Two barriers were raised during the consultations: difficulties in costing individual support packages because of lack of data; and the lack of integration of different funding streams.
- 4.16 The lack of unit cost data was cited by authorities as a barrier to rolling out IB to families with disabled children. This was particularly the case in authorities where there were directly provided residential services. Most authorities admitted that they did not have the unit cost data for any form of residential services and that it was difficult to obtain it as residential institutions were not willing to provide information in that form. One authority said that it was easier to cost services provided through an outside agency, as each agency had a contract with the authority. But without the unit cost data it was difficult to provide service users with the comparative cost information that would allow them to make informed choices about what services – and how much – they wanted to purchase.
- 4.17 One authority in which an IB pilot for adults had been rolled out, said that it had not been a barrier in adult services because there was no in-house residential provision. Where there was considerable in-house provision this could act as a barrier to the IB process. There was more concern in Children's Services about the impact of an IB approach on local authority residential services. The question of whether or not an IB could be used to purchase directly provided residential services was frequently raised.
- 4.18 The second issue, of the integration of funding streams, was widely regarded as a barrier to effective implementation. Several local authorities said that it was necessary for different sources of funding for IBs to be aligned more effectively. This barrier was particularly raised with respect to the proposed roll out of IBs to families

- 4.19 The lack of integration of health and social care funding streams was seen as undermining the IB approach by restricting choice. The example was cited of the eligibility criteria for continuing NHS health care and direct payments. Individuals receiving direct payments from social services are no longer eligible for direct payments once they move to receiving continuing care. The implication that an individual had either health care needs or social care needs but not both was seen as unduly restrictive and as limiting an individual's independence through the removal of direct payments.
- 4.20 The main concern amongst stakeholders was about the lack of a coherent legal structure setting out which funding sources could form part of the IB budget. It was felt that this would be a barrier to the implementation of IB pilots for families with disabled children, where local authorities were likely to want to draw on a wider range of funding streams than in the case of the Adult IB pilots.

Provider level barriers

Limitations of provider market

- 4.21 A major constraint on the delivery of the IB approach was seen by consultees to be the underdevelopment of the marketplace. This resulted from the fact that the traditional model of service provision involved block contracts by local authorities, and large providers were not geared up to respond to the demand for different kinds of services from individuals. One authority said that the demand for short-term and flexible services was difficult for service providers to respond to initially. Another authority expressed concern that service users' expectations were being raised about the variety of services that they could purchase although the market was not able to meet these expectations. One stakeholder commented that families were being offered large budgets – sometimes in the region of £50,00 - £100,000, but the services were not necessarily available to meet their needs.
- 4.22 One aspect of the change in demand for services is the increased demand for support services, including personal assistants, to enable people to live more independently. One authority highlighted the importance of providers moving to delivering 'support services as opposed to care services'. This fundamental shift means that authorities will need to engage with providers to bring them on board and encourage them to buy-into this change. However, some authorities were concerned that providers reliant on block contracts would be resistant to adapting their services. They thought that in the short-term innovative and flexible services might be forthcoming from the voluntary and community sector, but that it was important that

- 4.23 One authority had held a providers forum to communicate the IB approach but the larger providers of children's services had not participated. The authority felt that these large providers felt secure currently in their block contracts and lacked the incentive to adapt their services.

Staff shortages

- 4.24 Closely related to the barrier of underdeveloped marketplace, is that of a shortage of personal assistants and care workers to meet an increased demand for support workers. Several consultations highlighted the frustration expressed by service users who had difficulty recruiting personal assistants. Reasons for these difficulties included delays in obtaining information on how to recruit PAs, uncompetitive pay rates, some service users only requiring a small number of hours, and an overall shortage of PAs. Some service users after failing to find a PA/care worker, turned to an agency to supply someone. This sometimes meant that the service user had to pay a higher hourly rate and could afford fewer hours.
- 4.25 The issue of the employment conditions for assistants directly employed by a family was also raised as a factor affecting supply. Some stakeholder organisations expressed concern that PAs might lack support themselves and be asked to work long hours or be disadvantaged in terms of the pay and benefits that they received. Some interviewees thought that these concerns reinforced the importance of providing service users with guidance and advice on becoming an employer. Carers' organisations were keen to see the development of a best practice framework for the employer of carers to protect both service users and support workers.

Barriers experienced by service users

- 4.26 Interviews conducted with individual parents/representatives of parents' forums and analysis of the parents and young people's survey suggested that the barriers experienced by service users were closely related to the barriers to effective delivery identified by local authorities and stakeholders. They included:
- Difficulties in coping with the new role of being an employer. In the survey 30% of respondents deemed the recruitment and retention of staff and the extra burden to be a great drawback of the IB approach
 - Financial management and administration of the IB
 - Problems in finding good quality personal assistants or care workers
 - Reluctance of some professionals to support the IB approach. Some families felt they were not trusted to make decisions
 - Delays in receiving IB payments

- Inability to combine some funding streams within an IB – e.g. continuing care and direct payments
- Difficulty in exercising choice of services due to the limitations in what was available. This reinforced a tendency to fall back on traditional services and to assume that if an alternative did not already exist, it would not be possible to obtain it.

Key success factors

- 4.27 We asked all the consultees for their views on what would be the key requirements of a successful IB approach. This provided the opportunity to suggest how the barriers that had been identified might be overcome. A wide range of responses were given as discussed below.

Local Authorities

- 4.28 The following were the main success factors highlighted by local authority interviewees:

- **Leadership from senior management** - There needs to be a senior-level champion, such as the Head of Children's Services, to drive the pilot forward and communicate the benefits of IB.
- **Allocation of sufficient in-house staff resources to support all elements of the pilot** – This will include a full-time project manager, project workers, part time performance officer and input from the finance team and legal departments.
- **Sufficient engagement from senior members of the health, education and adult services teams in addition to social services** – This wider engagement is needed to ensure progress is communicated across the teams and therefore that the value of the work is made clear to those who can be influential to the success of new initiatives.
- **Investment in awareness raising and training to enable a process of culture change** – This will require training for all staff involved, both frontline and managers.
- **Support options for service users should be put in place from the beginning of the pilot** - There should be a menu of options including in-house provision, independent advocacy, support brokers and peer support. Their roles will include providing support with one or more aspects of the IB process from drawing up the initial support plan to managing the budget and commissioning services.
- **Skills training for staff already employed by the local authority** should be provided so that these staff can help meet the demand for support workers.

- **IT resources will be required** – Each local authority needs to develop appropriate systems to track all activities within the pilot and ensure effective monitoring and auditing of the IB pilot.
- **Use of an appropriate assessment process** – There is currently a divergence of opinion with some authorities using the in-Control RAS (in a series of adapted forms) and others preferring an outcomes focussed assessment.
- **Provision of a spectrum of choice for deployment of IB funds** – IB funds should be available in a variety of ways to ensure they are accessible to all families with disabled children, regardless of their background. The options may include a form of direct financial payment to the family, a third party holding and managing the IB, a service provider holding and managing the funds, the setting up of a Trust and the local authority managing the IB on behalf of the family.
- **Service users and providers should be involved from the outset in the development of the pilot** - This may take the form of awareness raising events, input to the steering group, training days and peer support groups of IB beneficiaries and potential beneficiaries. The authorities should look to developing partnerships with parent-led organisations and the voluntary and community sector.
- **The safeguarding issue needs to be addressed** and consideration given to developing a good practice framework with guidelines for both staff and service users. Some authorities take responsibility for ensuring that CRB checks are conducted, whereas others do not. Consistency across the authorities is required.
- **National guidance is required on the potential integration and alignment of funding streams** – This should include which funding streams can be feasibly included in an IB and the methods by which this integration/alignment can be developed.

Market development

- **Intensive market development is required** to build capacity for providing innovative and user-led services - This will require working with the independent, voluntary and community sectors and providing awareness raising and training. The key shift will be the need for providers to be responsive to the service users – children and parents – rather than primarily to the local authority.
- **Local authorities will need to review the commissioning process** and the balance of advantages and disadvantages of block contracts, spot purchasing and consider what is the appropriate balance between traditional commissioning procedures and the use in some circumstances of a more flexible procurement process.

- Where the potential demand within a local authority for a specialist service is relatively small scale, consideration could be given to **joint commissioning** of services by neighbouring authorities or on a regional basis.

Service users

- **Awareness raising and guidance** is essential so that families understand the reasons for the use of IB, and the potential benefits
- Families need **signposting to the options for support planning** so that they can make an informed choice
- Tailored **support on financial management and the employer role**
- **Families need support in identifying potential providers** in their area and the services they can offer
- To address the problems of finding suitable personal assistants, service users need **assistance in recruitment and information related to safeguarding issues.**

4.29 The table below summarises the findings from both the literature review and the consultations.

Table 4-2 Summary of overall 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>	<p>Local authority barriers</p> <ul style="list-style-type: none"> • Commissioning of support services is relatively underdeveloped in many local authorities • Shortage of Personal Assistants to provide IB services • Lack of existing infrastructure available to develop appropriate support brokerage <ul style="list-style-type: none"> • Safeguarding – difficulties in monitoring adequacy and quality of service provision, signalling a potential need to develop Inspection frameworks. Need for consistent procedures across authorities. • Some stakeholders thought there was a conflict between promoting control for families and the duty of car. Some thought that there was too much focus on risks rather than how risks could be mitigated • Transformation of service provision requires significant cultural change - resistance amongst care staff to promote IB approach • Funding streams were not integrated - difficulties in aligning health monies into an IB due to legislative barriers. Need for different sources of funding to be aligned more effectively • Lack of integration of health and social care funding streams seen as undermining the IB approach by restricting choice • Lack of unit cost data on services, especially residential services • 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

Analytical framework question	Finding
	<ul style="list-style-type: none"> ➤ Ensure links with finance departments • Commissioning process requires review – 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. <p>Provider level barriers</p> <ul style="list-style-type: none"> • Under-development of the provider market. Large providers used to block contracts not able to respond quickly to user-led demand • Shortage of personal assistants and care workers to meet demand <p>Barriers experienced by service users</p> <ul style="list-style-type: none"> • Role of employer and financial management seen as difficult • Problems in finding personal assistants • Perception that not trusted by professionals • Delays in receiving payments • Limited choice of available services
<p>What is the evidence on key success factors for IB?</p>	<p>Consultations identified the following key requirements:</p> <ul style="list-style-type: none"> • Leadership from senior management • Allocation by local authority of sufficient in-house resources from different departments, including finance and IT • Investment in awareness raising/training for staff - frontline & managers • Consistent and appropriate assessment process • Engagement with service users and involvement from outset in development of pilot • Provider engagement to encourage building of capacity to meet IB demand • Intensive market development • Review by local authorities of commissioning process • Awareness raising, and training for service users • Support for families in identifying suitable service providers and recruiting personal assistants

Source: SQW Consulting

5: Demand and added value

Introduction

- 5.1 In the literature review, we examined existing evidence on the question of the potential demand for an IB approach from families with disabled children. There is relatively little evidence from which to draw firm conclusions, and the most relevant data comes from the PwC review of the market for children’s services (PwC, 2007). This study suggests that for some services – particularly short break schemes - 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.
- 5.2 We also examined the evidence on the added value associated with an IB type approach. The research on service users’ responses indicated that the majority of users of self-directed support experienced positive outcomes to some extent. As awareness of the potential benefits for service users increases, this may encourage take up by the target population of families with disabled children.
- 5.3 Table 5-1 provides a summary of the literature review findings against each of the relevant research questions.

Table 5-1 Summary of literature review 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

Findings from fieldwork

- 5.4 Following the literature review, we conducted a series of consultations and case studies. This exercise explored the views of a wide range of informants on the likely demand for an IB approach from families with disabled children, and what types of services might be requested. We also asked them for their views on the added value

associated with IB approaches. In this chapter, we set out the findings from these consultations.

Demand for an individual budget type approach

- 5.5 The local authorities and other stakeholders were generally not able to provide an estimate of the potential numbers within the target group who would be interested in taking up an IB approach. However, there was a widely held view that many service users would welcome the notion of greater choice in type of services and how they were delivered. Some stakeholders felt that there might be a significant number of potential beneficiaries who would not wish to have the responsibility for managing a budget or employing a carer. However, it was not feasible to provide any estimate of how this might limit potential demand.
- 5.6 Several authorities pointed out that the disabled children's team was currently only providing services to a small proportion of the total number of disabled children and that it was difficult to predict what the take-up might be if an IB approach was actively promoted.

Types of services requested

- 5.7 Most local authority informants were able to suggest the kinds of services that they thought were likely to be requested by families who had an IB. These views were based on evidence from consultation exercises, or on evidence from existing pilot work, such as the BHLPs. The most frequently mentioned were **respite care and short breaks**. A wide range of services come under this heading including home based-support, overnight stays in residential homes, community based activity support, and school holiday play schemes. Several interviewees thought that parents would be most likely to use IBs to pay for alternatives to the Residential Care Units provided by authorities. This would imply an increased demand for home-based and community services, including assistance to enable a disabled child to go on day trips or other leisure activities. One authority that had consulted parents had found that they did not want their child to go to the respite unit; instead they wanted an extra pair of hands to help them out at home, and to employ someone to go on day trips with them.
- 5.8 These views were supported by the consultations with parents. In the survey of parents and young people, the most sought after provision for purchase via an IB was respite care. The types of respite care included both home-based and community based care available on a more flexible basis to meet changing needs during the year, including school holidays, after school and during the weekends. A consultation with parents on short breaks carried out by one local authority, found there was support for ad-hoc services to be available such as a drop-in centre.
- 5.9 Other suggestions from local authorities and parents about the main ways in which IBs might be used by families with disabled children included:

- Personal assistants and help with domestic work. The IB approach allows the individual to decide how much personal support is needed and from whom this might be provided, including family and friends
- Befriending for young people – to enable teenagers to lead a normal life and go out and about in the local community. One authority is working with the Children’s Society to develop a volunteer service.
- Equipment and adaptations to the home
- Mainstream recreational activities which disabled children can access out of school houses e.g. weekends, holidays, and before or after school
- Access to transport solutions tailored to the individual’s needs – eg purchase of a car for use by family/support worker
- Additional educational support – drama lessons, sports coaching etc
- Some parents also expressed the wish to use some of the IB funding to support the siblings of a disabled child.

Added value

5.10 The views of local authorities, other stakeholders and parents supported the findings in the literature review about the added value of the IB approach. Most of the focus was on qualitative changes in the following areas:

- **User choice and control over services.** There was general agreement that IBs provided families with the ability to decide which services were most appropriate for their children and think creatively about the options. Parents contrasted this with situations in which they had been provided with a single choice to which they could either access or not, but were not provided with any alternative. Some of those consulted said that they now felt they have more power to influence service providers to provide the appropriate services.
- **Improved partnership working between professionals and families in a user-led approach.** One stakeholder commented: ‘Families have been disempowered by the divide between professionals and parents. The IB approach could help the process of empowerment.’
- **Greater consistency in service delivery.** Because the IB enables the family to purchase the support they require they are more likely to be able to reduce the number of different carers/assistance. Under the traditional model of service delivery, support is fragmented and a family may be dealing with as many as 20 carers over a week.
- **Greater cost transparency.** Service users are often unaware of the comparative cost of different types of provision. Responsibility for the budget means that they have more understanding of what different services cost and are able to make a more informed choice about which services they want.

- 5.11 In addition to these changes, some authorities also highlighted the potential cost effectiveness of the IB approach. Where cost reductions were cited as an added value for the authority, this was usually attributed to reductions in the time spent with clients by social workers, as responsibility for commissioning services and managing budgets is devolved to the service user. But the set-up costs of training the professionals in the new approach should be set against the cost savings. There was no consensus as to whether the IB assessment process took less time or more time than the traditional assessment, and some authorities thought that an outcomes focussed assessment could mean that more time was required in agreeing outcomes and designing the support plan.
- 5.12 Another source of potential cost effectiveness mentioned was when individuals chose to purchase less expensive services as alternatives to residential care. However, most authorities do not have the unit cost data on which to compare different types of provision.
- 5.13 Several consultees also emphasised the potential added value that could be developed through the integration and alignment of the IB pilots with complementary programmes i.e. The Transition Programme, Short Breaks Programme, Early Support Programme etc.
- 5.14 The table below summarises the findings from both the literature review and the consultations.

