

# Individual Budgets for Families with Disabled Children - Interim report 2010

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This research report was written before the new UK Government took office on 11 May 2010. As a result the content may not reflect current Government policy and may make reference to the Department for Children, Schools and Families (DCSF) which has now been replaced by the Department for Education (DFE).

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

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## The team

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SQW Consulting (SQW) was commissioned by the former Department for Children, Schools and Families to lead a consortium to undertake the evaluation and support/challenge role for the Individual Budget Pilots for Families with Disabled Children. The consortium comprised of two distinct teams – the evaluation and support teams – where the evaluation component has been conducted by SQW and Ipsos MORI, and the support function has been undertaken by iMPower and Helen Sanderson Associates.

Separate evaluation and support teams were developed to ensure: the pilot sites could approach the support team for assistance; while the evaluation team reviewed progress. In this way pilot sites did not need to feel concerned that asking for support would be viewed negatively by the evaluation team. Moreover, pilot sites were asked to provide feedback on the support that they received, which SQW used to provide direction to the support team.

### ***The Evaluation team***

**Graham Thom**, an Associate Director at SQW Consulting, acted as the Project Director of the Evaluation.

**Meera Prabhakar**, a Senior Consultant at SQW Consulting, acted as the Project Manager of the Evaluation.

Jennifer Hurstfield, Urvashi Parashar, Lisa McCrindle and Robert Turner, Laura Henderson and Rhian Johnson formed the remainder of the SQW research team.

**Claire Lambert** and **David Jeans** acted as the leads for Ipsos MORI.

### ***The Support team***

**Jeremy Cooper** and **David Colbear** acted as the support team leads for iMPower and **Jo Harvey** acted as the lead for Helen Sanderson Associates.

## Executive summary

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1. Six local authorities and primary care trusts (PCTs) – Coventry, Derbyshire, Essex, Gateshead, Gloucestershire and Newcastle - were commissioned to test whether the Individual Budget (IB) concept and approach work in practice. An IB in this context is defined as follows:

An individual budget (IB) applies to an arrangement whereby a service user gains direct control over the application of funding allocated to them following an assessment process or processes, and where funding is sourced from a number of income streams held by local statutory bodies. The intention in bringing different funding streams together is to go beyond current direct payment arrangements, and provide a more holistic and joined up package of support.

*Source: Individual Budgets for Disabled Children and their Families Pilot Specification and Application Pack*

2. The IB pilots will run from April 2009 until March 2011. The evaluation is capturing evidence on:
  - The process involved in setting up and delivering IBs (and therefore incorporates an assessment of the common delivery model)
  - The resultant inputs, processes, outputs, outcomes and impacts that are undertaken and are experienced by the families with disabled children participating in the pilot.
3. This report presents a detailed assessment of the progress made by the pilot sites over the first year of the programme. As such, the report focuses on the set-up and initial implementation stages of the programme and the baseline views of families at the point at which they became part in the pilot.

### Our approach

4. A multiple-method approach was adopted to undertake the evaluation. Table 1 presents a summary of the research tools that have been used to undertake the evaluation of year one of the programme. The specifics of each tool are presented below.

Table 1: Evaluation research tools for year one

Research tool	Inputs from	Resultant outputs
<b>Pilot delivery plan</b>	<ul style="list-style-type: none"> <li>Support team (iMPower)</li> <li>Pilot site delivery staff</li> </ul>	Finalised delivery plan
<b>Family registration form</b>	<ul style="list-style-type: none"> <li>Pilot delivery staff in conjunction with the families and disabled children participating in the pilot</li> </ul>	Timely electronic registration data
<b>Monitoring tool</b>	<ul style="list-style-type: none"> <li>Pilot delivery staff</li> </ul>	Timely electronic monitoring data
<b>Case study research</b> <ul style="list-style-type: none"> <li>To include secondary and administrative data collation</li> </ul>	<ul style="list-style-type: none"> <li>Pilot site delivery staff</li> <li>Wider stakeholders e.g. Project Board members</li> <li>Providers</li> </ul>	Consultation evidence from a range of staff and stakeholders
<b>Family survey</b> <ul style="list-style-type: none"> <li>Baseline survey</li> </ul>	<ul style="list-style-type: none"> <li>Evaluation survey team (Ipsos MORI)</li> <li>Families and disabled children participating in the pilot</li> </ul>	Baseline evidence from participating families
<b>Survey of professionals</b> <ul style="list-style-type: none"> <li>Baseline survey</li> </ul>	<ul style="list-style-type: none"> <li>Pilot site delivery staff – project officers who manage individual case loads</li> </ul>	Baseline perceptions from staff supporting participating families

Source: SQW Consulting

### Progress against the Common Delivery Model

- The developments in each site have been guided by, and assessed against the ten elements of a Common Delivery Model (CDM), which was specified in the Application Pack and derived through a prior scoping study.

#### **Element 1: Adequate staff and organisational engagement**

- At the point of drafting this report, all sites had recruited the majority of their IB pilot-specific team and set up appropriate governance structures and they were subsequently in the process of refining their existing infrastructure to meet the requirements of the pilot. Some of the IB teams recruited a further cohort of staff at the beginning of 2010 to facilitate the resource allocation and support planning

stages of the process, which was felt to require significant time inputs from 'frontline' staff.

***Element 2: A change management programme for all staff involved in the pilots***

7. Sites have focused their initial efforts on engaging and raising awareness in the teams that have been the most accessible during the first year of the programme. This has included the children's social care team, but often not the PCT and education delivery teams who were felt to be more risk averse in their attitudes towards the personalisation agenda as a result of national design. It will be important for the sites to focus their efforts on drawing in the less engaged stakeholders during Year two of the programme.
8. Both formal and informal training and change management were viewed as effective. The experience of the sites implies that the process of change management needs to be undertaken throughout the course of the programme and specifically tailored to meet the needs of particular audiences.

***Element 3: Facilitation of awareness raising and information dissemination for potential families***

9. The sites have used a variety of mechanisms to raise awareness and share information with prospective families with disabled children. The most effective mechanism has been personal one-to-one contact facilitated through members of the pilot teams that were well versed in the workings of the pilot and could therefore provide reassurance and manage the expectations of the families when required.
10. Personal one-to-one contact has proven to be resource intensive and has involved considerable input from the pilot project managers. Therefore, it will be important to ensure sufficient numbers of appropriately skilled people are drawn in to undertake family engagement in the event that the activity of the pilots is rolled out.

***Element 4: Provision of advocacy and support brokerage for IB users***

11. The majority of sites have commissioned an external advocacy service to offer support to families. Its effectiveness will be assessed as part of the family follow-up survey that is to be conducted in late 2010.
12. The support planning process was felt to form an integral part of the resource allocation process (see CDM element 7). Three main models of support planning have emerged:



- Majority independent support planning provision sourced from the third sector
- Majority in-house support planning (i.e. within the local authority)
- Mixed forms of provision that combine both internal and external provision.

These methods have included the use of the Planning Live approach (a group based approach and has been provided in some sites by Helen Sanderson Associates as part of the support provided to the pilots) and 'self-support planning', where the latter is facilitated by the family in the main.

13. Early feedback from support planners indicates that the support planning process has led to the identification of new, more holistic information that is regularly absent from the traditional systems that are currently used. The feedback also identified a widely held view that a key part of their role was to help families build links with community-based provision.
14. Similarly, early feedback from a small number of families showed that they were largely positive about the support planning process and were starting to use the opportunity to change some of the elements of their support planning. In addition, anecdotal perceptions from support planners indicated that families were receptive to new ideas and may become more radical over time if their initial choices work as they hope.
15. As support planning activities had only recently begun, it is too early to assess the effectiveness of the different models and therefore this element of the CDM will be revisited during the course of Year two of the programme.

***Element 5: Facilitation of peer support mechanisms***

16. To date, this provision has been relatively informal in its nature and has been driven largely by the families themselves. Peer support is likely to develop further as families proceed through support planning and on to sourcing and managing service provision.

***Element 6: Development of IT resources***

17. This element was approached in one of two ways: the first involved some sites integrating the requirements of the pilot onto existing systems; and the second involved the development of relatively low technology, standalone systems. The Integrated Children's System (ICS) has proven to be too rigid in its nature to facilitate useful IT provision for the IB pilot sites. Rather, low technology, standalone systems

have been used. This will suffice for the lifetime of the programme, however this solution is not likely to be sustainable.

***Element 7: Development and implementation of a resource and funding mechanism (and support planning)***

18. Over the first year of the pilots, it has become increasingly clear that resource allocation and support planning are integrally linked. This has meant that the development of both these strands has been delivered simultaneously and resulted in the creation of a single process in each site, through which families will progress.
19. Three sites opted to use an adapted version of the Taking Control model (i.e. the Resource Allocation System (RAS) version 4 or 5), two sites had opted to develop their own alternative system and one site chose to develop both a RAS and alternative system (where each will be used for different age groups).
20. All but one of the models has included the provision of an indicative budget to the participating families at some stage of the planning cycle, as this form of financial information was felt to be necessary to enable both families and support planners to form realistic support packages.
21. The main differences between the RAS based models and alternative models appear to lie in:
  - The preparatory elements involved prior to the provision of an indicative budget
  - The degree of systematisation through which the scale of resource is decided.
22. Figure 1 summarises the resource allocation and support planning processes used by the sites.
23. It is too early in the process to properly test the results from each of the models. However, the sites raised a number of areas for development in relation to their chosen model, each of which will be explored further during Year two of the programme. It will also be important to track how the differences of approach lead to different types or scale of change in the support packages, satisfaction with the process, levels of innovation and the outcomes achieved.

Figure 1: Resource allocation and support planning processes used by the sites



Source: SQW Consulting

**Element 8: A Spectrum of choice for management of IB funds**

24. Sites intend to offer families a number of means by which they can manage their IB funding. This includes in-house management, the family managing the budget themselves, third party management and other variations. It is currently too early to comment extensively on this element of the CDM, given that only a small number of

IBs had gone live at the point of drafting the report. Therefore, this element will be explored in more detail during year two of the programme.

***Element 9: Facilitation of sufficient market development***

25. The majority of the sites had begun to focus attention on developing the market to ensure that the required forms of provision were available. This includes the development of community capacity to enable families to access local and universal services. Concerns were raised about the extent to which the IB approach would lead to declining demand for traditional services, which were generally managed through long-term block contracting arrangements. Sites added that they were unsure whether they would be able to honour such contracts if the market changed sufficiently, which implied that larger providers would have to deal with the challenge of decommissioning services and move towards the provision of more flexible services.
26. Sites stated that the provision of an IB was likely to increase the demand for personal assistants (PAs) and therefore, that this aspect of the market may require stimulation and intensive support. For example, one site intended to support the development of PAs by providing them with assistance to become effective support workers.

***Element 10: Engagement of all parties in the development of the pilot***

27. While some sites have successfully engaged the majority of the relevant stakeholders, others were still in the process of gaining 'buy-in' from most of the main players. In the cases where successful engagement had been achieved, a 'shared understanding' of the purpose and added value of an IB had been established. This outcome had in some cases also led to the contribution of funding from the relevant service heads for inclusion in the IB packages.

***Summary of progress against the CDM***

28. All sites perceived themselves to have made considerable progress against all elements of the CDM over the first year of the pilot. Evidence gathered through the case study research would support this sense of achievement. However, no site had reached a steady state and therefore that each should be viewed as still in the development/set up phase.

***Funding streams and services***

29. The sites have exhibited mixed progress, where some sites had been successful in broadening the scope of their IB packages beyond social care funds, others were

much less advanced. For example, one site had only included a contribution from the social care core budget in their IB packages, whereas another site had successfully drawn in social care, PCT and education based funding, thereby illustrating what can be achieved in the appropriate circumstances. Where other funds had not been drawn in sites were still seeking to adopt a more holistic view of needs than may have been the case previously.

30. The general consensus from the sites highlighted that although progress had been made with some of the PCT fund holders, they had only contributed limited funds, most of which carried restrictions. However, the biggest barriers were encountered during attempts to draw in education funding streams, where only one site had really made any form of progress.

The families and young people taking part in the pilot

31. Each of the IB pilot sites was tasked to engage 30-50 families with disabled children to take part in the pilot. Although the sites reported initial concerns about the engagement deadline at the outset of the programme, all sites successfully engaged a cohort of families to take part in the pilot. However, just three sites achieved their engagement within the original deadline.
32. The families recruited represent a good range of diversity between participating families in relation to: socio economic groups; nature of the child/young person's disability; and previous use of personalised approaches. This diversity suggests that personalised approaches may appeal to a range of families if approached and delivered in an appropriate manner.

Baseline survey of families and young people

33. Of the 185 families enrolled on the pilot that were eligible to take part in the survey, interviews were conducted with 173 parents/carers, representing a 94% response rate. This high level of response rate gives considerable reassurance about the robustness of the findings and a sufficient number to allow for robust findings to be gathered even if there is some attrition when the follow-up survey is conducted in late 2010.
34. Families were almost equally divided as to whether or not they were or were not satisfied with the support that they received in relation to their child's disability. This division is interesting, as it suggests that the concept of an IB has appealed to families even when they were satisfied with their previous support. The majority of

families felt that they lacked very much (if any) control over the help they received in relation to their child/young person's disability prior to IB.

35. Prior to enrolling on an IB, families were in particularly strong agreement that they were involved in the decisions affecting the care of their child/young person but they were less satisfied that the staff providing services for their child/young person were joined up. The majority of families felt they had access to at least most of the education and health services that they required prior to their enrolment on an IB. However, families felt themselves to be lacking access to social care services.
36. The majority of families were yet to begin support planning at the time the survey was undertaken. Experiences of the support planning process (and the time taken to complete the process) varied considerably across families. Early experiences of families suggest that increased access to personal assistants may be an important element of IB provision.

#### Professional survey

37. The survey of professionals sought to collect an external view on the position of families prior to their enrolment on the pilot. As with the parent survey there was most concern about families having sufficient access to the required social care services.
38. There was a great deal of uncertainty amongst professionals on how the IB provision will vary from traditional service provision, which was to be expected in a baseline survey. However, it was also evident that the children/young people most expected to experience a 'great deal' of change in their service offer (or the way the services were delivered) were those with profound or complex needs.

#### Emerging findings

##### ***What has worked well***

39. The sites have progressed broadly in line with the speed and scale envisaged in the pilot design. They have now recruited a cohort of families, who in turn are proceeding through support planning. The range of families involved suggests that, if explained properly, IBs can be attractive across the social spectrum and to families with young people facing a wide range of disabilities

40. The families include a number who are both satisfied and dissatisfied with their current support and so the evaluation will be able to test how levels of satisfaction change, if at all, from different starting points.
41. The early feedback from resource allocation and support planning suggests that some families have used the opportunity to significantly change their support package (even in some cases where they have been allocated fewer resources).

***What has worked less well***

42. The sites have put in place a series of processes, but having now tested these with a first cohort of families recognise the need for substantial refinement and adaptation. While resource allocation mechanisms have been developed these have not always worked smoothly and further refinement and development is required.
43. An important barrier for the sites has been around their linkages to other parts of their own authority. For example, there have been compatibility issues around the of IT systems, or of transferring the experience of adult social care to the very different environment of young people. The sites have made some progress in attracting funding streams outside social care, but this has been difficult and so further efforts will be required in Year two.

***Overview***

44. Overall however the good progress made by sites in the first year, the on-going relationships between the sites and the evaluation team, and the coverage and inferences of the baseline survey data suggest that the overall pilot programme is well placed to provide further and much deeper insights in March 2011. This in turn should provide a much more robust evidence base for policy makers to refine their thinking around the IB approach as an appropriate means to deliver much needed, high quality support to families with disabled children.

# 1: Introduction

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## The Individual budgets programme

- 1.1 The Government is committed to the personalisation of services and increasing choice and control for families with disabled children. One way of delivering this is through the facilitation of individual budgets (IBs) for disabled children. An IB in this context is defined as follows:

An individual budget (IB) applies to an arrangement whereby a service user gains direct control over the application of funding allocated to them following an assessment process or processes, and where funding is sourced from a number of income streams held by local statutory bodies. The intention in bringing different funding streams together is to go beyond current direct payment arrangements, and provide a more holistic and joined up package of support.

Under IB, the service user will also be offered the support of a broker to help manage the allocation provided - some of which may be in cash form, but can also be services provided in-kind. The broker may also hold the budget on behalf of the beneficiary.

*Source: Individual Budgets for Disabled Children and their Families Pilot Specification and Application Pack*

- 1.2 A commitment to pilot IBs for families with disabled children was expressed in Aiming High for Disabled Children (DCSF (2007) *Aiming High for Disabled Children (AHDC): Better support for families*). This led the former Department for Children Schools and Families to commission SQW Consulting in April 2008 to undertake a scoping study prior to the piloting of IBs for families with disabled children. The primary purpose of the study was to inform the development of the IB pilot programme and therefore the research sought to review a range of existing approaches that were being used to deliver IBs and interventions of a similar nature. This highlighted a wide range of existing activity, which was either adult focused or sought to support the personalisation of services for children with additional or complex needs using approaches that did not align with the above definition of an IB. As such, the report identified a lack of robust evidence on the effectiveness of IB provision for families with disabled children, which when combined with the widely held view that many



families would welcome the notion of greater choice and control in the type of support/services they receive, re-enforced the need to pilot the IB approach for families with disabled children.

- 1.3 [Individual budgets \(IBs\) for families with disabled children: A scoping study](#) (hereafter referred to as ‘the Scoping Study’) was published in October 2008 and concluded by recommending the use of a Common Delivery Model (CDM) which set out ten key elements to be addressed by the pilot sites (see Table 1-1 below for a summary of the elements and refer to Annex A for a detailed description of the CDM). Each requirement was: based on a rationale which was identified during the course of the research; but defined in a way that was flexible as to how each element should be delivered to ensure sites were given the autonomy to test different approaches to address each issue.

Table 1-1: Summary of the Common Delivery Model

**Element of the CDM**

1. Adequate staff and organisational engagement
2. A change management programme for all staff involved in the pilots
3. Facilitation of awareness raising and information dissemination for potential beneficiaries
4. Provision of advocacy and support brokerage for IB users
5. Facilitation of peer support mechanisms
6. Development of IT resources
7. Development and implementation of a resource and funding mechanism
8. A spectrum of choice for management of IB funds
9. Facilitation of sufficient market development
10. Engagement of all parties in the development of the pilot

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*Source: SQW Consulting (2008) Individual Budgets for Families with Disabled Children: Scoping Study, DCSF Research Report RR057*

- 1.4 The recommendations from the scoping study were subsequently taken forward and in March 2009 a number of local authorities along with their primary care trust (PCT) partners were invited to apply to pilot IBs for families with disabled children. Six pilot sites were commissioned in April 2009 (see Table 1-2).

Table1-2: IB pilot sites

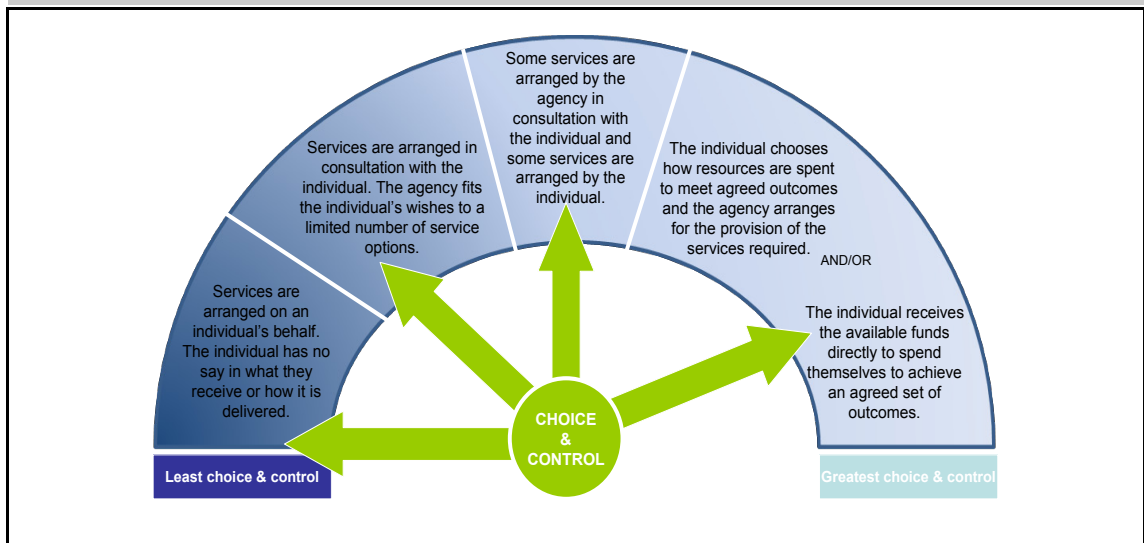
• Coventry	• Gateshead
• Derbyshire	• Gloucestershire
• Essex	• Newcastle

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***Objectives of the programme***

- 1.5 The IB pilots will run from April 2009 until March 2011, with a possible extension to March 2012, subject to available funding. Sites will receive between £200,000 and £280,000 in grant funding over the two years to deliver the pilots.
- 1.6 The activities of each site are feeding into the national pilot programme, which has been set up to establish if an IB:
- enables disabled children and their families to have more choice and control over the delivery of their support package
  - improves outcomes for some, or all, disabled children and their families.
- 1.7 The sites are also seeking to:
- establish whether or not the IB pilots result in some, or all, disabled children and their families reporting increased levels of satisfaction with the experience of gaining service provision through an IB
  - identify any unintended consequences and critical barriers experienced by the pilot Local Authorities and PCTs to the successful implementation of IBs, and record successful approaches to addressing those barriers
  - assess the relative importance of the 10 factors making up the common delivery model to the successful implementation of IBs
  - facilitate a range of means of providing user control - as shown in Figure 1-1, therefore, they are considering the facilitation of more than just direct cash payments, where securing alternative means of building user control will be particularly important in bringing health services and additional resources into the pilots
  - provide a comparison of the costs to the Local Authorities and PCT of implementing IBs for disabled children and the costs of providing services through current arrangements.

Figure 1-1: Spectrum of choice and control



Source: IB Application Pack

- 1.8 Individual budgets require a person-centred approach which calls for partnership and integrated service delivery between providers. Therefore each pilot site has been set up to be delivered by both local authority and PCT partners. Each local authority has also been encouraged to develop their assessment procedures and resource allocation and funding mechanisms. In conjunction with this, the sites have also been asked to determine the exact scope of their funding, where there is an expectation that sites will incorporate as wide a range of service provision and funding streams as possible (i.e. move beyond the devolution of just social care funding).

## An introduction to the evaluation

1.9 The pilots were commissioned to test whether the IB concept and approach work in practice (and to what extent the approach is cost-effective). Following the evaluation a decision on roll out of the pilots will be made. Therefore it is intended that the evaluation will provide an evidence base for both the Department and others wishing to facilitate the provision of IBs to families with disabled children.

1.10 The aims of the evaluation, as set out in the Terms of Reference (ToR), are as follows:

- evaluate whether provision secured through an IB improves outcomes for some, or all, disabled children and families compared with provision secured through existing routes to accessing services
- test whether the IB pilots result in some, or all, disabled children and their families reporting increased levels of satisfaction with the experience of gaining service provision through an IB
- identify any critical barriers experienced by the pilot local authorities and PCTs to the successful implementation of IBs, and record successful approaches to addressing those barriers
- assess the relative importance of the 10 factors making up the common delivery model (CDM) to the successful implementation of IBs
- provide a comparison of (a) the costs to the local authority and PCT of implementing IB for disabled children and (b) the costs of providing services through current arrangements
- recommendations on the likely costs of extending IBs to all eligible families with disabled children in the pilot areas and the actions that the Government could take to support the extension of IBs for disabled children and young people beyond the pilot areas.

1.11 Thus, the evaluation is capturing evidence on:

- the process involved in setting up and delivering IBs (and therefore incorporates an assessment of the common delivery model)
- the resultant inputs, processes, outputs, outcomes and impacts that are undertaken and are experienced by the families with disabled children participating in the pilot.

## Purpose and structure of the report

- 1.12 This report seeks to present a detailed assessment of the progress made by the pilot sites over the first year of the programme. As such, the report focuses on the set-up and initial implementation stages of the programme and the baseline views of families at the point at which they became part in the pilot. *The report therefore does not seek to provide an assessment of the outcomes or distance travelled by participating families, as this aspect of the evaluation will be measured over the course of the second year of the programme.*
- 1.13 The remainder of the report is structured as follows:
- **Chapter 2: Evaluation approach for year one** – sets out our approach to the evaluation and introduces the evaluation framework
  - **Chapter 3: Introducing IBs and the pilot sites** – presents a summary discussion of the contextual policy landscape and an introduction to the IB pilot sites
  - **Chapter 4: IB processes and activities** – sets out the development that has taken place in the pilot sites over the first twelve months of the programme, where progress is measured against the ten elements of the Common Delivery Model
  - **Chapter 5: Resource Allocation and Support Planning** – provides a detailed description of the development and implementation of resource allocation models and support planning activities that have taken place to date
  - **Chapter 6: Funding streams and services** – presents a discussion on the budgets/services that have been successfully drawn into the IB packages and those that have proved more challenging to include
  - **Chapter 7: Pilot inputs and cost** – details the financial and in-kind inputs expended to facilitate the first year of the programme
  - **Chapter 8: The families and young people taking part in the pilot** – sets out the recruitment profile of the programme, the characteristics of participating families, an initial snapshot of the first tranche of IB packages and families reactions to the process to date

- **Chapter 9: Baseline survey of families** – presents an analysis of the baseline survey undertaken with participating families at the point at which, or just after they joined the programme
- **Chapter 10: Baseline survey of young people** - presents an analysis of the baseline survey undertaken with participating disabled young people at the point at which, or just after they joined the programme
- **Chapter 11: Professional survey** – sets out the findings of the survey of professionals, which sought to collect an external view on the position of the families prior to their enrolment on the programme
- **Chapter 12: Emerging findings and issues** – presents a summary of the achievements of the programme to date, the challenges faced and the means by which they have been addressed, ongoing issues that require attention during year two, intentions for year two and the next steps for the evaluation team.

1.14 The report also contains the following annexes:

- **Annex A: The Common Delivery Model** – provides a detailed description of the CDM.
- **Annex B: The evaluation framework** – sets out the comprehensive evaluation framework that was designed to underpin the research.
- **Annex C: Progress update from the Support Team** – presents an overview of the approach used by the support team and an assessment of progress to date.

## 2: Evaluation approach for year one

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- 2.1 This chapter introduces the evaluation framework that was developed to underpin the evaluation and the associated approach used to undertake the research during year one of the programme.

### **The evaluation framework**

- 2.2 Given the overarching aims of the evaluation (as set out in Chapter 1) – with their focus on understanding the set up and delivery processes required to provide IBs to families with disabled children, the subsequent outcomes experienced by families and the evidence on achievements relative to costs – SQW initially carried out scoping work with stakeholders and a literature review, in order to develop a framework for interpreting the evidence and a set of questions to inform the research design.

### ***Structure of the evaluation and research questions***

- 2.3 The scoping work resulted in the development of an evaluation framework made up of two components:
- one which seeks to assess the process of setting-up and delivering IB provision (referred to as the *IB process*);
  - and the second, which seeks to measure the resultant family engagement and subsequent outcomes that are experienced as a result of taking up the IB offer (referred to as the *family journey*).
- 2.4 The framework is based on the structure illustrated in Table 2-1. The IB process has been separated from the family journey for the sake of clarity of presentation, but it is important to emphasise that the two overlap considerably. For example, the quality of each family's journey will influence how many proceed to take up the IB offer and potentially their satisfaction with the package developed. Therefore, while we retain the two way split in the sections that follow, we draw attention where relevant to these areas of overlap.
- 2.5 Our scoping work also involved the development of a set of potential family-related outcomes and impacts, which may be achieved through the provision of an IB and

will therefore be assessed as part of the evaluation process. These outcomes/impacts have been divided into two components, the first of which relates to the disabled child/young person and the second which, relates to the family (see Table 2-2).

Table 2-1: Outline framework

IB process	Evaluation framework component	Family journey
What are the key contextual conditions in the pilot sites? What was the situation prior to the IB pilot?	← <b>CONTEXT</b> The way in which activity is currently happening →	What are the characteristics of the families? What was their position prior to the IB pilot?
What are the main objectives of each pilot site? What is the starting point of each area and how does each pilot intend to implement each component of the CDM?	← <b>OBJECTIVES</b> The intended purpose of the intervention →	What do the family / disabled child hope to achieve by taking up the IB offer?
What were the main financial and non-financial inputs to the process?	← <b>INPUTS</b> Resources – people, time, materials, funds – dedicated to the design and delivery of the interventions →	Time/effort contributed towards setting up and managing the IB How much time/effort did they expect to put in to manage the IB? How much funding was allocated to the disabled child?
How have each of the ten components of the CDM been implemented? What additional activities were delivered? What partnerships and networks have been set up? Identify any critical barriers and success factors	← <b>ACTIVITIES AND PROCESSES</b> The support and services provided by partners to deliver the interventions →	What activities did the family/disabled child undertake to receive an IB? How were the IB funds managed? How did the family/disabled child access the appropriate services? Identify any critical barriers and success factors
Assessment of the extent of implementation of each of the ten components of the CDM Number of beneficiaries recruited relative to the target number	← <b>OUTPUTS</b> Direct effects from the interventions that can be targeted and monitored →	How many support plans have been developed and finalised? How many families are in receipt of IB funds? How many families dropped out of the pilot? And why did they drop out? Which services did families access using their IB funds?
How have each of the components of the CDM supported the effective delivery of the pilot? How has the process changed the behaviour of those involved?	← <b>OUTCOMES</b> Changes in the behaviour, capacity and performance of the people and organisations associated with the interventions directly and indirectly →	How has the provision of an IB changed the behaviour and well-being of families and their perceptions of service performance?
How has the process changed the way in which services are provided to beneficiaries?	← <b>IMPACTS</b> Changes in conditions driving changes over the longer term and at higher levels →	What are the long term changes that may occur as a result of the provision of IBs?

Source: SQW Consulting



Table 2-2: Beneficiary related outcomes and impacts framework

	Disabled Child/Young Person outcomes/impacts	Theme	Family-based outcomes/impacts
<b>OUTCOMES</b>	<ul style="list-style-type: none"> <li>Increased user satisfaction with service provision</li> <li>Increased control over daily life</li> <li>Increased personal costs e.g. increased responsibility</li> </ul>	← <b>INCREASED CHOICE AND CONTROL</b> →	<ul style="list-style-type: none"> <li>Increased user satisfaction with service provision</li> <li>Increased control over daily life</li> <li>Increased responsibility of coordination/personal costs</li> </ul>
	<ul style="list-style-type: none"> <li>Improved access to more appropriate services</li> <li>Greater continuity of care</li> <li>Improved quality of care</li> <li>Fewer unmet needs</li> </ul>	← <b>QUALITY AND APPROPRIATENESS OF CARE</b> →	<ul style="list-style-type: none"> <li>Improved access to more appropriate services</li> <li>Greater continuity of care</li> <li>Improved quality of care</li> <li>Fewer unmet needs</li> </ul>
↓			
<b>IMPACTS</b>	<ul style="list-style-type: none"> <li>Improved health (self perceived)</li> <li>Increased user satisfaction with service provision</li> </ul>	← <b>BE HEALTHY</b> →	<ul style="list-style-type: none"> <li>Improved health (self perceived)</li> <li>Reduction in family stress levels</li> <li>Increased user satisfaction with service provision</li> </ul>
	<ul style="list-style-type: none"> <li>Increased sense of safety when undertaking activities both inside and outside of the home</li> </ul>	← <b>STAY SAFE</b> →	<ul style="list-style-type: none"> <li>Reduced anxiety associated with child undertaking activities inside and outside of the home</li> </ul>
	<ul style="list-style-type: none"> <li>Increased enjoyment of learning/school</li> <li>Improved educational attainment</li> </ul>	← <b>ENJOY AND ACHIEVE</b> →	<ul style="list-style-type: none"> <li>Increased labour market participation</li> <li>Improved educational attainment of siblings</li> </ul>
	<ul style="list-style-type: none"> <li>Increased self confidence</li> <li>Increased independence</li> <li>Increased social engagement and participation in the community</li> </ul>	← <b>MAKING A POSITIVE CONTRIBUTION</b> →	<ul style="list-style-type: none"> <li>Increased parental confidence</li> </ul>
	<ul style="list-style-type: none"> <li>Increased range of social and economic opportunities available</li> <li>Improved quality of life</li> <li>Increased labour market participation or engagement in non-compulsory education (for children in transition)</li> </ul>	← <b>ACHIEVE ECONOMIC WELL BEING</b> →	<ul style="list-style-type: none"> <li>Wider range of social and economic opportunities available</li> <li>Improved quality of life</li> <li>Strengthened family units</li> <li>Increased labour market participation or engagement in non-compulsory education</li> </ul>

Source: SQW Consulting

- 2.6 The family-related outcomes and impacts framework hypothesises that families and disabled child/young person may first experience increased choice and control, and improved quality and appropriateness of care, as a result of taking up IB provision. These outcomes may then lead to the achievement of the subsequent impacts, which relate to the five elements of the Every Child Matters Outcomes Framework. The evaluation will seek to assess (a) which of the outcomes and impacts are achieved (including an exploration of additional unintended outcomes), and whether (b) the sequential hypothesis is appropriate.
- 2.7 Tables B-1 and B-2 in Annex B set out the comprehensive evaluation framework developed to underpin the evaluation process; and information on the research methods/tools associated with each element of the framework.

#### Our approach

- 2.8 A multiple-method approach was adopted to undertake the evaluation. This approach was chosen to ensure/enable:
- sufficient evidence was gathered to respond to each of the research questions set out in the evaluation framework
  - the building of a comprehensive understanding of the progress made by the pilot sites both from a process and participant perspective
  - an appropriate level of flexibility in the delivery of each element, to ensure that the evaluation could be tailored to accommodate any challenges faced and the pace at which each pilot site progressed.
- 2.9 Table 2-3 presents a summary of the research tools that have been used to undertake the evaluation of year one of the programme. The specifics of each tool are presented below.

Table 2-3: Evaluation research tools for year one

Research tool	Inputs required from	Resultant outputs
<b>Pilot delivery plan</b>	<ul style="list-style-type: none"> <li>Support team</li> <li>Pilot site delivery staff</li> </ul>	Finalised delivery plan
<b>Family registration form</b>	<ul style="list-style-type: none"> <li>Pilot delivery staff in conjunction with the families and disabled children participating in the pilot</li> </ul>	Timely electronic registration data
<b>Monitoring tool</b>	<ul style="list-style-type: none"> <li>Pilot delivery staff</li> </ul>	Timely electronic monitoring data
<b>Case study research</b> <ul style="list-style-type: none"> <li>To include secondary and administrative data collation</li> </ul>	<ul style="list-style-type: none"> <li>Pilot site delivery staff</li> <li>Wider stakeholders e.g. Project Board members</li> <li>Providers</li> </ul>	Consultation evidence from a range of staff and stakeholders
<b>Family survey</b> <ul style="list-style-type: none"> <li>Baseline survey</li> </ul>	<ul style="list-style-type: none"> <li>Families and disabled children participating in the pilot</li> </ul>	Baseline evidence from participating families
<b>Survey of professionals</b> <ul style="list-style-type: none"> <li>Baseline survey</li> </ul>	<ul style="list-style-type: none"> <li>Pilot site delivery staff – project officers who manage individual case loads</li> </ul>	Baseline perceptions from staff supporting participating families

Source: SQW Consulting

### ***Pilot delivery plan***

- 2.10 Each pilot site was asked to draft a year one delivery plan at the outset of the programme, the results of which were reviewed by the evaluation team in conjunction with the support team and the Department to ensure that each component had been appropriately completed. A single set of comments were subsequently fed back to each area, thereby providing the areas with the opportunity to address the comments and finalise their plan.
- 2.11 The finalised plans have been used as a reference point against which the evaluation has been undertaken. That is, the research team has cross referenced the information in the delivery plans with the information supplied in the monitoring returns to understand whether it has been possible to implement the pilot activity as planned. And similarly, the team have investigated the reasons for any changes that have occurred during the case study research.

### ***Beneficiary registration form***

- 2.12 The beneficiary registration form was developed to gather the contact details and basic characteristics of each participating family. This set of information was required to enable the delivery of the beneficiary survey, which is described in more detail below.

- 2.13 Characteristics data was included on the registration form to provide the evaluation survey team, Ipsos MORI, with enough information to enable them to facilitate an appropriate form of contact with each family.
- 2.14 The registration form was completed at the point at which each family signs up to participate in the pilot, where it was emphasised that the process of sign up should make clear that a family has agreed to take part in the evaluation survey (see family survey section below for more details). This data was then transferred into the relevant section of the monitoring tool, which was subsequently shared with the evaluation team via appropriate data sharing mechanisms.

### ***Monitoring tool***

- 2.15 The SQW team developed a monitoring tool which provided a framework within which pilot sites were asked to record their progress. This included both process-related and family-related tools. Table 2-4 presents a summary of the informational requirements.
- 2.16 The monitoring tool contained a set of eight worksheets, where each sheet began with an introduction box to illustrate the rationale for collection, expected frequency of collation, data type and instructions for completion.
- 2.17 Some of the data was required on a monthly basis, whilst other data was requested on a quarterly basis. The justification for sending some information through on a monthly basis reflected or enabled:
- the pace at which initial development was expected to take place, where regular collation and submission of data enabled the evaluation team to oversee and support the progress of the sites in terms of both infrastructure and delivery developments
  - monthly transferral of family contact details to the survey team, thereby facilitating the timely undertaking of the baseline survey soon after recruitment of a family to the pilot
  - the support team to tailor their activities in a more appropriate and efficient manner.

Table2-4: Summary of monitoring tool requirements

Monitoring category	Brief description	Frequency of collation
<b>Risk Register</b>	The risk register was designed to support the delivery of the Individual Budget Pilots through the identification, analysis and communication of risks and issues relating to the pilot.	August 2009 - June 2010 - Monthly updates to be sent within 7 days of the end of each month  July 2010 - March 2011 - Quarterly updates covering Jul-Sept 10, Oct-Dec 10, Jan-Mar 11 to be sent within 7 days of the end of the relevant quarter
<b>P1. Process traffic light</b>	This tool was designed to provide a regular indication of progress against each of the elements of the CDM. It also sought to provide an indication of the phasing used to develop and implement each element and the length of time it takes to set up.	August 2009 - June 2010 - Monthly updates to be sent within 7 days of the end of each month  July 2010 - March 2011 - Quarterly updates covering Jul-Sept 10, Oct-Dec 10, Jan-Mar 11 to be sent within 7 days of the end of the relevant quarter
<b>P2. Pilot &amp; additional funding</b>	This tool was designed to provide a means of assessing the total amount of expenditure required to deliver the pilot and information on any additional sources of funding that is required to deliver the pilot	Quarterly updates to be cover Jul-Sept 09, Oct-Dec 09. Jan-Mar 10, Apr-Jun 10, Jul-Sept 10, Oct-Dec 10 and Jan-Mar 11 to be sent within 7 days of the end of the relevant quarter
<b>P3a. CDM details</b>	This tool sought to gather information on how each of the ten components of the CDM have been implemented	Quarterly updates to be cover Jul-Sept 09, Oct-Dec 09. Jan-Mar 10, Apr-Jun 10, Jul-Sept 10, Oct-Dec 10 and Jan-Mar 11 to be sent within 7 days of the end of the relevant quarter
<b>P3b. Costing the CDM</b>	This tool sought to gather information on the costs of implementing the CDM and other costs incurred during the set-up and running of the pilot.	Quarterly updates to be cover Jul-Sept 09, Oct-Dec 09. Jan-Mar 10, Apr-Jun 10, Jul-Sept 10, Oct-Dec 10 and Jan-Mar 11 to be sent within 7 days of the end of the relevant quarter
<b>F1. Registration data</b>	This tool sought to gather family registration data to help facilitate the delivery of the evaluation family-related survey and the analysis of characteristics data.	August 2009 - January 2010 - Monthly updates to be sent within 7 days of the end of each month  Subsequent updates are unlikely to be required and will therefore be subject to discussions later on in the process
<b>F2. Aggregate Output data</b>	This tool sought to gather information to provide evidence on the effectiveness of the recruitment process; looking at the number of potential families who expressed an interest in the pilot, the number of families actively engaged in the process and the number of families who have dropped out.	August 2009 - June 2010 - Monthly updates to be sent within 7 days of the end of each month  July 2010 - March 2011 - Quarterly updates covering Jul-Sept 10, Oct-Dec 10, Jan-Mar 11 to be sent within 7 days of the end of the relevant quarter

Monitoring category	Brief description	Frequency of collation
F3. Family-related data	This tool sought to gather information to provide evidence on the effectiveness of the recruitment process, the IB funding allocation, the management of the funds and the services used by each family.	August 2009 - June 2010 - Monthly updates to be sent within 7 days of the end of each month  Subsequent updates are unlikely to be required and will therefore be subject to discussions later on in the process

Source: SQW Consulting

### **Case study research**

2.18 Six pilot-specific case studies (i.e. one in each pilot site) were undertaken. The case studies sought to explore the context, process and initial activities of the pilot sites. They incorporated:

- a review of contextual data on the relevant population covered by the pilot
- evidence from consultation with IB delivery teams, key stakeholders, providers and support brokers
- a means of verifying the additional qualitative supporting information provided in the monitoring data that is collated on behalf of the evaluation team.

2.19 Pilot areas were asked to provide quarterly input to the evaluation. This was facilitated through six monthly face-face visits to the area to undertake consultations, supplemented at the intermediate three month stage with telephone update discussions, which generally only involved the IB project manager and Strategic Lead. The timing of these visits was tailored to take differing starting points and sensitivities into account, and was therefore determined through discussions with the IB Project Manager, to ensure that any burden was minimised.

2.20 The IB project manager, project/support officers and where relevant, wider stakeholders e.g. Adult Services and providers/support brokers were consulted on a six monthly basis.

### **Family baseline survey**

2.21 The evaluation involves undertaking a longitudinal survey to assess the progress and outcomes experienced by all families who participate in the pilot. The survey is being undertaken in two stages:

- **baseline survey (from autumn 2009)** – families were interviewed as close to the point of recruitment on to the pilot as possible, to ensure that the baseline position of the families was captured
- **follow-up survey (from autumn 2010)** – families will be interviewed as close to the end of the pilot activity as possible to enable the evaluation to measure distance travelled from the baseline position.

2.22 The baseline survey has been undertaken during the course of year one of the pilot. Fieldwork took place from November 2009 to March 2010, which involved undertaking face-to-face interviews in the family home. As part of the interviews, Ipsos MORI aimed to interview a parent or legal guardian, and where possible, the disabled child.

2.23 In line with industry guidance, Ipsos MORI did not interview children aged under 11 and requested parental consent and consent from the child before interviewing a child aged 11 to 18. Therefore, the decision to interview the child or not rested with the parent and child, and their assessment of whether it would be appropriate or not.

2.24 This resulted in the following:

- 173 interviews achieved with parents/carers out of a total population of 185 families, i.e. a response rate of 94%, which provides a good basis to measure change over the course of the pilot
- 57 interviews achieved with disabled children and young people (CYPs), signifying:
  - An unadjusted response rate of 33% from the total 173 addresses where parent/carer interviews were achieved (i.e. unadjusted response rate = number of interviews / total sample and therefore includes addresses where it was not feasible to undertake an interview with a disabled child or young person)
  - An adjusted response rate of 45% (i.e. adjusted response rate = number of interviews / total eligible addresses, where the denominator excludes children under 11 years of age).

2.25 The fieldwork team sought to monitor the reasons why particular children and young people did not participate. The main reasons for non-participation were that 45 young people (26% of the total population) were aged under 11 and so were not approached, while in 55 (32%) cases the young person had such a profound

disability that their parents judged it would be not be appropriate for them to complete the survey.

2.26 We would like to emphasise the importance of gaining the views of the families, who as a group provided invaluable information on their existing situation. The success of this element of the process was dependent on both the pilot sites and the evaluation team:

- pilot sites were asked to explain the process to each family at the point at which they signed up to the pilot, and that by participating in the pilot they were giving their consent to take part in the evaluation survey. It was therefore important that when required, pilot sites offered reassurances that personal details would be transferred in a secure manner
- the survey team undertook the survey in a sensitive and appropriate manner.

2.27 The process was undertaken as follows:

- families' contact details collected via registration form
- families contact details were securely transferred from the pilots to the evaluation team
- families were sent an advance letter sent explaining that a survey was about to take place on individual budgets for families with disabled children, and that a researcher from Ipsos MORI would be in touch shortly to arrange an interview. The letter also provided the contact details of the project team, in the event they had any questions.
- the interviewer visited the family to arrange an interview and subsequently undertook the interview at the arranged time/date.

2.28 As a result of feedback from a small number of families, the approach to families (the forth and final bullet point above) was slightly modified one month into the fieldwork period. This involved interviewers phoning the family in the first instance to arrange a convenient time/date to undertake the face-to-face interview, as unexpected face-to-face visits were sometimes felt to be problematic.

### ***Survey of professionals***

2.29 We are undertaking a two-stage Local Authority/PCT officer survey, which is running in tandem with the existing two-stage family survey. This involves the use of a baseline and follow-up self-completion survey, which is to be completed by the care



managers/social workers/relevant professionals who oversee the pilot families within each of the pilot areas.

- 2.30 The first assessment was undertaken just after the families had been recruited and hence asked the relevant individuals to provide their baseline views on each participating family. The survey was completed between January and March 2010, where 58 professionals completed the survey on behalf of the 173 families engaged in the pilot as of the 1<sup>st</sup> of March 2010 (i.e. coverage of 100%).
- 2.31 The second assessment will be conducted during the latter half of year two. It will run alongside the family follow-up survey, and will ask the same individuals to provide an assessment of the distance travelled by the participating families once they are in receipt of IB funds.
- 2.32 The comparator survey tool was developed on the same basis as the family survey and therefore will ultimately focus on the assessment of distance travelled against the set of family-related outcomes that are being tested as part of the evaluation. This will provide an external view of the benefits achieved to put alongside those reported by families. Therefore, this additional research tool was developed to enable the evaluation team to add depth to the outcomes component of the evaluation.

#### ***Reporting and communication***

- 2.33 The above information was synthesised into a set of quarterly reports, which have been published by the former DCSF, and will ultimately feed into a final evaluation report in March 2011.
- 2.34 The evaluation team has also sought to ensure that each pilot site is kept up to date with the progress of the evaluation and where relevant, given an opportunity to influence the direction of the research. To date, this has been facilitated through ongoing phone and email contact with each of the sites and attendance at each of the support workshops by the evaluation Project Manager.

## 3: Introducing IBs and the pilot sites

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### IBs and the policy landscape

- 3.1 *Improving Life Chances for Disabled People* (Prime Ministers Strategy Unit, Jan 2005) recommended that IBs should, in principle be extended to families with disabled children. This recommendation was taken forward through *Aiming High for Disabled Children (AHDC)*. AHDC is being delivered through multiple work strands - of which the IB pilot programme is one.
- 3.2 Services for disabled children and their families are underpinned by a Core Offer (<http://www.everychildmatters.gov.uk/socialcare/ahdc/coreoffer/>). This sets out a national statement of expectations for how disabled children and their families will be informed and involved as their needs are assessed and the necessary services are delivered. The Core Offer covers:
- information and transparency
  - assessment
  - participation and feedback.

### ***Existing approaches user to deliver IB and interventions of a similar nature***

- 3.3 Several models have been tested to date to increase user control.
- Direct Payments for parents of disabled children and disabled 16 and 17 year olds were introduced by the Carers and Disabled Children Act 2000. The Health and Social Care Act 2001 introduced a duty for local authorities to provide social care services through direct payments where this is requested by the user.
  - Personal budgets originated as an alternative method of providing choice and control over social care funding. Personal budgets allow individuals entitled to social care funding to choose whether they take their budget as a Direct Payment or allow councils to commission services for them, whilst choosing how and by whom their needs are met. Where necessary, users can be supported to make decisions on how to use the budget to which they are entitled. The Department of Health envisages that by 2011 every adult in receipt of social care will have the opportunity to have a personal budget

(Department of Health (2007) *Putting People First: a shared vision and commitment to the transformation of Adult Social Care*).

- Individual budgets (IB) widen the scope of choice and control to include more funding streams (DCSF (2009) *Individual Budgets for Disabled Children and their Families Pilot Specification and Application Pack* ). In an IB, different funding streams to which a person is entitled are integrated, allowing the user greater flexibility to choose how resources are used. Users can choose to take this monetised budget as cash, services or a mixture of the two. The flexibility of individual budgets allows individuals to tailor the support they receive to meet their needs as a whole, rather than being provided with compartmentalised and fragmented support. IBs can also be held and managed by a broker who in turn can support service users in: managing the budget, arranging care, facilitating a package of support designed around the beneficiary, coordinating provision of services and avoiding duplication in provision, and in improving outcomes for the family.

3.4 The IB pilot programme was set up to develop and test the personalised approach for a specific client group, thereby providing a focus on disabled children.

### ***Complementary programmes***

3.5 The Individual Budget pilot programme is one of three related pilot programmes which aim to support user control in social care, health and universal state support.

3.6 Lord Darzi announced in the NHS Next Stage Review (Department of Health (2008) *High quality care for all: NHS Next Stage Review final report*) that in 2009, the Government would start piloting **personal health budgets**, as a way of giving patients greater control over the services they receive and greater choice over the providers from which they receive services. The personal health budgets pilots were therefore set up to look at personalised budgets for a range of care groups.

3.7 Seventy sites across England have been awarded provisional pilot status for personal health budgets. Of these, twenty have been selected for an in-depth study as part of a wider evaluation exploring the potential of personal health budgets to benefit different groups of people. The pilot programme is now underway and will run for three years until 2012.

3.8 Similarly, through the December 2008 Department for Work and Pensions White Paper (DWP (2008) *Raising expectation and increasing support: reforming services*

for the future), the Government set out plans to introduce a right to an individual budget for disabled adults through new legislation scheduled for 2009 with commencement of the new right in 2010. Under the right, disabled adults who access the right to control will be told the monetary value that they are entitled to receive in eligible state support and be able to choose how that money is used to achieve agreed outcomes. The following support services will form part of the IB packages:

- Access to Work
- Work Choice
- Supporting People
- Disabled Facilities Grants
- Community Care Services
- Independent Living Fund.

3.9 The **Right to Control** programme will be tested for disabled adults in eight local authority areas in England, which are referred to as *trailblazer sites*. Evaluation of these sites will be used to inform decisions about wider roll-out.

The IB pilot sites

3.10 The IB pilot sites that are the focus of this report, were commissioned in April 2009, following a selection process which sought to include sites of varying nature to facilitate a comparison of provision in differing contexts. This led to the selection of six sites:

- covering a range of both rural and urban areas
- with mixed starting points and therefore existing infrastructure and experience of the personalisation agenda e.g. including areas which were already piloting an IB type intervention for families with disabled children and those which were not currently delivering this form of activity
- with the capacity and capability to meet the requirements of the pilot within the timescales of the activity.

3.11 Each site was asked to engage between 30-50 families with disabled children to take part in the pilot. While offering IBs to the full range of eligible children and families,

the sites were also given the option to identify a target group upon whom they wished to focus. The groups were:

- **children coming out of early support** - in this group, sites were expected to build on the tailored support of joint planning and control of the services already experienced while on the Early Support programme
- **young people in transition** - in this group sites were tasked to explore how an IB can be used to support personal development plans for more independent living and alignment with adult services
- **newcomers to the social care system** - the scoping study suggested that newcomers to the social care system tended not to have any preconceived ideas of service provision, which allowed them to think more innovatively about what provision might be needed. Therefore sites in this group were expected to explore how an IB package is used by this group and how it compares to existing service users.

3.12 Table 3-1 sets out the target number of families with disabled children each site proposed to recruit and their chosen target group for the pilot.

Table 3-1: The pilot sites

Pilot Site	Target number of families with disabled children	Target group for Pilot
Coventry	30	Young people in transition
Derbyshire	25	Young people in transition
Essex	30	Young people in transition
Gateshead	30	Age range 0–16
Gloucestershire	40	Newcomers to the social care system
Newcastle	30	Young people in transition

3.13 When asked to explain the reasons behind their choice of target group, the sites provided three primary motivations: the first related specifically to the transition sites, which expressed a desire to broker stronger alignments between Children’s and Adult services; the second centred on the premise that the particular target group was already viewed as a priority for the local authority and/or the PCT and therefore it made sense to build on existing work; and the third related to a desire to use the IB pilot to extend existing provision to a previously unexplored group.

***What was the position of the pilot sites prior to enrolling on the IB programme?***

3.14 Looking at the position and existing experience of the pilot sites prior to enrolling on the IB programme, it was evident that all sites had had some experience of facilitating personalised approaches for families with disabled children and in some cases for disabled adults. The form of experience varied significantly, with some sites exhibiting a range of established previous practice, whilst others had only recently begun to deliver a more personalised form of service provision. The selection process for the pilot sites sought to choose sites that had differing levels of previous experience, enabling the evaluation to assess the importance of the starting position of the sites.

3.15 Previous relevant experience included:

- a considerable number of direct payments to 16-17 year olds – which were felt to have raised issues that would be pertinent to the IB pilot
- a Short Breaks Pathfinder
- a Dynamite pilot – sought to provide IBs for disabled children at transition stage to facilitate a seamless move from child-based to adult-based services
- a Taking Control pilot – focused on the provision of IBs to children with disabilities who are 0-18 years of age
- a Budget Holding Lead Professional pilot – 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 providers
- a Department of Health Adult Individual Budget pilot – piloted the IB approach for older people and disabled adults
- a person centred planning team – facilitated a process of life planning for individuals, based around the principles of inclusion and the social model of disability
- a My Way Project – focused on the transition group, through the facilitation of a person-centred approach to support young people and their families to plan for their future.

3.16 The majority of the above experience has been driven by the social care divisions of the local authorities, with varying degrees of PCT involvement. For example, one of the sites had established a multi-agency resource panel to distribute social care funding, which had representation from the PCT, whereas PCT engagement in another site had been minimal prior to enrolment on the IB programme. Sites also noted that although previous adult-related experience would be beneficial during the development stage of the pilots, it would be important to acknowledge that systems set up for adults were often not directly suitable for children, as a result of different regulatory frameworks. Therefore, this form of experience should be used with caution and an explicit understanding that an adult based system cannot simply be transferred to children.

***Why did sites bid to become pilots***

3.17 Each of the pilot sites was asked to provide their rationale for applying to be a pilot, which in the main related to the opportunity to extend and link up various strands of the personalisation agenda. Sites also stated that the pilot would provide them with the necessary thinking time, project management capacity and opportunity to test the effectiveness of the IB offer. They added that it would be important to explore how existing systems and processes could be changed over the longer term to extend the offer to a wider cohort of families.

3.18 Looking across the sites, it was evident that they all intended to build on their existing personalisation work/initiatives, which have arisen from both child and adult-related activities. That said, the sites had developed such offers to very different extents. At the outset of the pilot programme, the sites with more experience of personalisation from a child-related perspective had clearer and more defined ideas on how they intended to take their pilot forward, whereas those working from a more adult-related base were still in the process of designing and formulating their overall direction and ideas.

3.19 Each site was also asked to provide a view on both their short and long term objectives for their pilot. Table 3-2 details the range of objectives cited by the pilot sites.

3.20 The set of objectives indicates a desire on the part of the pilot sites to provide disabled children and their families with greater choice and control over the support they receive, in combination with understanding how current working practices need to evolve to facilitate this change. It was also evident that the sites saw the

programme as a ‘true’ pilot and therefore any decisions on roll out of the approach would be made following the collation of evidence on its effectiveness.

Table 3-2: Short and long term objectives of the pilot sites

#### Short term objectives

- Provide disabled young people and families with greater choice and control over the services they receive
- Facilitate a higher level of inclusion and presence in the community for disabled children
- Develop a smoother transition to adult life
- Reduce dependence on specialist and residential solutions
- Develop an effective Resource Allocation Model
- Develop a partnership with providers
- Transform strategic commissioning
- Develop a performance framework based on linking resources to outcomes
- Develop systems and processes to deliver a continuum of self-directed support
- Work with partners to ensure there is ‘true’ cooperation in the IB pilot and thereby broker a greater understanding of what an IB means for each partner
- Develop more choice in the market for families with disabled children
- See where IBs add value from a PCT perspective and what difference they make to families
- Explore the personalisation agenda for disabled children and young people and their families

#### Long term objectives

- Understand more about whether IBs work and whether they are a useful way of working
- Facilitate a higher level of inclusion and presence in the community for disabled children and their families
- Convince colleagues of the value of the approach thereby increasing engagement from other agencies
- Enable disabled children and families to live ordinary family lives as a matter of course
- Provide disabled children and families with greater choice and control over the support they receive
- Inform longer term commissioning and required changes to existing contracting arrangements
- Pilot will enable the site to form a better understanding of the benefits and outcomes for disabled children and young people and their families of IBs to support them in making informed decisions about whether to make a long term change to this approach for all disabled children and young people or to consider it as one of a range of approaches to support families

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*Source: SQW case study research*

#### ***Position of each site in relation to the CDM prior to enrolling on the IB programme***

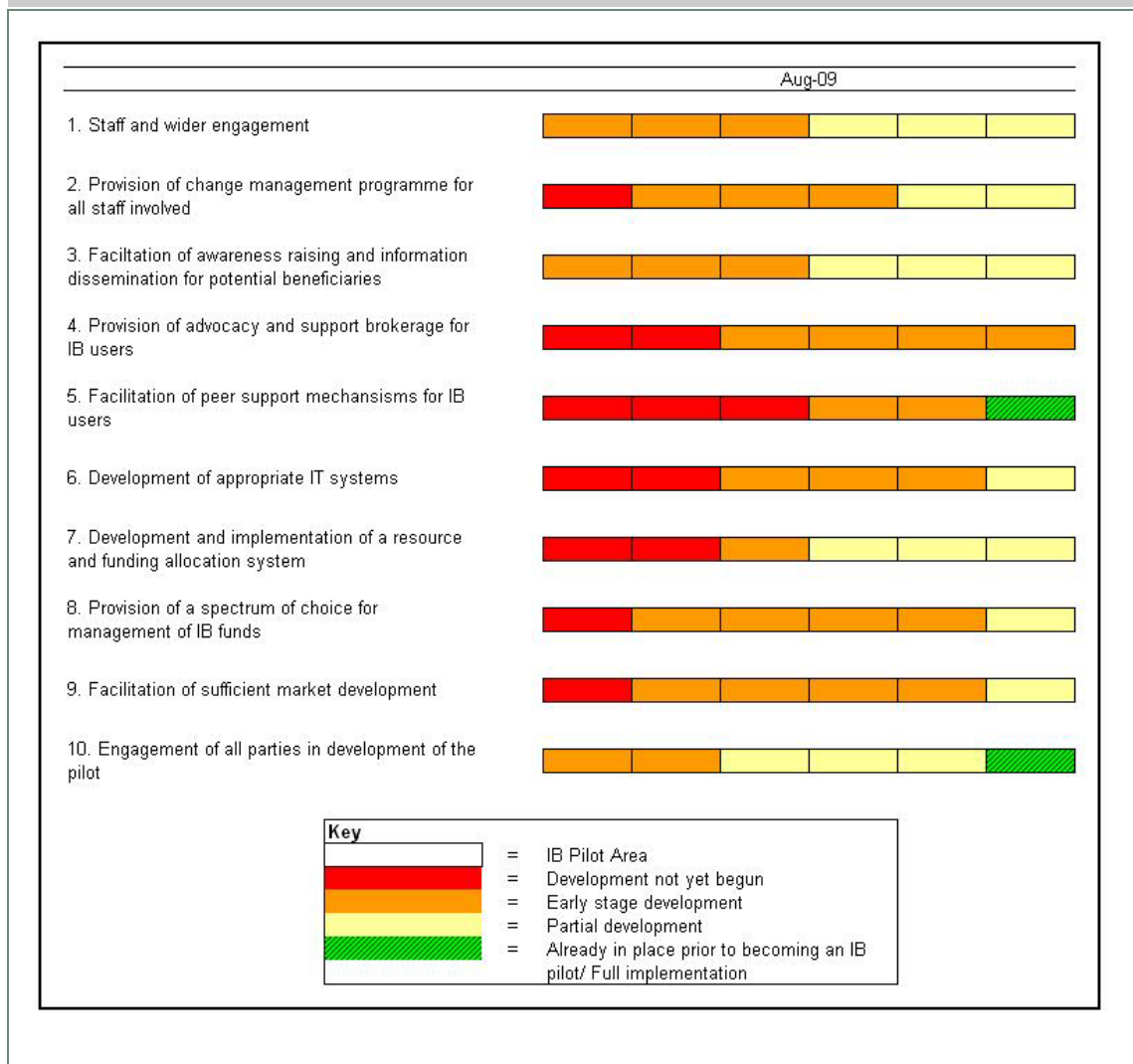
3.21 Figure 3-1 illustrates the perceived position of the sites in relation to elements of the CDM in August 2009 (this is based on self assessments from the sites, and as such should be taken as indicative) i.e. during the initial stage of the programme. As expected, each pilot site had differing levels of infrastructure in place and therefore



assumed a different starting point at the outset of the programme. For example, those sites that had well established AHDC teams in place prior to the programme indicated that they had a 'strategic head start' in terms of market development, engagement with families and partnership working. This is reflected in Figure 3-1, which illustrates that sites were most advanced in relation to elements 1, 3 and 10, where they perceived themselves to be either at early stages of development or further.

- 3.22 Looking now at the elements that were least developed at the outset of the programme, the evidence illustrated that elements 4, 5, 6 and 7 were generally not well developed. Of this group, two elements – 4 and 7 – related to the development of the process through which participating families would progress, whilst elements 5 and 6 were dependent on either this process or would be based around the views of the recruited families, all of which could not have been fully developed prior to enrolling on the IB programme.

Figure 3-1: Level of implementation against each element of the CDM, August 2009



Source: SQW Consulting

3.23 When asked which of the elements would be the most challenging to develop, the majority of sites anticipated that change management for staff and the development of a resource and funding allocation system would prove 'the most difficult to get right'. The former was perceived to be a challenge, as it required engaging and gaining buy-in from both senior policy makers and operational managers, and the latter was simply viewed as 'a challenge in its own right', as the effectiveness of existing models had not been proven as yet.

**What did the sites offer in their applications to the programme?**

3.24 During the application process, each prospective site was asked to illustrate the activities they planned to deliver in the event they were awarded pilot status. Over and above the desire to support families with disabled children through the pilot, this in the main consisted of the following process-related activities:

- building additional staff capacity to help develop and facilitate the IB approach
- provision of appropriate training for a wide range of staff to raise awareness of the IB approach and to create a 'shared understanding' of how the approach was to be delivered
- development of appropriate systems to facilitate the IB approach, including the creation of a resource allocation and support planning system and monitoring/auditing systems
- partnership building with relevant agencies and stakeholders, including NHS commissioners, brokerage agencies, youth and community organisations, advocacy organisations, social work and health providers and user representative organisations
- alignment and if possible, pooling of funding streams and services that are relevant to families with disabled children, including short breaks provision, the social care core budget, domiciliary care, childcare, integrated community equipment funding, community nursing services, physiotherapy and occupational therapy services, residential services, extended services funding and former LSC funding
- stimulation of the provider market, which was to be asked to increase the flexibility of provision to families with disabled children.

3.25 The development was intended to take place in a staged way, where emphasis would be first placed on building staff capacity and the appropriate pilot delivery team, followed by subsequent developments.

#### Summary

3.26 The Government's national transformation programme for disabled children's services – *Aiming High for Disabled Children* - was launched in 2007. The programme is being delivered through multiple work strands, of which the IB pilot programme is one. As such, IBs delivered in accordance with the Common Delivery Model provided a means to test 'how' they can contribute to meeting the aims of the programme.

3.27 The IB pilot sites were commissioned in April 2009, following a selection process which sought to include sites of varying nature to enable a comparison of provision in differing contexts. This led to the selection of the following sites – Coventry,

Derbyshire, Essex, Gateshead, Gloucestershire and Newcastle. Each site was asked to engage between 30-50 families with disabled children and was given the opportunity to identify a target group upon whom they wished to focus.

3.28 It was evident that all sites had had some experience of facilitating personalised approaches for families with disabled children and in some cases for disabled adults prior to enrolling on the IB programme. As such, all the sites intended to build on their existing personalisation work/initiatives that had largely been led by the social care divisions of the relevant local authorities.

3.29 Each site was asked to provide a view on their objectives for their pilot, which indicated a desire to:

- provide disabled children and their families with greater choice and control over the support they receive
- understand how current working practices need to evolve to facilitate increased choice and control
- assess the effectiveness of the IB approach to inform a decision on roll out.

## 4: IB processes and activities

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### Introduction

- 4.1 This chapter covers the development that has taken place in each site over the first 12 months of the IB programme. Progress to date is shown against each of the ten elements of the CDM.