Table 5-2 Summary of overall findings

Analytical framework question	Finding
How large is the potential target population of disabled children and their families?	<ul style="list-style-type: none"> Inherent difficulties in estimating the target population, given the lack of consistent statistical data. Consultations with local authorities did not provide firm figures but indicated that they anticipated that many serviced users would be interested in taking up the IB approach, but that some would not want the added responsibility of managing a budget or being an employer
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. The consultations supported the notion that the IB approach was appropriate for all families with disabled children
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?	<p>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.</p> <p>Evidence from the consultations points to a variety of services that the target group would like to access, including a wide range of flexible options for short breaks, more accessible mainstream recreational facilities, personal assistants, equipment and adaptations, and transport support.</p>
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. Some stakeholders also highlighted greater consistency in support delivery through a reduction in the number of different carers, greater cost transparency, and an improved relationship between professionals and service users.

Source: SQW Consulting

6: Funding

Introduction

- 6.1 The literature review identified the main funding streams that have been used within an Individual Budgets (IB) package. This found that 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).
- 6.2 We also examined the funding streams that were used by the Department of Health Adult IB Pilot Programme, which advocated the use of six funding streams which could be brought together to form an IB. Table 6-1 illustrates the six streams, where each was subject to its own legal structure and policy guidance.

Table 6-1: 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

Source Waters and Duffy (2007)

- 6.3 The Social Care budget was the largest in size and in comparison to all the other funding streams was flexible in its nature, whilst the other streams come with more constraints. It is also important to note that the adult IB pilots were stated to be limited in their nature as it was not possible to integrate income streams (i.e. creation of a single pot of funding which is not bound by the individual restrictions of the incorporated funding streams) in the absence of legislative or rule changes, therefore alignment (i.e. creation of a pot comprising of distinct funds, where individual contributions from separate funding streams are each bound by their associated restrictions) was largely all that was possible. (Routledge, 2007).

- 6.4 At present 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 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.
- 6.5 Table 6-2 provides a summary of the literature review findings against the research questions set out in the analytical framework.

Table 6-2 Summary of emerging findings from the literature review

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
What are the potential service related implications associated with an IB approach?	No current evidence

Source: SQW Consulting

Supporting evidence from the fieldwork

- 6.6 Following the literature review, we conducted a series of consultations and case studies. This exercise sought to further our understanding of the main funding streams currently used in IB packages (with a particular emphasis on those used for families with disabled children), the reasons why other funding streams are currently excluded, the set of funding streams that would be desirable to include in an IB and the challenges associated with the integration/alignment of these funding streams.
- 6.7 Annex F presents some additional information (sourced through a supplementary desk-based exercise) on a number of the funding streams explored during the research.

Funding streams currently used in IB packages*Adult beneficiaries*

- 6.8 Consultation evidence indicated that the majority of local authorities which were offering an IB to disabled adults were heavily reliant on the social care budget. Small amounts of additional funding have been drawn in from additional sources, such as the Integrated Community Equipment Services (ICES), the Independent Living Fund and the Disabilities Facilities Grant (DFG). However, difficulties have been experienced with both the ILF and DFG as a result of incompatible eligibility criteria and separate assessment, monitoring and audit requirements. For example, the ILF was cited to be constrained by its Trust Deeds, which prohibited the integration or the alignment of the fund at the local level. Consultees went on to state that IB users had been required to complete an ILF application form and were therefore not guaranteed a contribution from the fund. This meant that ILF resources could not be included in the initial budget and entailed that the fund could not be used flexibly within an IB.
- 6.9 Looking specifically at the DFG, one local authority stated that they had found it difficult to understand the regulations surrounding DFGs and had had little national guidance to support them to do so. They added that the DFG required a more complex assessment than the IB assessment and that they had had problems providing their staff with the additional training to enable them to undertake this lengthier process.
- 6.10 General frustration was also expressed at the lack of national commitment and guidance on funding integration/alignment for service provision of this nature. Consultees emphasised the need to adapt and change the current policy/legal framework surrounding the use of distinct funding streams, as it was seen to be restricting the ability of local authorities to integrate/align funding streams. For example, several consultees discussed the differing and incompatible eligibility criteria between direct payments/IBs and the provision of continuing care, which essentially resulted in an individual being eligible for either one or the other, even if they had both social and health care needs.
- 6.11 Looking specifically at the integration/alignment of health budgets within an IB package, little progress appears to have been made in this area. However, we identified two local authorities which had used health funding within an IB/DP package. The first successfully managed to incorporate continuing health care monies into one of their IB packages, which was helping to support the recipient to remain at home. The second local authority creatively used health funds to meet the needs of one of their DP recipients who also had complex health needs. This arrangement was facilitated by the local authority paying for the necessary health provisions, which was later invoiced from the PCT. Therefore, evidence suggests that joint working between the social services team at the local authority and the PCT can facilitate innovative combinations of service provision.
- 6.12 Encouragingly, one consultee also stated that although it is was not currently possible to directly allocate health monies into the IB pot, there was potential to pool

health budgets on the premise that they pass Section 75 of the National Health Service Act 2006 (which is essentially the same as Section 31 of the Health Act 1999).

Families with disabled children

- 6.13 Local authorities which have piloted IB provision to families with disabled children have encountered a similar set of difficulties to that of adult provision. The main barrier was again cited as a lack of coherent policy/legal structure detailing which funding sources could form part of an IB package.
- 6.14 Although a number of the local authorities were still considering which funding streams to include within their IB pot, those local authorities which had completed their funding alignment process were using the following:

Children aged 0-16 years

- **Social Care budget.** - All local authorities accessed social care funding, which formed the majority of the IB. Social care funding was said to be less complicated to access than any other funding stream.
- **Short Breaks funding** – Some of the Short Break Pathfinder areas have successfully integrated some of their short breaks funding into the IB packages. This integration process had been unproblematic.
- **Pooled health budgets** - A small number of local authorities reported the use of pooled budgets between the local authority and health. The pooled fund allows partners to contribute funds to be spent on a commonly agreed plan.
- **Education based transport funding.** – One local authority was in the process of drawing in some education funding to reimburse the petrol costs incurred by a disabled young person on their way to and from school/college.
- **Integrated Community Equipment Service Fund** – A number of local authorities have found it easy to draw the ICES into an IB as it was jointly funded i.e. a 50/50 split, by health and social care.
- **Additional funding streams applicable to children aged 16+ years**
- **Independent Living Fund.** ILF has been accessed by IB recipients who are 16+. However, consultees stipulated that stringent assessment and financial criteria, coupled with constraints on what the ILF funding could be used for had meant that IB users were essentially being paid their IB and ILF monies separately. Therefore integration had not really occurred.
- **Learning and Skills Council Individual Learner Funds** – Although none of the consulted local authorities had integrated this form of LSC funding into an IB package, stakeholders identified that progress had been made in the East of England, which would enable the integration of this funding in the future.

- 6.15 In addition, one local authority that was in the process of setting up a Taking Control pilot, stated that it had facilitated the pooling of funds between the local authority and the PCT through its Children's Trust prior to the pilot. This budget had been used to fund several services, which included social service provision for children and families, SEN, statementing, occupational therapy, community medical child health, and it was hoped that this service offer could be extended to their IB users in the future.

Funding streams local authorities would like to use as part of an IB for families with disabled children

- 6.16 All consultees were asked for their views on which funding streams they felt should be included in an IB package for families with disabled children in order to maximise their impact. Responses were largely similar and again echoed the need to integrate social care, health and education funding streams to ensure their IB pot included a critical mass of funding. Consultees went on to state the subsequent need for clear national guidance to enable the integration/alignment of the desired funding streams.
- 6.17 Looking specifically at health funding streams, nearly all consultees stated that there was a clear need to integrate particular health monies into an IB package to ensure that it offered a holistic approach to service provision. The following health funding streams were identified as necessary to facilitate a holistic approach:
- **Continuing care funding** – Consultees expressed a desire to ensure that a disabled child who had complex/continuing health care needs could access both social care and continuing care funding through an IB. They added that the prevalence of complex needs had increased over recent years and that there was therefore a rising need to effectively support these children and their families. One parent voiced their frustration at the fact that their son had had his direct payment stopped when he had started to receive continuing care funding. They added that when they went back to the local authority to query the change, they had been told that an individual could not receive both a direct payment and continuing care, as a result of funding regulations. In summary, consultees felt that current legal structures prohibited the inclusion of this funding stream within an IB.
 - **Community health budget/funding for therapy services** - Consultations indicated a demand for services such as speech, language and occupational therapy by families with disabled children. A number of consultees also stated that traditional provision of such services was restrictive and intrusive for families, who were expected to transport their disabled child to and from appointments. The AHDC strategy also reinforces the importance of therapy services in improving outcomes for disabled children. However, consultees again cited that legal restrictions have prohibited the inclusion of this funding stream within an IB for families with disabled children.

- 6.18 Discussions around the integration of education budgets also revealed a desire to include particular forms of education funding. These included the Extended Schools, Sure Start and Children's Centre budgets, which could all be used to meet the current demand from families with disabled children for intensive childcare support. However, local authorities are currently unclear whether childcare provision can form part of IB service provision, which dictates a need for guidance from the DCSF on this issue.
- 6.19 One local authority was in the process of pooling money from their extended schools budget to develop an 'inclusion grant' which could be used as a flexible allowance for a range of services for disabled children. Although this had not been integrated into their IB provision, it provided scope to support the provision of transport and short break services and therefore may in the future be form part of their IB provision.
- 6.20 A number of consultees also stated a desire to include education allowances which were 'tied to the child' within an IB package. However, several consultees also expressed their concerns on the use of this nature of budget for this purpose. For example, one consultee stated that it would be extremely difficult to connect an IB to the statementing process, as it required a distinct professional assessment, which was likely to be more complex than the IB assessment and subject to separate review arrangements, which were unlikely to align with the IB review process. They therefore felt that the SEN budget should not be included within an IB.

Concluding statements

- 6.21 The issue of funding streams is proving to be one of the most difficult in terms of implementation. As discussed above, existing IB pilots have made little progress in integrating/aligning health and education funding streams largely as a result of confusion on how funding streams can legally be used, current policy restrictions and a lack of clarity and guidance from the various government departments. However, stakeholders, local authorities and parents have expressed a need to alleviate these barriers to enable the provision of an IB package which can facilitate the provision of social care, health and education services i.e. a holistic package of support. It is also important to note that the research findings indicate a demand for both health and education services (in addition to social service support), in the form of therapy, continuing care and specialist childcare provision, as part of an IB package.
- 6.22 Table 6-3 provides a summary of the research findings against each of the relevant research questions.

Table 6-3 Summary of emerging findings

Analytical framework question	Finding
What budgets did the existing pilots draw upon in their delivery?	<p>DH Adult IB pilots:</p> <ul style="list-style-type: none"> • Social Care budget • Supporting People • Independent Living Fund • Disabled Facilities Grant • Access to Work • Integrated Community Equipment Service <hr/> <p>Existing IB pilots for families with disabled children currently commonly using:</p> <ul style="list-style-type: none"> • Social care budget <p>More innovative and unusual use includes:</p> <ul style="list-style-type: none"> • Integrated Community Equipment Services budget • Pooled health budgets – using Section 75 of the National Health Service Act 2006 • Short Breaks funding • Education based transport funding • Independent Living Fund • LSC Individual Learner Funds
What set of income streams are applicable to the families with disabled children, which could form part of the IB package?	<p>In addition to those set out above, the following funding streams were stated as necessary additions to maximise the impact of IBs:</p> <ul style="list-style-type: none"> • Pooled health, social care and education budgets – via joint commissioning powers of Children’s Trust • Continuing Health Care • Community Health budget/funding for therapy services • Extended Schools budget • Sure Start budget • Children’s Centres budget <p>Note: The majority of the above will require legislative/structural change at the national level to facilitate their integration into an IB package.</p>
Specifically with regard to health, how and which budgets have been pooled to facilitate an IB type approach?	<p>Little evidence but is likely to involve:</p> <ul style="list-style-type: none"> • Using Section 75 of the National Health Service Act 2006 to pool budgets between the PCT and the local authority <p>AND/OR</p> <ul style="list-style-type: none"> • Pooled health, social care and education budgets – via joint commissioning powers of Children’s Trust
What are the potential service related implications associated with an IB approach?	<p>Existing pilot funding limits the IB user to sourcing mainly social care provisions. An extension of this funding to include more extensive use of education and health funding streams will facilitate a wider and more holistic provision of support services.</p>

Source: SQW Consulting

Next steps

- 6.23 This chapter has highlighted a number of issues around the funding streams that can be drawn in to IBs. The views gathered are from a practitioner perspective. In most cases they have been able to report what they would like to do, but have only a low level understanding of why this was not possible. The message as understood at local level is that there are often policy or legal blockages to being able to access other funding streams, in particular around education and health. For example, on the health side continuing care and funding for therapy services were cited as being inaccessible at present, and on the education side, consultees were unclear about which funding streams could be accessed and therefore requested more national guidance on the matter.
- 6.24 In the course of this study we have not sought to approach this issue from the other direction, i.e. by going to national policy makers or legal experts to test this understanding. However, if IBs are to move forward as many would like, then resolving these issues will be important. This would be best done through detailed discussions between DCSF and other government colleagues around a series of key questions. This approach would have several advantages as it would:
- Be more cost effective than each local area seeking its own resolution
 - Provide for a consistent response across the country, which could be communicated to appropriate parties through respective communication channels
 - Enable possible work around or adaptations to be discussed where barriers exist.
- 6.25 The agenda for these meetings should be based around a series of questions which the DCSF should seek to clarify with other teams within the DCSF and other government departments:
- The Department or team's policy towards the personalisation of benefits and services agenda in general
 - Their knowledge of IBs for young people or adults
 - Have they assessed the suitability of their funding streams for IB
 - Have they issued any guidance in relation to IBs more generally, or do they plan to
 - Have they received any requests for approval or clarification using funding streams to contribute to IBs. If so in relation to which funding streams and how did they respond
 - Are they aware of any legal barriers to using their funding streams to contribute to IBs

- Are there ways in which the legal barriers can be worked around (for example the case above where families bill the local authority which then invoices the PCT). If so have these been used in practice or the possibility highlighted
- Are there any other barriers to the use of these funding streams as part of IBs
- Again, can these barriers be overcome and has this been done in practice
- Where legal or other barriers are identified and no workaround appears possible, what would need to happen to address this?

7: Recommended features of a common delivery model

Introduction

- 7.1 Evidence from the research suggests a need for a set of clear and flexible guidance to underpin the delivery of the forthcoming pilots. The information gathered also suggests that thinking and evidence are sufficiently advanced to promote a general model at this point in time. The guidance should include both a 'loose' common delivery model, which sets out the basic shape and format of the pilots, and strategic guidance from the DCSF. Flexible guidance of this nature will ensure a sufficient level of consistency is maintained between the pilot sites and in addition, that each site is given the autonomy to deliver the pilot in a way that they feel is suitable.
- 7.2 This approach will also aid the evaluation of the IB pilots, as it will facilitate the analysis of both consistent (and therefore comparable) and distinct factors across the pilot sites. This will provide an opportunity to examine the process by which the guidance is implemented across the sites and any resultant variations in both delivery methods and outcomes. Potential evaluation criteria are discussed in more detail in Chapter 10.
- 7.3 The following chapter sets out the recommended common delivery model and accompanying information and guidance required from the DCSF for the forthcoming pilots. This guidance draws on the evidence gathered during the research.

Recommended common delivery model

- 7.4 The common delivery model provides recommendations on ten essential requirements for the forthcoming pilots. Each requirement is based on a rationale which was identified during the course of the research and has been developed from existing and suggested good practice.

1. Staff and wider engagement

- 7.5 The effective delivery of an IB approach was identified as being dependent on the commitment of a set of key staff. This included a variety of expertise, which included the following core set of staff:
- **A senior-level champion** to drive the pilot forward, effectively champion and communicate the benefits of IB and promote the necessary cultural change associated with the new form of service provision. Evidence also indicated that a key senior representative would help to initiate the integration of work and funding practices across social care, education and health teams. Examples of this form of champion included the Head of Children's Services and a member of the Executive Board of a local authority.
 - **A dedicated project manager** to ensure that the pilot and associated organisational culture change are effectively managed.

- **1-2 project workers** to support the project manager and undertake project-related tasks e.g. engaging potential users, supporting the development of the resource and funding allocation system, supporting the assessment procedure.
- **A part-time performance officer** to monitor and review progress against pilot objectives/targets (e.g. numbers and characteristics of beneficiaries), planned expenditure against actual expenditure for individual IB users (i.e. audit support) and progress against outcomes set out in individual support plans.
- **Dedicated time from the commissioning and finance teams** in the former case, to enable and manage the culture change and market development process required on the part of the provider market, and in the latter case, to support the development of financial auditing systems and the resource & funding allocation system.
- **Engagement from members of the health, education and adults services teams in addition to social services** to ensure progress is communicated across the teams and therefore that the value of the work is made clear to those who can be influential to the success of new initiatives.

7.6 We recommend that each pilot site seeks to recruit and engage this crucial set of staff.

2. Provision of change management programme for all staff involved

7.7 All existing provision of IBs or interventions of a similar nature involved a significant level of cultural change on the part of the local authority staff, beneficiaries and service providers. Looking specifically at the former of these groups, the success of a pilot of this nature will be dependent on sufficient investment in awareness raising and training for staff. This form of support will help to promote the benefits of IB and reduce confusion and anxiety around changes in staff responsibilities which has occurred in several cases.

7.8 We recommend that sufficient investment is allocated to awareness raising and training for staff. We would like to emphasise that we are not advocating any specific form or delivery method for these activities and therefore encourage each pilot site to develop appropriate and innovative means of undertaking this recommendation.

3. Facilitation of awareness raising and information dissemination for potential beneficiaries

7.9 Following on from recommendation 2, evidence also indicated a need to effectively promote the benefits of and processes associated with IB to potential beneficiaries, to ensure users are sufficiently informed and can therefore make an educated choice about whether to take-up the new form of service provision or not. This activity has included members of the local authority undertaking home visits to discuss the merits of the IB approach with a disabled child and their family and short taster sessions,

which have sought to promote the intervention and address any questions posed by potential users.

- 7.10 We recommend that sufficient investment is allocated to awareness raising and information dissemination for potential beneficiaries.

4. Provision of advocacy and support brokerage for IB users

- 7.11 Existing provision has also shown that once a disabled child and their family have signed up to receive an IB, it is crucial for the local authority to facilitate some form of individual and tailored advocacy and support brokerage services. This provision will ensure that the IB offer is accessible to all disabled children and their families, regardless of their support requirements.

- 7.12 We recommend that each pilot site develops an advocacy and support brokerage service at the inception of the pilot. This service may be provided via one of the following options as to date there is no conclusive evidence of which works best:

- Local authority, in-house provision
- Commissioned out to the independent sector – including use of user-led organisations and planning workshops
- Multi-disciplinary approach to support brokerage – where users can benefit from both local authority knowledge of service availability and independent advice.

- 7.13 The service should provide the necessary support to the IB user, which is likely to range from the drawing up of the initial support plan to managing the budget and commissioning services. We also recommend that the service provides some form of payroll and administrative support to families to ensure they adhere to employment legislation and the monitoring/auditing requirements of the pilot.

5. Facilitation of peer support mechanisms for IB users

- 7.14 A number of the local authorities consulted emphasised the importance of peer support between their IB/BHLP/DP users, which was echoed by a number of the parents consulted during the research. Both local authorities and parents stated that this form of mutual support was invaluable when trialling new and experimental forms of service provision, and parents added that it helped to reduce their anxieties during the organisation of their support.

- 7.15 This form of support for families with disabled children is currently facilitated through a range of mechanisms which include email groups, the facilitation of regular user meetings at the local authority and support through user-led organisations.

- 7.16 We recommend that each pilot site facilitates some form of peer support for their IB users.

6. Development of appropriate IT systems

- 7.17 Existing evidence suggests the need to develop appropriate IT resources, to enable the tracking of all activities within the pilot and to ensure effective monitoring and auditing of the pilot. Existing systems have generally comprised of short-term additions to active IT resources and therefore do not constitute a long-term solution. However, a small number of local authorities have developed and implemented an IT resource which acts as an overarching social care, assessment and review tool. These more comprehensive systems seek to:
- Monitor and review progress against pilot objectives/targets (e.g. numbers and characteristics of beneficiaries)
 - Incorporate the resource and financial allocation system and therefore record the results of assessment procedures
 - Retain details of all support plans and their associated commissioned support and planned expenditure
 - Monitor and review planned expenditure against actual expenditure for individual IB users (i.e. audit support)
 - Measure progress against outcomes set out in individual support plans.
- 7.18 We recommend that each pilot site develops an IT resource, which aligns with an existing system and which undertakes the set of tasks listed above. It will also be important to consider the timeliness of the monitoring/auditing/review procedures, where a balance should be struck between ensuring that funds are used appropriately and that families are not over-burdened with administrative responsibilities.

7. Development and implementation of a resource and funding allocation system

- 7.19 All existing IB pilot sites have developed some form of resource and funding allocation system, which has been used as the basis for allocating IBs. This in the main has taken the form of the adapted children's based in Control Resource Allocation System (RAS), and a few noteworthy exceptions which have chosen to develop their own outcomes-based system. Both systems include some form of assessment process, which has again varied from a self-assessment to a professionally supported assessment.
- 7.20 As the adapted RAS and outcomes-based systems have not yet been formally evaluated, it is unclear whether one system is more appropriate and effective than the other. Therefore, we recommend that pilot sites are given a choice between development of either a RAS based systems or an outcomes-based system, but overall a mix of approaches should be trialled. This will enable the evaluation of both systems and therefore inform the future development of IB provision for families with disabled children.

8. Provision of a spectrum of choice for management of IB funds

7.21 One of the key requirements of the forthcoming pilots is the need to ensure that the IB offer is accessible to all disabled children and their families. Evidence suggested that accessibility was in part dependent on the provision of a spectrum of choice for the management of IB funds, as without this, some families would be deterred by the financial responsibility associated with the intervention. Therefore, we recommend that each pilot site offers a choice of management support for the IB fund, which should include an appropriate selection of the following:

- Family or disabled young person is paid the budget directly and manages the money themselves
- A third party or representative holds and manages the money on the families/disabled young person's behalf
- A trust is set up to act on behalf of the disabled child and their family, which holds and manages the money
- The IB is paid directly to a service provider who manages the money through an Individual Service Fund, which stipulates that funding is ring-fenced and can only be spend on behalf of the disabled child and their family
- The care manager or the local authority acts on behalf of the disabled child and their family and organise service provision based on their allocated budget
- Offer a 'phased approach' to the deployment of IB funds, where the family is provided with management support until they feel they are equipped to take on the management of the budget themselves.

7.22 We also recommend that the assessment process take into account the amount of support required by a family to manage the budget and allocate additional funding (within the IB) to accommodate those families who choose to use a managed fund (which will require payment for managed services). Alternatively, a local authority could top slice their overall IB budget to facilitate this form of support.

9. Facilitation of sufficient market development

7.23 Intensive market development is required to build sufficient and appropriate capacity to provide innovative and user-led services. Therefore we recommend that each pilot site undertakes the following activities:

- A review of all applicable service provision in the area – to include both local authority and independent provision
- A review of commissioning processes to understand what the appropriate balance is between traditional commissioning procedures and the use of more flexible procurement processes

- Awareness raising activities and the provision of capacity building training for local service providers (including from the voluntary and community sectors), to enable a key shift from supply-led to demand-led service provision.

7.24 This activity is not expected to transform the provider market in its entirety (as the pilots will only offer an IB to a limited number of families with disabled children) and is instead intended to act as a catalyst for further market development.

10. Engagement of all parties in development of the pilot

7.25 Evidence from the consultation exercise highlighted the need to involve both providers and parents/disabled young people alongside local authority staff in the development of the pilots. This engagement process was advocated as it supplied a continuous form of feedback, ensured that the views of all parties were taken into account and facilitated a transparent and open process during the development of the pilot.

7.26 Potential forms of engagement include the recruitment of parent and provider representatives on pilot steering groups, the development of a provider/parent/young disabled people's forums and the creation of an appropriate reference group.

7.27 We recommend that each pilot site engages both a set of appropriate parents/disabled young people and providers to support the development of activities throughout the course of the pilot. We would like to emphasise that we are not advocating any specific form or delivery method for these activities and therefore encourage each pilot site to develop appropriate and innovative means of undertaking this recommendation.

Recommendations for the DCSF

7.28 One of the key points identified from the consultation exercise was the need for the DCSF to ensure the provision of a considerable amount of support to work alongside the pilots and a need for clear (but loose - to maintain flexibility of IBs) guidance on a number of issues. In addition, the majority of requests made by both local authorities and stakeholders emphasised a need for strong political leadership for a pilot of this nature to ensure that positive and clear messages were passed to pilot sites. This should include drawing in related Departments and services that they fund.

7.29 The following consensus of suggestions have been identified from the research, which we recommend the DCSF provides either from the outset of the pilots or develops during the pilots:

Provision from the outset of the pilots

- **Implementation and delivery support** to all pilot sites
- **Monitoring and evaluation tools** which are likely to be centrally designed by the contracted evaluation team

- **Guidance on the integration and alignment of funding streams**, which should include which funding streams can be feasibly included in an IB and methods by which this integration/alignment can be developed i.e. provision of guidance on what is permissible and associated references to additional documents which clarify the approaches which could be used to integrate/align the various funding streams. In providing this DCSF should seek the endorsement of other government departments as appropriate
- **Guidance on safeguarding**, which should set out a minimum standards to be adopted across all the pilot sites and consider issues such as whether everyone providing a service should be subject to CRB checks, including employed family members?
- **An information pack which sets of the key differences between Direct Payments and Individual Budgets** to inform users and delivery staff of the important distinctions between the two forms of self-directed support.

Evidence base to be developed during the pilots

- **Legal guidance** for local authority staff, providers and families/disabled young people on subjects such as personal liability insurance. As the legal framework of each pilot will be defined by the relevant local authority, it will be important for the DCSF to formulate working guidance on the broad standards to be met rather than the detail of how this should be done.
- **Eligibility of who an IB can and cannot be spent on** e.g. can an IB be used to support the siblings of a disabled child, if this will support the family, or can it only be used to directly support the disabled child?
- **Guidance on what an IB can and can't be spent on** (again framing this loosely, to avoid constraining the use of IBs and innovative solutions), which should include the provision of **an information bank of examples of how IBs have been used**. This dissemination of information will encourage uptake and the innovative use of IB.
- **Ongoing guidance on commissioning and market development.**

Forthcoming pilots

- 7.30 The research advocates that each pilot site meets the ten core requirements set out in the common delivery model and that the DCSF provides the set of guidance and information set out above. It is also important to consider and define the target group(s) for the forthcoming pilots, which forms the content of the following chapter.

8: Purpose of the pilots and the pilot options

Purpose of the pilots

- 8.1 In May 2007, the government through its AHDC Strategy made a commitment to pilot Individual Budgets for disabled children and young people, to increase the flexibility and choice in the provision of services. The Strategy also recommended the inclusion of as many funding streams as possible at a local level, with a particular emphasis on 'health funding streams, where there is already the potential and legal provision of pooled budgets, and where needs are predictable and specific to an individual'.
- 8.2 This set of recommendations determines the purpose and main aims of the forthcoming pilots. The analysis presented previously in this report provides additional clarity about the purpose for the pilots. In summary, the evidence available to date which we have gathered in respect of the analytical framework provides a series of indicative conclusions. While some of these are better based on evidence than others, and on some there is broad practitioner agreement while on others there is not, it is apparent that the pilots present a significant opportunity to develop the evidence base. This lack of evidence is not unexpected at this stage in the policy development process, but rather emphasises the importance of careful pilot design to maximise the amount of robust evidence that can be extracted to fully inform future direction and possible roll out.
- 8.3 The first question is the most fundamental
- Is the provision of Individual Budgets to families with disabled children a viable alternative to traditional forms of service provision for some or all families?
- 8.4 There needs to be realism about what can be assessed in the period that will be available for the pilots. However, while there is anecdotal evidence to support this, greater attention should be paid to what type of person/family benefits and similarly the characteristics of those who do not. Indeed, while evidence exists around some groups, it is difficult to understand the implications of this for the whole cohort.
- 8.5 Following from this are then a series of questions around cost and demand implications and then about process and good practice in delivery. In terms of costing the available evidence is inconclusive and we suspect this may remain so at an individual level. What could however be drawn out is:
- Changes in levels of demand as new families take up services (even at standard unit costs this would add to aggregate costs)
 - The cost implications of providing brokerage and support services set against possible savings in commissioning and management.
- 8.6 Then at a process level the key issues will be around:

- Which income streams can successfully be integrated or aligned into an Individual Budget package
- What are the characteristics of the families who take-up the Individual Budget offer
- Does the timing or delivery of certain elements (such as brokerage) in some ways more positively influence outcomes than others

8.7 The remaining part of the chapter sets out the list of potential pilot options developed during the research, the feedback gained on the feasibility and desirability of these options and a set of recommendations on which options should be taken forward as part of the forthcoming IB pilots.

Potential pilot options

- 8.8 The third aim of the scoping study was to develop costed options for the forthcoming pilots to be taken forward as part of the AHDC programme. The first step in this process involved compiling a long list of potential pilot options whose feasibility and desirability could be considered during the consultation and case study stages of the research. These options were mainly identified through either the literature review or the scoping consultations, and in a small number of cases, options were developed to potentially fill gaps in existing service provision or as a result of additional suggestions made during the consultation exercise.
- 8.9 The list below details the final set of potential pilot options identified during the research, which were discussed during the consultation and case study exercises.

Targeting by type of disability

- Target **children in continuing care** with complex health needs (CDC, 2006) – the CDC stated that resources should be targeted at this group as a result of the increasing prevalence of children with complex health needs, who in general require very expensive service provision which can be intrusive to family lives. They also state that this group of children are easily identifiable and usually known to a multi agency team, which could be used as the basis of support and who could review the way in which resources are allocated.
- Target **children needing 24 hour continuity** to accommodate severely challenging behaviour – the CDC provides the following justification for targeting provision at this group: “there are a small number of identifiable children in each authority with severely challenging behaviour. The evidence suggests these children need a high level of continuity in relation to the management of behaviour. An Individual Budget pilot would look at whether there were better ways, within current resources, at providing continuity and preventing placement out of authority”.
- Target **specific age groups with high support needs** (ODI reference in the CDC, 2006) – children with high support needs are generally associated with

- Target children and young people with an **Autism Spectrum Disorder (ASD)** – the Short Breaks Full Service Offer states that provision must ensure that children and young people with ASD are not disadvantaged in accessing short breaks. Therefore a focus on this group will complement the Short Breaks Programme of AHDC.
- Target children and young people **aged 11+ with moving and handling needs that will require equipment and adaptations** - the Short Breaks Full Service Offer states that provision must ensure that this group are not disadvantaged in accessing short breaks. Therefore a focus on children and young people aged 11+ with moving and handling needs will complement the Short Breaks Programme of AHDC.