### Progress against the CDM

#### ***Element 1: Adequate staff and organisational engagement***

- 4.2 All sites had recruited the majority of their IB-pilot specific teams by the end of November 2009. In most cases, this has included the provision of both IB-funded posts and in-kind staff contributions, to facilitate the role of the strategic pilot lead, pilot project manager and project support officer(s). Some sites have also funded contributions from the commissioning, finance and legal teams, to ensure that the pilots can draw on particular forms of expertise as and when required.
- 4.3 Some sites had suffered delays in recruiting staff, which was caused by two main reasons. The first related to challenges in recruiting appropriately qualified staff to manage and facilitate their pilot activities. This implied that considered recruitment of pilot staff was necessary, to ensure the teams consisted of individuals with the appropriate mix of skills. The second reason for delayed staff recruitment related to sluggish or restrictive local authority recruitment processes.
- 4.4 The scale of delays experienced can be illustrated by the speed at which the IB pilot project manager was recruited in each site, where the first and final IB pilot project managers were recruited in June and October 2009 respectively. As such, it became apparent that the speed of progress made by the pilot sites during the initial six months was directly related to the recruitment of the pilot delivery team.
- 4.5 Following the recruitment of the 'core' delivery teams, some sites have since expanded their teams to increase their delivery capacity and to enable the facilitation of the resource allocation and support planning stages of the process. This has involved contributions from social workers, project officers or lead professionals in the main and illustrates a need for significant 'frontline' staff contributions at key stages of the development/delivery process.

- 4.6 At the time of drafting this report, two of the sites were still experiencing minor recruitment delays, as a result of lengthy job specification approval processes within either the local authority or PCT. However, both sites were optimistic that the relevant posts would be filled at the beginning of year two of the programme.
- 4.7 All sites set up appropriate governance structures within the first six months of the pilot, which has involved the creation of a pilot specific project board. The project board in turn generally reports to the relevant existing council structures, which includes: the Children with Disabilities Strategy Group and subsequently the Children's Trust; a multi agency Children with Disabilities Strategic Commissioning Group; a Children and Young People's Strategic Partnership; and the AHDC Programme Board. As such, it was evident that each of the sites felt it important to embed their pilot structures in sustainable structures that would support the development of the sites and help to create a shared understanding of the objectives of the pilot.

### Summary

- 4.8 Table 4-1 presents a summary of the progress made against element one of the CDM.

Table 4-1: Progress made to date on the recruitment of adequate staff and organisational engagement

#### Emerging findings and lessons

- Some sites experienced delays in recruiting pilot staff as a result of either restrictive internal recruitment processes or shortages of appropriately skilled staff.
- At the point of drafting this report, all sites had recruited the majority of their IB pilot-specific team and were in the process of refining their existing infrastructure to meet the requirements of the pilot.
- The sites have set up appropriate governance structures, which generally report to established structures, for reasons of sustainability and to help create a shared understanding of the objectives of the pilot.
- Some of the IB teams recruited a further cohort of staff at the beginning of 2010 to facilitate the resource allocation and support planning stages of the process, which was felt to require significant time inputs from 'frontline' staff.

#### Issues of interest over the next 12 months of the programme

The evaluation will seek to explore the following issues over the course of Year two:

- How long was the set up phase of the pilot and what staff resources were required to facilitate this phase?
- What staff resources were required to facilitate pilot delivery in Year two? Does this differ from Year one?
- Has the embedding of the IB pilot project board into existing governance structures added value to the development and delivery of the pilot?
- What staff resources (and skills set) are likely to be required if the IB approach is rolled out to a wider cohort of families with disabled children?

***Element 2: A change management programme for all staff involved in the pilots***

- 4.9 All sites have undertaken some form of change management process. This has in the main been facilitated through awareness raising and information sessions. The form of change management appears to have been heavily dependent on the starting point of each site, where sites with more experience of child-related personalisation have tended to adopt more informal processes, as the cultural change was perceived to have begun prior to the pilot. Other sites have delivered more formal training sessions, which have included the facilitation of resource allocation and support planning training and meetings with key budget holders and service leads.
- 4.10 The majority of the change management activity has focused on the social care workforce and the pilot delivery teams. Other stakeholders, such as PCT delivery/operational staff and colleagues from education services have been less engaged in the change management process. This was felt to be because both groups of staff were more risk averse in relation to personalisation as a result of national design, which meant they had been introduced to the concept much later than colleagues in social care. As such, they generally had a less developed understanding of the objectives of the IB programme and were 'less willing to engage'.
- 4.11 Therefore, the sites have focused initial efforts on engaging the teams and individuals that have been 'more accessible' during the first year of the programme and it will be important for the sites to focus their efforts on the less engaged stakeholders over the course of year two. This will ensure that a shared vision for the pilot is embedded throughout the relevant structures and teams and may therefore enable the sites to expand the coverage of their IB packages and pilot the provision of more holistic packages of support.
- 4.12 When asked about the effectiveness of the change management activities that had been facilitated to date, the sites reported that they felt the 'hearts and minds' of the pilot delivery team and a considerable number of the wider children's social care team had been changed. However, influencing the practicalities of implementation, delivery and daily working arrangements of colleagues was proving to be challenging. For example, one site stated it had found that the general perception amongst the area's social workers was that IBs were felt to be more labour intensive and would therefore create extra work. The site added that it had therefore had to 'work harder' to broker joint-working arrangements between the IB and social work team, which would almost certainly lead to a sharing of the workload and not to an

increased burden on the part of the social workers. This implies that the process of change management needs to be undertaken in continuous stages and specifically tailored to meet the needs of the particular audience. This may require different approaches and intensity of approach being used for different staff groups/teams.

- 4.13 Both formal and informal training and change management were viewed as effective. The more formal resource allocation and support planning training was felt to have been successful, as it had facilitated the required ‘sign up’ and ‘breadth of understanding’ from staff, which was perceived to be as important as the development of the system itself. Similarly, although less tangible, the value of more informal approaches to change management should not be underestimated. For example, one site has co-located the IB pilot delivery team with the Children with Disabilities team, which has facilitated increased joint-working and a shared understanding of the pilot.

#### *Summary*

- 4.14 Table 4-2 presents a summary of the progress made against element two of the CDM.

Table 4-2: Progress made to date on the provision of a change management programme for all staff involved in the pilots

#### **Emerging findings and lessons**

- All sites have adopted formal, informal or a mixed approach to change management, which has sought to build on the existing experience and associated cultural change of the relevant teams. Both informal and formal training were viewed as effective.
- Sites have focused their initial efforts on engaging and raising awareness in the teams that have been the most accessible during the first year of the programme. This has included the children’s social care team and excluded the PCT and education delivery teams in the main. As such, it will be important for the sites to focus their efforts on engaging the less engaged stakeholders during Year two of the programme, to enable the sites to fully exploit their pilot status and to expand the coverage of their IB packages.
- The experience of the sites implies that the process of change management needs to be undertaken throughout the course of the programme and specifically tailored to meet the needs of particular audiences. This may require different approaches being used for different staff groups/teams.

#### **Issues of interest over the next 12 months of the programme**

The evaluation will seek to explore the following issues over the course of Year two:

- How have the sites changed their approach to change management to engage those teams/individuals that proved difficult to engage during the first year of the programme? And how effective were these approaches?
  - Were additional funding streams/services drawn into the IB packages as a result of increased efforts to raise awareness and tailor change management processes?
  - Which teams/individuals remained challenging to engage and what were the reasons for this?
-



***Element 3: Facilitation of awareness raising and information dissemination for potential families***

- 4.15 Information has been disseminated in a variety of ways including: explanatory letters followed by visits from a parent participation officer; briefing sessions for prospective parents; publicity leaflets; promotion via the Parent Council/Forum; one to one meetings between the pilot project manager and prospective families; coffee mornings for prospective families; information events; and dissemination through social workers.
- 4.16 Sites stated that they had faced two main challenges when delivering this element of the CDM. The first related to the need to provide information about a relatively complex process in a format that parents could relate to, as opposed to providing them with jargon. The second related to an underlying need to ensure that the expectations of the families were managed and therefore that they did not expect the IB to deliver more than it could in reality.
- 4.17 Consequently, personal one-to-one contact, speaking to families in their 'own language' was widely seen as the most effective form of engagement, particularly for those families from more deprived backgrounds, who were traditionally harder to reach. The success of this approach was felt to be dependent on the knowledge and capabilities of the people providing the information to families, who really needed to understand the programme, to ensure they could provide responses to any concerns that may be raised. This again reiterates the need for considered recruitment of the pilot delivery teams, as a means of ensuring that effective family engagement can be undertaken.
- 4.18 This form of approach has in most cases proven to be more resource intensive than originally anticipated and has involved considerable input from the pilot project managers across the sites. It was also noted that social workers had played an important role in engaging families, as they had been able to build on existing relationships and that more time had been spent with the harder to reach families, as they required tailored information and more reassurance to engage them in the programme. The resource implications involved with any form of roll out would therefore imply a need to ensure more people with the appropriate skills are drawn in to undertake this work and are given time to deliver.

## Summary

- 4.19 Table 4-3 presents a summary of the progress made against element three of the CDM.

Table 4-3: Progress made to date on the facilitation of awareness raising and information dissemination for potential families

### Emerging findings and lessons

- The sites have used a variety of mechanisms to raise awareness and share information with prospective families with disabled children.
- The most effective mechanism has been personal one-to-one contact facilitated through members of the pilot teams that were well versed in the workings of the pilot and could therefore provide reassurance and manage the expectations of the families when required. This therefore reiterates the need for considered recruitment of the IB delivery teams, to ensure that effective family engagement can be undertaken.
- Personal one-to-one contact has proven resource intensive and has involved considerable input from the pilot project manager. Therefore, it will be important to ensure sufficient numbers of appropriately skilled people are drawn in to undertake family engagement in the event that the pilots are rolled out.

### Issues of interest over the next 12 months of the programme

The evaluation will seek to explore the following issues over the course of Year two:

- How did the IB delivery teams ensure that all members of the team involved in family engagement were sufficiently informed about the pilot? In hindsight, would they have done anything differently?
- In the event that sites continue to engage and recruit families to the pilot in Year two, what approaches were used to facilitate this activity?
- How satisfied were the families with the engagement approach? Did they feel they were given sufficient information and support to understand the coverage and limitations of the pilot?

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### ***Element 4: Provision of advocacy and support brokerage for IB users***

- 4.20 Focusing first on advocacy, which can be defined as ‘the provision of support to help an individual get their views across and take part in decisions that affect their lives (definition adapted from the National Standards for the Provision of Children’s Advocacy Services, Department of Health 2002), the majority of sites have commissioned an external advocacy service to offer support to families. Its effectiveness will be assessed as part of the family follow-up survey that is to be conducted in late 2010.
- 4.21 Looking next at support brokerage, all six sites have developed and are embedding their support planning processes. This is being delivered through a variety of mechanisms, each of which is described below in conjunction with the rationale for selection:
- **majority independent support planning provision sourced from the third sector** - the relevant pilot delivery team had a strong view that this form of

support planning would be more appropriate and equitable for families as it would encourage the building of community links

- **majority in-house support planning (i.e. within the local authority)** – the pilot site had previous and established experience of conducting in-house support planning and therefore used this expertise to facilitate the required provision
- **mixed forms of provision that combine both internal and external provision** – as there is no conclusive evidence to support the effectiveness of any one form of support planning, a number of the sites have facilitated both internal and external provision to test the effectiveness of the different processes.

4.22 Two supplementary forms of support planning have been facilitated by a number of the pilot sites. The first of these relates to the use of the Planning Live approach (Planning Live has been provided in some sites by Helen Sanderson Associates as part of the support provided to the pilots ), which provides a means by which families and their supporters can plan together via the help of trained facilitators. The second form relates to the facilitation of ‘self support planning’, whereby the family and disabled child draft the plan themselves, with support provided as and when required.

4.23 A number of the sites have produced support planning guidance, where early indications have shown that clear guidance that facilitates a flexible and inclusive approach is key to the success of the overarching support planning process. Figure 4-1 provides an example of the support planning criteria used in one of the sites.

Figure 4-1: Example of support planning criteria used in one site

- What is important to you? *The plan needs to be individual and specific.*
- What do you want to change or achieve? *The plan needs to be clear, with no changes imposed by others and no changes that can make life worse.*
- How will you be supported? *The plan needs to be detailed and should not put others at risk.*
- How will you use your IB? *The plan should specify how the money will be spent.*
- How will your support be managed? *The plan should say how the day to day support will be managed*
- How will you stay in control of your life? *The plan should show that the young person has made the relevant decisions.*
- What are you going to do to make this plan happen? *A clear plan of action of who is doing what should be included.*

Source: IB pilot site

- 4.24 Early feedback has shown that the support planning processes used by the pilot sites has led to the identification of new, more holistic information that is regularly absent from the systems that are used currently. This information includes a specific summary of the assets of the child or young person and the community activities that they currently use and wish to use through the provision of an IB. The feedback also showed that those individuals that are involved in the delivery of support planning activities feel that a key part of their role was to help families build links with community-based provision. These linkages were viewed as an important means of developing more effective and appropriate support packages. However, it is currently too early to assess the added value that can be drawn through community-based support.
- 4.25 At the point of drafting this report, most families were beginning to proceed through the support planning processes in each of the sites. Therefore, the report has not sought to make judgement on the effectiveness of each process and has instead sought to describe the different and evolving practices that are currently emerging. This element will be revisited during the course of year two.
- 4.26 As support planning forms an integral part of resource allocation, a detailed description of the processes used and an assessment for both this element and resource allocation is detailed under Element 7 of the CDM which is set out in Chapter 5.

## Summary

- 4.27 Table 4-4 presents a summary of the progress made against element four of the CDM.

Table 4-4: Progress made to date on the provision of advocacy and support brokerage for IB users

### Emerging findings and lessons

- The majority of sites have commissioned an external advocacy service to offer support to families. Its effectiveness will be assessed as part of the family follow-up survey that is to be conducted in late 2010.
- Three main models of support planning have emerged:
  - Majority Independent support planning provision sourced from the third sector
  - Majority in-house support planning (i.e. within the local authority)
  - Mixed forms of provision that combine both internal and external provisionThese methods may also include the use of the Planning Live approach and 'self support planning', where the latter is facilitated by the family in the main.
- Early feedback from support planners indicates that the support planning process has led to the identification of new, more holistic information that is regularly absent from the traditional systems that are currently used. Feedback also identified a widely held view that a key part of their role was to help families build links with community-based provision.
- Support planning forms an integral part of the resource allocation process.
- As support planning activities had only recently begun, it is too early to assess the effectiveness of the different models and therefore this element of the CDM will be revisited during the course of Year two of the programme.

### Issues of interest over the next 12 months of the programme

The evaluation will seek to explore the following issues over the course of Year two:

- Provision of a detailed description of all the support planning models used.
- How effective were the different forms of support planning and what were the associated limitations?
- Did one approach prove to be more effective than another and if so, why? Are particular approaches more suitable for families with particular characteristics?
- Did the sequencing of the resource allocation and support planning processes lead to different types of support packages?
- What were the outcomes of the different approaches?
  - How satisfied were the families and disabled young people?
  - How innovative were the results?
- What issues remain unresolved? How could the process be improved?

### ***Element 5: Facilitation of peer support mechanisms***

- 4.28 Sites have committed to ensure the appropriate support mechanisms are supplied for participating families. Therefore, each has sought to consult their families to understand the types of peer support that was required. This has to date, led the majority of peer support to be facilitated through informal networking undertaken between participating families, user led groups or through 'champion' families that were already in receipt of a 'personal budget' prior to the inception of the IB pilot.

- 4.29 One site highlighted the use of an informal email group that had been set up by participating parent/carers in their site. The site had enabled signposting between the families, who were sharing their experience and information as they progressed through the pilot. A tangible example of where this had worked well was evidenced through a set of families who have coordinated their transport to meetings as a result of remaining in regular email contact.
- 4.30 Peer support is likely to develop further and potentially become more formal in nature as families proceed through support planning and onto sourcing and managing service provision. Therefore, this element of the CDM should be viewed as a ‘work in progress’ that will be re-visited during year two of the programme.

### *Summary*

- 4.31 Table 4-5 presents a summary of the progress made against element five of the CDM.

Table 4-5: Progress made to date on the facilitation of peer support mechanisms

#### **Emerging lessons**

- Sites have consulted participating families to understand the types of peer support that were required during Year one of the programme.
- To date, this provision has been relatively informal in its nature and has been driven largely by the families themselves.
- Peer support is likely to develop further and potentially may become more formal in nature as families proceed through support planning and onto sourcing and managing service provision.

#### **Issues of interest over the next 12 months of the programme**

The evaluation will seek to explore the following issues over the course of Year two:

- What peer support have the sites delivered in Year two? Is this different to the provision in Year one and if so, why?
- How satisfied were families with the forms of peer support and what value has it added to their IB journey?

### ***Element 6: Development of IT resources***

- 4.32 Each site was tasked with developing an appropriate IT resource to enable the effective monitoring and auditing of the pilot. To date, this element has been approached in one of two ways: the first has involved some sites integrating the requirements of the pilot onto existing local systems; and the second has involved the development of relatively low-tech and standalone systems.
- 4.33 Looking at each of the approaches in turn, integration into existing systems has been possible in sites that had already developed bespoke IT systems to monitor their AHDC activities and in one site that was using the CareFirst system (OLM’s social

care system that has been taken up by several local authorities across England). These sites have therefore experienced a relatively unproblematic IT development process.

- 4.34 Development of low-tech, standalone systems has been undertaken by sites that are solely dependent on the Integrated Children’s System (ICS), where the integration of resource allocation and support planning processes has proven problematic. Sites stated that the ICS was too rigid in its nature and did not allow an individual local authority to make the required additions to the existing fields of information. As such, the sites have had to input their IB data into a standalone specifically developed system and attach it as a supplementary case note in the ICS, as opposed to in the relevant ICS record itself. This causes problems, as attachments will not trigger case reviews in the same way as a care plan. Therefore, although this solution will suffice for the lifetime of the programme, it is unlikely to be sustainable over the longer term should the IB approach be rolled out.

*Summary*

- 4.35 Table 4-6 presents a summary of the progress made against element six of the CDM.

Table 4-6: Progress made to date on the development of IT resources

**Emerging findings and lessons**

- This element was approached in one of two ways: the first involved some sites integrating the requirements of the pilot onto existing systems; and the second involved the development of relatively low tech, standalone systems.
- The Integrated Children’s System (ICS) has proven to be too rigid in its nature to facilitate useful IT provision for the IB pilot sites. This is because the system does not allow an individual local authority to make the required additions to the existing fields of information.
- Low tech, standalone systems will suffice for the lifetime of the programme, however, should the programme be rolled out over the longer term, this solution is not likely to be sustainable.

**Issues of interest over the next 12 months of the programme**

The evaluation will seek to explore the following issues over the course of Year two:

- How have the IT systems been used, what types of information are recorded and how is this information used?
- Does the utility of different IT systems change as the packages go live and monitoring and review is required?
- What are the limitations of each of the systems and how could these be resolved?
- What, if any changes are made at a national level to facilitate the use of the ICS in the IB pilot programme?

***Element 7: Development and implementation of a resource and funding mechanism (and detailed description and assessment of support planning to date)***

- 4.36 Please refer to Chapter 5 for details on this element of the CDM.

### ***Element 8: A Spectrum of choice for management of IB funds***

- 4.37 Sites intended to offer participating families a number of means by which they can manage their IB funding. This included: direct payments, local authority managed budgets, third party budgets and individual service funds (an individual service fund is facilitated where the IB is paid directly to a service provider who manages the money, where the funding is ring-fenced and can only be spent on behalf of the disabled child and their family in accordance with the support plan). This spectrum of choice should address the fear of management burden identified during the scoping study by making the IB offer more accessible to the families taking part in the pilot.
- 4.38 Early findings have shown that a number of the sites intended to offer training to families that wished to manage the funds but lacked the confidence or experience to do so. However, as only a small number of IBs had 'gone live' at the point of drafting this report, this element of the model could not be comprehensively assessed and will therefore be explored further during Year two of the programme.

#### ***Summary***

- 4.39 Table 4-7 presents a summary of the progress made against element eight of the CDM.

Table 4-7: Progress made to date on the provision of a spectrum of choice for the management of IB funds

#### **Emerging findings and lessons**

- Sites intended to offer families a number of means by which they can manage their IB funding. This includes in-house management, the family managing the budget themselves, third party management and other variations.
- It is currently too early to comment extensively on this element of the CDM, given that only a small number of IBs had gone live at the point of drafting the report. Therefore, this element will be explored in more detail during year two of the programme.

#### **Issues of interest over the next 12 months of the programme**

The evaluation will seek to explore the following issues over the course of Year two:

- What range of choice was offered to each of the families in the pilot sites?
- Were all families offered the relevant suite of options or was the list of options varied for each family depending on their circumstances?
- How did the accounting and finance teams in the pilot sites work with the families to facilitate each approach and how effective were the results?
- Which options proved to be the most popular with families? And were particular options favoured by families with particular characteristics?

### ***Element 9: Facilitation of sufficient market development***

- 4.40 Prior to the inception of the IB programme, demand-led, as opposed to supply-led market development had been stimulated through the general evolution of the AHDC



strategy and associated programmes including the Short Breaks Pathfinder programme. Therefore, sites intended to build on the existing development that had been undertaken.

- 4.41 It was widely recognised that market development was likely to be limited as a result of the small size of the pilots. As such, the challenge will be to ensure that providers are prepared for the future and in a position to be better able to support people if the pilot is rolled out. Therefore, the majority of the sites had recently begun to focus their attention on developing the market to ensure that the required forms of provision were available for participating families. In most cases this development was intended to be undertaken 'organically', whereby families suggest and develop ideas during the support planning stage and the sites subsequently investigate ways to stimulate the market. The sites also recognised the need to undertake this activity as quickly as possible, to minimise any delay in the provision of services/activities.
- 4.42 In addition, the sites were also seeking to develop community capacity to enable families to access local and universal services, to enable the:
- introduction of new providers into the mix
  - creation of new forms of service provision for families
  - re-shaping of the market over both the short and longer term.
- 4.43 Community-based provision was felt to be a 'much needed' alternative to the more commonly used specialist services, that were often more expensive and less appropriate/convenient for both the family and the disabled child. This view was put forward by the sites and will be explored further during Year Two of the evaluation to understand whether the participating families share the same views.
- 4.44 Sites also stated that the provision of an IB was likely to increase the demand for personal assistants (PAs) and therefore, that this aspect of the market would require stimulation and intensive support. For example, one site intended to support the development of PAs by providing them with assistance to become effective support workers.
- 4.45 Concerns were raised by the sites about the extent to which the IB approach would lead to declining demand for traditional services, which were generally managed through long-term block contracting arrangements. Sites added that they were unsure whether they would be able to honour such contracts if the market changed sufficiently, which implied that larger providers would have to deal with the challenge

of decommissioning services and move towards the provision of more flexible services.

- 4.46 Looking specifically at the resources required to stimulate market development, one of the sites stated that this form of development activity required ‘patience’ and an ‘innovative workforce’ that were willing to ‘challenge providers’. They also commented that in their experience, it had often required capacity building resource for both community based organisations and the families themselves, to enable all the relevant individuals to acquire the capability and capacity to access/provide the appropriate services/activities.

### *Summary*

- 4.47 Table 4-8 presents a summary of the progress made against element nine of the CDM.

Table 4-8: Progress made to date on the facilitation of market development

#### **Emerging findings and lessons**

- Prior to the IB programme, demand-led market development had been stimulated through the general evolution of the AHDC strategy and its suite of programmes. This existing activity was intended to form the basis of market development in the IB pilot sites.
- The majority of the sites had recently begun to focus their attention on developing the market to ensure that the required forms of provision were available. As such, at the point of drafting this report it was too early to explore this element of the CDM in detail.
- The sites were seeking to focus significant attention on the development of community capacity to enable families to access local and universal services. This activity was intended to include provision of support to personal assistants to ensure they were able to provide the required services/support.
- Concerns were raised about the extent to which the IB approach would lead to declining demand for traditional services, which were generally managed through long-term block contracting arrangements.

#### **Issues of interest over the next 12 months of the programme**

The evaluation will seek to explore the following issues over the course of Year two:

- What partnerships and networks were built as a result of the pilot and how have these added value?
  - How willing were providers to respond to user-led provision?
  - Were providers given access to capacity building resources/training where required? If so, who facilitated this?
  - How was community-based provision developed? And how many families took up this form of provision?
  - Has the market development that was undertaken influenced wider commissioning processes, e.g. changes to contracting processes?
  - To what extent did the families demand new services post support planning and therefore make a shift away from traditional services?
-

#### ***Element 10: Engagement of all parties in the development of the pilot***

- 4.48 Evidence from the IB Scoping Study highlighted the need to involve wider stakeholders, providers and parents/disabled young people alongside local authority staff in the development of the programme. Although the majority of the sites felt that they had successfully engaged the range of relevant individuals and stakeholders, assessments made by both the evaluation and support teams indicated mixed progress across the sites.
- 4.49 Looking first at wider stakeholders, it was evident that some sites had successfully engaged the 'main players' in this group. This included staff from the AHDC team, Children with Disabilities team, PCT, Adult Services, Education Services and providers, that were engaged through the IB pilot project board. However, many sites were still experiencing difficulties engaging some of these partners, as the relevant partners seemed unsure of both the value of their potential contribution and subsequently how they could contribute. It was also evident that a number of partners had engaged on a speculative basis and were in effect waiting to see results from the relevant pilot sites prior to fully engaging in the process.
- 4.50 As a result, some of the sites were still in the process of gaining 'buy-in' from some partners, which in a lot of cases was taking longer than first anticipated.
- 4.51 Successful stakeholder engagement had in the majority of cases led to the development of a 'shared understanding' of the purpose and added value of an IB. This outcome had in some cases also led to the contribution of funding from the relevant service heads for inclusion in the IB packages. However, the difficulties faced have had consequences for the nature of the funding streams drawn in or not to the IB in most areas (see Chapter 6 for more details).
- 4.52 Turning our focus now to the engagement of parents and disabled children, it was again evident that some sites had made more progress than others. For example, one site had engaged their parent council and was accessing resources through this group to feed into the development of their pilot. A second example included the appointment of parent representatives onto the IB pilot project board to enable co-production of the pilot.
- 4.53 Engagement of disabled children and young people appeared to be less defined at the point of drafting this report. Therefore, this element will be followed up over the course of Year two of the programme.
- 4.54 Table 4-9 provides a summary of progress against CDM element ten.

## Summary

Table 4-9: Progress made to date on the engagement of all relevant parties in developing the pilot

### Emerging findings and lessons

- The sites have made mixed progress against this element of the CDM, where some sites have successfully engaged the majority of the relevant stakeholders, whereas others were still in the process of gaining 'buy-in' from most of the main players.
- In the cases where successful engagement has been achieved, a 'shared understanding' of the purpose and added value of an IB had been established. This outcome had in some cases also led to the contribution of funding from the relevant service heads for inclusion in the IB packages.
- Parental engagement had been strong in some sites, but weak in other sites and the engagement of disabled children in the development of the pilot appeared to be less defined at the point of drafting this report.

### Issues of interest over the next 12 months of the programme

The evaluation will seek to explore the following issues over the course of Year two:

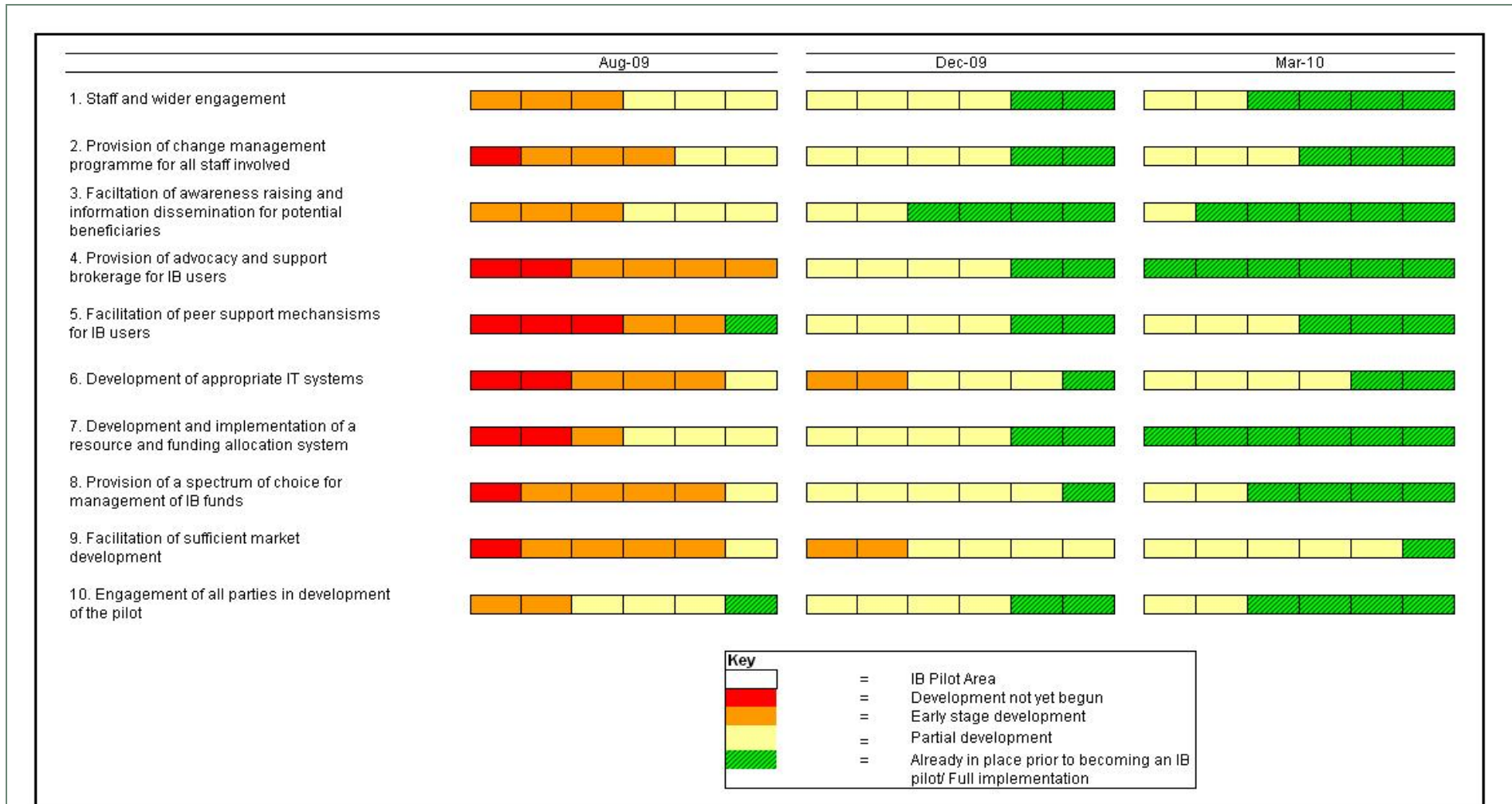
- What mechanisms were used to engage wider stakeholders? Could these be replicable in other sites?
- Which stakeholders remained a challenge to engage and what were the reasons for this?
- How have parents and disabled children been involved in the development of the pilot sites?
- In the cases where parents and/or disabled children have not been involved, what are the reasons for this?

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## Summary of progress against the CDM

- 4.55 Figure 4-2 illustrates the perceived position of the sites, as reported in the sites' own monitoring submissions, in relation to the elements of the CDM in August 2009, December 2009 and March 2010 (please note that the Figure shows the range of positions indicated by each of the six pilot sites, where one column does not represent an individual site). This shows that all sites perceived themselves to have made considerable progress against all elements of the CDM over the first year of the pilot, where sites felt they had moved from very early stage development at the outset of the pilot to either 'partially' developed or 'full implementation' against all ten elements of the CDM by March 2010.
- 4.56 Evidence gathered through the case study research would support this sense of achievement and direction of travel, although it has also indicated that no site had reached a steady state and therefore that each should be viewed as still in the development/set up phase. Indeed, 'full implementation' from a site perspective has often implied that a site had developed an initial blueprint for the relevant element, which could as a result be tested and therefore delivered. However, all elements of the model are likely to be subject to review and refinement over the course of the programme.

Figure 4-2: Level of implementation against each element of the CDM, August 2009



Source: SQW Consulting

## Safeguarding

- 4.57 The pilot sites raised the issue of safeguarding as a key delivery challenge early in the programme and have since considered how to ensure sufficient safeguarding processes are in place for the pilot. It is not explicitly covered in the CDM, but has emerged as an important consideration, hence its discussion here.
- 4.58 The sites have sought to build upon existing local authority practices e.g. direct payment guidance, to ensure that safeguarding and the assessment of risk is a running theme through all IB-related activities.
- 4.59 All sites recognised the need to undertake risk assessments on an individual family basis, where the relevant professional would assess what the family were proposing to do and whether it was appropriate. This has led the sites to develop several safeguarding mechanisms, which included:
- discussion of safeguarding with families at the point of sign up to the pilot, thereby building it into the conditions agreed with the family from the outset
  - risk assessment built into the support planning process, where families were asked to consider the safety of both their child and the provision
  - support planning approvals process specifically sought to assess any risks involved in the proposed support package, where plans would not be signed off if the activities were not felt to be in the child's best interest and CRB checks may be enforced in the cases where a child is felt to be at risk
  - omission of 'at risk' children and children on the child protection register from involvement in the pilot at this stage, as they wanted to embed effective safeguarding procedures into the offer prior to including these groups of children.
- 4.60 Sites also stated that as they moved towards more community-based provision, it would be important to assess the extent to which the community as a whole can be charged with safeguarding responsibilities. This would be likely to include a need to raise the expectations of the community and the potential for IBs to facilitate a wider appreciation of safeguarding.