Targeting by age group

- Target **children coming out of the Early Support Programme** i.e. those aged 5/6 yrs (CDC, 2006) – the Early Support Programme (ESP) provides support for disabled children aged 0-5 yrs to manage the services they receive, however this provision ceases after the age of 5 and is not available in any form until the child reaches transition stage i.e. 14 yrs old. Therefore, the provision of an IB at the end of the ESP will provide continuity in service provision and is likely to lead to a number of cost effective solutions.
- Target **disabled children who are moving from primary to secondary** schooling i.e. those aged 11/12 yrs – this group of children were identified as requiring additional support during the transition from primary to secondary schooling, which can lead to a significant change in the support required for both the child and their family e.g. new equipment and transportations requirements.
- Target **disabled children aged 5-14 yrs**, to ensure a continuous spectrum of service provision from the Early Support Programme (0-5 yrs) through to the Transition Programme (14-25 yrs) – this option is essentially an amalgamation of the two previous options and has been suggested as a means of providing a continuous spectrum of choice/control service provision for a disabled child and their family as they progress through life.
- Target disabled children **aged 14+ yrs i.e. those in transition** - the Short Breaks Full Service Offer states that provision must ensure that this group are not disadvantaged in accessing short breaks. A focus on young people aged 14 and in transition will complement the Short Breaks and Transition Programmes of AHDC.

Targeting by point of entry to the system

- Target **newcomers to the social care system or disabled children at the point of intervention** – emerging findings from the consultation exercise suggested that families with disabled children may be content with their current package of service provision and therefore that any new form or provision i.e. Individual Budgets, can justifiably be targeted at those who are new to the service/at the point of intervention.

Targeting by socio-economic characteristics

- Target **disabled children from Black and Minority Ethnic (BAME) groups** as a means of understanding the cultural needs of different groups of families with disabled children – the literature has identified the BAME community as a potential group of unmet need, who have in general not accessed traditional services but are more likely to access IB type services as they are perceived to be more culturally sensitive.
- Target **disabled children from families from low-income groups**. This is likely to include families from deprived communities who are unaware that they are eligible to receive services and those who feel unable to access traditional services – this option has been suggested as a means of ensuring the provision of care is provided to all those who are eligible for support and is likely to require a significant amount of out-reach work.

Target by geographical location

- Target a **mixture of both rural and urban areas** to gain an understanding of the differences in service provision required to accommodate geographical characteristics – it is likely that the provision of IBs will vary between locations and may exhibit significantly different characteristics when piloted in urban and rural areas. Therefore, it may be important to pilot the intervention in both settings to understand more about these differences.

Comprehensive offer

- **Offer IBs to a target number of families with disabled children regardless of type of disability, age, socio economic characteristics** etc – it may be more equitable to offer the IB services to all families with disabled children. This will also facilitate a means of testing which groups are more likely to take-up the service and the reasons for this choice.

Extension(s) of existing service provision

- Extend the **current adult IB pilots** to cover families with disabled children – the current adult IB pilots have developed their infrastructure and resource bases and have begun to develop their provider markets and therefore may be in a good position to adapt their provision and pilot the initiative for families with disabled children.

- Extend only **those adult IB pilots that have a disproportionately high demand for IB and number of disabled children** – this option has been proposed for similar reasons to the option above, with the addition that it may be more effective to only pilot the initiative in those areas which experienced a very high demand for IB and who house a large number of potential beneficiaries.
- Extend the **service provision offered by the existing BHL P pilots** to families with disabled children – again as the BHL P pilots have begun to develop the required infrastructure and have begun their transformation towards the delivery of self-directed support, they may be in a good position to extend their current model of service provision to cover families with disabled children and pilot the initiative.

Review of the options

Targeting a specific type of disability

- 8.10 Feedback received on the potential pilot options which proposed to target a specific type of disability is reflected in Table 8-1 below. This highlights that although consultees felt that a number of the groups required intensive support and were therefore likely to benefit from IB service provision, the general consensus was that targeting by diagnosis would be inequitable. There was also a concern about how far lessons learned from a specific group would be transferable to the wider client base, which for consultees would represent a missed opportunity. Moreover, such targeting would probably reduce the numbers of potential beneficiaries, which again might limit the extent to which general lessons could be drawn from the pilots. Consultees also emphasised the fact that a more comprehensive pilot which was aimed at a wider group would cater for the target groups of children.

Table 8-1: Feedback received on the pilot options which proposed to target a specific type of disability

Pilot	Positive aspects	Negative aspects	Indicative conclusion
Children in continuing care	<ul style="list-style-type: none"> This group require intensive support and are likely to benefit from IB type provision 	<ul style="list-style-type: none"> Inequitable Problems integrating continuing care funding Difficulty in recruiting sufficient nos 	<ul style="list-style-type: none"> Inequitable to target by diagnosis Too specific Comprehensive offer will reflect spread of disabilities
Children needing 24 hour continuity	<ul style="list-style-type: none"> This group require intensive support and are likely to benefit from IB type provision 	<ul style="list-style-type: none"> Inequitable Need to ensure joint funding with health is available Difficulty in recruiting sufficient nos 	<ul style="list-style-type: none"> Inequitable to target by diagnosis Too specific Comprehensive offer will reflect spread of disabilities
Specific age groups with high support needs	<ul style="list-style-type: none"> This group require intensive support and are likely to benefit from IB type provision 	<ul style="list-style-type: none"> Inequitable Identification of target group – where do we draw the line? Difficulty in recruiting sufficient nos 	<ul style="list-style-type: none"> Inequitable to target by diagnosis Too specific Comprehensive offer will reflect spread of disabilities
Children and young people with an Autism Spectrum Disorder (ASD)	<ul style="list-style-type: none"> The ASD group lack any structured form of service provision at present Will complement the Short Break Core Offer 	<ul style="list-style-type: none"> Inequitable Difficult to identify support needs during early stages of condition Difficulty in recruiting sufficient nos 	<ul style="list-style-type: none"> Inequitable to target by diagnosis Too specific Comprehensive offer will reflect spread of disabilities
Children aged 11+ with moving and handling needs that will require equipment and adaptations	<ul style="list-style-type: none"> Will complement the Short Break Core Offer 	<ul style="list-style-type: none"> Inequitable Already encompassed within Direct Payments Difficulty in recruiting sufficient nos 	<ul style="list-style-type: none"> Inequitable to target by diagnosis Too specific Comprehensive offer will reflect spread of disabilities

Source: IB Scoping Study consultation and case study research

Targeting a specific age group

8.11 Looking specifically at the potential pilot options which proposed to target specific age groups of disabled children and young people (see Table 8-2 for detailed feedback), the majority of consultees responded positively to both a pilot which targeted children coming out of the Early Support Programme (ESP) and Children aged 14+ in transition. In the former case, feedback highlighted a need for early intervention and the facilitation of a continuous approach to tailored support, as there is currently limited personalised support for children passing out of the ESP. Similarly, the transition group (children aged 14+ years) were identified by almost all consultees as requiring intensive support to manage their move from children's to adult services and to help equip young disabled people to achieve outcomes that relate to independence. A number of consultees also highlighted that it would be

valuable to build on the work of the DH Adult IB pilots, some of which targeted older children in transition.

- 8.12 A number of the consultees also discussed the possibility of targeting the 0-5 years of age group. However, the majority felt that they were unlikely to benefit from IB provision as it was generally too difficult to effectively assess the needs of this group, as their conditions were unlikely to be sufficiently developed.
- 8.13 Consultation evidence highlighted a mixture of both positive and negative responses towards targeting a pilot at disabled children who are moving from primary to secondary school or at children aged 5-14 years of age. For example, although a large number of consultees stated that there was a current lack of self-directed service provision for the 5-14 years of age group and were therefore in favour of supporting this group, others felt that it would be more effective to target resources at children aged 5-6 years and therefore encourage and promote early intervention. They added that targeting the 5-6 year olds would facilitate the provision of choice and control from an early stage, which they hoped would enable a family to ‘cope and manage’ more effectively from day one and therefore prevent both family crises and any further deterioration in the health of their disabled child.

Table 8-2 : Feedback received on the pilot options which proposed to target a specific age group

Pilot	Positive aspects	Negative aspects	Indicative conclusion
Children coming out of the Early Support Programme	<ul style="list-style-type: none"> • Important to begin personalised support as early as possible to make transitions seamless and enable a family and child to be integrated in decision making throughout the child's life • Will facilitate a continuous approach to tailored support, where families will have had an experience of joint planning and collaborative approaches • Provide support for transition from early years into mainstream education • Worthwhile targeting beneficiaries as early as possible to provide support and assistance in the absence of preconceived ideas, fear or suspicion of the IB approach 	<ul style="list-style-type: none"> • Diagnosis can remain unclear for young children, especially those aged 0-5 years. 	<ul style="list-style-type: none"> • Yes • Should be incorporated into comprehensive offer, where pilot is given the option to target this group within their general pilot
Disabled children who are moving from primary to secondary education	<ul style="list-style-type: none"> • Support for transition would be beneficial 	<ul style="list-style-type: none"> • Some LAs operate a tertiary education system • For children in special school, transition support not necessarily required • Only targets those in mainstream education 	<ul style="list-style-type: none"> • Inconclusive • This group will be reflected in part by the comprehensive offer pilot
Children aged 5-14 years	<ul style="list-style-type: none"> • Currently only limited self-directed service provision for this group 	<ul style="list-style-type: none"> • Should begin targeting at 5 years and not leave it till later 	<ul style="list-style-type: none"> • Inconclusive • This group will be reflected in part by the comprehensive offer pilot
Children aged 14+	<ul style="list-style-type: none"> • Transition from children's to 	<ul style="list-style-type: none"> • Lack of joined up working 	<ul style="list-style-type: none"> • Yes

Pilot	Positive aspects	Negative aspects	Indicative conclusion
i.e. those in transition	adult services requires intensive support <ul style="list-style-type: none"> Will serve to test how the Transition Programme and IB provision can be integrated 	between Children's and adult services	<ul style="list-style-type: none"> Should be incorporated into comprehensive offer, where pilot is given the option to target this group within their general pilot

Source: IB Scoping Study consultation and case study research

Other forms of targeting

- 8.14 Consultees were also asked to provide their views on a number of other potential forms of targeting for the forthcoming IB pilots, which are reflected in Table 8-3. Responses highlighted that all consultees favoured the comprehensive pilot over and above all other options, and felt there was a need to pilot in both rural and urban local authorities. This lack of targeting was identified as being equitable and would facilitate the most flexibility and therefore learning. It was also felt that the type of disability/age group was not the key factor, as each child and their family responded in different ways and therefore stated the IB offer should be an opportunity which is extended to all families with disabled children.
- 8.15 Targeting disabled children who originate from ethnic minority communities was also felt to be important, as this group were less likely to access traditional services and may respond positively to more tailored forms of provision. However, consultees stated that it would be inequitable to only target this group and therefore that they should form a component of all the pilots.
- 8.16 Evidence from the consultation exercise highlighted the effectiveness of targeting IB forms of provision at newcomers to the system. This was largely a result of the child and their family having 'no preconceptions' of service provision, which allowed them to 'think outside the box' and 'trust their own instincts'. This finding was echoed by many of the consultees, who felt that it would be valuable to target both this group and existing service users.
- 8.17 Looking specifically at disabled children from families from low-income groups although consultees agreed that there was a need to ensure that families from deprived backgrounds formed part of the target group, they also felt it would be inequitable to only target this group. They also highlighted the inherent difficulty in defining and identifying this group and therefore felt that it would be sufficient to ensure that the IB offer was accessible to all, regardless of their socio-economic background.

Table 8-3 : Feedback received on the pilot options which proposed other forms of targeting

Pilot	Positive aspects	Negative aspects	Indicative conclusion
Newcomers to the social care system	<ul style="list-style-type: none"> • Important to target families and individuals before they become 'used to' traditional service provision • Develop trust and understanding early • Early intervention to avoid crisis • Easier to recruit beneficiaries 	<ul style="list-style-type: none"> • Reliant on newcomers to the system, who may come in 'drips and drabs' 	<ul style="list-style-type: none"> • Yes • Should be incorporated into comprehensive offer, where pilot is given the option to target this group within their general pilot
Children from BAME groups	<ul style="list-style-type: none"> • BAME communities less likely to access traditional service provision due to general access issues and may respond positively to more tailored provision • IBs will enable families to purchase more culturally sensitive support 	<ul style="list-style-type: none"> • Inequitable to offer only to this group 	<ul style="list-style-type: none"> • May not be appropriate to undertake a pilot of this nature due to equity considerations • Should instead ensure that beneficiaries targets are set for all pilots to ensure they are representative of the general population
Children from families from low-income groups		<ul style="list-style-type: none"> • Group will be difficult to identify • Inequitable 	<ul style="list-style-type: none"> • No
Rural and urban areas	<ul style="list-style-type: none"> • Very important to pilot in a mixture of urban, rural and mixed areas to understand how this form of service provision works in difference contexts 		<ul style="list-style-type: none"> • Yes • Will be reflected in the choice of local authorities
Comprehensive offer	<ul style="list-style-type: none"> • Equitable • Will facilitate wider testing of activities and more comprehensive results • Has the potential to expose the differences between high and low level needs • Needs of a child and family vary 	<ul style="list-style-type: none"> • Need to be sensitive to variations in client group • May have larger cost implications 	<ul style="list-style-type: none"> • Yes • Should also include choice of themes e.g. 5-6 year olds and transition group.

Source: IB Scoping Study consultation and case study research

Extension of existing pilots

8.18 The last group of potential pilot options involved the extension of existing IB and similar forms of activity. This set of options were not supported by the majority of consultees, as it was felt that this would limit activity to particular local authorities, which was felt to be inequitable. Consultees also added that the provision of adult IB would differ significantly from provision to disabled children and their families and that there would therefore be limited benefit in extending the DH Adult IB pilots.

Table 8-4 : Feedback received on the pilot options which proposed to extend existing pilot activity

Pilot	Positive aspects	Negative aspects	Indicative conclusion
Extension of current adult IB pilots	<ul style="list-style-type: none"> Can build on existing development 	<ul style="list-style-type: none"> Only limited number of adult IB pilots focused on transition group Provision of adult IB services significantly different to provision to children Inequitable as only limited no of authorities can participate Personalisation funding should be spread across local authorities and not simply given to the 'usual suspects' 	<ul style="list-style-type: none"> No
Extension of adult IB pilots with high demand for IB and large no of disabled children	<ul style="list-style-type: none"> Can build on existing development 	<ul style="list-style-type: none"> Only limited number of adult IB pilots focused on transition group Provision of adult IB services significantly different to provision to children Inequitable as only limited no of authorities can participate Likely to lead to pilots in urban areas only Demand for IBs has not been formally identified 	<ul style="list-style-type: none"> No
Extension of the BHL P pilots	<ul style="list-style-type: none"> Can build on existing development 	<ul style="list-style-type: none"> Only one BHL P pilot focused on service provision for disabled children Inequitable as only limited no of authorities can participate 	<ul style="list-style-type: none"> No need for specific pilot, it is likely that some BHL P pilot sites will bid to become part of the FDC IB pilot However, it will be important to ensure that extension of BHL P work is considered when choosing the pilot sites

Source: IB Scoping Study consultation and case study research

Recommendations for forthcoming pilots

- 8.19 Synthesis of the research findings suggests a strong desire to base the forthcoming IB pilots on the 'comprehensive offer' for reasons of both equity and completeness. Therefore, we recommend that the set of forthcoming pilots should all offer an IB to a target number of families with disabled children, regardless of their disability or age.
- 8.20 To ensure the delivery of an equitable set of pilots, each site should also aim to engage a sample of beneficiaries that are representative of their overall population. Therefore, each pilot site should set specific targets at the outset of their activity, which should reflect the ethnic mix of the resident population.
- 8.21 As the research also highlighted an interest in developing IB provision for particular groups of disabled children, we recommend that each pilot site should also be given the choice to develop one of the following themes as part of their general pilot
- Children coming out of the Early Support Programme

- Children aged 14+ i.e. those in transition
- Newcomers to the social care system

8.22 The addition of a theme will facilitate a detailed understanding of the challenges and successes of delivering to the specific groups and will provide an additional depth to the pilot, allowing learning to be developed about specific needs in the context of the wider model rather than in isolation. This will enhance the pilots and influence the future direction and development.

Number of pilot sites and targeted beneficiaries

8.23 We recommend that the DCSF selects between 8-10 pilot sites to ensure that each theme is supported by at least two pilot sites. This will also facilitate the pairing or grouping of pilot sites, which can support each other during the development of their specific IB provision.