## 5: Resource allocation and support planning

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- 5.1 Over the first year of the pilots, it has become increasingly clear that resource allocation and support planning are integrally linked. This has meant that development of both these strands has been delivered simultaneously and resulted in the creation of a single process in each site, through which families will progress. This chapter seeks to describe the processes that have been developed by the pilot sites, provides early findings and impressions on these processes and presents some of the feedback given by families to the pilot sites.
- 5.2 In terms of the resource allocation model, three sites opted to use an adapted version of the Taking Control model (i.e. the Resource Allocation System (RAS) version 4 or 5), two sites opted to develop their own alternative system and one site chose to use the RAS and to develop an alternative system (where each will be used for different age groups).

### The in-Control RAS and associated support planning processes

- 5.3 Taking each resource allocation model in turn, an adapted version of RAS 4 and Taking Control RAS questionnaire has been used by two of the sites. Using one of these sites as an example, it was clear that the site had significantly modified the questionnaire through several iterations of development. Modifications had been made to ensure the questionnaire offered a more tailored means of assessing the support needs of a disabled child and their family and therefore, that it was suitable for use in the context of the site. This resulted in the development of a questionnaire based on a set of 26 'positively' framed outcome statements. The statements are structured around the five Every Child Matters (ECM) outcomes and have been developed to reflect the most common needs and outcomes of families that are currently in receipt of services in the site.
- 5.4 Table 5-1 provides a detailed example of the modified model used in the site. This shows that each outcome statement is associated with a traffic light system, which seeks to assess:
- the level of need in relation to each outcome statement;
  - and subsequently the associated level of support required (based on four categorisations of support) to achieve each outcome statement.

Table 5-1: Example of the enjoy and achieve outcome in the model

The enjoy and achieve outcome is associated with the following statements:

- My child is able to communicate
- My child has interests/activities out of school and in their holidays or at weekends
- Our family spend time together.

Each outcome statement is measured by the parent/carer and the child/young person (where appropriate) answering statements using a traffic light system, where each colour represents the following answers:

<b>No, not at all</b>	<b>Partly/sometimes/not enough</b>	<b>Yes always/completely/not an issue</b>
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The parent/carer and child/young person (where appropriate) is then asked to decide whether support is needed to achieve the statement, and where support is required, the level of support needed:

<b>Specialist support is needed to achieve this i.e: Trained nurse</b>	<b>I / My child needs lots of help to achieve this</b>	<b>I / My Child needs some extra help to achieve this</b>	<b>I / My child can do this with expected levels of help for age etc</b>
------------------------------------------------------------------------	--------------------------------------------------------	-----------------------------------------------------------	--------------------------------------------------------------------------

Each statement is allocated a maximum number of points, which are weighted to reflect the costs of provision to achieve the relevant outcome statement. The associated support needs for each statement then breaks these points down, providing more points for higher needs. The individual point score for each support need is then aggregated to produce a total score, which is converted into an indicative Individual Budget, through the use of a 'price point' (where one point = a specified amount of money). Therefore each indicative budget allocation is based on the total score produced through the assessment.

**a. My child is able to communicate**



How much support is needed to achieve this?

18	12	4	0
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**b. My child has interests / activities out of school and in their holidays or at weekends**



How much support is needed to achieve this?

15	6	1	0
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The final price point was developed on the basis of analysis of existing cases, where the team used around 100 existing care packages to identify the funding associated with each package.

Source: SQW case study research



- 5.5 This two stage approach again differs from that of the original RAS questionnaire, as does the categorisation of four levels of support relative to three categories (no support, some support and lots of support) in the original questionnaire. The modifications were made by the site to make the model more effective in their context.
- 5.6 Two sites have adapted RAS 5 for use in their IB pilots, which apportions IB funds on the basis of a percentile distribution as opposed to using a price point system. This has been facilitated via the following three stages:
- **first stage:** Each site costed the existing service packages of all the families that have been recruited to take part in the pilot. The total value of these packages has then formed the basis of an 'IB pot' of funding, which is to be distributed to the families
  - **second stage:** The RAS questionnaire, which is again based on the five ECM outcomes has been undertaken with each family, thereby producing a score for each family
  - **third stage:** The RAS 5 calculator is used to divide the 'IB pot' appropriately between the families, on the basis of the RAS scores, thereby allocating each family an indicative budget.
- 5.7 Modifications were again made to the RAS 5 model in both the relevant sites. For example, one of the sites increased the number of support categories from the original three (no support, some support, lots of support) to five categories (no support, small support, some support, lots of support and exceptional support). The site also developed a points range for each support category, as opposed to restricting each category to a distinct point score, to allow a judgement to be made as to whether a family and child or young person should be allocated low or high points within the band.

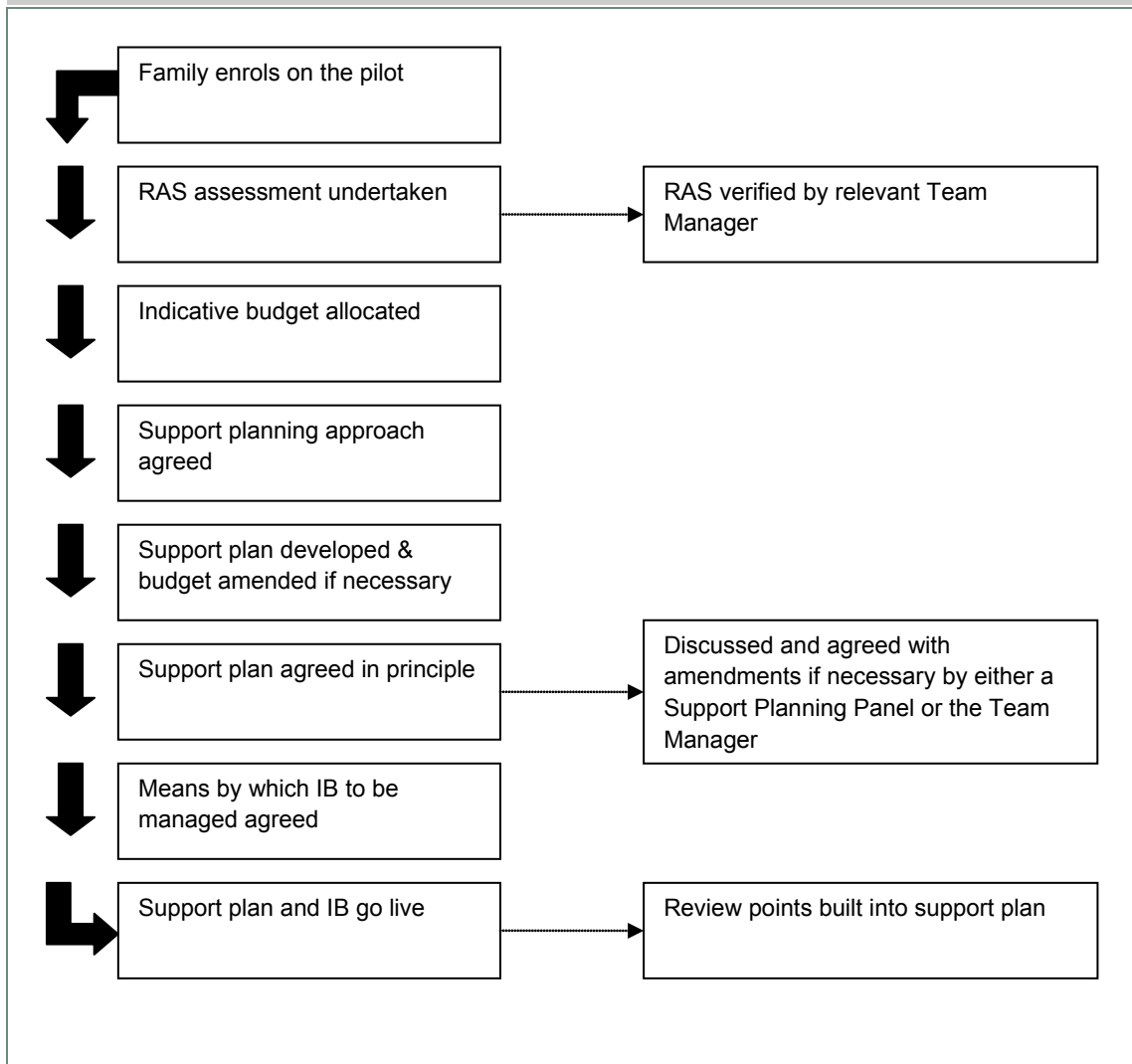
### ***The RAS and support planning***

- 5.8 Combining the RAS and support planning development activities, the resultant process used by the three relevant sites is illustrated in Figure 5-1. This shows that once a family has been given their indicative budget, they proceed onto support planning, where they are given a choice of how they would like to undertake this process (where each of the three sites has offered a different set of support planning options). This process is used as a means of enabling the family and their child to

identify the outcomes they wish to achieve using their IB, which is guided by the ECM framework that underpins the RAS questionnaire. The support plan is then developed and agreed with the family and child/young person, which in some cases has involved the amendment of the indicative budget produced through the RAS to ensure the funding can accommodate the services/activities required to meet the needs of the family and the child.

- 5.9 Once the support plan has been agreed the plan is taken to either a support planning panel or the relevant team manager for approval/vetting. This approvals process includes the finalisation of both the plan and associated final IB funding allocation (see Chapter 7 for more details).
- 5.10 Families have been invited to attend the panel, where the relevant support plan is discussed, amendments are made as necessary and approvals are subsequently made on both the plan and the final budget allocation. Families have therefore been provided with the opportunity to explain the rationale for the individual components of their support plan and can therefore challenge the decision of the support panel. Alternatively, this process is facilitated between the support planner, the family and the relevant Team Manager.

Figure 5-1: Resource allocation and support planning process for sites using the RAS



Source: SQW case study research

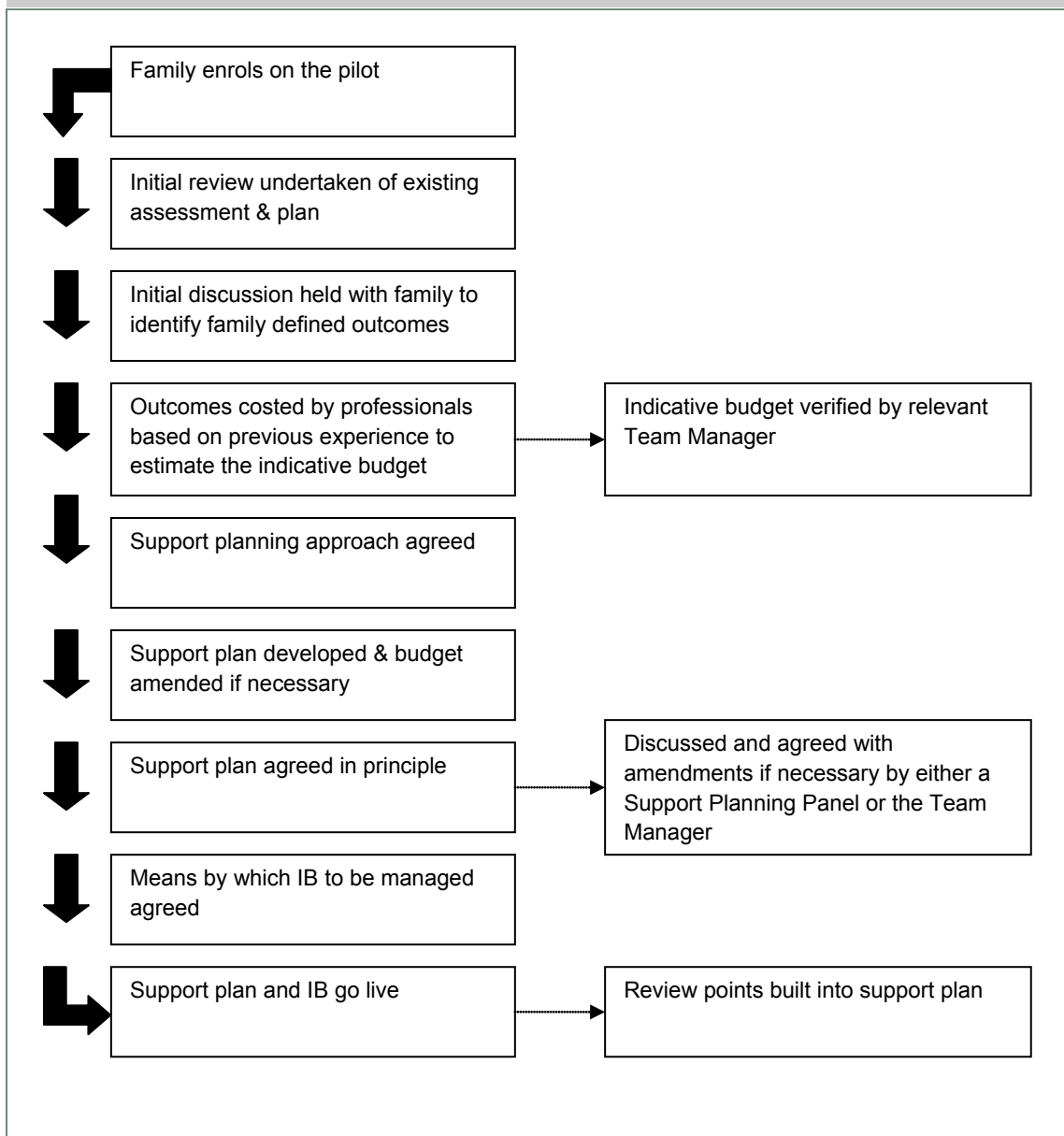
### Alternative forms of resource allocation and associated support planning

- 5.11 Three sites have developed an alternative resource allocation model, two of which are similar in their nature and sequencing (referred to as *alternative model 1*) and the third of which has been modelled around the BHLP approach (albeit without the additional resources for support available for BHLP), as an early intervention model (referred to as *alternative model 2*). Looking first at alternative model 1, initial work has been undertaken to review the assessment and existing care plans of the families recruited. Subsequently, the families were contacted and an initial discussion was held to discuss what was and wasn't working and what outcomes the family and child/young person would like to achieve. The identified outcomes were then costed by the professionals either on the basis of the level of support required to achieve each outcome, where financial values were attached to each level of support, or on

the basis of the unit costs of service provision that would be required to achieve the outcomes, both of which are derived from previous experience and lead to the estimation of an indicative budget. Once the indicative budget has been approved by the relevant team manager, the family were informed and the support planning process began, which has been facilitated in a similar sequence to that of the RAS sites.

5.12 Figure 5-2 summarises the resource allocation and support planning process used to facilitate alternative model 1.

Figure 5-2: Resource allocation and support planning process for sites using alternative model 1

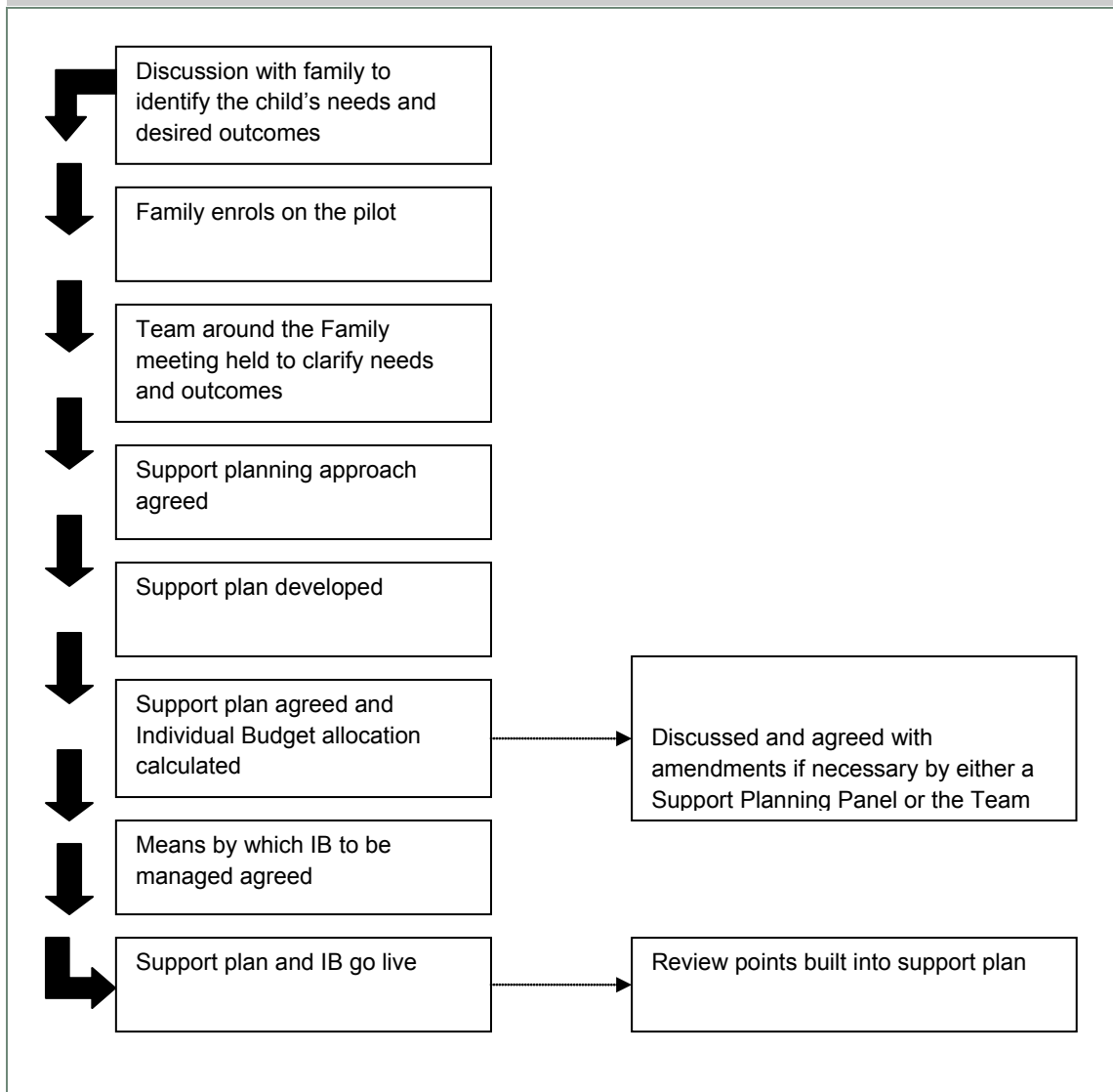


Source: SQW case study research

5.13 Alternative model 2, the early intervention approach has been facilitated through lead professionals, who initially visit the family to identify their and their child's needs and desired outcomes, following which a 'Team around the Family' (TAF) meeting is held to clarify the needs and outcomes of the relevant child and their family. Following agreement of the needs/outcomes, support planning takes place and the individual budget is calculated on the basis of the chosen services/activities. The support plan then proceeds through a similar approvals process to that of the other models, after which, the plan and IB go live.

5.14 Figure 5-3 summarises the resource allocation and support planning process used to facilitated alternative model 2.

Figure 5-3: Resource allocation and support planning process for sites using alternative model 2



Source: SQW case study research

## Early findings and impressions of the resource allocation and support planning processes

5.15 Early findings have shown that the main differences between the RAS and alternative models are as follows:

- the in-Control RAS-based approach uses a questionnaire at the outset, which seeks to assess the needs of the family against a pre-specified set of outcomes (that are based on the five ECM outcomes) and subsequently apportions an indicative budget to meet the identified needs, following which support planning takes place.
- the alternative approaches undertake intensive planning work with the family prior to the support planning process, to determine the outcomes the family would like to achieve, following which an indicative budget is developed, based on unit costings/the funding required to deliver the agreed outcomes and support planning begins.

5.16 As such, the main differences between the RAS based models and alternative models appear to lie in: the preparatory elements involved prior to the provision of an indicative budget; and the degree of systematisation through which the scale of resource is decided. It will therefore be important to track how the differences of approach lead to different types or scale of change in the support packages, satisfaction with the process, levels of innovation and the outcomes achieved.

5.17 At the point of drafting this report, many families were going through the resource allocation and support planning processes. Therefore, we have not sought to make a judgement on the effectiveness but rather will revisit this issue in much more depth over the course of Year two. However, sites have provided some of initial feedback and concerns in relation to their resource allocation and support planning processes:

- development of the relevant resource allocation model was reported to have required dedicated and intensive 'thinking time' from the pilot delivery teams and other involved parties. This often involved several development sessions which sought to develop, test and refine the chosen model and in most cases, training to ensure that all parties were able to effectively use the model.
- the majority of sites felt that the introduction of an indicative budget at some point in the process was required to enable both families and support planners to form realistic support packages, although they varied on what

point this was needed. Some raised concerns around the sequencing of the RAS process, where it was felt that highlighting the amount of resource available to the family prior to support planning, may lead the family to plan and make decisions based on the money available, as opposed to taking a wider view on what was best for the child. For others this degree of transparency was seen as a strength.

- each resource allocation model was viewed as a 'work in progress', where sites anticipated making refinements as the pilot progressed and similarly, resource allocation was in no way an 'exact science' and required 'room for manoeuvre' to take differing circumstances into account. In some cases sites were concerned about the reliability of the RAS-based indicative budgets, especially where these differed considerably from previous allocations.
- a number of families had received an individual budget that differed significantly from their traditional service provision budget and were still taking part in the pilot. The scale of change appeared to be partially a reflection that the previous system was not based on meeting specific outcomes and often included greater judgement and persuasion by professionals. That families have continued with the pilot despite fewer resources was often the result of effective management on the part of the sites in suggesting to families that the greater flexibility of an IB might outweigh the loss of resource.
- it appeared that the continuity and quality of support was likely to have a strong influence on the success of the process from the point of view of the family.
- newcomers to the system by their nature do not have a previous traditional service budget and therefore cannot bring money into the 'IB Pot'. Therefore any resource allocation model that is based on the pooling of the value of existing service packages of participating families may be methodologically flawed.
- most sites have created a contingency budget, which is formed by holding back a proportion of either the overall IB pot or a proportion of each IB funding allocation for emergency purposes. However, in normal ways of working local authorities have contingency outside of the existing service packages offered. This implies that sites have in effect double funded their

contingency. One result of this would be a slight lowering of the value of packages across the cohort.

- 5.18 Each of the above points and concerns will be explored further over the coming months as more families pass through the resource allocation and support planning processes.

#### The IB package

- 5.19 At the point of drafting this report, families were proceeding through the resource allocation and support planning processes. As such, the following section presents some of the early results of the resource allocation and support planning processes and a selection of initial impressions and reactions of participating families.
- 5.20 Looking first at resource allocation, the process had produced significant changes in the distribution of funding between families. This resulted in similar numbers of indicative budgets producing funding allocations that were less, more or equal to the funding associated with the families' traditional service provision. This degree of change is likely to be partially caused by the apparent disconnect or discontinuity between the traditional method and IB approach to both needs assessment and service provision; if models change it is to be expected that so will allocations.
- 5.21 Due to the scale of some of the changes arising through the process all sites were applying an element of judgement to the process, which had resulted in significant manual adjustment of the indicative budgets produced by the RAS-based models in particular. In addition, a number of the pilot sites had developed mechanisms to minimise the extent of this variation within the pilot, to manage the transition from the traditional to the IB approach.
- 5.22 The majority of the sites had also developed contingency budgets that sat outside of the IB funding allocations. This form of budget was created to allow flexibility to adjust IB funding allocations at the support planning stage, and to ensure any unexpected situations could be accommodated. The budget was created in one of two ways, the first of which involved top-slicing the IB pot, which was commonly undertaken by the pilots using a RAS-based model. The second method involved pooling 20% of each indicative funding allocation into a contingency fund, which was explained to all families participating in the pilot. Year two of the evaluation will seek to understand the extent to which and how the contingency budget is used.



- 5.23 As only a small number of IBs had been finalised and had therefore gone live, it is too early to comment on the variation between the IB funding allocation and the previous traditional service funding allocation. This issue will be explored in more detail in Year Two.

***Initial family impressions and reactions***

- 5.24 This section sets out the initial views gathered by the sites through their interaction with families. As explained above, many families were still proceeding through support planning and so the impressions below come from their early experiences. Moreover, the full impact of the different support planning and resource allocation approaches will take time to emerge. However, given the nature of some of the initial feedback it is important to acknowledge it here, not least to give a flavour of some findings and issues that may emerge in the next phase.
- 5.25 Feedback from the sites indicated that families had recognised that they were taking part in pilot activities and therefore that the models and processes that they were implementing, were part of a wider development process, which could require refinement and review. Therefore, there was an appreciation that the pilot team would not necessarily get ‘everything right’ and there had been a push to ‘foster an honest relationship’ between the pilot teams and the families, to ensure they felt they could provide honest feedback. To date, this feedback has included some families voicing concerns that the RAS questionnaire was not currently sufficiently robust to accommodate the comprehensive needs of the child and family.
- 5.26 Sites reported that families had had mixed reactions to their indicative budgets. For example, one site had experienced relatively positive feedback, where families had stated that they valued the honesty of the pilot delivery team, who had explained that there was no new money available and that the IB approach was more about deploying existing money more effectively. Conversely, one site had experienced negative responses in the cases where the indicative budget had come out less than the traditional service budget.
- 5.27 Initial findings indicate that a number of families that had experienced a reduced budget (relative to their traditional service budget) were finding their IB resource could stretch further than they expected. For example, families had found that the cost of directly employing a PA cheaper than through traditional agency-sourced provision and that provider-sourced provision was generally cheaper than local authority-based provision. Therefore, these families were purchasing greater

quantities of support than they previously had under the traditional system. However, this move from traditional to independently sourced support is likely to have been accompanied by increased administration time to facilitate the employment of the relevant individual. One issue for the future may be who pays for this increase in search and administrative time.

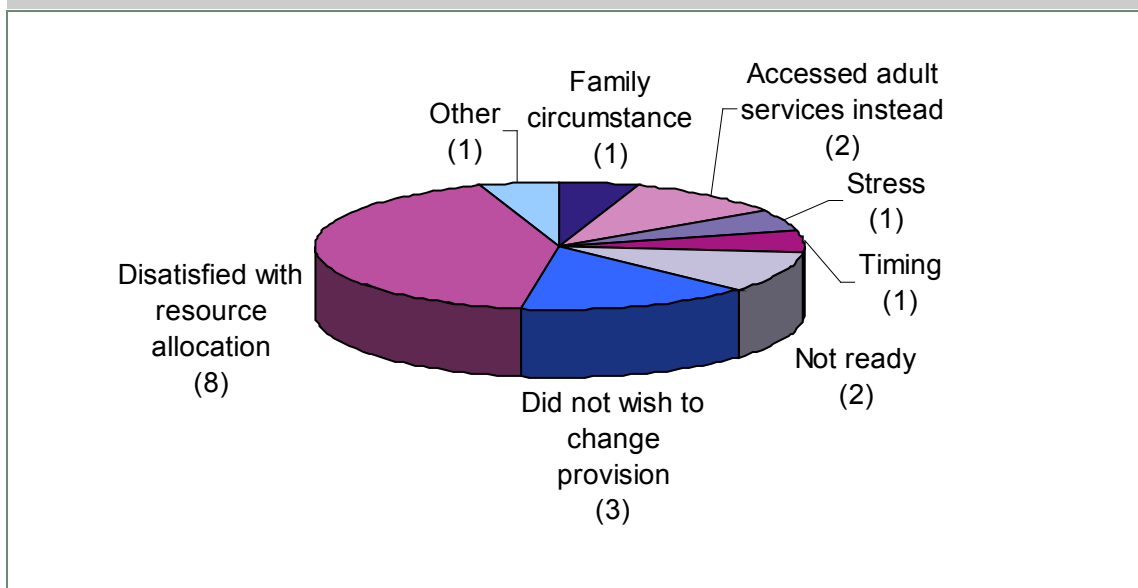
- 5.28 Feedback on support planning indicated that families appreciated being 'listened to', had felt 'properly engaged' for the first time and 'valued the opportunity' to be able to shape the support plan. In addition families appreciated the independence that the process provided, without placing the emphasis on the parent 'to do everything'. As such the view was that over time the IB approach would begin to have a positive impact.
- 5.29 Support planners reported that families through the process were becoming more open to considering more innovative and creative ideas that lay outside of the service provision they had been offered in the past. They added that this was helping them to understand the potential outcomes of greater involvement on their part and the value of the IB approach. As such, it had been easier to formulate ideas around particular outcomes, e.g. enjoy and achieve, staying health and being safe, but that families had struggled to find skill building experiences.
- 5.30 Interestingly, it was noted by one consultee that it was starkly obvious which families saw the IB offer as an opportunity to be involved in developing a personalised plan for their young person and those who saw it as an opportunity to get more from the system. This view was supported by another consultee who noted that some parents were too focused on the cost side of the process rather than the quality of the provision or the benefits for their young person.
- 5.31 From a young person's perspective, early findings indicate that their key outcome focused on a need to gain their independence from their parents/carers. This therefore created a demand for activities that would enable the young person to either spend more time on their own or with peers from their own age group.

#### ***Families that have dropped out of the pilot***

- 5.32 The sites have seen a number of families drop out of the pilot, particularly in the months since January 2010. Ten per cent of the families (19) had dropped out of the pilot by the end of March 2010, the vast majority of which (95%) coincided with a general drive to develop and finalise support plans and get families into receipt of IB (see Figure 5-4).

5.33 Over half of the families who dropped out (11) did so because they did not wish to change their current provision, 8 of whom were stated to be dissatisfied with their resource allocation. Two families felt they were not ready to participate in the process at this stage, but would consider engaging at a later date. It was also interesting to note that one site in particular had experienced significant numbers of families dropping out of the pilot as a result of their indicative budget allocation coming out lower than their traditional service allocation. However, the learning shared by this site has led other sites to handle this issue more sensitively and therefore minimised drop out in other cases.

Figure 5-4: Reason family dropped out of the pilot



Source: SQW Consulting, Site Monitoring Returns

5.34 The issue of drop out will be closely monitored over the course of Year two, where the evaluation will undertake additional research to understand the rationale behind these decisions.

#### Summary

5.35 Table 5-2 presents a summary of the progress made against element seven of the CDM.

Table 5-2: Progress made to date against elements seven of the CDM

### Emerging findings and lessons

- Over the first year of the pilots, it became increasingly clear that resource allocation and support planning were integrally linked. This has meant that development of both these strands has been delivered simultaneously and resulted in the creation of a single process in each site, through which families will progress.
- Looking first at the choice of resource allocation model, three sites opted to use an adapted version of the Taking Control model (i.e. the Resource Allocation System (RAS) version 4 or 5), two sites had opted to develop their own alternative system and one site chose to develop both a RAS and alternative system (where each will be used for different age groups).
- All but one of the models has included the provision of an indicative budget to the participating families at some stage of the planning cycle, as this form of budget was felt to be necessary to enable both families and support planners to form realistic support packages.
- The main differences between the RAS based models and alternative models appear to lie in: the preparatory elements involved prior to the provision of an indicative budget; and the degree of systematisation through which the scale of resource is decided. It will therefore be important to track how the differences of approach lead to different types or scale of change in the support packages, satisfaction with the process, levels of innovation and the outcomes achieved.
- It is too early in the process to map out the results of each of the models. However, the sites raised a number of initial concerns and areas for development in relation to their chosen model, each of which will be explored further during Year two of the programme.
- Families were largely positive about the support planning process and are starting to use the opportunity to change some of the elements of their support planning. In addition, anecdotal perceptions from support planners indicated that families were receptive to new ideas and may become more radical over time if their initial choices work as they hope.

### Issues of interest over the next 12 months of the programme

The evaluation will seek to explore the following issues over the course of Year two:

- How did the various models differ and did they lead to different:
    - types or scale of change in the support packages
    - satisfaction with the process
    - levels of innovation
    - outcomes achieved.
  - On average, how many hours did it take to facilitate the process with a single family? How did it compare to existing arrangements?
  - What were the limitations of each model and how if at all were these addressed?
  - Were families satisfied with the process and their resultant budgets and support packages?
  - What auditing and review processes were undertaken once the IB had gone live?
  - Were the models and associated systems revised or reviewed during Year Two of the programme? And if so, what was changed as a result?
  - If new funding streams/services were brought into the pilot site, how were these integrated into the existing IB packages of the participating families?
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## 6: Funding streams and services

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### Introduction

- 6.1 The *IB Pilot Specification and Application Pack* detailed a set of objectives and expectations for the pilot sites. This included guidance on the types of services/funding streams that could be considered for inclusion in the IB packages, with an expectation that each IB pilot site would bring together different funding streams, and therefore go beyond current direct payment arrangements.
- 6.2 The guidance stated that the scope of services should be considered on an individual local authority and PCT basis, in consultation with disabled children, young people and their families. This process was to be facilitated through consideration of the services that should be included, as opposed to initially focusing on funding streams. The justification for this approach centred on the view that some of the relevant services that could be appropriately included in the IB model would not be funded through specific, dedicated grants issued directly from Government. As such, the guidance proposed consideration of inclusion of the following services/funding streams:
- **Children’s core social care services**
  - **Area Based Grant (ABG)** – non-ringfenced grants, made up of a wide range of former specific grants from seven Government Departments, including funding previously allocated to support disabled children in travelling to and from school and the former Carers Grant
  - **PCT baseline funding** – where research suggests that NHS services with greatest relevance to disabled children and those with complex health needs include NHS continuing care, equipment and wheelchair services, mental health services, therapy services, end-of-life care and services to meet needs arising from long term conditions
  - **AHDC block funding** – which is contained within the Sure Start, Early Years and Children Grant (SSEYCG)
  - **Non school based education funding** – for example to facilitate transport provision or educational support.