8.24 Discussions with local authorities and stakeholders highlighted the need to target a sufficient and realistic number of beneficiaries in each pilot site. This number should ensure that results and outcomes can be used to inform both local and national policy and should consider what can be realistically achieved within the timescales of the pilots. Evidence from existing activity has indicated that current IB provision to families with disabled children has been undertaken on a relatively small scale (with an average of 8 families per local authority) and has therefore only produced indicative findings. Consultation evidence also suggested that the larger scale BHLF and DH Adult IB pilots targeted between 30-50 disabled individuals, which proved to be an achievable target within a two year timescale and produced sufficiently robust results. Therefore, we recommend that each pilot site is set a target of between 30-50 beneficiaries, which is likely to be dependent on both the starting point e.g. whether the site is already piloting an IB approach, and size of the local authority.

Selection of pilot sites

8.25 Evidence from the consultation exercise highlighted a desire to pilot the intervention in both rural and urban local authorities, to facilitate a comparison of provision in differing contexts. Consultees also felt that it would be useful to extend some of the current BHLF and Taking Control/Dynamite pilots to enable them to build on existing developments and in some cases to extend the IB service offer to a larger and more diverse group of families with disabled children.

8.26 Consequently, we would recommend that the pilot site selection criteria includes the following:

- A **range of both urban and rural local authorities** to ensure their delivery facilitates an understanding of how IB service provision works in different geographical environments
- A selection of **local authorities who are already piloting an IB type intervention for families with disabled children** (i.e. BHLF and Taking

Control/Dynamite pilot sites) **and those who are not currently delivering this form of activity**

- **A range of sites who wish to pilot the in Control RAS and some who wish to develop their own outcomes-based assessment framework**
- All pilot sites should be **moving towards the provision of self-directed support** and should therefore **have the capacity and capability to meet the requirements of the common delivery framework** within the timescales of the pilot activity.
 - As a sub-set of this point – all pilot sites **must show that they have committed the appropriate staff resources to the project** from the outset of the pilot.

Summary

8.27 We have proposed that the DCSF delivers **a set of pilots which meet the requirements of the common delivery model and their own strategic and political guidance and which all deliver the ‘comprehensive IB offer’**. Within the comprehensive offer, the DCSF should ensure that: each pilot site targets a representative number of users from **ethnic minority groups**; there is a good spread of **rural** as well as **urban** pilot sites; the **pilot sites include** a selection of **those local authorities who are already piloting an IB type intervention** as well as those who are not currently delivering this form of activity; the sites include **local authorities who wish to pilot the in Control RAS and those who wish develop their own outcome-based assessment framework**; and that each pilot site chooses to develop one of the following themes:

- Children coming out of the Early Support Programme – **5-6 year olds**
- Children aged 14+ yrs i.e. **those in transition**
- **Newcomers** to the social care system.

8.28 In addition, we have recommended that the DCSF **commission between 8-10 pilot sites** to ensure that each theme is supported by at least two pilot sites and that **each site targets between 30-50 beneficiaries**.

9: Cost implications of the pilot options

Introduction and method

- 9.1 The analytical framework developed during the scoping stage incorporated an initial typology of costs to be addressed as part of the study, based on an early evidence review (see Table 2-3 in the main report). In developing the typology we made several assumptions; these were based on our understanding of the study brief and discussions that took place at the inception meeting for the study.
- 9.2 A critical assumption was that options for IB were to be costed at Local Authority Level and for implementation only. We had also assumed that opportunity (or economic) costs need to be accounted for, but not necessarily quantified as part of a costed option. Many of these economic costs will be accrued by the individual, but some will be accrued by local authorities and partners. We have assumed that costed options will not include exchequer or departmental costs, although we have identified and listed them in this section. It was also agreed at the outset that the presentation of costs will take the form of a 'range' rather than a point estimate, and will be accompanied by a series of underlying assumptions and contextual evidence.
- 9.3 The literature review and case study fieldwork in the study utilised the typology to gather and collate costs as far as possible. The study also gathered stakeholder views on an ideal model for an IB Pilot, and the specific themes that could be addressed in a pilot. This valuable evidence informed the derivation of the common delivery model and identification of thematic options (see Chapters 7 and 8 of the main report).
- 9.4 The key activities associated with the requirements set out in the common delivery model have tended to overlap with activities related to the initial typology of costs developed at the start of the study. This is not surprising as the initial typology was informed by the evaluation of the DH Adult IB pilots, which several of the stakeholders interviewed as part of the scoping study had had experience of. Therefore, the common delivery model in conjunction with the initial cost typology has dictated the costing exercise for the purposes of this report, and has determined the over-arching high level activities that will need to be costed and accounted for when implementing an IB pilot.
- 9.5 The sections below present a **range of costs** associated with setting up and running an Individual Budget Pilot for families with disabled children, based on the common delivery model. Note that the ranges do not indicate minimum and maximum costs.
- 9.6 The main sources of evidence are costs gathered during the case study fieldwork, and cost data collated and analysed during the literature review phase. We have also illustrated the extent and ways in which the costs associated with the common delivery model are affected under each of the thematic options.

Year one costs

9.7 The table below presents the types and ranges of costs associated with year one of an Individual Budgets pilot. There are some broad assumptions that we have made in deriving and analysing these costs:

- All pilots are delivered from existing Local Authority premises; this is based on the evidence that a majority of local authorities are already delivering some form of intervention that shares the principles of IB. Hence the costing exercise excluded capital costs.
- We have not costed an IB package, i.e. we have not included costs of services that social services, health and education currently provide and that families are likely to use their IB for. This was not within the remit of the scoping study. However, we have attempted to cost additional services that stakeholders have identified as crucial and those that parents are likely to demand within the core framework– examples are advocacy and brokerage and peer support networks. These services are also most likely to be resourced by Local Authorities.
- We have not included costs borne by Local Authorities currently in providing mainstream services such as residential respite care. Hence the costs presented in the tables below are assumed to be additional, and assume some transfer of resources from mainstream service provision to IB provision. It is possible that there will be some efficiency savings in transferring to the IB approach (see Demos, 2007) and in offering IB support packages compared to support packages based on traditional models. On the other hand, there may well be additional economic or opportunity costs associated with transfer of activity. This is discussed later in the section. However, for the purposes of the study, we have assumed that Pilots will need to measure any costs or efficiency savings resulting in moving to an IB system as there is little evidence on the ground at present.
- All pilots have 30-50 disabled children on IB. Note that per person costs are specified, they have been aggregated to assume 30-50 service users.

Table 9-1 Year one costs of an Individual Budget Pilot Site

Cost Type	Range	Assumptions
Resource costs : salaries and remuneration of implementation staff		
Dedicated Project Manager and Team salaries	£90,000-£125,000	Total in house costs of salaries per annum Costs are based on the assumption that the team constitutes F/T project manager, P/T performance officer, F/T Project worker to work with CYP, families, providers and deliver training, P/T finance officer, and commissioning time (Source: Adult IB Pilot Site and BHLPI Pilot Site)

Cost Type	Range	Assumptions
Workforce development and training		
Staff development and training	£13,000 - 20,000	Average cost per site; This includes any external consultancy (Source: Adult IB Site, BHLP Site)
Provision of advocacy and support brokerage: resource costs		
Advocacy worker	£3465-£5775	Assuming no capital costs Provision of 1 advocacy worker with a ratio of 1:50 for issue-based advocacy Average salary of advocacy worker is £30,000 per annum Average contact time is 7 hours and £16.5 per hour per user (Source: The evaluation of the pilot independent mental capacity advocate (IMCA) service, DH 2006, DRC 2007) Aggregated for 30-50 users
Brokerage worker	£1800 - £3000	Assuming no capital costs 1 Broker for a maximum of 35 hours and a minimum of 3 hours per user (Source: in Control, 2005) in a year @£20 per hour (Source: National Broker Network) Aggregated for 30-50 users
Aggregate advocacy and brokerage resource costs	£1800 - £6000	
Brokerage and advocacy service costs	£30,000 - 50,000	Costs of providing brokerage and advocacy services for each site and also assuming that the service caters to at least 25 recipients (Source: Adult IB Site, LA provided cost for Direct Payments)
User-led organisations and peer support networks		
In house peer support	£5500	This includes interventions which in Jacob's et al's (2006) report titled 'Training for Individual Budgets: Early findings' are reported as training as they include an element of workforce development. Hence this is mainly a resource cost (Source: Adult IB Site)
Setting up of a peer support or IB user group	£6000	Contract with an existing user led organisation (Source: LA provided cost)

Cost Type	Range	Assumptions
IT Systems		
IT Systems development	£14,000 – 20,000	IT Systems development, including setting up an electronic database for the Outcomes Focused Assessment. This excluded auditing costs (Source: Adult IB Site, LA Adult IB pilot site)
Development of an assessment framework		
Development of an assessment framework	£25,000 - £33,000	Development of a RAS type assessment and an Outcome Focused Framework (Source: Adult IB Site, LA Adult IB pilot site)
Capacity Building		
Provider training and capacity building	£40,000	External consultancy fees for conferences and events (Source: BHL P Pilot Site)
User capacity building and planning	£20,000 - £33,000	Person Centred Planning (PCP) @£658 per person (Source: The Economic Impact of Person Centred Planning - Renee Romeo and Martin Knapp, 2005)
Marketing and Promotion		
Advertising costs	£3000 - £8000	Awareness campaign with providers, voluntary sector organisations (Source: Adult IB Pilot Site)
Aggregate range of Year one costs	£200,000 - £300,000	

Source: various

Year two costs

9.8 We made some broad assumptions in deriving and analysing the costs that would be incurred in Year 2:

- These costs relate to Y2; we have not costed Y3 as the Pilots are being planned for 2 and a half years
- Several of the types of Y1 costs tend to re-appear in Table 10-2 as recurrent, albeit at a different scale.
- There will be some costs related to overheads; however we have assumed here that these costs will be absorbed within the overall overheads within the Local Authority. Moreover, evidence (Demos, 2007) suggests that

administrative overheads are expected to be reduced when self-directed support packages are introduced in place of traditional models.

9.9 The table below presents the types and ranges of recurrent costs involved in running the Individual Budgets beyond Year 1 of the pilot.

Table 9-2 Year two costs of an Individual Budgets Pilot Site		
Cost Type	Range	Assumptions
Resource costs : salaries and remuneration of implementation staff		
Staff salaries	£90,000 - £95,000	<p>Costs are based on the assumption that the team constitutes F/T project manager, P/T performance officer, F/T Project worker to work with CYP, families, and providers and deliver training, P/T finance officer, and commissioning time. Also includes one social worker and one support worker</p> <p>Costs go down in the second year because as commissioning or research staff is not required and the development had been done. Most of the staff (and the proportions) stay the same.</p> <p>These costs also include ongoing administration and management costs, including employing one administrative worker</p> <p>(Source: Adult IB Pilot Site and BHLP Pilot Site)</p>
Ongoing workforce development and training		
Training staff at LA in house	£500	<p>£125 per course (Source: BHLP Pilot Site)</p> <p>Assuming Quarterly training</p>
Ongoing provision of advocacy and brokerage service and support		
Brokerage worker	£1800 - £3000	<p>Assuming no capital costs</p> <p>1 Broker for a maximum of 35 hours and a minimum of 3 hours per user (Source: in Control, 2005) in a year @£20 per hour (Source: National Broker Network)</p> <p>Aggregated for 30-50 users</p>
Brokerage and advocacy service costs	£30,000 - 50,000	<p>Cost per site and also assuming that the service caters to at least 25 recipients</p> <p>(Source: Adult IB Pilot Site, LA provided cost for Direct Payments)</p>
IT Systems maintenance		
Systems maintenance	£2500	IT purchases, email and desktop support and maintenance (Source: BHLP Pilot Site)

Cost Type	Range	Assumptions
Revisions to assessment frameworks		
Revisions to RAS and other assessment frameworks		Should be included in time and salaries for Finance Officer and Project Officer (see above)
Ongoing capacity building and support planning		
Provider capacity building	£19,000	External consultancy fees for organisation of conferences, visits and exhibits.
User capacity building	£600	Other small expenses in the second year running included incentives for users to come to one of the evaluation events; equipment for the evaluation etc (Source: Adult IB Pilot Site)
Administration and Payroll		
Outsourcing of payroll services	£14,000 – £23,000	Outsourced contract of £117,00 per annum pro rated for 30-50 users only (Source: LA provided cost)
User-led organisations and peer support networks		
In house peer support	£5500	This includes interventions which in Jacob's et al's (2006) report titled 'Training for Individual Budgets: Early findings' are reported as training as they include an element of workforce development. Hence this is mainly a resource cost (Source: Adult IB Pilot Site)
Ongoing cost of supporting peer support or IB user group	£6000	Contract with an existing user led organisation (Source: LA provided cost)
Aggregate ongoing costs (Y2)	£170,000 - £200,000	

Source: Various

Pilot options and associated variations in costs

9.10 We have proposed that the delivery of the 'comprehensive offer' ensures that there are representative numbers of users from **ethnic minority groups** within each pilot site, there is a good spread of **rural** as well as **urban** pilot sites, the **pilot sites include a selection of those local authorities who are already piloting an IB type intervention** as well as those who are not currently delivering this form of activity and that each pilot site chooses to develop one of the following **themes**:

- Children coming out of the Early Support Programme – **5-6 year olds**
- Children aged 14+ yrs i.e. **those in transition**
- **Newcomers** to the social care system

- 9.11 The following section discusses potential cost variations which may be associated with the type and theme of the pilot sites.

Ethnic Minority Groups

- 9.12 There is little evidence of costs associated with provision of self-directed support to ethnic minority communities. However, there is ample evidence to suggest that users from these communities are disadvantaged in terms of access of services (DH, 2004 for example). There was some recognition by our stakeholders that some aspects of the IB implementation may need to be tailored for disabled children from ethnic minority backgrounds. This was particularly the case for user led or peer support networks and advocacy and brokerage services. Furthermore, some current examples of good practice in providing specific services to adults and young people from ethnic minority communities were identified recently in a CSIP report (Hatton, 2005)¹⁴ in the areas of advocacy, person-centred planning and Direct Payments.
- 9.13 Hence we anticipate that costs may vary for those pilot sites where there are large populations of disabled children from ethnic minority groups, and where the Local Authority is already focusing on setting up partnerships to enable effective working and implementation to cater for users from ethnic minority communities.

Rural and urban delivery

- 9.14 Findings from our literature review (CIN, 2001) suggested that costs could vary by geographical location and spatial characteristics; 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.

Children coming out of the Early Support Programme

- 9.15 There is little evidence with regard to costs associated with service delivery to children aged 5 and 6. A majority of the children will already be covered via Special Educational Needs (SEN) funding from schools. They would also benefit from IB offered through the common delivery model.
- 9.16 However, costs could vary if the IB offer enabled children to be moved from special to mainstream schools. Support costs, including advocacy, brokerage costs and person centred planning costs could also be affected as the target group is relatively young and have changing needs, and support to families who have been used to the intensive support via the Early Support Programme could be greater. Other costs could be associated with local authority and contracted provision in schools to deal with children moving from special schools to mainstream schools under IB.

¹⁴ Hatton (2005) Improving Services for People with Learning Disabilities from Minority Ethnic Groups: Results of a National Survey of Partnership Board, CSIP.
<http://www.nwtdt.com/Ethnicity/EthnicitySurveyExamples.pdf>

Children in Transition

- 9.17 Transition from children's to adult services requires intensive support. There is already a Transition Programme underway. Although the effects of targeting children in transition on core pilot costs are largely unknown, evidence from the case studies suggests that some Local Authorities have already put staffing and other arrangements in place to ensure that IB to children in transition can be offered effectively. This mainly relates to employing a transition worker who almost acts as a key worker and liaises with adult services as well as children's services, and helps families in assessment and planning.. The average cost per family per year for a key worker scheme with case loads varying from 16 to 60 could cost £1300 - £2000. Key worker contact time with users could cost an average of £700 annually for each family (Source: Greco, 2005) and £151 per contact.¹⁵
- 9.18 It is also possible that time costs associated with commissioning, finance and legal teams in both children's and adult services within a local authority increase when targeting children in this age group, mainly driven by the requirement to ensure consistency and effective working between adults and children's services.
- 9.19 These costs will need be to accounted for, and acknowledged when targeting children in transition.