- 6.3 Table 6-1 details the inclusion criteria set out in the guidance, which advised that any funding stream should be considered if it met the criteria.

Table 6-1: Funding stream inclusion criteria

- The funding stream will enable disabled children and young people to overcome barriers associated with illness or impairment
- The funding stream is able to address the additional needs and difficulties experienced by disabled children, young people and their families, thus enabling disabled children and young people to fully participate in all aspects of their lives, including at home, at work and in the community, implying the funding is likely to have a positive impact on the lives of disabled people
- A funding stream should not be included in the IB model if it is for a universal services where eligibility is not determined by an individual needs assessment
- While the AHDC pilots will only be open to disabled children and their families, IB pilots need not restrict the inclusion of funding streams or services to those access exclusively by disabled people.

*Source: IB Pilot Specification and Application Pack (2009)*

- 6.4 This chapter describes the progress that had been made in relation to the pooling and aligning of funding streams/services for inclusion in the IB packages at the end of the Year one of the programme.

Pooling and aligning of funding streams and services for inclusion in IB packages

- 6.5 The sites have exhibited mixed progress, where some sites had been successful in broadening the scope of their IB packages beyond social care funds, whereas others were viewed as a 'work in progress'.
- 6.6 For those sites that had drawn in multiple funding streams/services, their success appeared to have been driven by a willingness to engage on the part of key local fund holders. Conversely, those that had made less progress stated that they had found this engagement more challenging as a result of locally determined circumstances. For example, the availability of PCT funding had been limited in some sites as a result of constrained and conflicting health priorities, which in one site had meant that although the relevant PCT was actively engaged in the pilot, it would not contribute funds into the IB pilot at this stage.
- 6.7 As of April 2010, the spectrum of funding streams/services to be included in the resultant IB packages across the pilot sites included:
- **Social care services/funding** – including Short Breaks services/funding, Childcare funds, Domiciliary services, Budget Holding Lead Professionals funding.

- **PCT services/funding** – including limited and/or restricted funding that can for example be used for community nursing to meet physical and mental health needs, or for health-related equipment. One site was also looking at the possibility of using a notional budget to tailor health-specific elements of the relevant IB packages.
- **Education services/funding** – including Extended Services funding (involving the allocation of a set amount of funds per family), Early Years funding and may also include transport services and Young People’s Learning Agency (ex-LSC) funds, both of which are currently subject to negotiation in the relevant sites.
- **Other funding streams** – discussions are currently being undertaken with Connexions in two of the sites that were focusing on the transition group, to understand whether the service and/or its funding streams could be used within an IB.

6.8 Table 6-2 provides an anonymised site-level map that sets out the funding streams/services that had been drawn into the IB packages at the end of Year one. This shows the range of progress that has been achieved by the sites, all of which had included funding from the social care core budget and half of which had included Short Breaks funding and/or PCT funding. Similarly, one site in particular had successfully aligned social care, PCT and education funding, which represents what can be achieved in the appropriate circumstances.

Table 6-2: Funding stream/service inclusion by site						
	Site					
Funding stream/service	1	2	3	4	5	6
<b>Year one</b>						
Short Breaks funding		✓	✓		✓	✓
PCT funding			✓	✓	✓	✓
Social care funding from the core budget	✓	✓	✓	✓	✓	✓
Early Years funding		✓				
Extended services funding					✓	

Site						
Funding stream/service	1	2	3	4	5	6
<b>Potential funding streams/services for inclusion in Year two</b>						
Young People's Learning Agency funding	✓	✓	✓		✓	
PCT funding	✓			✓		
Connexions funding					✓	
Education funding						✓

*Source: SQW case study research*

6.9 Where additional funding streams have been drawn in, they have often come with some restrictions which differ across areas. Taking PCT funding as an example this included:

- a focus on a limited number of cases where young people 'bring PCT funds with them', where the funding will remain directly linked to the relevant young people and re-shaped (and as such, will not be available to all children and young people)
- PCT funds used for health equipment purposes only, as requested by families
- an intention that PCT funding would be available for individual IB users who may want to purchase alternative services to those currently delivered – for both physical and mental health services
- reshaping of health funded overnight services from a particular provider.

6.10 Where other funds had not been drawn in sites were still seeking to adopt a more holistic view of needs than may have been the case previously, to enable them to test the principles of an IB as fully as possible.

6.11 Looking ahead to Year two, the sites intended to continue their efforts to draw in additional funding streams/services. At the point of drafting this report, this had included discussion with the Council colleagues taking over responsibility for the previous Young People's Learning Agency funding, PCT, Connexions and Education fund holders. Therefore, this aspect of the evaluation will be closely monitored over the course of Year two.



### ***Barriers to accessing funding streams/ services***

- 6.12 The general consensus from the sites highlighted that although progress had been made with some of the PCT fund holders, they had only contributed limited funds, most of which carried restrictions. Therefore, sites may need to work with their PCT colleagues over the next year to extend the scale and coverage of this funding stream.
- 6.13 The biggest barriers were encountered during attempts to draw in education funding streams. This was felt to be in part because sites had found it difficult to gain buy-in from the relevant fund holders and therefore had been unable to make in-roads on the funding front. One site added that they felt their education colleagues had distanced themselves from the IB work, as they did not feel that personalisation was relevant to their area of work. Therefore, the slower pace and sometimes lack of cultural change towards more personalised approaches outside of social care appeared to have hindered a number of the sites. This may imply that the sites need to focus their efforts on engaging this group of fund holders in the early part of Year two, and that Government support is required to enable this activity, to maximise the funding contributions that can be drawn into the IB packages.
- 6.14 Other examples of barriers to accessing funding streams/services included:
- issues with block contracting - block contracts cannot be broken up during their commissioned period and therefore the creation of flexible funds cannot be facilitated in the short term
  - the state of the economy has meant that funding cuts had to be made during 2009/10, which has 'squeezed' any budget that could have been contributed to the IB packages
  - absence of a 'safety net' for PCT contributions – no safety net (or double funding mechanism) was available to support the transition from centrally commissioned services to an individually directed service, which prohibited the PCT from contributing funds.

### Summary

- 6.15 The sites have exhibited mixed progress, where some sites had been successful in broadening the scope of their IB packages beyond social care funds, whereas others were much less advanced. For example, one site had only included a contribution from the social care core budget in their IB packages, whereas another site had

successful drawn in social care, PCT and education based funding, thereby illustrating what can be achieved in the appropriate circumstances.

- 6.16 The general consensus from the sites highlighted that although progress had been made with some of the PCT fund holders, they had only contributed limited funds, most of which carried restrictions. However, the biggest barriers were encountered during attempts to draw in education funding streams, where only one site had really made any form of progress. Issues with both PCT and education colleagues were felt to be in part because the relevant individuals were not sufficiently engaged in the pilot due to a slower pace of cultural change towards the provision of more personalised services. It was also felt to be a reflection of the constraints faced in relation to block contracting and an absence of additional funding to enable the required double funding of services in the transition.
- 6.17 Looking ahead to Year two, the sites intended to continue their efforts to draw in additional funding streams/services. It is hoped that this will include ex-LSC, PCT, Connexions and Education funding. As such, the evaluation will closely monitor the activities of the sites to understand how fund holders were engaged, the successes and challenges associated with this engagement, the means by which any contributions are incorporated into the IB funding packages and the resultant outcomes.

## 7: Pilot inputs and cost

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- 7.1 The following chapter sets out the pilot inputs and costs involved in delivering the first year of the pilot; both in terms of the use of expenditure from the former DCSF funded IB grant allocation and in-kind time contributions from staff who were not directly funded by the pilot. The chapter draws on the monitoring data, which was provided by the pilot sites on a regular basis.
- 7.2 As the pilot sites have not yet reached a steady state, it has not been possible to separate the analysis of set-up and running costs of the sites in this report. As such, this chapter details the Year one costs incurred to set up and implement the ten elements of the Common Delivery Model and the other monetary costs incurred up to the end of March 2010. For illustrative purposes the costs have been provided by site, although the data have been anonymised to avoid disclosure at this stage.

### Financial inputs

#### ***Pilot and additional funding***

- 7.3 The total IB grant allocation from the former DCSF for 2009/10 and indicative allocation for 2010/11 are set out in Table 7-1. This indicates that the total allocation will increase by 6% in the next financial year. The sites have not yet drawn in additional sources of funding to support the delivery of the pilot, although sites have contributed considerable amounts of in-kind time (see below for more details).

Table 7-1: DCSF IB grant allocation for 2009/10 and 2010/11

2009/10	2010/11 (Indicative)
£713,631	£753,110

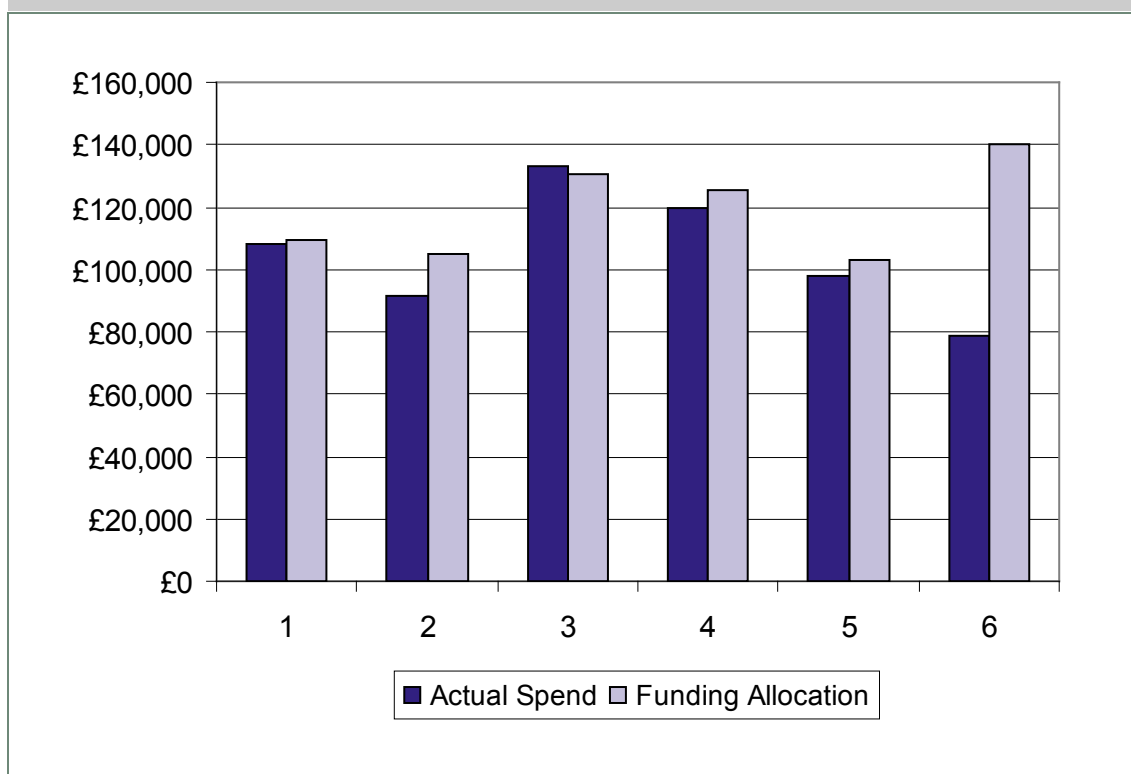
*The 2010/11 figure is an indicative amount based on funding allocations of the six pilot sites.*

*Source: SQW Consulting*

- 7.4 The majority of sites spent below their grant allocation in 2009/10, although this under-spend tended to be marginal. One site (labelled 6 in Figure 7-1) exhibited a relatively large under-spend (spending just 56% of their £140,000 allotted funding allocation). This site had already begun the development of several elements of the CDM prior to becoming part of the IB pilot programme and therefore absorbed much

of the costs of development into the existing council structure. Late recruitment of funded pilot staff (as opposed to staff contributing in-kind time) also led to lower than anticipated costs within the 2009/10 financial year. Conversely, one site reported an over-spend of approximately £2,400, the cost of which will be met by the relevant Council.

Figure 7-1: 2009/10 funding allocation and actual spend, by pilot site



Each pilot site is represented by a number 1-6

Source: SQW Consulting

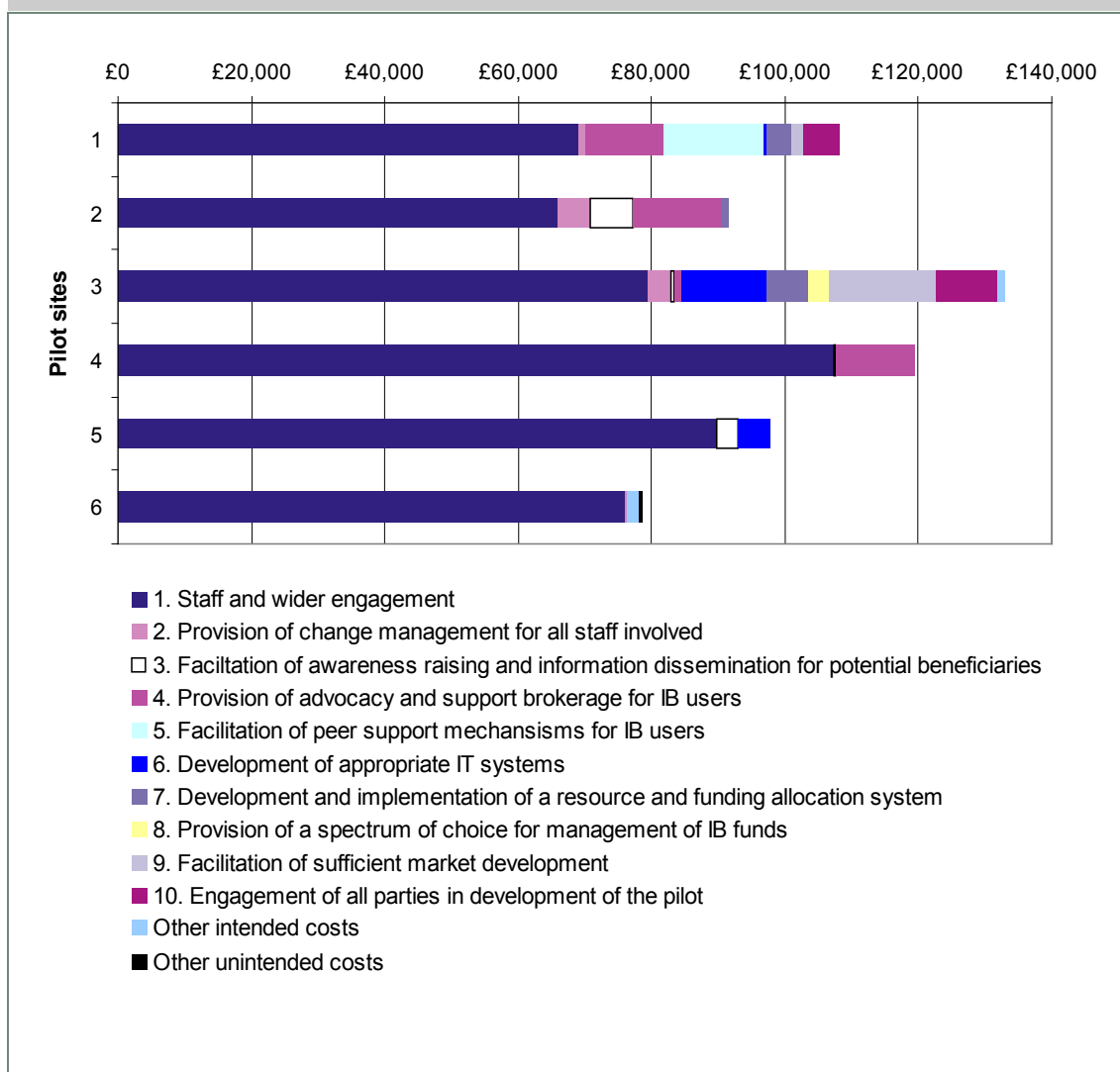
### Actual spend

7.5 The sites were asked to record spend incurred to set up and implement each element of the CDM. This spend was divided into cash costs funded from the IB grant allocation and in-kind time contributions from staff not directly funded by the pilot. In looking at both types of cost, the evaluation team will be able to form an estimate of the true cost of pilot delivery at the end of the programme.

7.6 Figure 7-2 illustrates the breakdown of financial costs incurred on each element of the CDM. This shows that staff and wider engagement represented the biggest financial expenditure across all the pilot sites, accounting for between 60% and 96% of expenditure. This of course reflects that the staff recruited under one element then use their time to deliver many of the other elements. The next largest financial cost was incurred in the development and delivery of CDM element 4 – the provision of

advocacy and support brokerage for IB user, where three sites used between 10%-15% of their expenditure to fund this element. This relatively high cost was used to commission several independent third sector organisations to facilitate support planning.

Figure 7-2: Breakdown of 2009/10 financial costs by element of the CDM



Each pilot site is represented by a number 1-6

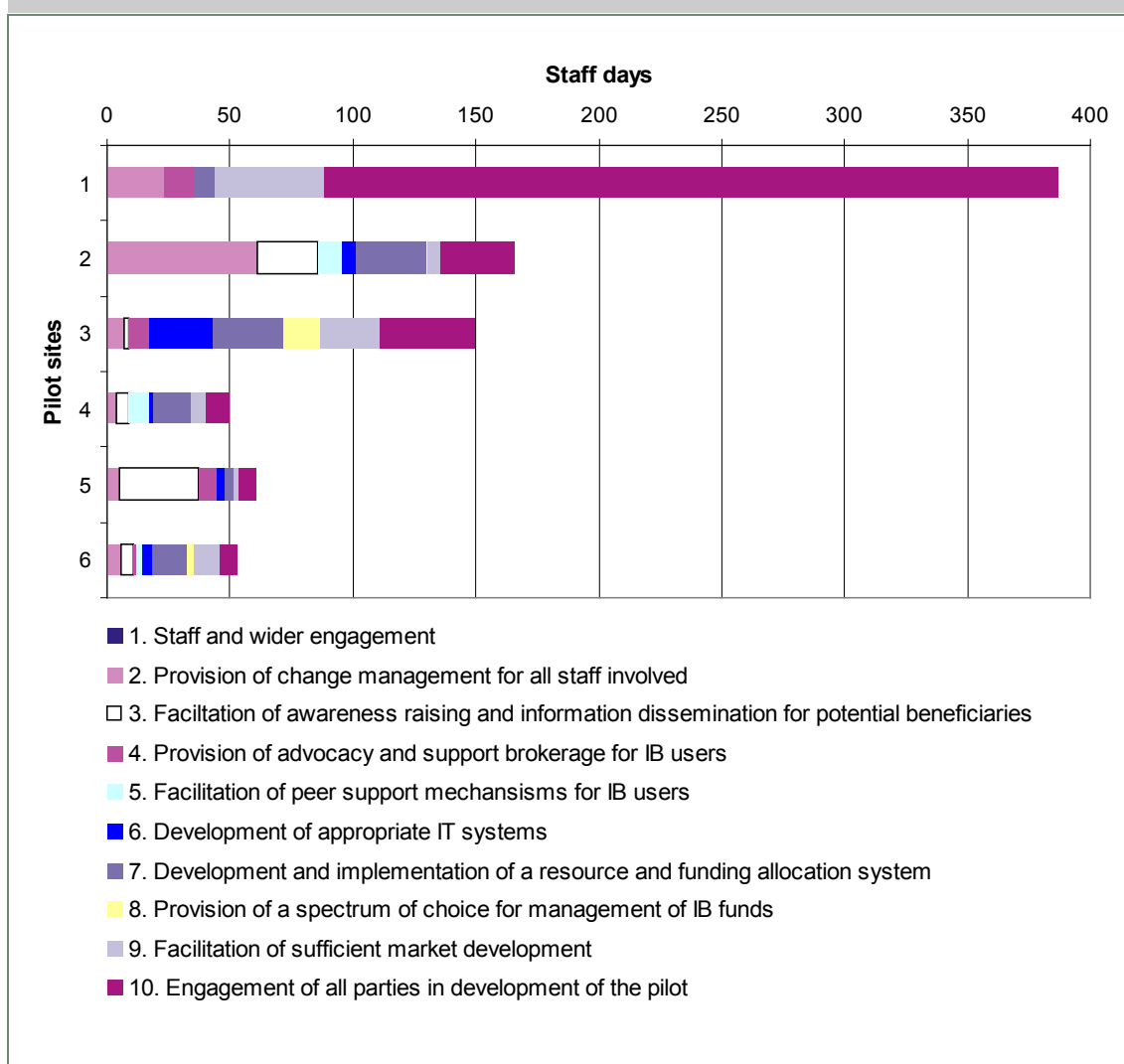
Source: SQW Consulting

7.7 There was substantial variation in the in-kind costs reported by the sites. For example, one site (labelled 1 in Figure 7-3) had particularly high levels of in-kind costs in 2009/10 (387 days), the majority of which (77%) contributed to the implementation of CDM element 10 (engagement of all parties in the development of the pilot). This relatively high cost reflects the governance structure of the pilot, which was made up of a series of working groups, each of which contributed to the

development of the pilot. Therefore, the time contributions of all members of the working groups have been accounted for in the monitoring data.

7.8 The provision of change management for staff also required a considerable amount of in-kind input within some sites. For example, in sites 1 and 2 in Figure 7-3, change management took 61 and 23 staff days respectively. Activities to facilitate change management included staff training, development days, conferences and contributions at various meetings.

Figure 7-3: Breakdown of 2009/10 in-kind costs by element of the CDM



Each pilot site is represented by a number 1-6

Source: SQW Consulting

7.9 As the sites were still in their set up phase at the point of drafting this report, it was too early to provide a comparison of the in-kind and cash costs incurred and the cost

effectiveness of the pilot sites. This form of analysis will be undertaken in the final evaluation report at the end of Year two of the programme.

### Summary

- 7.10 Pilot sites collected and submitted data to the evaluation team on the inputs and costs used to deliver the first year of the pilot; both in terms of the use of expenditure from the former DCSF IB grant allocation and in-kind contributions from staff who were not directly funded by the pilot. This showed that most sites had incurred costs broadly in line with what they had expected and that the largest financial costs had been spent on new staff and commissioning support. The data also showed significant in-kind time investment made by the pilot sites.

## 8: The families and young people taking part in the pilot

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- 8.1 Each of the IB pilot sites was tasked to engage 30-50 families with disabled children to take part in the pilot. Where possible, this engagement was expected to focus on the identification of a group of families that were representative of the overall population of the relevant area. This form of targeted engagement was suggested to enable the programme to build an understanding of how different groups of the population take the IB offer forward and in doing so, provide evidence on whether the offer needed to be varied in particular circumstances.
- 8.2 The following chapter details the means by which the pilot sites engaged their families and subsequently, sets out the numbers of families that took up the IB offer and therefore enrolled to take part in the programme. It then goes on to provide a description of the characteristics of the engaged families and young people.

### *Effectiveness of the engagement process*

- 8.3 The invitation to participate in the pilot was facilitated in one of two ways; the first invited a random sample of the population to participate; and the second invited a targeted set of eligible families with disabled children to participate. In all approaches, once invited, families were followed up in the event that they showed interest in taking part in the pilot. One exception to this general, broad approach was identified. This involved the relevant site adopting the random sample approach for half of its participants and a targeted approach for the second half of their engagement process. This was undertaken to ensure that a representative sample was recruited, which included families from different geographical locations and from different socio-demographic backgrounds.
- 8.4 A personalised approach was seen as critical to the engagement process. This approach sought to deliver the clear and consistent message that the IB approach was a new way to control and manage services. Within this message the aim was to emphasise that it was a 'new' approach which was exciting, but challenging; that it is an approach that puts the family 'in the driving seat' in terms of deciding what support was required. This message was reported by the sites as invariably gaining a positive response.



- 8.5 In general it was felt that whilst the message itself would be replicable across a wider group, the challenge would be in finding the resource to deliver the necessary personalised approach across a large number of families. The view was that it would be difficult to engage families with a less intense input as time needed to be spent in providing a detailed explanation and in answering families questions and concerns.

### ***Engagement profile***

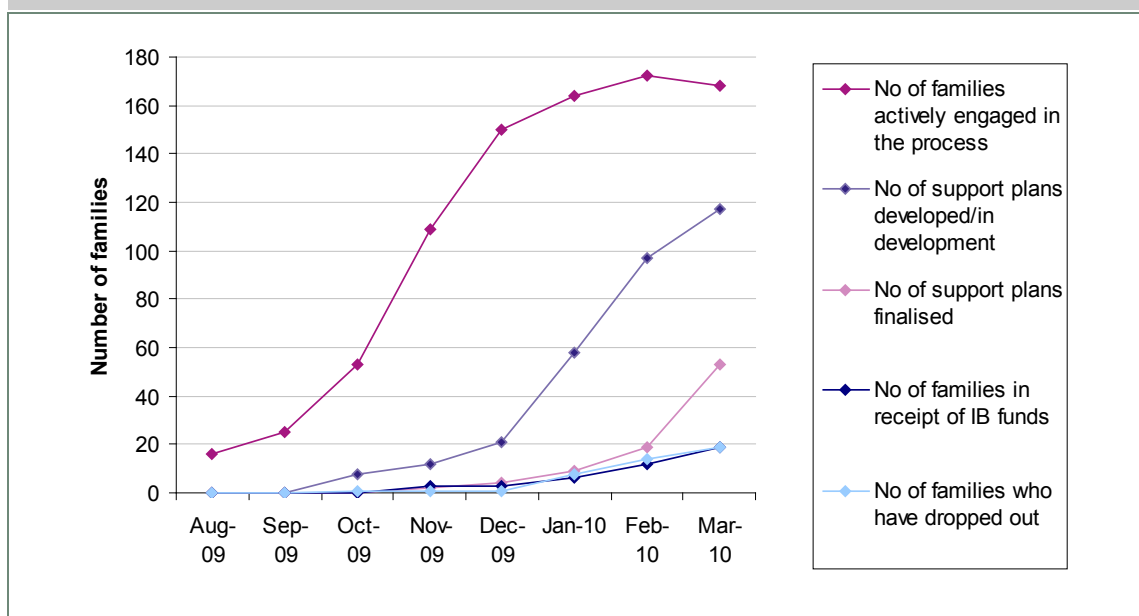
- 8.6 Sites were asked to complete their engagement activities by the beginning of 2010. This deadline was set to ensure that the family baseline survey could be undertaken sufficiently in advance of the follow-up survey and to allow benefits to begin to emerge for the families as a result of taking up the IB offer.
- 8.7 Although the sites reported initial concerns about the engagement deadline at the outset of the programme, all sites successfully engaged a cohort of families to take part in the pilot. However, just three sites achieved their engagement within the original deadline. As such, flexibilities were introduced by the evaluation team to accommodate delayed engagement in the remaining sites. The slightly extended time period offered (two months) led to all but one site either achieving or exceeding their engagement target (the one site that encountered a shortfall experienced particular challenges from one of the two teams that were to support engagement activities and was therefore granted an element of leeway), which reflects the significant efforts made by the pilot sites and indicates an apparent level of demand from families to take up the IB offer if the approach is made to them in an appropriate way as described above.
- 8.8 Looking across the programme as a whole, the pilot sites engaged 187 families, which exceeded the target of 185 families. The aggregate engagement figure includes 14 families that had been engaged over and above the target number in three of the pilot sites.
- 8.9 Table 8-1 sets out the engagement profile for the programme (and Figure 8-1 illustrates the profile graphically). This shows that two hundred and forty families expressed an initial interest in take part in the pilot, of which 187 children/young people and their families went on to enrol in the programme. The pace of engagement varied by site, in part as a result of the differing levels of infrastructure in place prior to the pilot and the different speeds at which the pilot teams were recruited. However, the overall figures do demonstrate how quickly demand could be built in some areas.

Table 8-1: Engagement Profile for 2009/10

2009/10									
	Aug-09	Sep-09	Oct-09	Nov-09	Dec-09	Jan-10	Feb-10	Mar-10	TOTAL
No of potential families who expressed an initial interest in taking part in the pilot	38	44	101	24	20	10	2	1	<b>240</b>
No of new families engaged in the pilot	16	9	29	56	41	21	14	1	<b>187</b>
No of support plans developed and finalised	0	0	0	2	2	5	10	34	<b>53</b>
No of families in receipt of IB funds	0	0	0	3	0	3	6	7	<b>19</b>
No of families who have dropped out	0	0	1	0	0	7	6	5	<b>19</b>

Source: Pilot monitoring returns

Figure 8-1: Families engaged at each stage of the Individual Budget pilot



Source: SQW Consulting

8.10 Table 8-2 illustrates the proportion of families engaged by target group for each of the sites. This shows five of the sites maintained their targeted approach to engagement, where over 60% of the families engaged were from the relevant groups. The remaining site achieved an engagement of only 36% from their target

group, as the site chose to focus on engaging a representative sample of their population, as opposed to a particular target group.

Pilot site	Proportion of engaged families from target group
1	89%
2	86%
3	36%
4	97%
5	63%
6	80%

Source: SQW Consulting, Site Monitoring Returns

- 8.11 By March 2010, 28% of enrolled children/young people (53) had had their support plans finalised, and a further 34% (64) were in the process of having their support plans developed.
- 8.12 The approach to support planning has varied across the pilot sites. One site, which had infrastructure in place prior to IB, took individuals through support planning and resource allocation during the recruitment process, while others adopted more of a staged approach – recruiting all children/young people, before taking them through the resource allocation and support planning process. Monitoring data from the sites shows that ten per cent (19) families are now in receipt of IB, and all are targeted to be in receipt by May 2010.

#### Nature of the participants

- 8.13 The following section presents an analysis of data gathered from both the monitoring returns and the family-baseline survey to describe the nature of participating families. This highlights a good range of diversity between participating families in relation to: socio economic groups; nature of the child/young person’s disability; and previous use of personalised approaches.

#### **Family economic status**

- 8.14 In 45% of families who responded to the family survey, the responding parent/guardian did not work and was not seeking work. A similar proportion were in some form of work: 24% were working part time and 16% full time. A sizeable minority of responding parents (6%) were listed as being long-term sick or disabled.

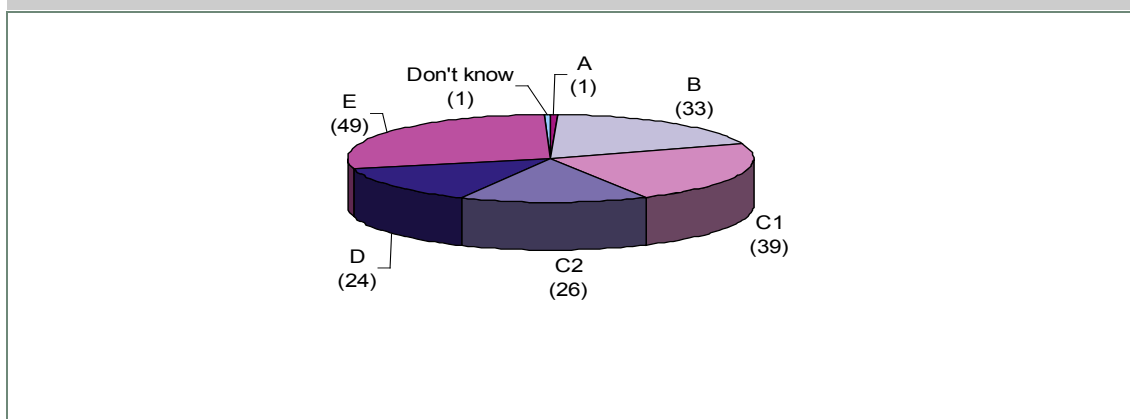
Where the enrolled child/young person lived in a dual parent household, the second parent tended to work full-time (see Table 8-3).