Targeting newcomers to the system

- 9.20 A lack of data on precise numbers of newcomers to the system and the extent and ways in which they could affect costs has not made it possible for us to cost this particular requirement at the scoping stage of the work.
- 9.21 However, stakeholder consultations suggested that a majority of disabled children appear to be already accessing mainstream services, and numbers of newcomers are likely to be small and could have little impact on overall costs.
- 9.22 There was some evidence from the case studies that children with particular complex needs such as Autism Spectrum Disorder may not be accessing mainstream services currently, and are often believed to fall through the gaps in service provision. Our review of the literature has suggested that costs could vary, and in many cases, increase, with complexity of need.

Extension of an existing Taking Control/Dynamite/BHLP pilot

- 9.23 Extending an existing Pilot intervention in the form of Taking Control could have several implications for the costs of implementing the common delivery model.
- 9.24 In terms of **Year one costs**, much of the groundwork in terms of organising a project manager and a team, with time from finance, commissioning and legal teams, would have been done. Furthermore, the current Pilots would have already undertaken some capacity building and development of networks with providers to initiate access

¹⁵ The study produced costs from a service level as well as from a user view.

to services. It is also possible that the current team implementing Taking Control or BHLP would have also undergone some staff training and development activities.

- 9.25 On the other hand, some of these existing pilots would not have developed a suitable Resource Allocation System or an Outcomes Focused Assessment System and hence would incur these costs when implementing IB.
- 9.26 Our consultations with Local Authorities that are already implementing such Pilots suggested that the number of users targeted for the Pilots were relatively small (8-10 users). The common delivery model assumes 30-50 users. This implies that the scale of activities and related costs could increase significantly.
- 9.27 Evidence from the case studies also suggests that costs incurred in implementing the current Pilots appears to have been absorbed or unaccounted for, in some cases. In many local authorities that are implementing Taking Control Pilots, there was no project manager or key worker in place, and existing social workers were playing the roles of key workers, brokers as well as advocates. If the common delivery model were to be implemented, distinct roles for key workers and project managers would need to be defined, established and costed accordingly. In addition, costs of advocacy and brokerage services will also need to be accounted for.
- 9.28 In the case of BHLP Pilots, only those children with ‘additional needs’ are being targeted; any extensions of BHLP Pilots are likely to involve additional costs as families of children with complex needs could require more intensive support, advice and guidance than what appears to be currently in place.
- 9.29 Finally, the case studies revealed that existence and use of peer support groups or networks for families with disabled children was rare. This aspect of the common delivery model is likely to be a significant and important addition to an extension of existing Pilots.
- 9.30 The Table below illustrates an indicative range of costs for implementing an extension.

Table 9-3 Costs of extending an existing Taking Control/BHLP/Dynamite Pilot Site		
Cost Type	Range	Assumptions
Resource costs : salaries and remuneration of implementation staff		
Dedicated Project Manager and Team salaries	£90,000-£95,000	Y2 cost assumed Total in house costs of salaries per annum Costs are based on the assumption that the team constitutes F/T project manager, P/T performance officer, F/T Project worker to work with CYP, families, providers and deliver training, P/T finance officer, and commissioning time (Source: Adult IB Pilot Site and BHLP Pilot Site)

Cost Type	Range	Assumptions
Provision of advocacy and support brokerage: resource costs		
Advocacy worker	£3465-£5775	Assuming no capital costs Provision of 1 advocacy worker with a ratio of 1:50 for issue-based advocacy Average salary of advocacy worker is £30,000 per annum Average contact time is 7 hours and £16.5 per hour per user (Source: The evaluation of the pilot independent mental capacity advocate (IMCA) service, DH 2006) Aggregated for 30-50 users
Brokerage worker	£1800 - £3000	Assuming no capital costs 1 Broker for a maximum of 35 hours and a minimum of 3 hours per user (Source: In Control, 2005) in a year @£20 per hour (Source: National Broker Network) Aggregated for 30-50 users
Aggregate advocacy and brokerage resource costs	£1800 - £6000	
Brokerage and advocacy service costs	£30,000 - 50,000	Cost per site and also assuming that the service caters to at least 25 recipients (Source: Adult IB Pilot Site, LA provided cost for Direct Payments)
User-led organisations and peer support networks		
In house peer support	£5500	This includes interventions which in Jacob's et al's (2006) report titled 'Training for Individual Budgets: Early findings' are reported as training as they include an element of workforce development. Hence this is mainly a resource cost Source: Adult IB Pilot Site)
Setting up of a peer support or IB user group	£6000	Contract with an existing user led organisation (Source: LA provided cost)
Development of an assessment framework		
Development of an assessment framework	£25,000 - £33,000	Development of a RAS type assessment and an Outcome Focused Framework – Year one costs (Source: Adult IB Pilot Site)
Revisions to the framework		Should be included in the staff time and salaries for finance officer and project officer

Cost Type	Range	Assumptions
Capacity Building		
User capacity building and planning	£20,000 - £33,000	Person Centred Planning (PCP) @£658 per person (Source: The Economic Impact of Person Centred Planning - Renee Romeo and Martin Knapp, 2005)
<i>Workforce Development</i>		<i>Expenditure undertaken already</i>
<i>IT Systems Development</i>		<i>Expenditure undertaken already</i>
<i>Capacity building with providers</i>		<i>Expenditure undertaken already</i>
<i>Administration and Payroll</i>		<i>Expenditure undertaken already</i>
Aggregate range of costs of extending existing Pilots	£150,000 - £180,000	

Source: various

Opportunity costs

Evidence from the literature

- 9.31 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.
- 9.32 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. Carers UK (2002) estimated these costs to be £57 billion.
- 9.33 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).
- 9.34 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.

- 9.35 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
- 9.36 The Wanless Review (2006) also highlighted a potential shift of costs of delivering Direct Payments from services to families and individuals.

Evidence from consultations and case study fieldwork

- 9.37 Our consultations with Local Authority, academic and policy stakeholders, both at the scoping stage and during the conduct of the case studies included seeking views on some of the economic and opportunity costs for service delivery, as well as for individual users associated in implementing IB.
- 9.38 *Firstly*, stakeholders were unanimous in their view that cultural change among professionals, local authority staff and providers required for successful implementation of IB is likely to take a long time and involve significant investments in terms of time and effort from senior managers in Local Authorities. Capacity building exercises with providers and users, and staff development and training could divert resources away from existing provision, especially when the implementation team within the local authority has not yet been set up.
- 9.39 *Secondly*, several local authority stakeholders identified a loss of economies of scale and double funding as a significant economic cost. Families could demand specific services under IB which may not be available within mainstream provision. In the short term, moving away from longer term block contracts with providers offering traditional services could prove to be problematic. This could result in a local authority having to fund or contract out provision under both mainstream and IB provision.
- 9.40 *Thirdly*, costing services accurately within IB is an issue. Often Children's Services in a local authority are having to struggle to keep up with the rates offered by adult services which are 'ahead of the game' in many ways. For domiciliary care it was easier to get costs, but for residential care it is very difficult to get costs from the providers that are transparent. Most residential providers would not sign up to full recovery costs and would charge what the market will bear. From the providers'

perspective, there was concern that a RAS may not be able to cost their provision accurately.

- 9.41 *Fourthly*, IB could distort the market to some extent; some local authorities felt that employment of families and relatives as Personal Assistants (PAs) was pushing up wages for PAs; moreover, families often end up paying higher rates to PAs and potentially receiving less support in order to secure retention and quality of provision.

Policy Costs

- 9.42 Although the Terms of Reference for the study did not require us to assess and quantify policy costs, or costs to the Department in implementing IB, evidence gathered during the study identified some potential policy costs.
- Working on **aligning the funding streams** and support to pilot authorities at a strategic level; this aspect was recognised as significant by a majority of stakeholders and local authorities. A top down approach to aligning and integrating funding streams was recognised as important in successful implementation of IB.
 - Costs of **enabling user-involvement**: provision of ring-fenced funding to set up user-led organisations that could support implementation of IB when it is rolled out.
 - **Offsetting double funding** – most local authorities that have tried this type of approach have found it very difficult to implement traditional as well as user-focused services at the same time, and have had to look for double funding in the short term. So there will be a cost of decommissioning traditional services. Out of authority placements could be particularly affected.
 - **Workforce issues** – a country wide roll out of IB could put pressures on the existing workforce and ways of working within Local Authorities, and require development and training of key workers, advocacy workers and brokers. Appropriate qualifications, training and development strategies at a macro level would be required at a macro level to enable supply of provision to meet demand effectively.
 - **Regulatory costs** – Evidence from case studies identified concerns for safeguarding as a result of uncertainty around appropriate and suitable regulation for the new ‘breed’ of workers that could enter the children’s services market as a result of IB – these include advocates, brokers and key workers. Their roles and responsibilities are currently ambiguous, and they may not be regulated by current regulatory bodies such as OFSTED, CSCI and GSCC. They may be a role for the Department in partnership with other Departments such as Health to develop and initiate suitable regulatory codes of conduct and practice to ensure quality of provision.

10: Recommended evaluation criteria

Introduction

- 10.1 The Cabinet Office report (2003), referred to two forms of piloting:
- **Impact pilots** – test the likely effects of new policies, measuring or assessing their early outcomes. They enable ‘evidence of the effects of a policy change to be tested against a genuine counterfactual’.
 - **Process pilots** – designed to explore the practicalities of implementing a policy in a particular way or by a particular route, assessing what methods of delivery work best or are most cost-effective.
- 10.2 The forthcoming IB pilots for families with disabled children are likely to seek to achieve both aims. That is, the pilots will investigate what will actually work, who it will and will not work for and at what cost. However, given the short delivery timescales of the pilots (and therefore the evaluation), it will not be possible to conduct a comprehensive impact evaluation and therefore emphasis should be placed upon measuring the early outcomes (for example, an increase in the confidence of the disabled child, increased satisfaction with service provision and improvement in the perceived quality of life of the family) of the pilots as opposed to their impacts on factors such as health outcomes, which will only become apparent over the longer term. Similarly, although the evaluation should consider the cost-effectiveness of the intervention, it is likely that only a partial assessment will be possible within the timeframe of the pilots and therefore the evaluation i.e. the cost of delivery per family and take up of services will be possible, whereas the undertaking of a value for money assessment will not.
- 10.3 It will therefore be important to construct a set of evaluation questions, which frame the pilots and facilitate the collation of process-related and outcomes material.

Recommended Evaluation criteria

- 10.4 The following set of basic evaluation questions echo the purpose of the pilots and have been developed, primarily on the basis of the research findings and the extensive evaluation experience of the SQW research team.
- Is the provision of Individual Budgets to families with disabled children a viable alternative to traditional forms of service provision for some or all families? In essence do families find themselves more satisfied with service provision which is organised through this mechanism.
- And, if the IB mechanism is found to be appropriate:
- Which delivery models have proven to be the most effective and does this effectiveness relate to particular groups of families with disabled children?

- How best can provision be organised, particular reference should be made to the most appropriate forms of:
 - Awareness raising and training for staff
 - Awareness raising and dissemination of information to potential families with disabled children
 - Support brokerage and advocacy services for IB users
 - Peer support mechanisms for IB users
 - IT systems
 - Assessment and funding allocation mechanisms
 - Management of IB funds
 - Market development
 - User, provider and key stakeholder engagement, where the latter should include members of the health, education and adult services teams.
- Which income streams can successfully be integrated or aligned into an Individual Budget package?
- How many families with disabled children took up the IB offer and what were their characteristics?

Characteristics should include:

 - Type of disability
 - Gender of disabled child
 - Age of disabled child
 - Ethnicity of disabled child
 - Newcomer to the social care system or existing user
 - Family situation e.g. lone parent family, no of siblings etc.
- What are the cost implication of a different model of service delivery, in particular the additional support costs involved in setting up the system against any savings at a later stage if families become increasingly self sufficient.
- What outcomes have been achieved by the family and disabled child, the local authority and the relevant providers as a result of the pilots e.g. an increase in the confidence of the disabled child, increased satisfaction with service provision and improvement in the perceived quality of life of the family.

Potential additional evaluation questions

10.5 Table 10-1 presents a summary of the common delivery model and an associated set of evaluation criteria for each of the ten requirements.

Table 10-1 : Summary of the common delivery model

	Rationale	Requirements for all pilots	Associated evaluation questions
1	Staff and wider engagement required to ensure pilot is driven forward and conducted effectively	<ul style="list-style-type: none"> Senior-level champion Dedicated Project Manager, plus 1-2 project workers Part time performance officer Resource from commissioning staff and finance team Engagement from health, education and adult services 	<ul style="list-style-type: none"> How does the engagement from health, education and adult services add value to the IB offer?
2	Requirement for significant cultural change and associated training for all staff involved.	<ul style="list-style-type: none"> Sufficient investment is allocated to awareness raising and training for staff to facilitate culture change 	<ul style="list-style-type: none"> What forms of awareness raising and training are used and which are effective?
3	Awareness raising on the part of the families with disabled children required to inform potential beneficiaries of the new form of service provision	<ul style="list-style-type: none"> Sufficient investment is allocated to awareness raising and information dissemination for potential beneficiaries 	<ul style="list-style-type: none"> What forms of awareness raising and information dissemination are effective?
4	Support brokerage required to ensure IB offer is accessible to all Capacity building for users	Provision of advocacy and support brokerage, which may be provided through: <ul style="list-style-type: none"> in-house provision contracted out to the independent sector mixture of the above two – multi disciplinary approach where users benefit from LA knowledge of service availability and use-led organisations Require some form of payroll and administrative support e.g. extension of Direct Payments support scheme. Could be supplied either by the LA or through an independent organisation.	<ul style="list-style-type: none"> Who provides brokerage and advocacy services? What goods and services are purchased? How is the behaviour of the individual influenced by the broker? How does the location of the broker influence their behaviour?
5	Successful Direct Payments and IB schemes have been associated with strong peer support elements	Peer support required which could take the form of: <ul style="list-style-type: none"> User-led network Facilitation of LA based user meetings 	<ul style="list-style-type: none"> Which forms of peer support are developed? Which form of peer support proved to be the most effective?

	Rationale	Requirements for all pilots	Associated evaluation questions
6	New form of service provision is associated with a need to develop appropriate IT systems	<p>Require the development of appropriate IT systems to facilitate the following activities:</p> <ul style="list-style-type: none"> Record results of the resource and funding allocation system – including assessment process Record details of support plan, commissioned support and planned expenditure Financial activities Monitoring Auditing of IBs Progress against outcomes 	<ul style="list-style-type: none"> How regularly are the families/individuals required to audit the use of their IB? What are the most effective means of monitoring and auditing an IB?
7	Pilots should seek to test new and innovative means of allocating funding In Control RAS and other forms of allocation have not been formally evaluated for this group	<p>Choice of development of either :</p> <ul style="list-style-type: none"> Resource Allocation System (In Control) Outcomes-based allocation system 	<ul style="list-style-type: none"> Which system is more effective?
8	Must ensure that IB offer is accessible to all families. Direct Payments not taken up by some families as they do not wish to take on financial responsibility.	<p>Require a spectrum of choice for management of IB funds, which should include a selection of the following:</p> <ul style="list-style-type: none"> Managed directly by the family Managed by a third party or representative on behalf of the child and family Trust is set up to act on behalf of the disabled child and their family, which holds and manages the money Individual Service Fund – money paid directly to the service provider who holds the fund, where any management fees must be set out in advance Budget held at the LA <p>Inclusion of question in the assessment around the support required to manage the budget/ongoing brokerage support to contract services to ensure that IB includes money to accommodate this requirement.</p>	<ul style="list-style-type: none"> What are the resource implications for each of the deployment options? How effective is each of the deployment options? Which option was chosen by individual and why? Are certain deployment options chosen by families and children from particular socio-economic backgrounds?
9	Market place is currently under developed and not positioned to provide a user-led service	<p>Intensive market development required, which should include:</p> <ul style="list-style-type: none"> awareness raising activities for LA staff, providers and beneficiaries capacity building for the independent sector training for the independent sector and other providers 	<ul style="list-style-type: none"> How did the pilot go about developing and re-shaping their existing service provision? What forms of new service provision came about as a result of the pilot?