	Occupation of responding parent/guardian		Occupation of second parent guardian	
	N	%	N	%
At home/not seeking work	78	45%	10	6%
Working part-time (less than 30 hours a week)	42	24%	9	5%
Working full-time (30 hours a week or more)	27	16%	71	41%
Long-term sick/disabled	10	6%	7	4%
Other	7	4%	4	2%
Registered unemployed	5	3%	5	3%
Full-time student	2	1%	0	0%
Fully retired (including retired early)	1	1%	3	2%
Not registered unemployed, but seeking work	1	1%	1	1%
Don't know	0	0%	1	1%
Not applicable	0	0%	62	36%

Source: SQW Consulting Ipsos MORI, Baseline Parent/Carer Survey

8.15 Figure 8-2 illustrates the range of social grade distribution of participating families. This shows that 42% families were from the higher social classes (ABC1 - these grades include: upper middle class, middle class, lower middle class), and 57% were from the working class (grades C2DE - including: skilled working class, working class and those at the lowest levels of subsistence). The largest proportion of families were categorised in social grade E, implying that the chief income earners occupation was in casual or lowest grade employment, or dependant on the welfare state.

Figure 8-2: Social grade of families



Source: SQW Consulting Ipsos MORI, Baseline Parent/Carer Survey

### Characteristics of children/young people

- 8.16 While the majority (57%) of the children and young people engaged in the programme were of transition age (14-18), there were participants across the spectrum of ages (see Table 8-4). Of the 41 enrolled young people aged 16 or over, the vast majority (90%) were in school, college or training, while the remaining 10% stayed at home.

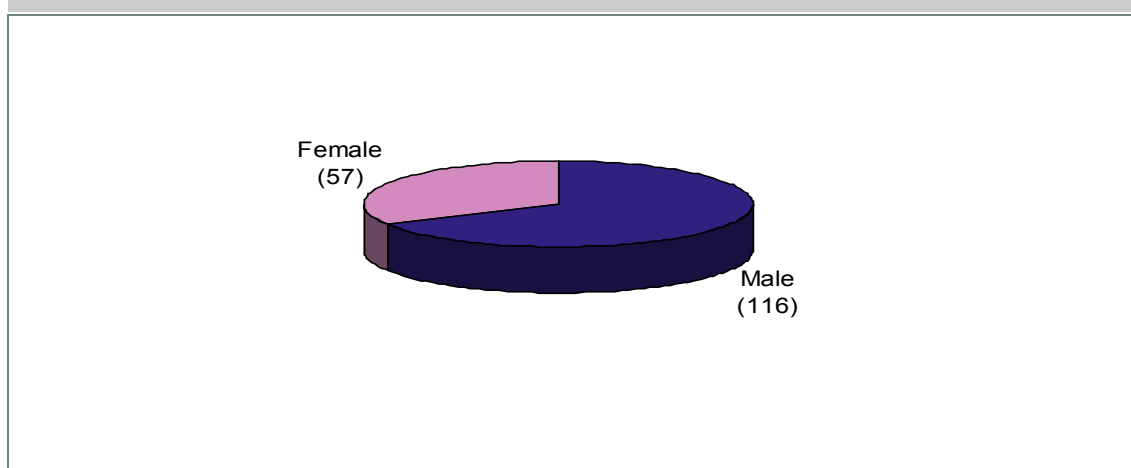
Table 8-4: Age group of children/young people

Age Group	Children of the adults interviewed in the Adult Survey		Children/young people still engaged in the IB pilot on 05/04/2010	
	N	%	N	%
0-5 years	12	7%	12	7%
6-11 years	40	23%	42	24%
12-13 years	20	12%	20	12%
14+ years	101	58%	99	57%
Total	173	100%	173	100%

Source: SQW Consulting & Ipsos MORI, data taken from Site Monitoring Returns and the Baseline Parent/Carer Survey

- 8.17 Approximately two thirds (67%) of the children/young people from the families surveyed were male (see Figure 8-3).

Figure 8-3: Gender of disabled children/young people



Source: SQW Consulting Ipsos MORI, Baseline Parent/Carer Survey

8.18 For the most part, the ethnic make-up of participating children/young people was in line with the population of the area, with small percentage point differentials between the proportion of participants and residents from a BME group (see Table 8-5). Two pilot sites engaged a higher proportion of BME participants than in their local populations as a whole, both of which had focussed on recruiting hard to reach individuals onto the pilot.

Table 8-5: Proportion of children/young people from a black and minority (BME) ethnic group

Area	Proportion of participants from a BME group	Proportion of residents from a BME group	Difference between proportion from a BME ethnic group (percentage point)
1	0%	3%	-3
2	20%	5%	15
3	9%	11%	-2
4	30%	20%	10
5	3%	4%	-1
6	0%	6%	-6
Total	10%	7%	3

Each pilot site is represented by a label 1-6. The proportion of residents from a BME group was calculated using ONS mid-2007 resident population estimates by ethnic group.

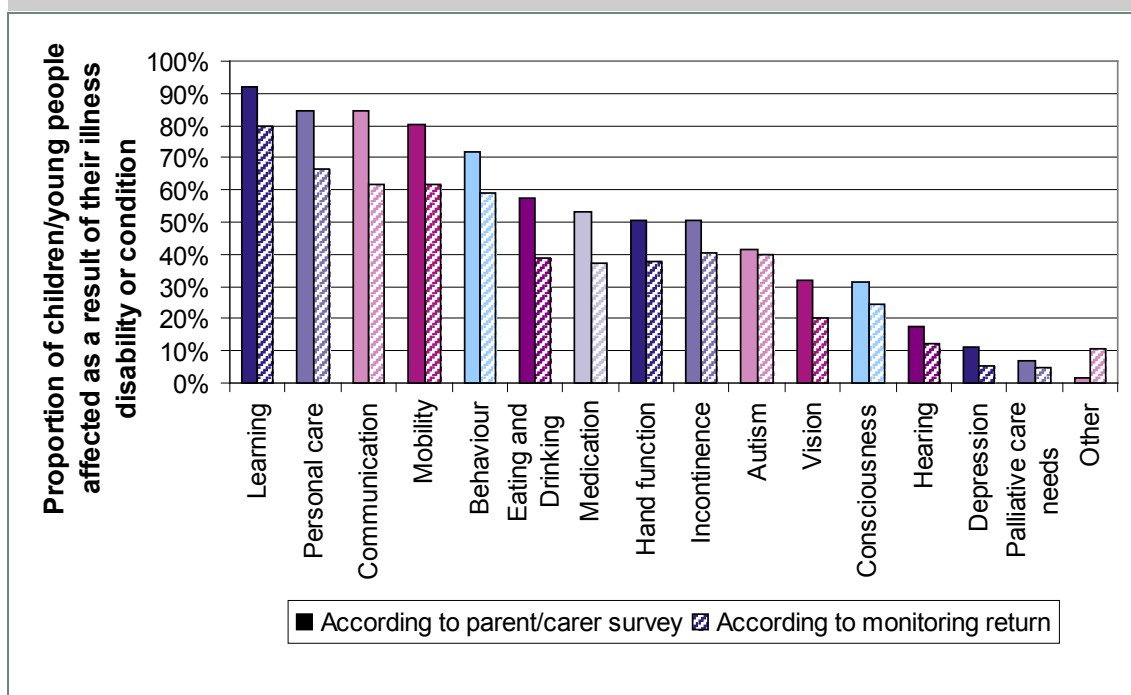
Source: ONS 2007 Mid-Year population estimates, SQW Consulting, Site Monitoring Returns

### **Nature of disability**

8.19 The majority (68%) of children and young people actively engaged in the pilot were felt by professionals to have severe, profound or complex needs. The data also

showed that the IB participants tended to report that their illness/disability/condition affected multiple areas of their lives. Figure 8-5 illustrates the data collected from both the parent survey and the monitoring return, which shows that family members/carers perceived the children/young people to be affected across more areas as a result of their disability than were stated in the monitoring returns. It also shows that the child/young person's condition was most commonly demonstrated through learning difficulties (92% of children/young people were felt by their parent/carer to be affected in this area), challenges in managing personal care (84%) and communication difficulties (84%). A small minority of the children/young people (7%) were reported to have palliative care needs.

Figure 8-4: Areas in which the children/young person is affected as a result of their illness, disability or condition



Please note that the proportion of children/young people affected by Autism include children/young people diagnosed with Autism, Aspergers Syndrome or an Autistic Spectrum Disorder (ASD)

Source: SQW Consulting & Ipsos MORI, data taken from Site Monitoring Returns and the Baseline Parent/Carer Survey

### Previous use of services

8.20 The majority of children/young people engaged in the pilot had accessed social care (75%), health (69%) and education provision (92%) prior to enrolling on the programme. However a notable minority had not accessed social care (24% - the majority of these families were engaged by the pilot site that sought to target

newcomers to the social care system), and 20% had not previously accessed health provision in relation to their condition.

Table 8-6: Previous use of services

	Yes		No		Unknown	
	N	%	N	%	N	%
Social care	130	75%	41	24%	2	1%
Health provision	119	69%	35	20%	19	11%
Education provision	160	92%	10	6%	3	2%

Source: SQW Consulting, Site Monitoring Returns

- 8.21 A large minority (40%) of respondent families had experienced personalisation approaches prior to enrolling in the programme. This most commonly included Direct Payments (36% of responding families), but also included the Early Support Programme (5% had received this form support), and Budget Holding Lead Professional support (3%). The proportion of families that had received Direct Payments prior to IB was higher for individuals with more severe disabilities.

#### Summary

- 8.22 Although the sites reported initial concerns about the engagement deadline at the outset of the programme, all sites successfully engaged a cohort of families to take part in the pilot. However, just three sites achieved their engagement within the original deadline. As such, flexibilities were introduced by the evaluation team to accommodate delayed engagement in the remaining sites. The slightly extended time period offered (2 months) led to all but one site either achieving or exceeding their engagement target (the one site that encountered a shortfall experienced particular challenges from one of the two teams that were to support engagement activities and was therefore granted an element of leeway), which reflects the significant efforts made by the pilot sites and indicates an apparent level of demand from families to take up the IB offer if the approach is made to them in an appropriate way as described above.
- 8.23 Both the survey and monitoring data illustrated a good range of diversity between participating families in relation to: ethnicity; socio economic groups; nature of the child/young person's disability; and previous use of personalised approaches. This diversity is particularly encouraging, as it provides evidence to support the argument that personalised approaches may appeal to a range of families if approached and delivered in an appropriate manner.



## 9: Baseline survey of families

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### Introduction

- 9.1 The following chapter sets out further findings from the baseline parent/carer survey, which was conducted face-to-face in respondents' homes by Ipsos MORI between November 2009 and March 2010. Of the 185 families enrolled on the pilot that were eligible to take part in the survey, interviews were conducted with 173 parents/carers, representing a 94% response rate. This high level of response rate enables the results to be interpreted as a census of the participating population and as such, gives considerable reassurance about the robustness of the findings.
- 9.2 Where appropriate, and with the permission of the parent and child/young person, the disabled child/young person was also interviewed in the home, the results of which are reported in chapter ten. This chapter seeks to set out a family perspective gained from the parent/carer respondents on life prior to IB, progress within the pilot, and changes since enrolling. It is principally a baseline against which to measure change, although at the end of this chapter we do provide some feedback from the small number of families who had experienced support planning. Chapter ten compares some of these responses to those expressed by the children/young people that participated in the survey.
- 9.3 The survey findings have been cross-tabulated by a number of characteristics, to understand whether the results illustrated significant differences between families of differing natures. This analysis included cross-tabulations based on differences in past experience of personalisation, the social grade of families, the child/young person's age and the severity of their disability. Significant findings (at the 5% significance level), along with additional principal findings are reported in the chapter.

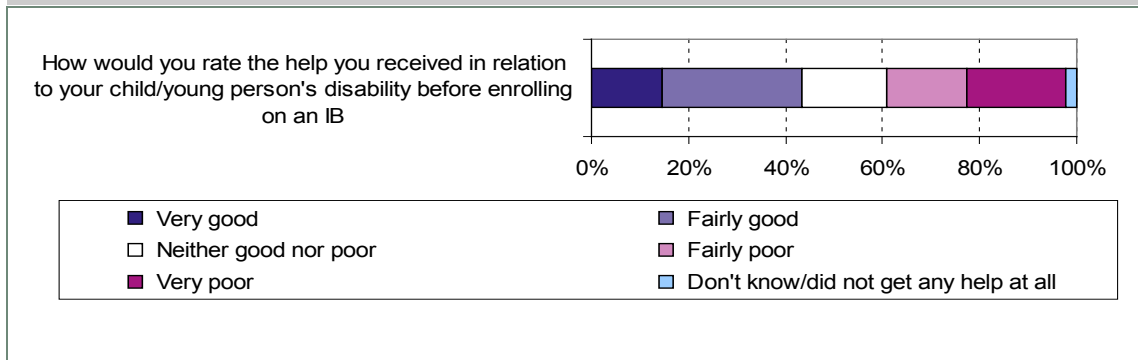
### Family baseline

#### ***Satisfaction with previous services***

- 9.4 Similar numbers of families reported that they were or were not satisfied with the support that they received in relation to their child's disability. Forty three per cent of families felt that the help that they had received in the past was good or very good, while 37% felt that the past help had been poor or very poor. This division is

interesting, as it suggests that the concept of an IB has appealed to families even when they were satisfied with their previous support.

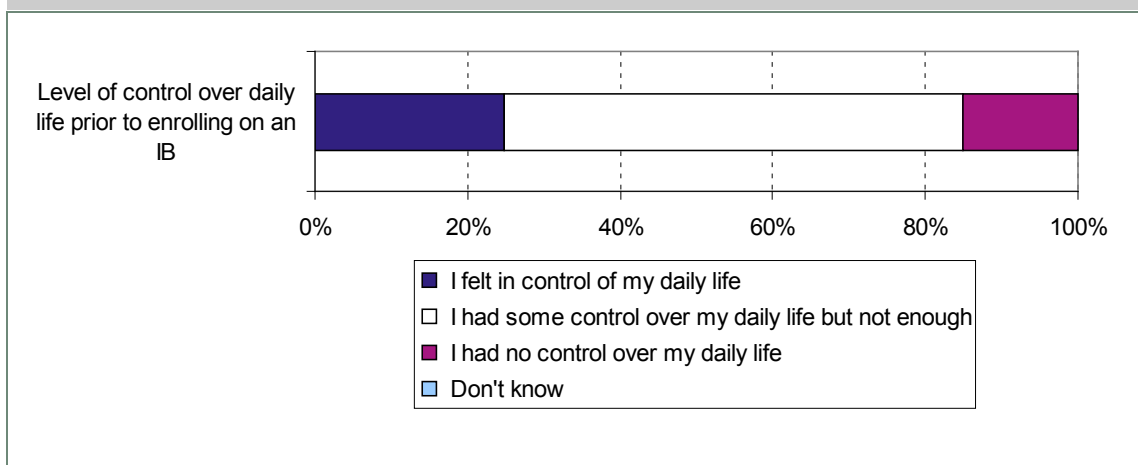
Figure 9-1: Help received prior to enrolling on an Individual Budget



Source: SQW Consulting & Ipsos MORI, Baseline Parent/Carer Survey

9.5 The vast majority (75%) of parents felt that they lacked control over their daily life prior to enrolling on an IB; either having no control (in 15% of cases), or more frequently (60% of families) having some, but not enough control (see Figure 9-2). Parents in dual parent households felt significantly more in control of their life.

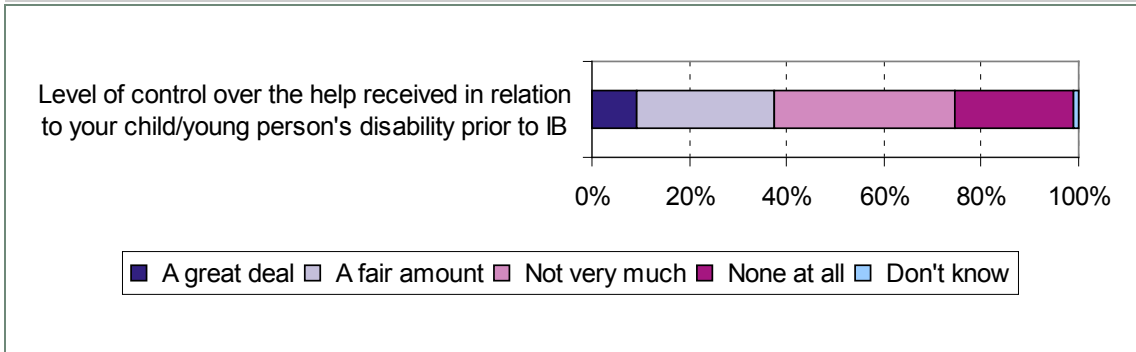
Figure 9-2: Control over daily life prior to enrolling on an Individual Budget



Source: SQW Consulting & Ipsos MORI, Baseline Parent/Carer Survey

9.6 The majority of families (61%) felt that they lacked very much (if any) control over the help they received in relation to their child/young person's disability prior to IB (see Figure 9-3). This finding was more pronounced in single parent families.

Figure 9-3: Control over help received in relation to their child/young person's disability prior to IB



Source: SQW Consulting & Ipsos MORI, Baseline Parent/Carer Survey

9.7 Great variation was reported on the average amount of time per week needed to access, coordinate and oversee the services of the disabled children/young people, which ranged from one hour to in excess of 51 hours per week. This implied that the mean length of time was just over 11 hours per week.

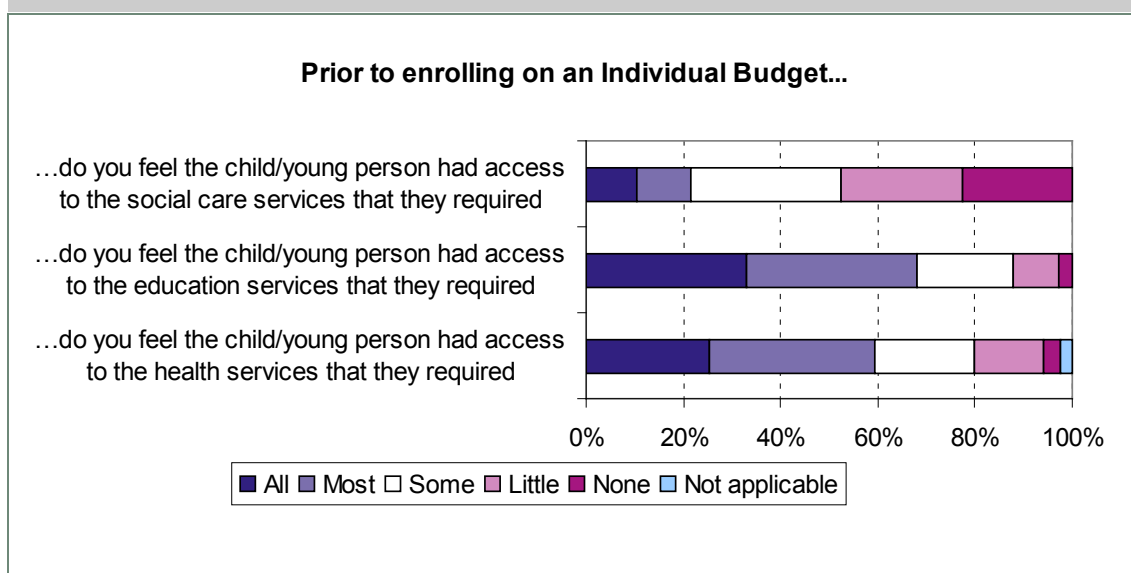
Table 9-1: Average number of hours spent accessing, coordinating and overseeing services for your disabled child/young person in a typical week

Average number of hours	N	%
1	31	18%
2	23	13%
3	5	3%
4	10	6%
5-6	12	7%
7-10	28	16%
11-15	10	6%
16-20	2	1%
21-30	12	7%
31-40	4	2%
41-50	3	2%
51+	5	3%
Don't know	28	16%

Source: SQW Consulting & Ipsos MORI, Baseline Parent/Carer Survey

9.8 The majority of families felt they had access to most or all of the education and health services that they required prior to their enrolment on an IB (as illustrated in Figure 9-4). However, families felt they lacked access to social care services. Only 21% of families felt they had access to most or all of the social care services that they required prior to enrolling on the pilot. This lower level of parental satisfaction with social care services is in line with the 2008-9 National Indicator 54 findings. The National Indicator data on parental experiences of services provided to disabled children shows there to be lower levels of satisfaction with social care than health and education in terms of four of the five Core Offer standards for services - information, assessment, transparency and feedback.

Figure 9-4: Provision prior to enrolling on an Individual Budget

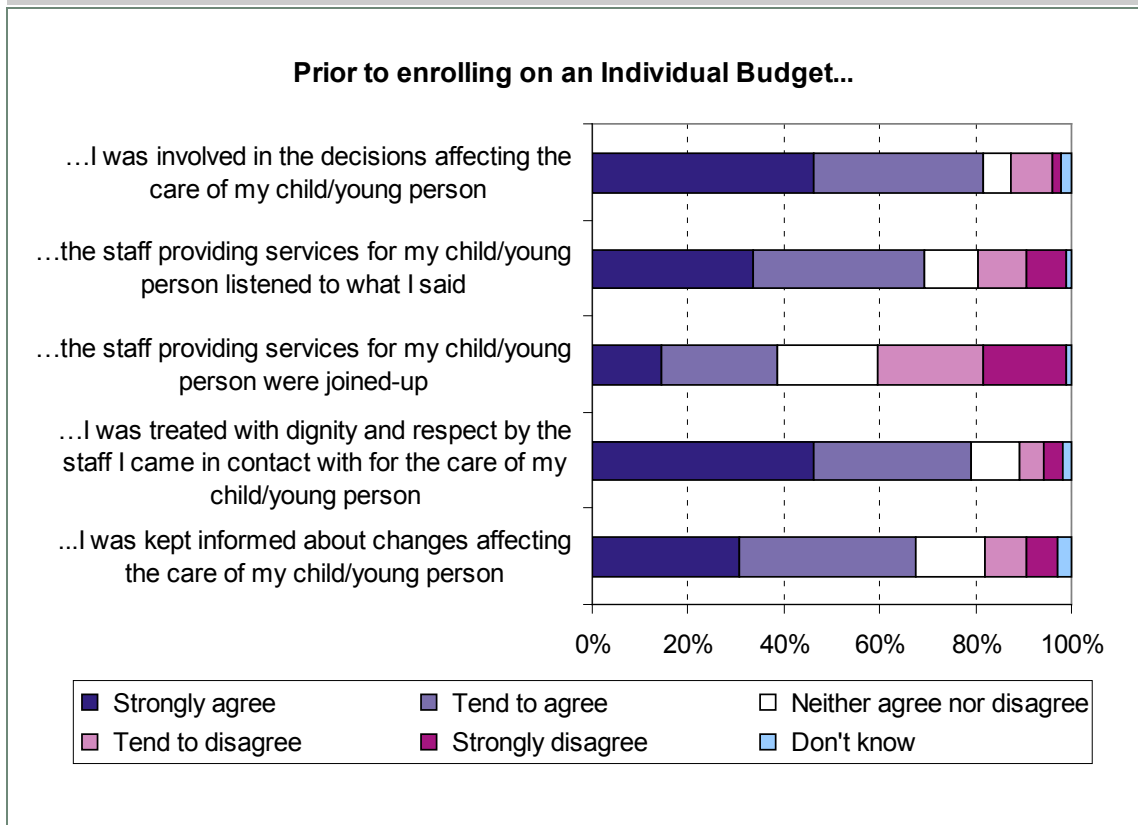


Source: SQW Consulting & Ipsos MORI, Baseline Parent/Carer Survey

9.9 Prior to enrolling on an IB, 82% of families either strongly agreed or agreed they were involved in the decisions affecting the care of their child/young person and 79% stated that they either strongly agreed or agreed that they were treated with dignity and respect by the staff they came in contact with for the care of their child/young person. However, families were less positive when asked about the level of joined-up working between the staff providing services for their child/young person, where just 39% either strongly agreed or agreed that this occurred (see Figure 9-5).

9.10 These results taken together with the findings reported above suggest that parents/carers were generally involved in decisions, but did not feel in control. It will be important to monitor if this changes following the provision of an IB, and if so in what circumstances.

Figure 9-5: Experience of provision prior to enrolling on an Individual Budget

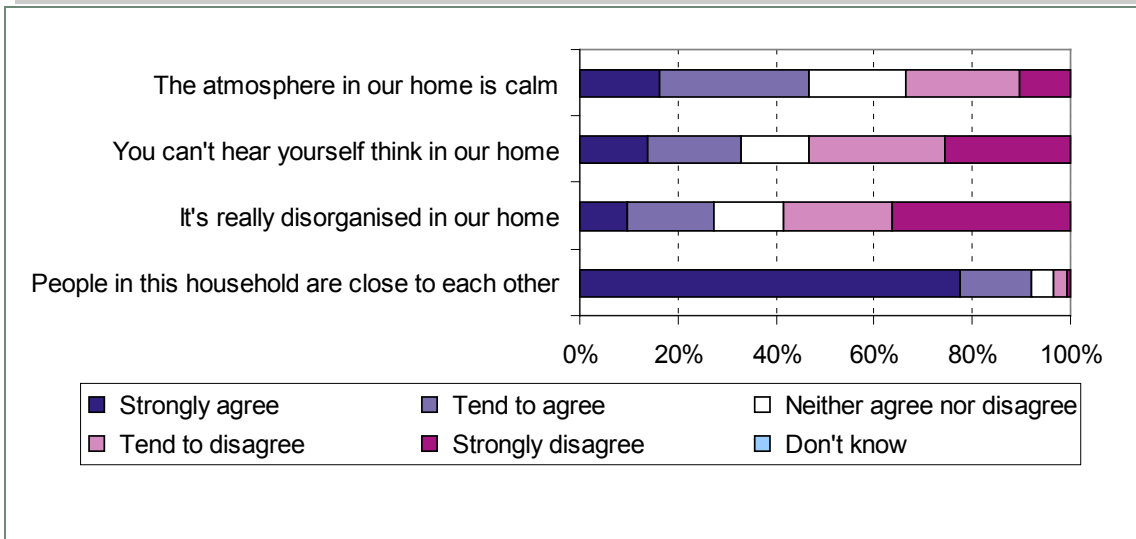


Source: SQW Consulting & Ipsos MORI, Baseline Parent/Carer Survey

**Household circumstances**

9.11 The majority of parents reported that their households were positive environments, and that relationships within the households were strong (see Figure 9-6). For example, seventy seven per cent of parents strongly agreed that people in their household were close to each other, and a further 14% tended to agree this was the case. In terms of the household environment, the majority of parents (58%) did not feel that their household was disorganised and a similar proportion (53%) reported that they either strongly disagreed or disagreed with the statement, ‘you can’t hear yourself think in our home’.

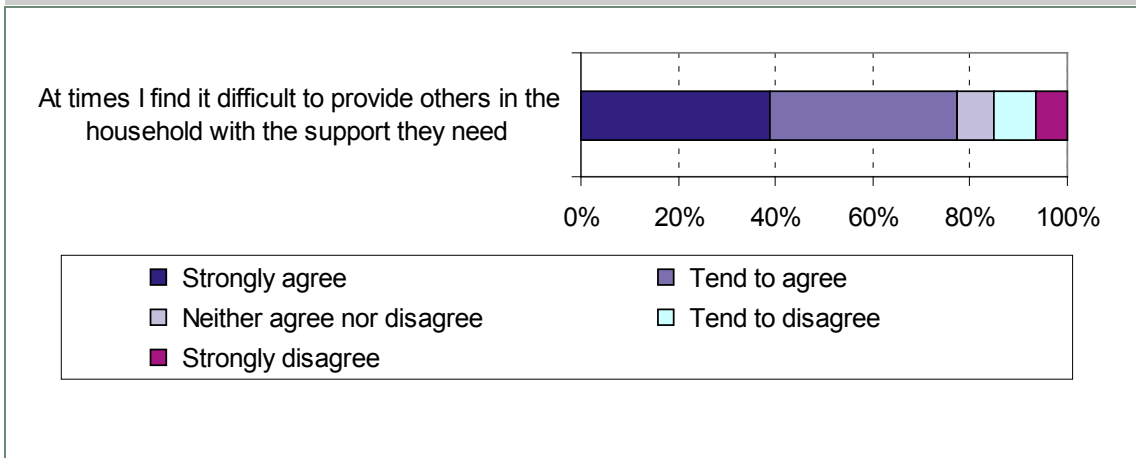
Figure 9-6: Judgements on the household within which the disabled child/young person is living



Source: SQW Consulting & Ipsos MORI, Baseline Parent/Carer Survey

9.12 The majority of parents/carers (77%) also reported that at times they found it difficult to provide others in the household with the support they need.

Figure 9-7: Strength of the family unit

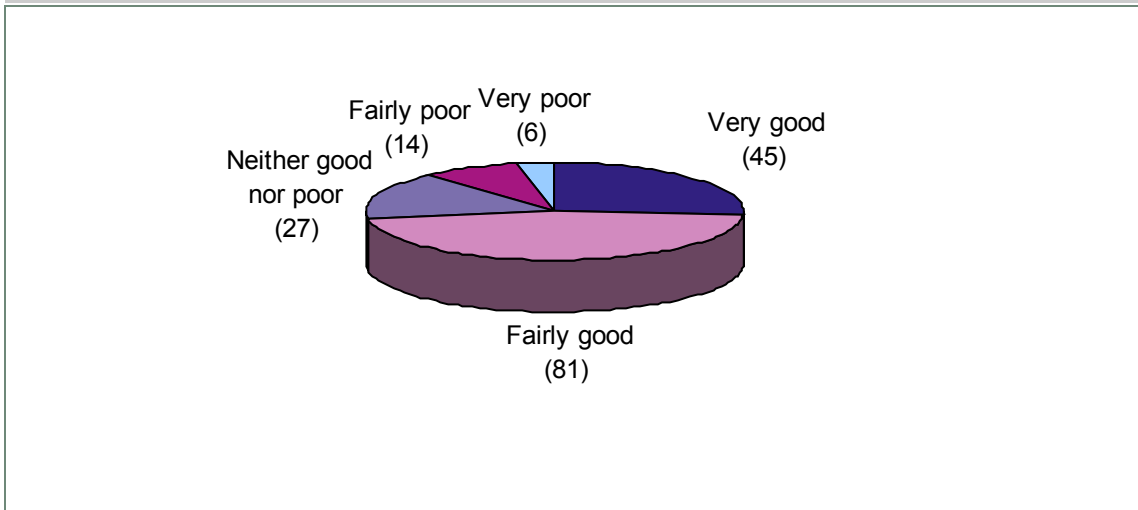


Source: SQW Consulting & Ipsos MORI, Baseline Parent/Carer Survey

**Parent/carers views of their child/young person**

9.13 The majority (73%) of children/young people enrolled on the pilot were felt by their parents/carers to be in good health, where 26% were felt to be in very good health (see Figure 9-8).

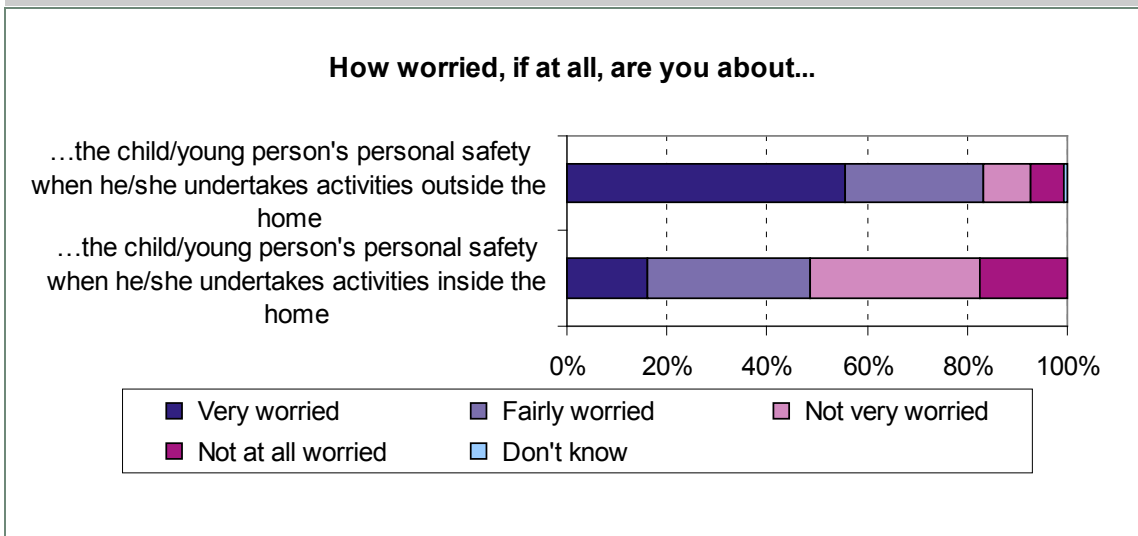
Figure 9-8: Health of the children/young people



Source: SQW Consulting & Ipsos MORI, Baseline Parent/Carer Survey

9.14 The vast majority (83%) of parents stated they were at least fairly worried about the child/young person's personal safety when they undertook activities outside the home. In addition, approximately half (49%) of parents reported concerns around the personal safety of the child/young person when they undertook activities inside the home.

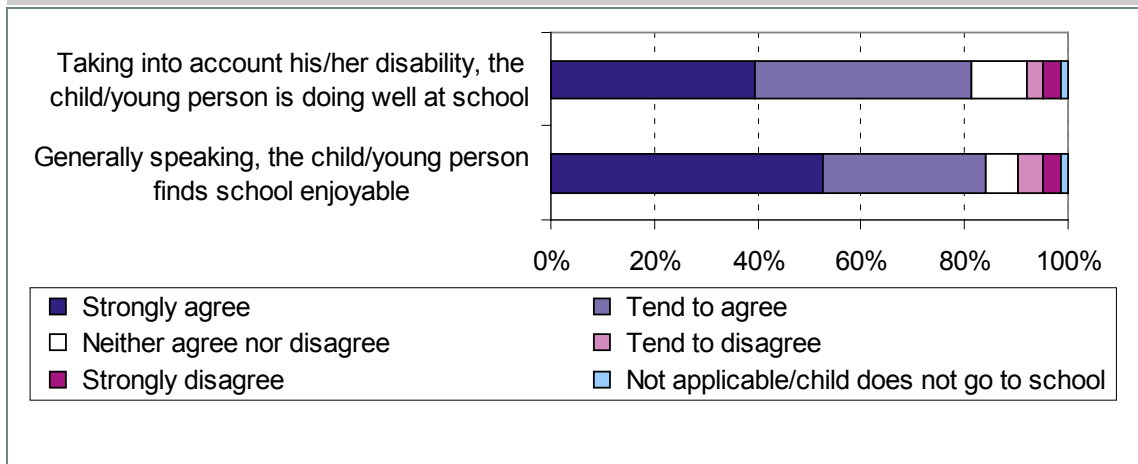
Figure 9-9: Concerns about the personal safety of the child/young person



Source: SQW Consulting & Ipsos MORI, Baseline Parent/Carer Survey

9.15 Over 80% of parents agreed that their disabled child/young person found school enjoyable and that, taking account of their disability, the children was doing well at school (see Figure 9-10). However, parents of older children (14+) were significantly less likely to report that their child enjoyed school.

Figure 9-10: Experience at school



Number of respondents: 169

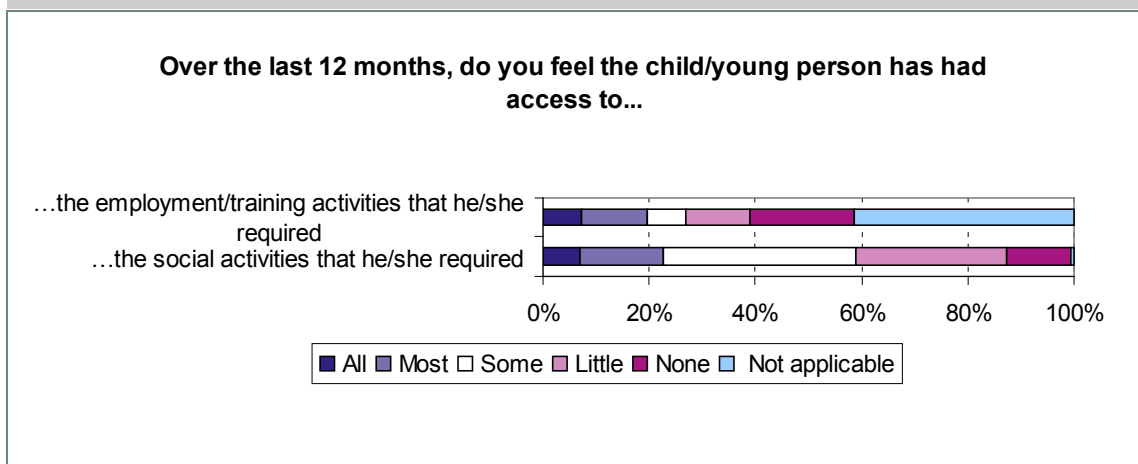
Source: SQW Consulting & Ipsos MORI, BaselineParent/Carer Survey

9.16 When asked to consider the extent to which the disabled child/young person had access to particular activities, parents reported the following:

- Over half (59%) stated they felt their child had access to some, most or all of the social activities that he/she required
- Just over a quarter (26%) stated they felt their child had access to some, most or all of the employment/training activities they required, which when adjusted to take out those parents that stated the question was not applicable amounted to 46% of the relevant sub-set of parents.

Figure 9-11 provides an illustration of the above figures.

Figure 9-11: Access to activities



...the employment/training activities that he/she required – Number of respondents:41

...the social activities that he/she required – Number of respondents: 173

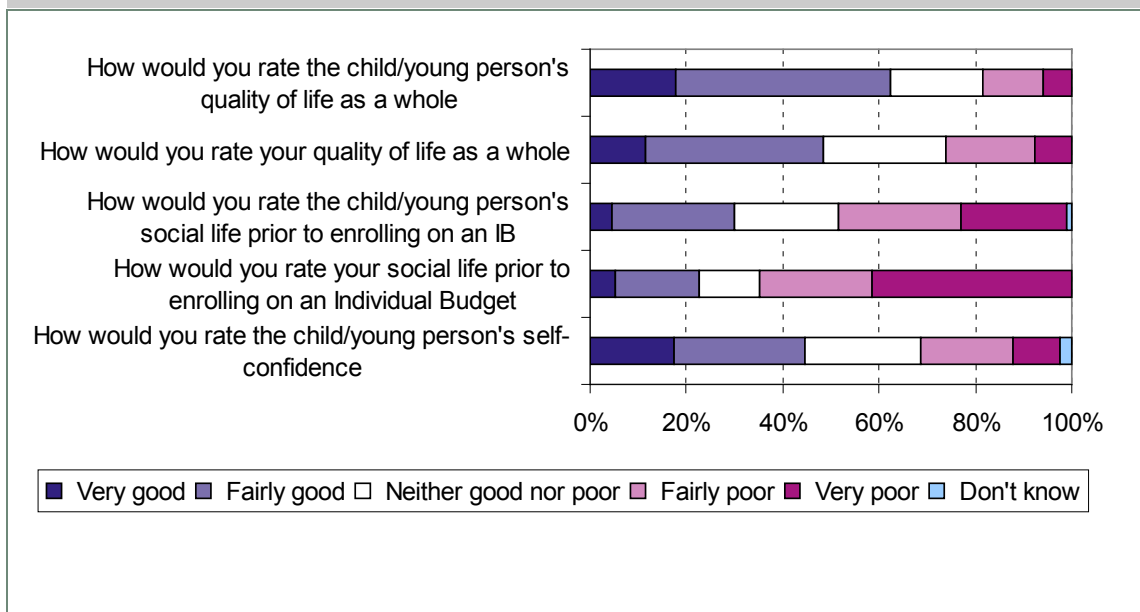
Source: SQW Consulting & Ipsos MORI, Baseline Parent/Carer Survey



9.17 Prior to enrolling on an IB, the majority (62%) of children/young people on the pilot were felt to have at least a fairly good quality of life (see Figure 9-12). Looking across the population as a whole, parents tended to perceive their own quality of life to be lower than that of their child (62% of children were felt to have at least a fairly good quality of life, compared to 49% of parents). Similar parental perceptions were reported when asked how they felt about their child's and their own social life, where 30% reported that their child had either a fairly good or very good social life, compared to 23% of parents.

9.18 Parents expressed a range of views when they were asked to rate the self-confidence of their child (see Figure 9-12). Further analysis also showed that children with Autism, Aspergers Syndrome or ASD were perceived to have less self-confidence than the average across the cohort.

Figure 9-12: Quality of life of the disabled children/young people and parents prior to enrolling on an IB



Source: SQW Consulting & Ipsos MORI, Baseline Parent/Carer Survey

### Family expectations of the benefits of IB

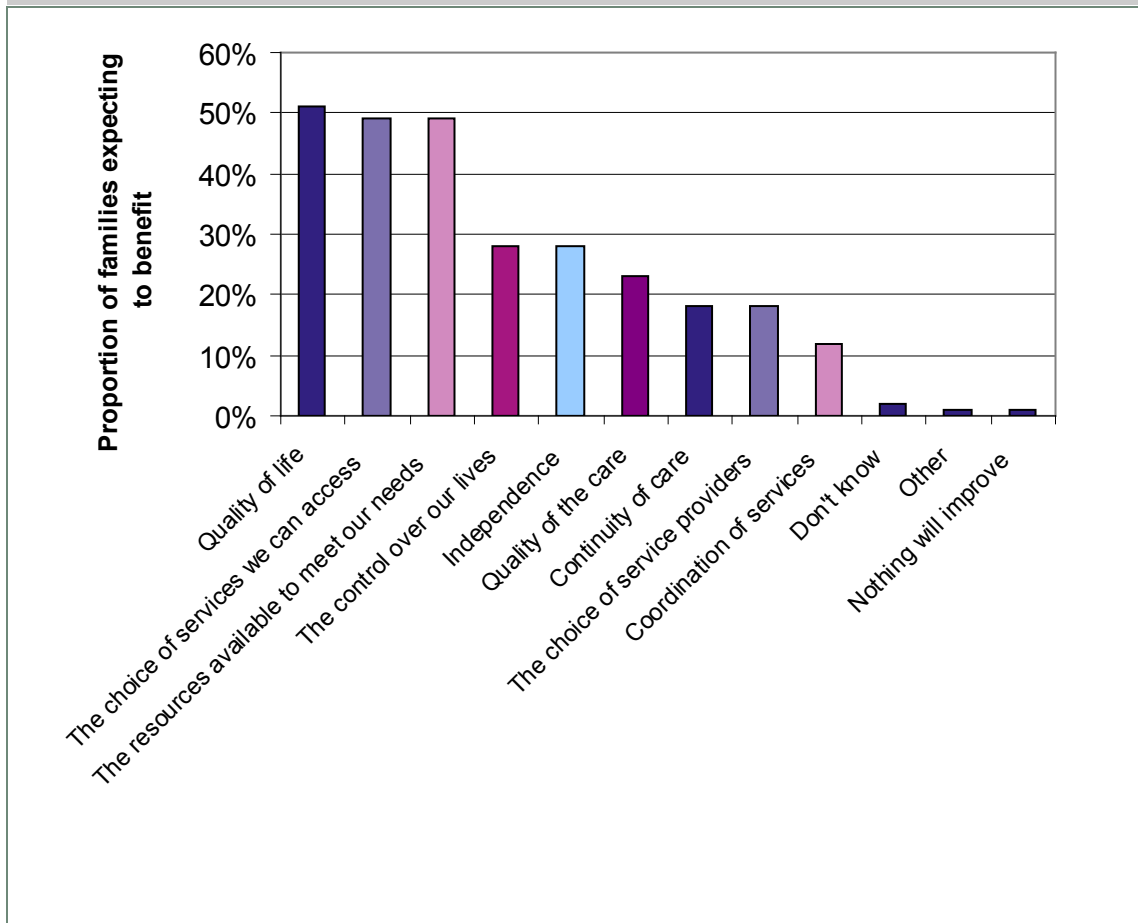
9.19 Each family was asked to identify up to three benefits they expected to achieve as a result of taking up the IB offer from a list of pre-specified benefits. This showed that that families expected the main improvements to occur in relation to:

- their quality of life (88 or 59% of families expected to see improvement in this area)
- the choice of services they were able to access (85 or 49% of families)

- the resources available to meet the need of the family (84 or 49% of families).

9.20 Looking comparatively at the results of both the family and professional surveys, the analysis showed considerable differences between the perceptions of the two groups in relation to the expected benefits of the IB offer. This is discussed at greater length in the professional survey analysis in chapter 11.

Figure 9-13: Areas expected to improve as a result of the Individual Budget



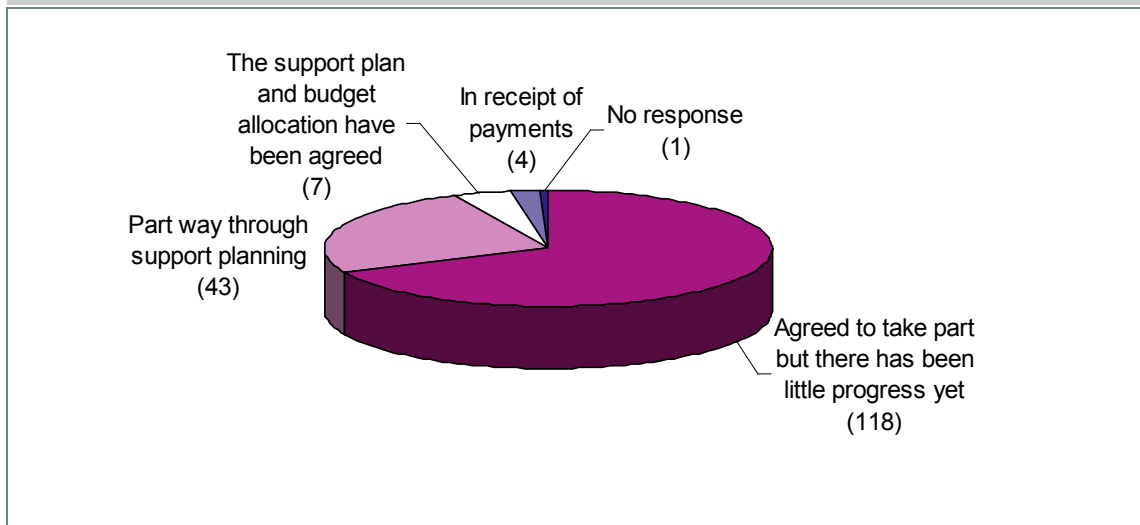
Number of respondents: 172

Source: SQW Consulting & Ipsos MORI, Baseline Parent/Carer Survey

### Early experiences

9.21 At the point at which the parent/carer survey was conducted, the majority of families (118) had agreed to take part, but were yet to begin support planning. Of the remainder, four were in receipt of payments, a further seven had had their support plan and budget allocation agreed, and 43 were part way through support planning.

Figure 9-14: Progress with regard to IB at the time the survey was conducted



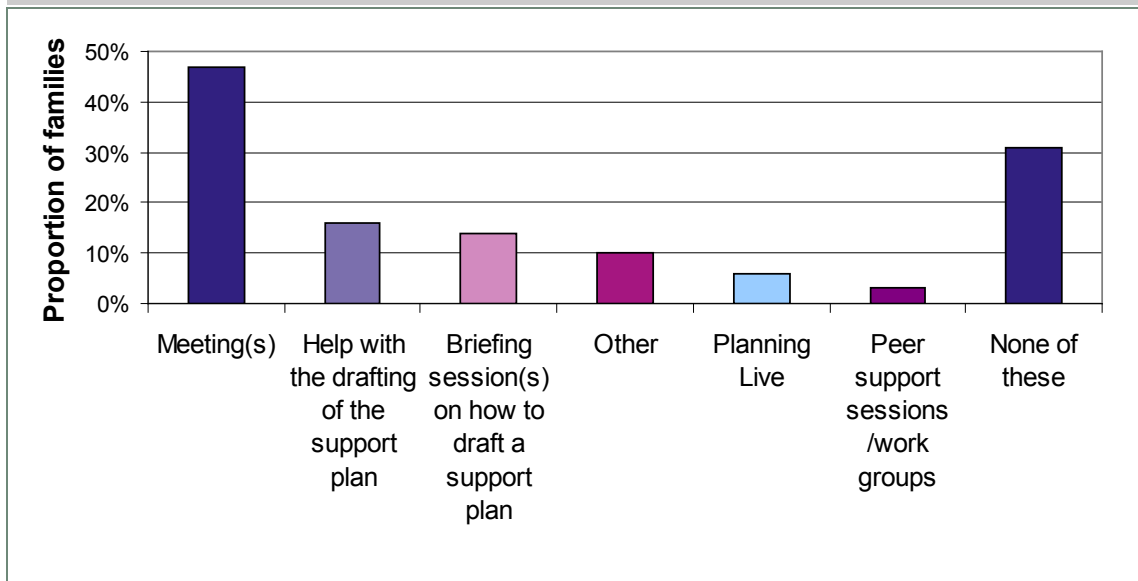
Source: SQW Consulting & Ipsos MORI, Baseline Parent/Carer Survey

9.22 When asked, which of a pre-specified list of activities the families had been involved in to set up their IB, the most common form of assistance was meetings with relevant Council/pilot staff (held with 47% of responding families). Other common activities included:

- help drafting the support plan (utilised by 16% of families)
- briefing sessions on how to draft a support plan (14%)
- other support (10%) including help filling in the initial questionnaire.

9.23 However, just over 30% of families had not accessed any of the forms of assistance illustrated in Figure 9-15, which was likely to be the result of the timing at which the survey was undertaken. In addition, there was large variation in the extent to which activities had been undertaken across the sites, which again is likely to be caused by the differing stage and pace of development of each of the sites.

Figure 9-15: Activities families involved in to assist with set up of IB



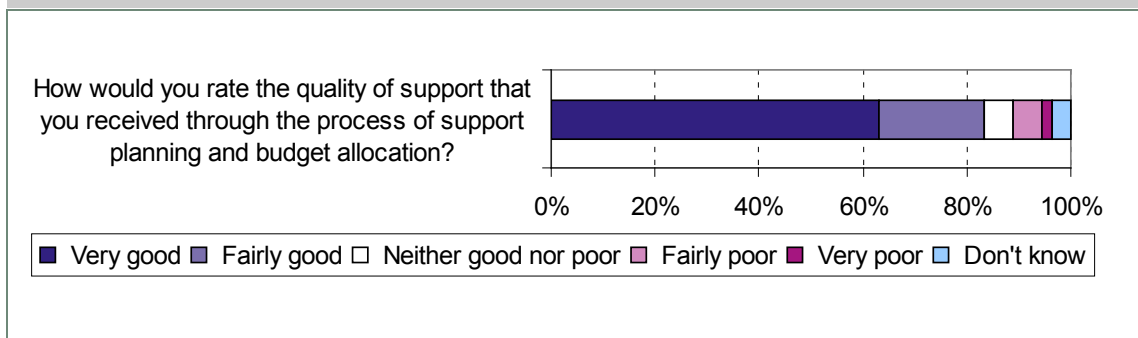
Number of respondents: 172

Source: SQW Consulting & Ipsos MORI, Baseline Parent/Carer Survey

### Setting up the support plan

9.24 Early experiences from families who had at begun the support planning process at the time of the survey have been positive. Of the 54 families who were in this position, the majority felt that the quality of support received through the process of support planning and budget allocation had been ‘fairly good’ (20%) or ‘very good’ (63%) (see Figure 9-16).

Figure 9-16: Perceived quality of support through the process of support planning and budget allocation

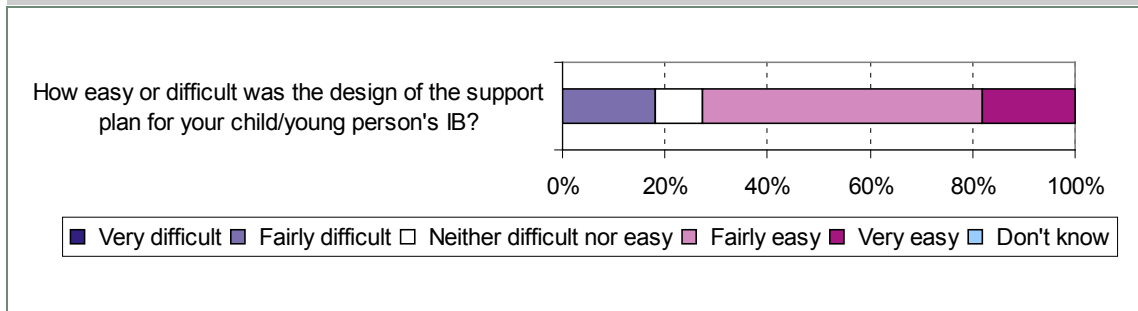


Number of respondents: 54

Source: SQW Consulting & Ipsos MORI, Baseline Parent/Carer Survey

9.25 Focusing now on the small number of families that had had their support plan and budget allocation agreed, the analysis highlighted that experiences had varied considerably by family. The majority (eight) of the eleven families who had progressed to this stage reported finding the design of the support plan easy, including two families who found the design of the support plan 'very easy' for their child/young person's IB.

Figure 9-17: Ease of support planning

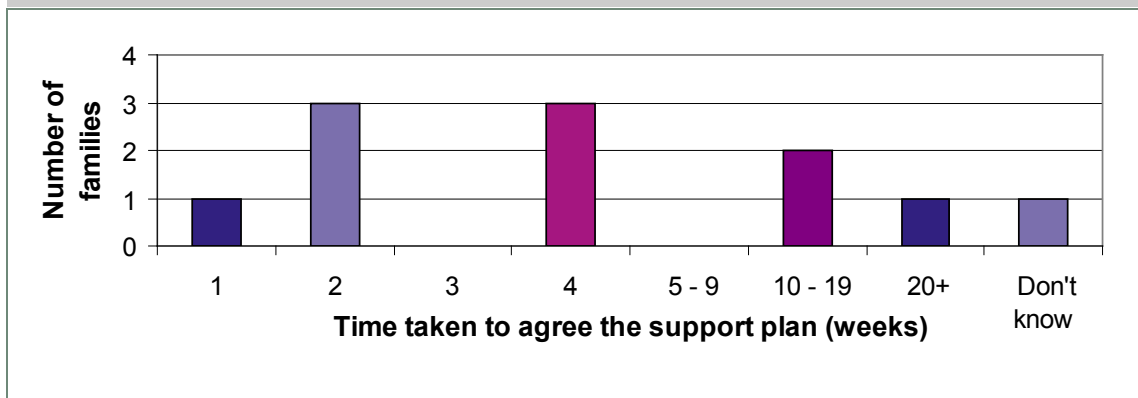


Number of respondents: 11

Source: SQW Consulting & Ipsos MORI, Baseline Parent/Carer Survey

9.26 For most of this small group of families, the support planning process took between one and four weeks, although for a small minority it took longer (see Figure 9-18). Similarly, the support planning process took different amounts of time to complete for different families (see Figure 9-19), where the results showed that on average, support planning took just under seven hours to complete.

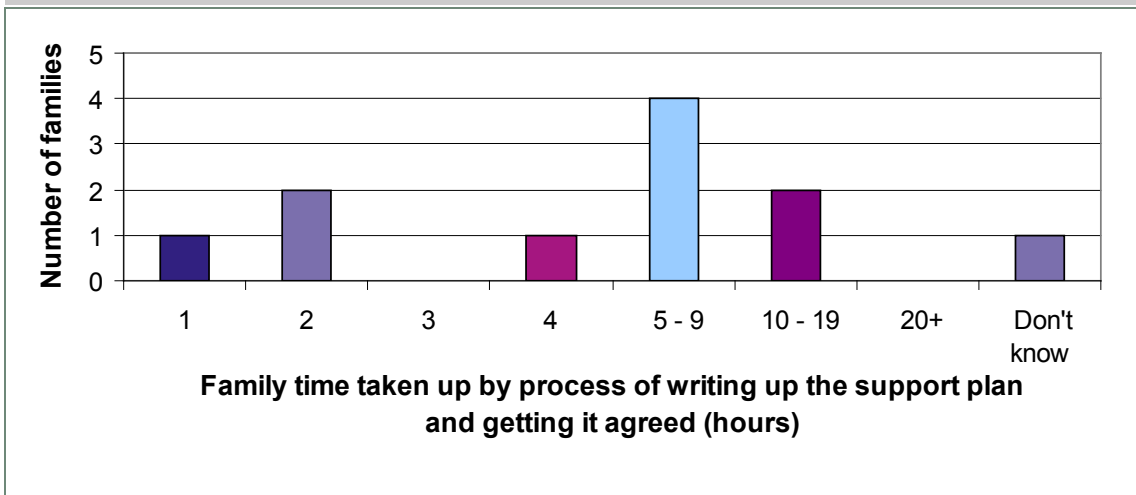
Figure 9-18: Length of the support planning process



Number of respondents: 11

Source: SQW Consulting & Ipsos MORI, Baseline Parent/Carer Survey

Figure 9-19: Family time taken up by the process of support planning



Number of respondents: 11

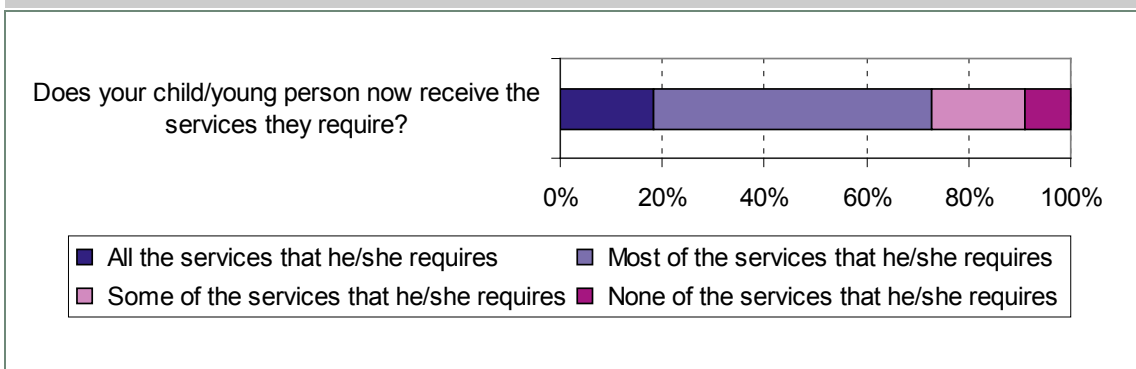
Source: SQW Consulting & Ipsos MORI, Baseline Parent/Carer Survey

9.27 Families were asked to compare the expected and actual length of time it took to complete the support planning process, which highlighted mixed results. That is, five of the families were unsure how long they had expected the support planning process to take, four felt the process had taken about as long as expected and of the two remaining families, one felt that it had taken longer than expected and the other felt the process had taken less time than expected.

### Changes in services

9.28 Focusing again on the 11 families who had their support plan and budget allocation agreed at the point at which the parent/carer survey was undertaken, it was apparent that families disagreed over the extent to which the services allocated via IB met their requirements. Most families (eight) felt that at least most of the services that the children/young people required were now provided.

Figure 9-20: Extent to which provision meets the needs of the children/young people



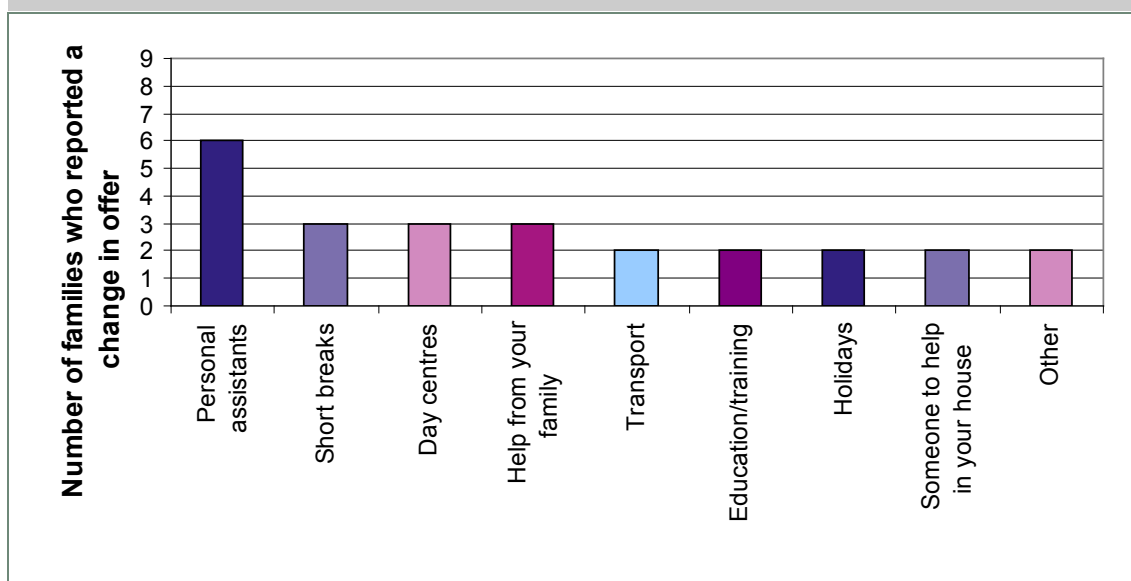
Number of respondents: 11

Source: SQW Consulting & Ipsos MORI, Baseline Parent/Carer Survey

9.29 Families were asked to what extent the services that were to be accessed as a result of the IB differed to the services the family had previously received. This showed that seven of the 11 families felt the services they had access to as a result of the Individual Budget differed ‘a great deal’ from previous service provision, and a further two families felt there had been ‘a fair amount’ of change. In addition, the seven families which experienced a great deal of change in the services they had access to felt that all or most of the services required by the child/young person were now being provided.

9.30 Of the families who noted a change in the provision offered (the ‘offer’) as a result of their IB, the changes were felt to have occurred across a number of services, as illustrated in Figure 9-21. This early indication suggests that increased access to personal assistants may be an important element of IB provision. Further analysis also showed that the families who reported that their short breaks offer had changed as a result of IB tended to feel that either the provision had increased, or that the way it was delivered had changed as a result of the pilot.

Figure 9-21: Changes in services families have access to as a result of the IB



Number of respondents: 9

Source: SQW Consulting & Ipsos MORI, Baseline Parent/Carer Survey

9.31 The responses of families who reported a change in access to services as a result of their IB are set out in Table 9-2. In a number of cases, families reported that provision had increased across the areas as a result of IB, and that there had been a change in the way services were delivered. Only one family reported a decrease in provision of services (via day centres).

Table 9-2: Extent to which provision has changed as a result of the IB, by change in service families have access to.

	<b>Total families reporting a change in offer</b>	<b>The provision has increased as a result of the Individual Budget</b>	<b>The provision has decreased as a result of the Individual Budget</b>	<b>The way it has been delivered has changed as a result of the Individual Budget</b>
Personal assistants	6	3	0	4
Short breaks	3	2	0	1
Day centres	3	1	1	2
Help from your family	3	0	0	3
Transport	2	1	0	1
Education/training	2	0	0	2
Holidays	2	1	0	2
Someone to help in your house	2	1	0	2

*Number of respondents: 9*

*Source: SQW Consulting & Ipsos MORI, Baseline Parent/Carer Survey*

9.32 The above figures provide a snapshot from the time the survey was conducted. As more families complete support planning and begin to receive their IB, we will gain a better understanding of how the offer and provision have changed as a result of IB. This will be reported at a later stage.

### Summary

9.33 The survey sought to identify family perspectives from parents/carers on their situation prior to receiving an IB, progress within the pilot and changes since enrolment. This showed that:

- the level of satisfaction with previous services was mixed, suggesting the IB offer had appealed to families even when they were satisfied with their previous support
- parents tended to report that their households were positive environments and that relationships within their household were very good, whereas general



consensus also showed that that at times they found it difficult to provide others in the household with the level of support they need.

- the majority of families were yet to begin support planning at the time the survey was undertaken. However, for those that had taken part on support planning, early experiences had been largely positive, showing that all but one family had experienced an increase or change in service provision as a result of their IB and suggested that increased access to personal assistants may be an important element of IB provision.

## 10: Baseline survey of young people

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### Introduction

- 10.1 This chapter sets out the findings from the baseline survey for young people, which sought to assess the views of young people (aged 11 and over) who enrolled on the pilot. The survey was conducted alongside the parent/carer survey, where parental consent was sought to approach the young person following completion of the parent/carer survey. Where parental consent was granted, the young person was then invited to participate.
- 10.2 In total, 57 interviews were conducted out of a possible 173 eligible young people, as explained in Chapter 2<sup>1</sup>. As such, the responses from the 57 young people provide an indication of young peoples' perceptions, but are unlikely to be representative of the cohort and instead be drawn from those with less complex needs. Where questions were not answered by all respondents, the number of respondents is given at the bottom of the figure.
- 10.3 This chapter provides a baseline picture of the position of responding young people near the start of the pilot and, where possible, assesses their experience and understanding of the support planning process. At points, comparisons are drawn with the results of the parent/carer survey.<sup>2</sup>

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<sup>1</sup> The main reasons for non-participation were that 45 young people (26% of the total population) were aged under 11 and so were not approached, while in 55 (32%) cases the young person had such a profound disability that their parents judged they were would able to complete the survey.