	Rationale	Requirements for all pilots	Associated evaluation questions
10	Pilots are experimental in their nature and should be developed alongside those who stand to benefit from the new form of service provision and all those who are likely to be affected by the activities	Development of pilot should include involvement from: <ul style="list-style-type: none"> • users • providers 	How have users, providers and stakeholders been involved in the development of the pilot?

Source: SQW Consulting

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

SQWC – SQW Consulting

TAC – Team Around the Child

ToR – Terms of Reference

YOT – Youth Offending Team

Annex B: Local Authority Topic Guide

Introduction

SQW Consulting (SQW), supported by Gerry Zarb from the Equalities and Human Rights Commission (EHRC), has been commissioned by the Department for Children, Schools and Families (DCSF) to undertake a scoping study on Individual Budgets (IB) for Families with Disabled Children. The research will inform the development of future IB pilot work in this area, which is planned to commence in October 2008 and run until April 2011.

The over-arching aims of the scoping study, as set out in the Terms of Reference (ToR), are as follows:

Draw together the existing national and international evidence on the effectiveness of Direct Payments and Individuals Budgets for families with disabled children;

Set out what further evidence is likely to emerge from existing pilot work currently being taken forward; and

Develop costs option for the forthcoming pilots to be taken forward as part of the AHDC programme.

The consultation exercise is seeking to take advantage of the range of pilot work already underway in related areas in order to set out in more detail what kind of IB pilots should be taken forward and how they can be designed to build on and add value to existing knowledge and innovation in this area.

The discussion held during the interview will remain confidential, where no comment will be attributed to an individual or Local Authority prior to gaining their consent.

Context

1. What is your position at the LA? How long have you been in this role and what are your primary responsibilities?

Approaches

2. What approaches have been used (or are you considering implementing) to deliver IB and similar interventions within your LA? And why have you chosen to adopt this approach?

Please consider the following approaches:

IB targeted at adults

Taking Control pilot

In Control adult IB pilot

Budget-Holding Lead Professional

Direct Payments –*please clarify the target group*

Early Support Programme

Dynamite pilot

Other – *please state.*

3. Has the intervention(s) been targeted at specific beneficiaries?

Please consider the following:

age group(s)

type of disability

Socio-economic background e.g. single parent families

BAME communities

4. How have the above approaches been delivered, why and how effective has this been? Please explain the steps through which a beneficiary is supported, what has worked well and what has worked less well.

Please consider the following:

Beneficiary recruitment process

Assessment process – e.g. self assessment, professional assessment, use of the Common Assessment Framework

Allocation of budgets – e.g. use of RAS or alternative method of resource allocation, notional or financial budgets

Support planning – e.g. provision of LA based support, independent support provided by the third sector etc.

Implementation – e.g. commissioning of support?

Review – e.g. how often are the individual's outcomes assessed?

5. What is the evidence on key success factors?

Please collate any hard copies or e-copies of evidence relating to the project(s).

Have any local evaluations or reviews been conducted?

Do you collate data on the numbers of beneficiaries and types of support requested?

6. What do you consider to be the key requirements of a successful IB/BHLP/DP intervention (please consider the key lessons learnt during the process)?

For example (please consider the following from both an LA and National perspective):

Systems development e.g. IT and resource allocation

Independent support brokerage

Staff training – culture change

Market development – review of commissioning procedures

Beneficiary training

Financial and legal support

Buy-in/leadership from senior management

Peer support

Other – please state.

Barriers to delivery

7. What are the legislative/organisational barriers and risks to the effective delivery of the current pilots and which of these may be relevant to the target audience?

For example:

Shortage of Personal Assistants

Under-developed market place

Slow development of IT resources

Staff reluctance

Prohibitive legal structure

Safeguarding – i.e. monitoring the adequacy and quality of support provision

Unmet need

Demand

8. Does the LA collate statistics on the numbers of disabled children within the area and if so, what are the main sources of information?

Is yes – can these be disaggregated by age, type of disability etc?

Would it be possible to pass on a copy to the research team?

9. Can you provide any data on take-up and the reasons why individuals declined the service offer?
10. What types of services were requested by beneficiaries? OR What types of services would families with disabled children like to access as part of the potential IB package?
11. Did you identify any evidence of unmet need during the course of the intervention? i.e. individuals who are eligible for support, were previously not accessing services, but would like to access the new form of service provision. *Please provide details where applicable.*

OR - Are you aware of any unmet need which may emerge if an IB approach is piloted in your area?

12. Is the IB approach more appropriate for specific sub-groups within the target population? E.g. age groups, type of disability, stage of development of disability etc.

SQWC researcher to run through the potential pilot options developed during the initial stage of the scoping study and discuss their feasibility.

Added value

13. What added value can IB bring to current practice? E.g. increased satisfaction with service provision, increased quality of life for beneficiaries *Please provide copies of any evidence where appropriate.*
14. Can you provide evidence on the cost savings and/or cost effectiveness of the intervention?
15. How could the provision of IB complement the delivery of other strands of the AHDC Strategy? E.g. Short breaks, Early Support Programme, Transition Programme

Funding

16. Which income streams did the existing pilot(s) draw upon in their delivery? What are the associated eligibility requirements?

Specifically with regard to health, how and which budgets have been pooled to facilitate an IB type approach?

17. What set of income streams are applicable to families with disabled children, which could form a component of the IB package? – looking specifically at health, education and social services budgets

Costing

18. Can you provide any data on the costs associated with the intervention? *Please provide copies of any appropriate data.*

For example:

Set up costs – e.g. systems development, workforce development, marketing and promotion, financial planning costs

Running costs – e.g. systems maintenance, support planning and brokerage, resources

Cost of specific service provision – e.g. Personal assistants etc.

Spend per head

Funding associated with a 'price-point'

19. What were the economic and opportunity costs of the intervention? E.g. personal investment in developing new skills to self direct support, costs associated with increase in efficiency of assessment process etc.

We may contact you to seek your permission should we wish to include a quote made during the interview in the scoping study report. Quotes will not be included in the event that permission is not granted. All quotes will be attributable to the LA and not to a particular individual.

SQW Consulting would like to thank you for participating in the scoping study.

Annex C: Stakeholder topic guide

Introduction

SQW Consulting (SQW), supported by Gerry Zarb from the Equalities and Human Rights Commission (EHRC), has been commissioned by the Department for Children, Schools and Families (DCSF) to undertake a scoping study on Individual Budgets (IB) for Families with Disabled Children. The research will inform the development of future IB pilot work in this area, which is planned to commence in October 2008 and run until April 2011.

The over-arching aims of the scoping study, as set out in the Terms of Reference (ToR), are as follows:

Draw together the existing national and international evidence on the effectiveness of Direct Payments and Individuals Budgets for families with disabled children;

Set out what further evidence is likely to emerge from existing pilot work currently being taken forward; and

Develop costs option for the forthcoming pilots to be taken forward as part of the AHDC programme.

The consultation exercise is seeking to take advantage of the range of pilot work already underway in related areas in order to set out in more detail what kind of IB pilots should be taken forward and how they can be designed to build on and add value to existing knowledge and innovation in this area.

The discussion held during the interview will remain confidential, where no comment will be attributed to an individual or Local Authority prior to gaining their consent.

Context

1. Please describe your specific areas of interest/research and how you/your organisation have been involved in the development and/or delivery of either IBs or interventions of a similar nature.

Please consider the following approaches:

IB targeted at adults

Taking Control pilot

In Control adult IB pilot

Budget-Holding Lead Professional

Direct Payments –*please clarify the target group*

Early Support Programme

Dynamite pilot

Other – *please state.*

Effectiveness of approaches

2. If you have been directly involved in developing or delivering an IB or similar intervention, please can you comment on how effective these have been to date? *Please consider the individual delivery elements of the intervention.*

For example, in the case of IB::

Assessment process – e.g. self assessment, professional assessment, use of the Common Assessment Framework

Allocation of budgets – e.g. use of RAS or alternative method of resource allocation, notional or financial budgets

Support planning – e.g. provision of LA based support, independent support provided by the third sector etc.

Implementation – e.g. commissioning of support?

Review – e.g. how often are the individual's outcomes assessed?

3. Can you provide any evidence on the key success factors of the interventions? Have any local or national evaluations or reviews been conducted? *Please collate any hard copies or e-copies of evidence relating to the project(s).*
4. What do you consider to be the key requirements of a successful IB/BHLP/DP intervention (please consider the key lessons learnt during the process)?

For example (please consider the following from both an LA and National perspective):

Systems development e.g. IT and resource allocation

Provision of support brokerage –from the independent sector, directly from the LA or from a combination of both

Staff training – culture change

Market development – review of commissioning procedures

Beneficiary training

Financial and legal support

Buy-in/leadership from senior management

Peer support

Other – please state.

Barriers to delivery

5. What are the legislative/organisational barriers and risks to the effective delivery of an IB or similar intervention?

For example:

Shortage of Personal Assistants

Under-developed market place

Slow development of IT resources

Staff reluctance

Prohibitive legal structure

Safeguarding – i.e. monitoring the adequacy and quality of support provision

Financial risks associated with unmet need

Demand

The SQWC research team would like to gain an indication of the demand for IBs within the disabled children and family community

6. What do you feel are the main statistical sources of information on the numbers of disabled children at the LA level?
7. Are you aware of any unmet need which may emerge if an IB approach is piloted? i.e. individuals who are eligible for support, were previously not accessing services, but would like to access the new form of service provision. *Please provide details where applicable.*
8. Is the IB approach more appropriate for specific sub-groups within the target population? E.g. age groups, type of disability, stage of development of disability etc.

Is the IB offer likely to be favoured by specific sub-groups of the target population?

9. SQWC has developed a set of initial options for the forthcoming pilots and would appreciate your views on the feasibility of each of these.

SQWC researcher to run through the potential pilot options developed during the initial stage of the scoping study and discuss their feasibility.

Can you identify any additional options which you feel we should consider? Please provide a supporting explanation.

10. What types of services would families with disabled children like to access as part of the potential IB package?

Added value

11. What added value can IB bring to current practice? E.g. increased satisfaction with service provision, increased quality of life for beneficiaries *Please provide copies of any evidence where appropriate.*
12. Can you provide evidence on the cost savings and/or cost effectiveness of the intervention?
13. How could the provision of IB complement the delivery of other strands of the AHDC Strategy (e.g. Short breaks, Early Support Programme, Transition Programme) or other complementary policy interventions?

Funding

14. What set of income streams are applicable to families with disabled children, which could form a component of the IB package? – looking specifically at health, education and social services budgets. *Please specify any associated eligibility criteria.*

Costing

One of the key aims of the study is develop a set of costed pilot options for the forthcoming pilots and therefore we would like to collate any available cost data.

15. Can you provide any data on the costs associated with an IB or similar interventions e.g. unit cost data? *Please provide copies of any appropriate data.*

For example:

Set up costs – e.g. systems development, workforce development, marketing and promotion, financial planning costs

Running costs – e.g. systems maintenance, support planning and brokerage, resources

Cost of specific service provision – e.g. Personal assistants etc.

Spend per head

Funding associated with a 'price-point'

16. What do you feel are likely to be the economic and opportunity costs of an IB type intervention? E.g. personal investment in developing won skills to self direct support, costs associated with increase in efficiency of assessment process etc.

We may contact you to seek your permission should we wish to include a quote made during the interview in the scoping study report. Quotes will not be included in the event that permission is not granted. All quotes will be attributable to the LA and not to a particular individual.

SQW Consulting would like to thank you for participating in the scoping study.

Annex D: User and Parent survey

SQW Consulting has been commissioned by the Department for Children, Schools and Families (DCSF) to undertake a scoping study on Individual Budgets (IB) for Families with Disabled Children. The research will inform the development of future IB pilot work in this area, which is planned to commence in October 2008 and run until April 2011.

The over-arching aims of the study are to:

Draw together the existing evidence on the effectiveness of Direct Payments and Individuals Budgets for families with disabled children; and

Set out what further evidence is likely to emerge from existing self directed support pilot work currently being taken forward.

What is self directed support?

Self Directed Support is a system for providing social care to people who need it. It enables you to organise and choose your own support and aims to radically improve the amount of choice and control you and your carers have in the way your needs are met.

Self Directed Support aims to:

- Increase the choice and control of people using social care services
- Allocate resources fairly and transparently
- Improve the quality of services
- Make better use of resources.

What is an Individual Budget?

The main idea behind individual budgets is to put the person who is supported (and their support network), or given services, in Control of deciding what support or services they get.

Individual Budgets:

- Give people a clear, up-front idea about how much money there is for their support.
- Make assessment quicker and easier and mean people have to give out information fewer times.
- Bring together different kinds of support or funding from more than one agency
- Let people use the money in a way that best suits their own needs and situation.
- Have support to plan what they want and to organise it, from a broker or advocate, family or friends, as the individual wants.

Individual budgets puts people in the centre of the planning process, and recognises they are best placed to understand their own needs and how to meet them. They are flexible enough to allow people who are satisfied with existing services to keep these, and also give people a range of options for building up more individually tailored support, using Direct Payments and other routes.

By participating in this questionnaire we wish to include the views of families with disabled children to help us understand the issues affecting families and how you may be better supported in the future. Your feedback is important and will help in the design and implementation of Individual Budgets for Families with Disabled Children.

Feedback from the questionnaires will remain confidential.

1) Does your child or do you (or have they in the past) receive support from any of the following self directed support schemes?

Direct Payments	YES/NO
Dynamite pilot	YES/NO
Taking Control pilot	YES/NO
Budget-Holding Lead Professional pilot	YES/NO
Early Support Programme	YES/NO
Other (please state)	

2) Prior to receiving this survey, how informed did you feel about self-directed support and individualised budgets? *Please select one from the options below:*

WAS UNAWARE OF THE CONCEPTS	
HAD HEARD OF THE TERMS BUT DO NOT KNOW MUCH ABOUT THEM	
HAD A GOOD UNDERSTANDING OF THE CONCEPTS	

3) Would you be interested in receiving an Individual Budget (as described above) for you/your child and family? YES/NO

4) Individual Budgets can be paid through a number of different methods. Which do you think would be most beneficial to you/your child and family?

Direct Payments	Cash payments made in lieu of social service provision. You will be responsible for paying and organising your own staff or commission support from an agency. To receive a Direct Payment you will need to open a separate bank account in which your money will be paid.	YES/NO
Individual Service Funds	The money is held and managed by a service provider of your choice provider, allowing you to decide how the money will be spent. They will have to agree to be able to work to meet the needs set out in your Support Plan.	YES/NO
Virtual or notional budget	Offers the freedom of choice that a Direct Payment offers without having to manage your own finances. Your Broker will organise the services on your behalf as agreed in your	YES/NO

	Support Plan. You can also choose to buy in-house services from the Council or from organisations and agencies we have contracts with.	
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- 4) What do you think are the advantages of Individual Budgets?
- 5) What do you think are the drawbacks of Individual Budgets and Self Direct Schemes?
- 6) What types of services would you like to be able to purchase to support you/your child and family using your Individual Budget?
- 7) If you had the opportunity to receive an Individual Budget are there any practical supports you would want to help you be in Control? E.g. IB user training, support for brokerage of services, payroll of employees, accounting, peer support etc.

SQW Consulting would like to thank you for participating in the scoping study.

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Annex F: Additional information on funding streams

The following table presents a summary of information on some of the potential funding streams explored during the research. The funds detailed in the list were identified during the consultation exercise of the scoping study research, where consultees felt it would be 'useful' to include the various funding streams but were generally unclear as to whether their inclusion would be feasible or of any associated eligibility criteria or barriers to integration/alignment.

Table 2: Summary of explored funding streams

Independent Living Funds (ILF)

Description	<p>The Independent Living Funds were set up as a national resource dedicated to the financial support of disabled people to enable them to choose to live in the community rather than in residential care.</p> <p>The Independent Living Funds provide a "direct payment" that enables people to purchase care from an agency or pay the wages of a privately employed Personal Assistant (PA).</p> <p>Awards are in the form of regular four-weekly payments to individuals, which are used to buy personal care in the community. Recipients may use care agencies or employ personal assistants, but may not employ relatives who live in the same house.</p> <p>The ILF was originally established in 1988, intended to run for 5 years. When the original Fund closed in 1993, two new Funds were created. The Extension Fund was created to administer the payments of people who applied between 1988 and March 1993 and who continued to receive awards under the old rules. The 1993 Fund was created with slightly different rules - mainly, the condition that Social Services should provide a minimum contribution of £200 per week - to take on new applications. By 2006, there were over 18,000 people using the ILF across the UK.</p> <p>The two Funds were united by the Independent Living (2006) Funds Trust Deed as of 1 October 2007. The ILF continues to fund existing users and new applicants.</p>
Funded by	<p>The Independent Living Fund (2006) is an executive non departmental public body, sponsored by the Department for Work and Pensions (DWP). It is wholly funded by the DWP and the Department for Social Development in Northern Ireland (DSD).</p> <p>It is financed by cash limited 'grants-in-aid' and managed by a board of trustees appointed by the Secretary of State for Work and Pensions. The trustees have discretion about whom they help within the framework of the Trust Deed. Their 2008/2009 budget for the UK is £343 million to help around 21,000 customers.</p>
Eligibility criteria	<p>Eligibility criteria:</p> <ul style="list-style-type: none"> •Receive at least £16,640 per year (£320 per week) in services or direct payments from your local Social Services Department. If you live in Northern Ireland you must receive at least £200 per week from your Local Authority. •Be at least 16 years of age and apply before your 65th birthday. •Receive the highest rate care component of Disability Living Allowance (DLA). •Expect to live in the community for the next six months. •Have capital of less than £22,250 (excluding the property you live in). This amount includes any capital your partner may have. <p>The Fund can pay up to a maximum of £455 per week on top of Social Services input and your assessed contribution (subject to the combined SSD and ILF input not exceeding £785pw).</p> <p>In all cases there is an expectation that the individual will contribute half of the care component of DLA, and all Severe Disability Premium, if the funding is paid to you with your Income Support, towards your care costs.</p> <p>Applications are subject to prioritisation. From 1 April 2008 the ILF has introduced budgetary measures. (See additional comments below)</p>

Additional comments	<p>Recent changes:</p> <p>The Independent Living Funds (ILF) has written to all of its users, applicants and their representatives living in Great Britain (GB) as well as Local Authorities and Disability Organisations, to inform them of changes to its rules from 1 April 2008. The changes relate to the threshold sum that Local Authorities must pay, which has been increased to £320 per week, and the date that ILF can pay increased awards from. Additionally, measures are being taken to manage valid applications received by the ILF from 1 April 2008. These measures will give priority to those applicants who are in work and on the lowest incomes.</p>
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Social Care Budget

Description	<p>‘One of the key elements of individual budgets is to bring together a variety of income streams in an integrated manner, to improve choice and control for the individual, and to facilitate coordinated provision of services. The majority of income streams being used by the individual budget pilot sites are only available to young people and adults over the age of 16. The largest potential source of income is the Social Care budget. Other budgets that could be included are the Integrated Community Equipment Services budget, and the Disabled Facilities Grant could be available for children under 16.’</p> <p>p.19 AHDC</p>
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Funded by	<p>Public money spent on social care comes from a combination of:</p> <ul style="list-style-type: none"> •central government grants •council tax revenues •user charges – individuals asked to contribute towards the cost of social care. Important to note that there are different arrangements for charging for residential and non-residential care that take into account the individual needs and situation of the person requiring care. <p>Some £2 billion is raised through user charges, which accounts for around 14 percent of gross expenditure on adult social care.</p> <p>It is up to individual councils to decide how to use that funding and how much of it to spend on social care. The overall gross expenditure on adult social care in 2005-06 was approximately £13.7 billion.</p>
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Eligibility criteria	<p>It is the responsibility of the Local Authority to set its eligibility threshold for social care. This has resulted in considerable variation between LAs, where a child in one LA may fall short of the threshold set out by their LA (and therefore be classed as having additional needs as opposed to complex needs), but fall within the threshold in a neighbouring LA.</p> <p>The relevant local authority is responsible for interpreting and applying the regulations and guidelines in order to decide what to charge.</p>
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Additional comments	<p>Government funding of voluntary sector organisations</p> <p>Central government also supports a number of projects managed by voluntary organisations through Section 64 grants.</p> <p>The Section 64 (S64) General Scheme of Grants helps to strengthen and further develop the partnership between the Department of Health and the voluntary and community sector. It is the Department's main funding stream for national voluntary organisations working in the health and social care fields.</p>
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Pooled Health Budgets

Description	<p>Health Act 1999 partnership arrangements</p> <p>The Health Act 1999 provides an enabling framework so that money can be pooled between health bodies and health-related local authority services, and resources and management structures can be integrated. The arrangements, which have been in use since April 2000, allow for the joining-up of commissioning for existing or new services and similarly for the development of provider arrangements. The arrangements are commonly referred to as Section 31 Health Act flexibilities:</p> <ul style="list-style-type: none"> • Lead Commissioning • Integrated Provision • Pooled Budgets
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Pooled budgets: 'Improved partnership working has also been facilitated by provision for pooling of health and social care budgets in the Health Act 1999. Pooled budgets and integrated funding provide the flexibility for funds to flow to where they are most needed, in order to provide a truly personalised service. Successful programmes using these flexibilities have already demonstrated a shift away from high-intensity specialist care to lower-level, often preventative services.'

p.49 Independence, Well-being and Choice: Our Vision for the Future of Social Care for Adults in England (March 2005)

Section 31 of the Health Act 1999 has now been repealed and replaced, for England, by section 75 of the National Health Service Act 2006, which has consolidated NHS legislation. The new provision is in exactly the same terms and existing section 31 arrangements will continue as if made under the new powers. Any new partnership arrangements should refer to the new powers rather than to section 31.

KEY PRINCIPLE OF A POOLED FUND ARRANGEMENT Regardless of what contributions NHS bodies or local authority(ies) commit to the pool, the pooled resource can be used on the agreed services as set out in the partnership arrangement. This will mean that the expenditure will be based on the needs of the users, and not on the level of contribution from each partner. This gives pooled budgets a unique flexibility, whilst being bounded by agreed aims and outcomes. (guidance document on pooled budgets).

Funded by	National level: DH Local level: PCT, NHS Trusts and LAs
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Eligibility criteria	<p>Who can use the flexibilities and grant arrangements and what are the conditions?</p> <p><u>The Flexibilities:</u> Primary Care Trust, NHS Trusts including NHS Foundation Trusts, Care Trusts, and Local Authorities can use the Health Act Flexibility Arrangements.</p> <p><u>S28 Grants:</u> Primary Care Trusts, Local Authorities and PCT based Care Trusts (ie commissioning Care Trusts) can use the S28 arrangements.</p> <p>All of these statutory partners will work closely with users, carers, staff organisations, other providers, and the wider community.</p> <p>The statutory partners must fulfil certain conditions for 'Health Act Flexibilities' including:-</p> <ul style="list-style-type: none"> • Partners should be satisfied that the arrangement will improve services for users • Consultation with those affected by the arrangements should have taken place (this may often be people working within the organisations about to participate within a formal arrangement) • The arrangement should fulfil the objectives identified in the Local Delivery Plan • There should be a clear written agreement, in a form as specified in the Regulations. <p>Conditions for use of S28 arrangements are contained in the Directions.</p> <p>A key criterion is that payment is likely to secure a more effective use of public funds than the deployment of an equivalent amount on the provision of the grant giving partner's services.</p> <p>Full details and requirements for S28 payments can be found at:</p> <p>http://www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/IntegratedCare/Healthact1999partnershiparrangements/index.htm</p>
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Additional comments

Health Act Flexibilities were introduced within S31 of the Health Act 1999. These have now been repealed and replaced, for England, by section 75 of the National Health Service Act 2006, which has consolidated NHS legislation. (The new provision is in exactly the same terms and existing section 31 arrangements will continue as if made under the new powers). Any new partnership arrangements should refer to the new powers rather than to section 31.

The aim of the flexibilities is to improve services for users, through pooled funds and the delegation of functions, (lead commissioning and integrated provision), thus fulfilling national and local objectives. They are permissive powers to support better co-ordination and innovative approaches to securing services across a wide range of NHS and local authority functions.

There is no limit to the size of the partnerships. Partners will agree on the functions to be fulfilled by the partnership, which can include all health related local authority functions, such as social service, housing and education functions, and community and acute health services (with specified exceptions – see Regulations 5 and 6 of SI 200 No 617).

‘Section 28 Grants’ may also be used to contribute to expenditure by another partner on their duties. This means that partners can offer funds towards the delivery of the other’s services and this is particularly relevant where there are complementary reasons for doing so e.g. to support a change in provision by one partner that may have a consequential effect upon demand for the other’s services. This grant arrangement can be used for capital as well as revenue.

Arrangements for the granting of funds from the NHS towards Local Authorities were introduced under S.28A of the NHS Act 1977. A similar power for Local Authorities to grant funds towards the NHS was introduced as an amendment to the 1977 Act within the Health Act 1999 and to be known as S.28BB.

These arrangements have also been consolidated within Sections 76 and 256 the NHS Act 2006 but as for the Health Act Flexibilities remain unchanged in terms of the powers available or the criteria as Set out in the earlier Secretary of State Directions.

S.31 and Direct Payments

A number of councils have been expressing some confusion about the use of direct payments by health organisations. The following statement has been issued to clarify the DH position:

- Whilst the Department of Health is unable to comment on individual cases, direct payments made under the Health and Social Care Act 2001 relate only to certain local authority social services.
- This means that where an individual has an identified health need which falls to the NHS, that part of any "care" package cannot be delivered as a direct payment within the meaning of the legislation, including where a local authority are acting under a partnership arrangement pursuant to section 31 of the Health Act 1999.

Use of S.31

There are various types of Section 31 partnership. For example community equipment partnerships create pooled budgets for commissioning equipment for disabled people. The Section 31 partnerships for community mental health services, older people’s services and learning disability services tend to be larger and have more of a direct impact on staff. For example around a third of the mental health and the learning disability partnerships and almost half of the older people projects involve integrated projects which include secondment or transfer of some staff.

Continuing care

Description

Continuing NHS healthcare and NHS-funded nursing care is provided over an extended period of time to meet physical or mental health needs that have arisen as a result of disability, an accident or illness. The care can be provided in a variety of settings including a hospital, nursing home, hospice or the patient’s own home.

NHS continuing healthcare is the name given to a package of services which is arranged and funded by the NHS for people outside hospital with ongoing health needs. You can get continuing healthcare in any setting, including your own home or in a care home. NHS continuing healthcare is free, unlike help from social services for which a charge may be made depending on your income and savings.

In your own home, this means that the NHS will pay for healthcare (e.g. services from a community nurse or specialist therapist) and personal care (e.g. help with bathing, dressing and laundry). In a care home, the NHS pays for your care home fees, including board and accommodation.

Funded by DH - NHS

Eligibility criteria	<p>Anyone assessed as requiring a certain level of care need can get NHS continuing healthcare. It is not dependent on a particular disease, diagnosis or condition, nor on who provides the care or where that care is provided. If your overall care needs show that your primary need is a health one, you should qualify for continuing healthcare. The primary health need should be assessed by looking at all of your care needs and relating them to four key indicators:</p> <ul style="list-style-type: none"> • nature – the type of condition or treatment required and its quality and quantity • complexity – symptoms that interact, making them difficult to manage or control • intensity – one or more needs which are so severe that they require regular interventions • unpredictability – unexpected changes in condition that are difficult to manage and present a risk to you or to others.
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Special Educational Needs Funding

Description	<p>The definition of special educational needs (SEN) The Education Act 1996 says that 'a child has special educational needs if he or she has a learning difficulty which calls for special educational provision to be made for him or her.' It also says that 'a disability, which prevents or hinders them from making use of education facilities', amounts to a learning difficulty if it calls for special educational provision to be made. Special educational provision is provision that is additional to or otherwise different from that normally available in the area to children of the same age.</p> <p>Disability and special educational needs Not all children who are defined as disabled will have SEN. For example, those with severe asthma, arthritis or diabetes may not have SEN but may have rights under the DDA. Similarly, not all children with SEN will be defined as having a disability under the Disability Discrimination Act. The Disability Rights Commission's Code of Practice for schools is helpful in explaining this in more detail.</p> <p>http://www.teachernet.gov.uk/wholeschool/sen/disabilityandthedda/disabilityandsen/</p>
Funded by	DCSF SEND
Eligibility criteria	<p>The Education Act 1996 says that 'a child has special educational needs if he or she has a learning difficulty which calls for special educational provision to be made for him or her.' It also says that 'a disability, which prevents or hinders them from making use of education facilities', amounts to a learning difficulty if it calls for special educational provision to be made. Special educational provision is provision that is additional to or otherwise different from that normally available in the area to children of the same age.</p>

Disabled Facilities Grant

Description	<p>A Disabled Facilities Grant is a local council grant to help towards the cost of adapting your home to enable you to continue to live there. A grant is paid when the council considers that changes are necessary to meet your needs, and that the work is reasonable and practical.</p>
Funded by	<p>Such grants are given by local councils under Part I of the Housing Grants, Construction and Regeneration Act 1996.</p> <p>The Disabled Facilities Grant is for adaptations recommended by a Council's occupational therapist following an assessment under the Chronically Sick and Disabled Persons Act 1970 or, in the case of children, the Children's Act 1986.</p> <p>Currently, 60 per cent of the funding for the DFG comes from specific Communities and Local Government grants, and local authorities are required to find the remaining 40 per cent from their own resources.</p> <p>From 2008-09 the DFG funding split of 60:40 no longer applies. Local authorities will receive a DFG allocation without a specified requirement to match this funding. This increased flexibility will allow local authorities to design services which fit with local delivery arrangements and the needs of individuals</p>
Eligibility criteria	<p>You can claim if you, or someone living in your property, is disabled and:</p> <ul style="list-style-type: none"> • you, or the person on whose behalf you are applying, are either the owner or tenant (including licensees) of the property • you can certify that you, or the person on whose behalf you are applying, intend to occupy the property as your/their only or main residence throughout the grant period - currently five years <p>A landlord may apply on behalf of a disabled tenant.</p>

Annex G: Consulted Local Authority and stakeholder organisations

Local Authorities who took part in the consultation exercise

- Brighton and Hove City Council
- Essex County Council
- Gateshead Council
- Leeds City Council
- London Borough of Brent
- Middlesbrough Council
- Norfolk County Council
- North Tyneside Council
- Sheffield City Council
- Swindon Borough Council

Case study Local Authorities

- Coventry City Council
- Gloucestershire County Council
- Newcastle City Council
- Northumberland County Council
- London Borough of Redbridge
- Case study local authority six

Stakeholder organisations who took part in the consultation exercise

- Association of Directors of Children's Services
- Calderdale Parents and Carers Council
- Carers UK
- CCNUK
- Contact a Family
- Council for Disabled Children

- Department for Children, Schools and Families
- Department of Health
- Helen Sanderson Associates
- in-Control
- Lancaster University
- Mencap
- National Brokerage Network
- NCH
- North West Training and Development Team
- Office for Disability Issues
- OPM
- Paradigm
- Real Life Trust
- The Children's Society

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Annesley
Nottingham
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Tel 0845 6022260
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Email dcsf@prolog.uk.com

Ref: DCSF-RR057

ISBN 978 1 84775 257 4

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Published by the Department for
Children, Schools and Families