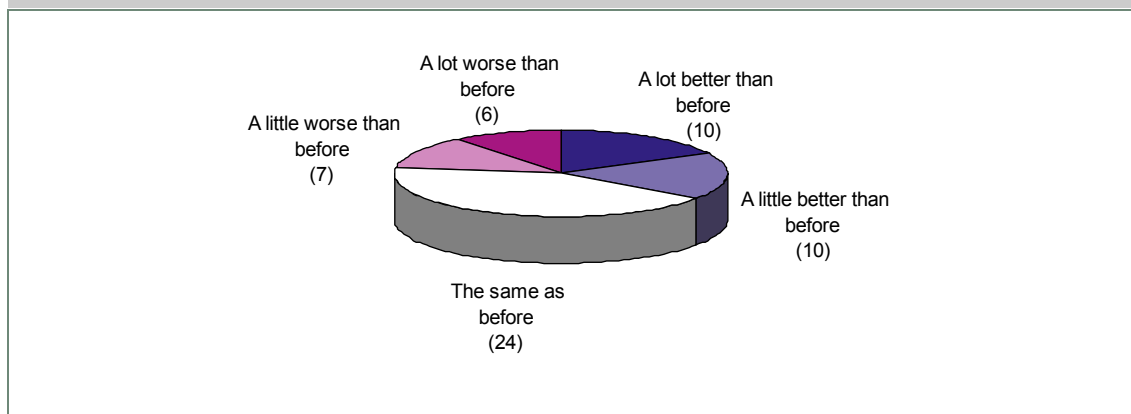
<sup>2</sup> The results from the young people are compared to the total parent sample to enable ready comparison with the previous chapter. It is possible that there are some biases in the group of families where young responded, however, the lack of statistically significant variation reported in chapter nine would suggest such biases to be minimal.

## Young person baseline

### **Young people views on their disability**

- 10.4 Forty two per cent of the young people consulted felt that their health had not changed in the last year, while 35% felt their health had improved, and 23% felt that their health had deteriorated somewhat (see Figure 10-1).

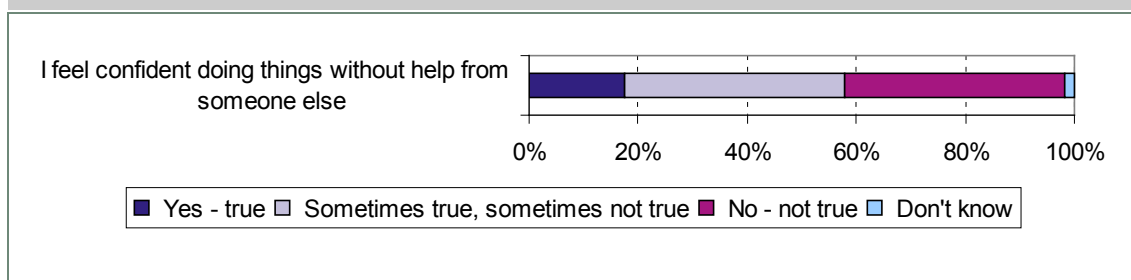
Figure 10-1: Health of the young people over the last 12 months



Source: SQW Consulting, Ipsos MORI, Baseline Survey of Disabled Young People

- 10.5 The disabled young people consulted had mixed levels of confidence (see Figure 10-2). While 18% of respondents felt confident doing things without help from someone else and 40% said that this was sometimes the case, a further 40% reported that they would not feel confident doing things without help from someone else.

Figure 10-2: Level of confidence

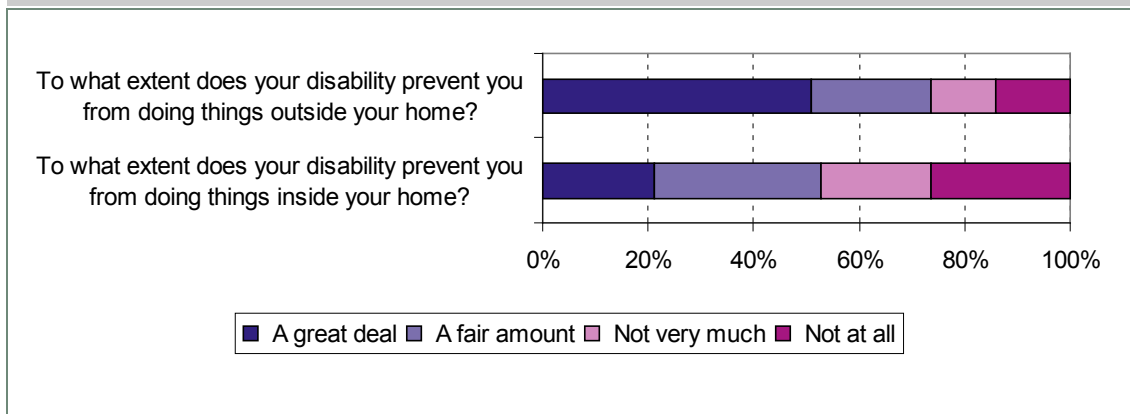


Source: SQW Consulting, Ipsos MORI, Baseline Survey of Disabled Young People

- 10.6 Almost three quarters of the young people consulted (74%) felt that their disability prevented them from doing things outside the house (including 51% who felt it prevented them from doing 'a great deal', and 23% who felt it prevented them from doing things 'a fair amount') (see Figure 10-3). This aligns with the proportion of parents who stated that they were concerned about their child/young person's personal safety when he/she undertakes activities outside the home – 28% said they get 'fairly worried' and a further 55% said they get 'very worried'. In contrast, young

people appear to feel less restricted by their disability when doing things inside the house. In line with this, parents reported feeling less concerned about the personal safety of the child/young person when they undertake activities inside the house.

Figure 10-3: Extent the disabilities of the cohort of young people prevents them from doing things inside and outside the house

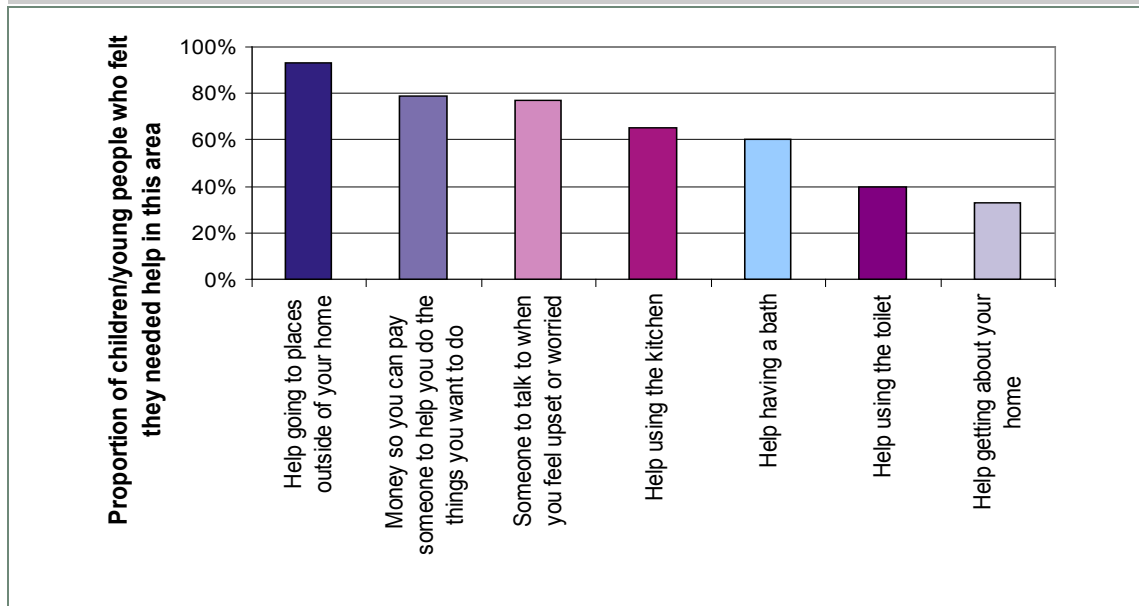


Source: SQW Consulting, Ipsos MORI, Baseline Survey of Disabled Young People

10.7 The young people were asked to consider their day to day lives and the help they required to keep clean, safe and well. This showed that the most frequently cited needs related to:

- help going to places outside of their home (93% of young people reported the need)
- money to pay someone to help them do the things they want to do (79% of young people)
- someone to talk to when you feel upset or worried (77% of young people, see Figure 10-4).

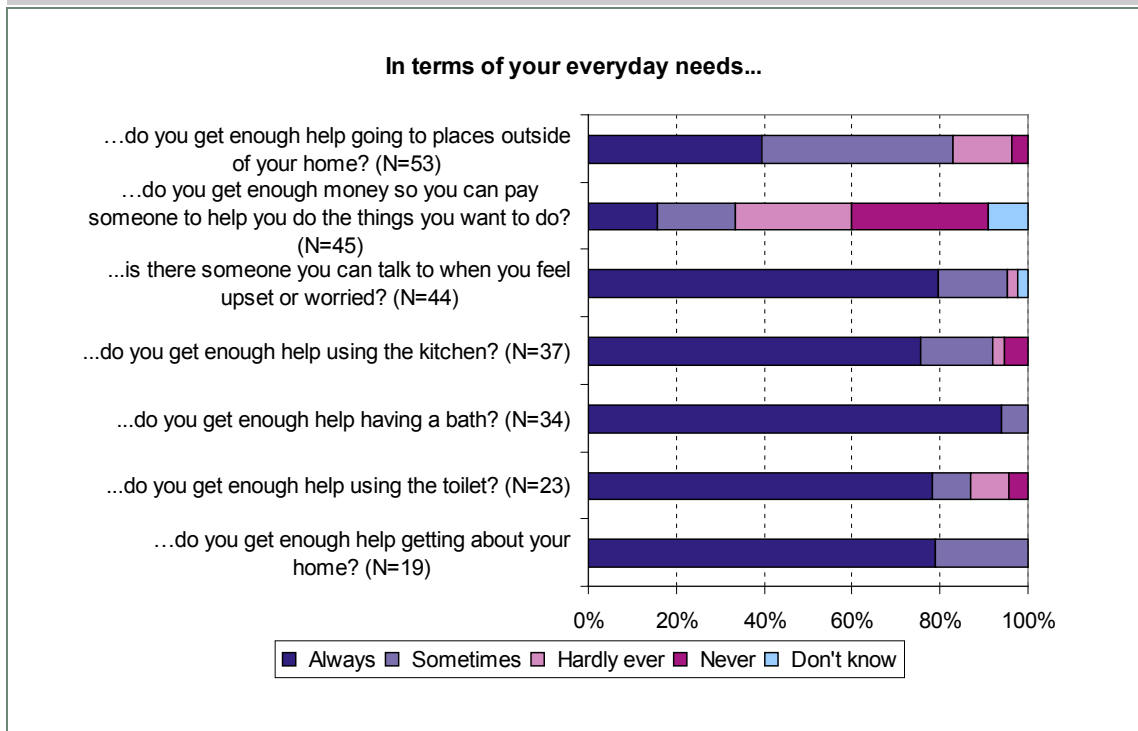
Figure 10-4: Areas in which young people need assistance in day-to-day life (either through another person or through adaptation)



Source: SQW Consulting, Ipsos MORI, Baseline Survey of Disabled Young People

10.8 Respondents were subsequently asked whether the needs identified were met, which showed that in most cases young people felt this was the case. Further analysis showed that the second most cited area of need (money to pay someone to help the young person do the things they want to do) was also the area where needs were least met. As illustrated in Figure 10-5, 31% of young people felt that this need was 'never met', while a further 27% of young people felt it was 'hardly ever' met. Previous analysis detailed in chapter 9, highlighted that the most common change in provision as a result of IB was predicted to be families hiring personal assistants, which may address this current unmet need, and therefore will be a key area of interest as more IB packages are finalised.

Figure 10-5: Extent to which the day-to-day needs of the young people are met



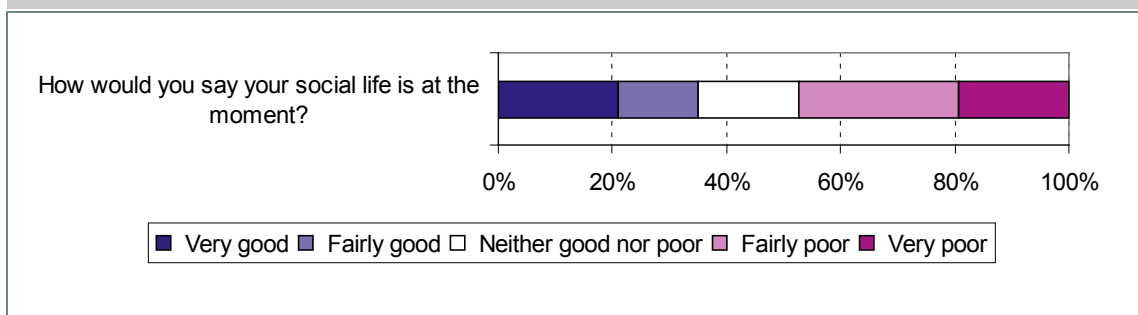
Number of respondents displayed in brackets next to each question

Source: SQW Consulting, Ipsos MORI, Baseline Survey of Disabled Young People

### Social activities

10.9 The young people reported varying qualities of social life (see Figure 10-6). These perceptions appeared to be slightly more negative than the perceptions of parents, and more in line with the professional views, particularly in terms of the proportion of young people felt to have a poor social life. This may reflect the older age group covered by the survey of young people.

Figure 10-6: Young people perceptions of their social life

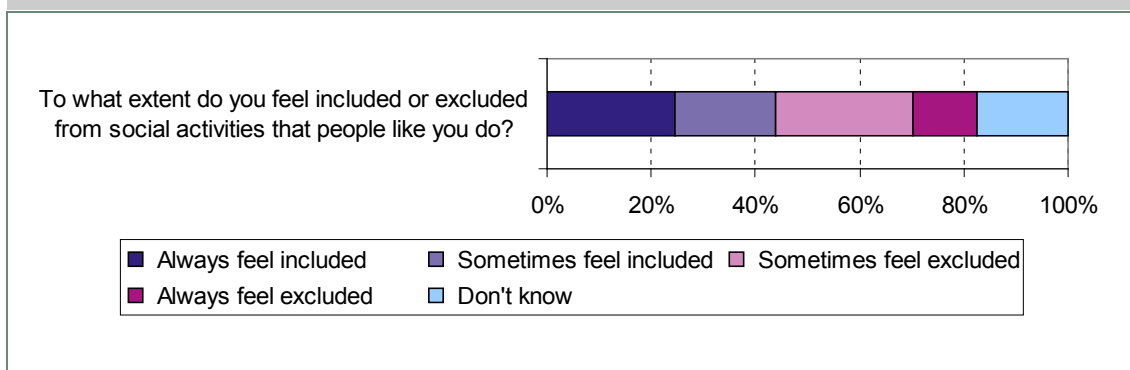


Source: SQW Consulting, Ipsos MORI, Baseline Survey of Disabled Young People

10.10 The survey results highlighted considerable variation in the extent to which the young people interviewed felt socially included or excluded (see Figure 10-7). Forty four per cent of the young people felt that they were either always included or at least sometimes included (with 25% feeling they were 'always included'), while 38% felt

that they were either sometimes or always excluded. Seven young people (12%) reported always feeling excluded.

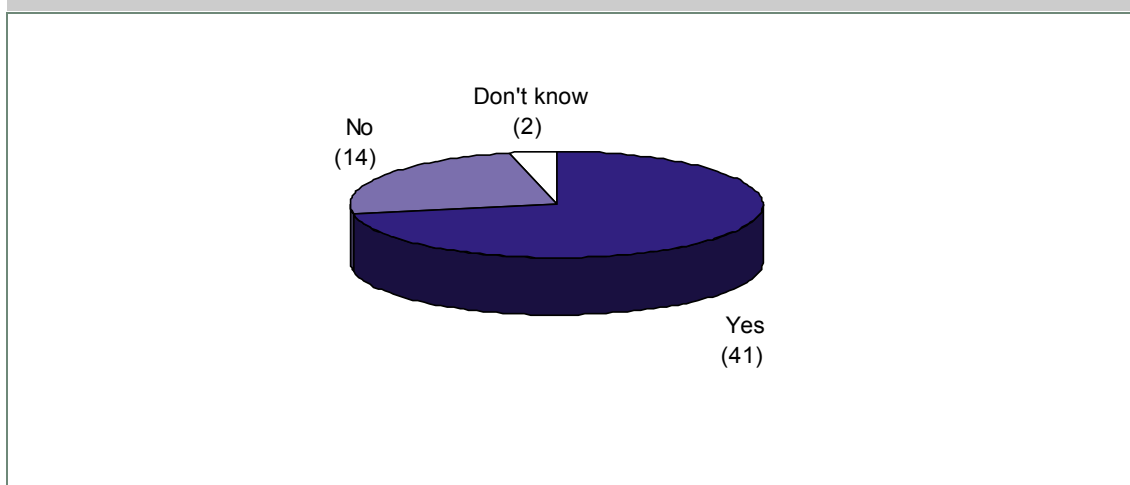
Figure 10-7: Extent to which the young people feel socially included



Source: SQW Consulting, Ipsos MORI, Baseline Survey of Disabled Young People

10.11 As a means of assessing their perceived quality of life respondents were asked to consider how often they undertook a pre-specified list of activities,. This showed that most (72%) of the disabled young people consulted had friends outside of their family who they liked to talk to or do things with (see Figure 10-8). However, as is set out in Table 10-1, many of the young people did not participate in activities outside the house including: playing sport (49% of respondents never play sport), going to a club or activity (33% never take part in this activity), and seeing friends (33% never take part in this activity). In contrast, 40% of respondents did things at home everyday, and a further 35% did things at home most days. A large majority of respondents (74%) reported that they did things with their family at least once or twice a week.

Figure 10-8: Do the young people have friends they like to talk to or do things with outside of their family



Source: SQW Consulting, Ipsos MORI, Baseline Survey of Disabled Young People

Table 10-1: How often the young people do the specified activities

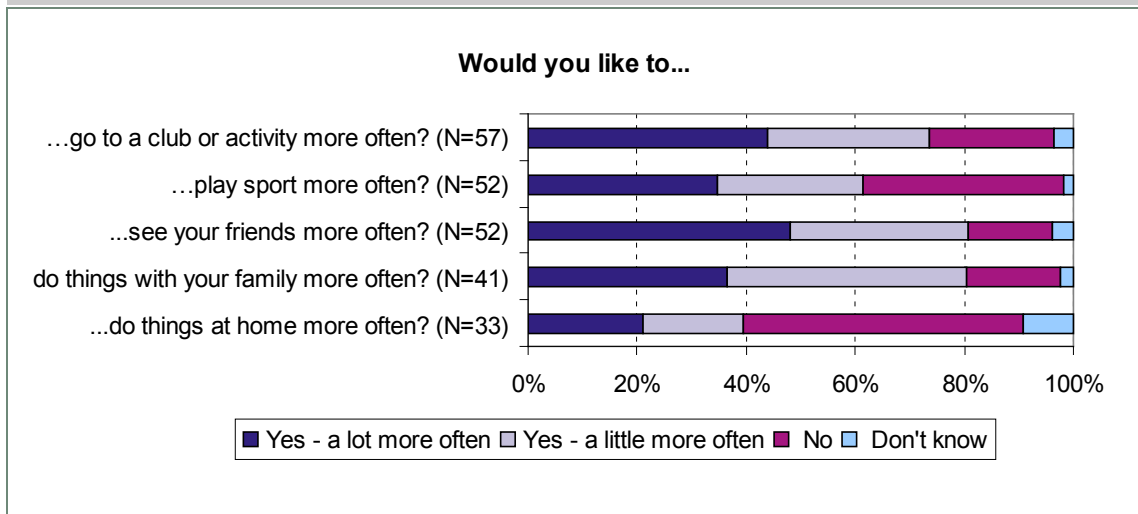
	Play sport		Go to a club or activity		Do things at home		Do things with your family		See your friends	
	N	%	N	%	N	%	N	%	N	%
Everyday	5	9%	0	0%	23	40%	15	26%	5	9%
Most days	2	4%	2	4%	20	35%	11	19%	4	7%
Once or twice a week	16	28%	27	47%	7	12%	16	28%	13	23%
Once or twice a fortnight	0	0%	2	4%	2	4%	2	4%	4	7%
Once or twice a month	0	0%	3	5%	0	0%	5	9%	3	5%
Once or twice every few months	2	4%	1	2%	0	0%	2	4%	2	4%
Once or twice a year	2	4%	0	0%	0	0%	2	4%	2	4%
Less often than once a year	0	0%	0	0%	0	0%	0	0%	2	4%
Never	28	49%	19	33%	3	5%	0	0%	19	33%
Don't know or can't remember	2	4%	3	5%	2	4%	4	7%	3	5%
<b>Total</b>	<b>57</b>		<b>57</b>		<b>57</b>		<b>57</b>		<b>57</b>	

Source: SQW Consulting, Ipsos MORI, Baseline Survey of Disabled Young People

10.12 Respondents were subsequently asked how often they would like to participate in the list of pre-specified activities. This showed that 74% of the young people would like to go to a club or activity more often (including 44% who would like to go a lot more often). and 81% would like to see friends more often (including 48% who would like to see friends a lot more often) (see Figure 10-9). In contrast and in conjunction with the findings above which showed that the majority of young people (88%) did things at home at least once or twice a week, less young people reported a wish to do things at home more often (39%, of whom 21% wished to do a lot more with their family).



Figure 10-9: Activities young people would like to do more often



Number of respondents displayed in brackets next to each question.

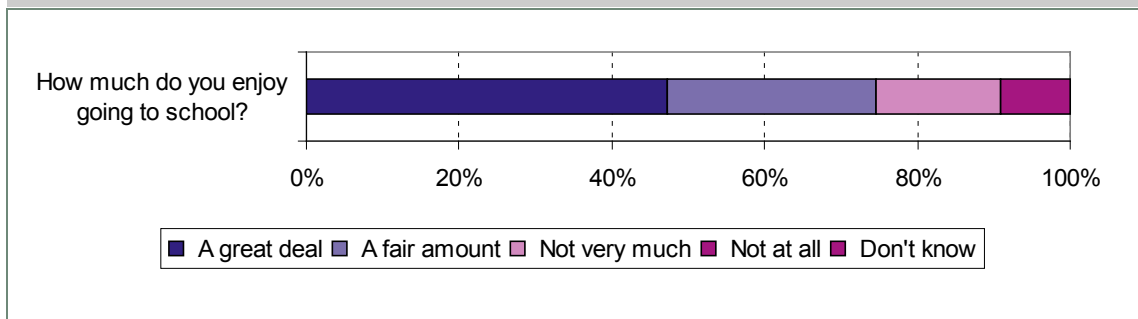
Source: SQW Consulting, Ipsos MORI, Baseline Survey of Disabled Young People

### Education & future training/employment prospects

10.13 The vast majority of young people interviewed (96%) were in education; with 89% in school and a further 7% at college. None of the young people consulted were in employment or looking for work.

10.14 The majority of the young people had positive views on school, which corresponded with the views expressed by the parents/carers. Seventy five per cent of the young people enjoyed school, including 47% who reported enjoying school 'a great deal' (see Figure 10-10). In addition to this, 31% of young people felt themselves to be doing 'fairly well' in their school or college work, with an additional 56% feeling that they were doing 'very well' (see Figure 10-11). However, these results are noticeably lower for young people from lower social grades (C2DE).

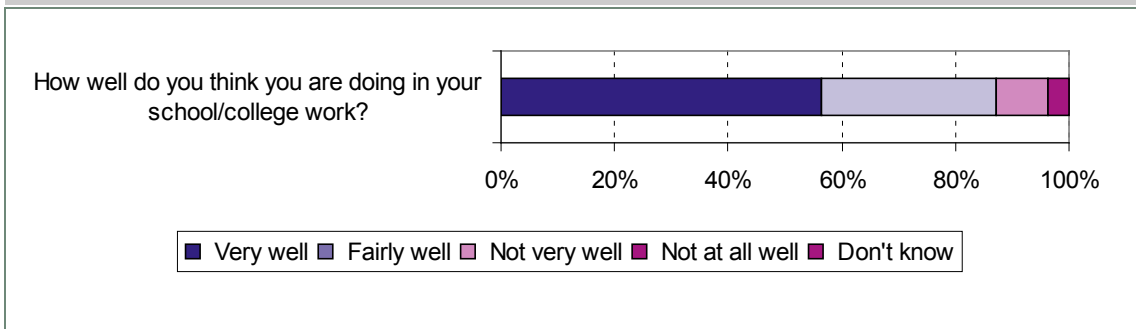
Figure 10-10: Experience at school



Number of respondents: 55

Source: SQW Consulting, Ipsos MORI, Baseline Survey of Disabled Young People

Figure 10-11: Experience at school

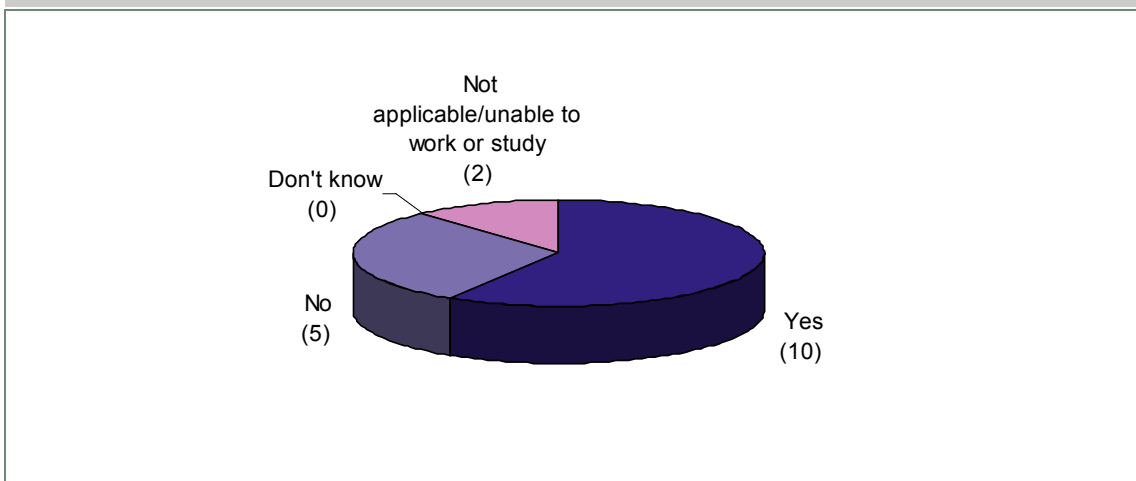


Number of respondents: 55

Source: SQW Consulting, Ipsos MORI, Baseline Survey of Disabled Young People

10.15 The majority (59%) of the young people aged 16 and over have spoken to someone outside of their family regarding what to do when they leave school (see Figure 10-12). However, the young people still expressed a lack of knowledge of the opportunities available to them when they leave school.

Figure 10-12: Have the young people spoken to anyone outside their family about what to do when they leave school



Number of respondents: 17

Source: SQW Consulting, Ipsos MORI, Baseline Survey of Disabled Young People

10.16 Of the 15 young people who felt they were able to study/work, two felt they knew a great deal about the things they could do to carry on learning after the age of 16, four felt they knew a fair amount, a further four felt they didn't know very much and the remaining five felt they knew 'nothing at all' (see Table 10-2).

10.17 Looking now at potential job opportunities, the gap in knowledge appeared to be even greater. That is, 5 of the fifteen young people reported knowing 'not very much' about the types of job they can do for the next few years, while seven stated they knew 'nothing at all'. These findings point to a potential need to improve the support

provided to disabled young people in transition, to ensure that they are aware of the opportunities that are available to them once they leave secondary school.

Table 10-2: Young person's knowledge of how to continue learning/enter employment post 16

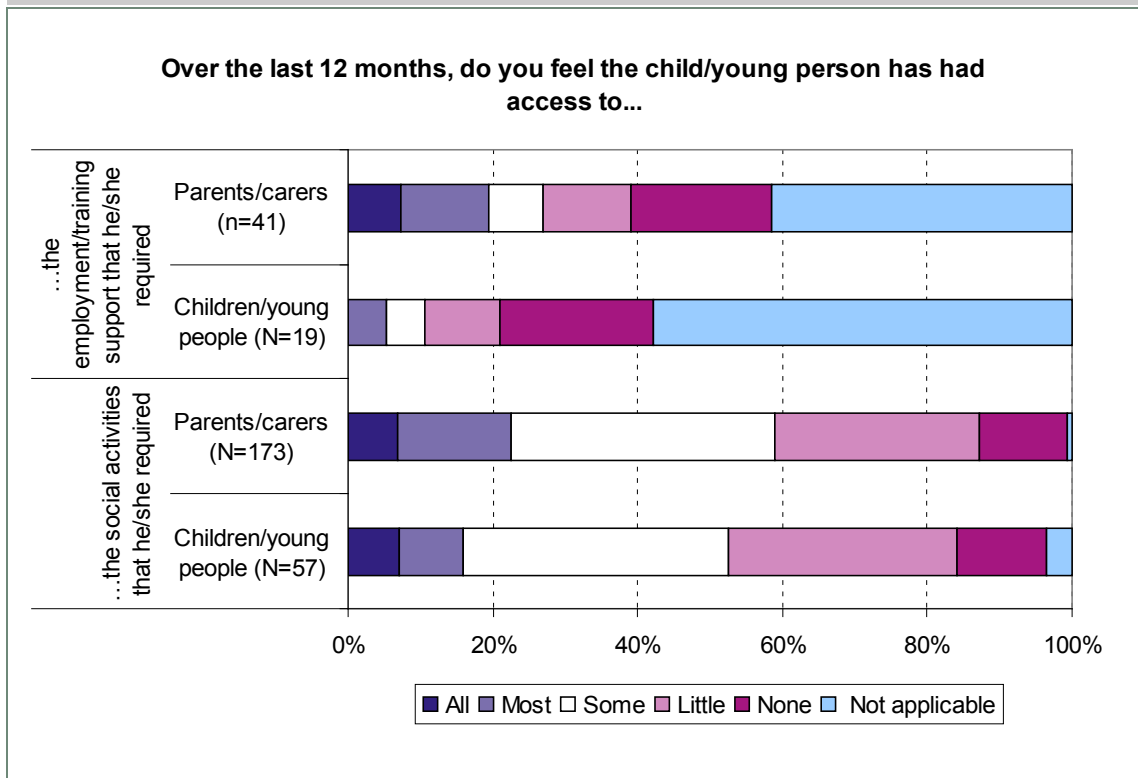
	How much do you feel you know about the things you can do to carry on learning new things after the age of 16?		How much do you feel you know about the types of job you can do in the next few years, from the age of 16?	
	N	%	N	%
A great deal	2	13%	1	7%
A fair amount	4	27%	2	13%
Not very much	4	27%	5	33%
Nothing at all	5	33%	7	47%
Total	15	100%	15	100%

Number of respondents: 15

Source: SQW Consulting, Ipsos MORI, Baseline Survey of Disabled Young People

10.18 Parents and young people shared relatively similar views on how well social activities and employment/training support had met the needs of the young person in the last year. In terms of social activities, the perception amongst young people and parents/carers tended to be that some, but not all (or even most) of their needs were being met (see Figure 10-13). Of those to whom the employment/training question was relevant, very few young people (5% of those who answered the question) felt that they had access to all or most of the employment/training support they required.

Figure 10-13: Extent to which social and employment/training needs met in the last 12 months



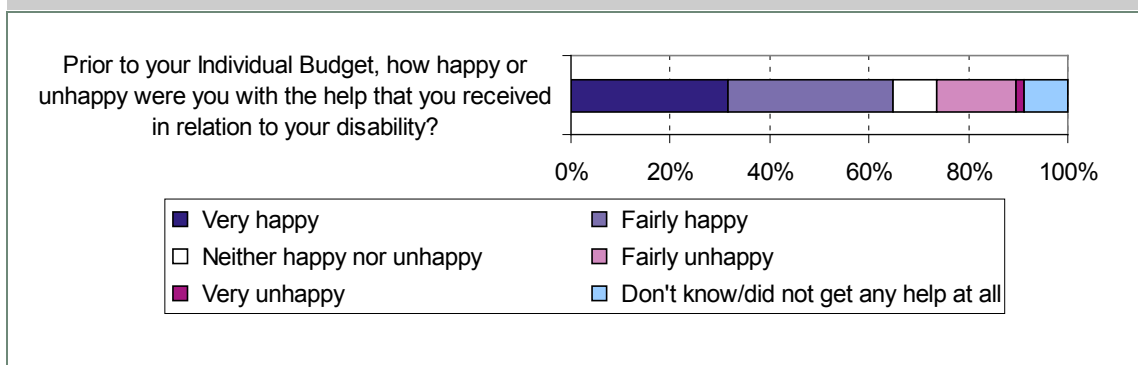
Number of respondents displayed in brackets next to each question.

Source: SQW Consulting, Ipsos MORI, Baseline Survey of Disabled Young People

### Satisfaction with previous services

10.19 Young people appear to have been relatively more content than their parents/carers with the support that they received in relation to their disability prior to enrolling on the IB pilot. The majority (65%) of the young people were happy with the help they had received in relation to their disability, with 32% 'very happy' (see Figure 10-14). In comparison only 43% of parents rated the help they had received in relation to their young person's disability as good.

Figure 10-14: Satisfaction with help, prior to enrolling on an Individual Budget

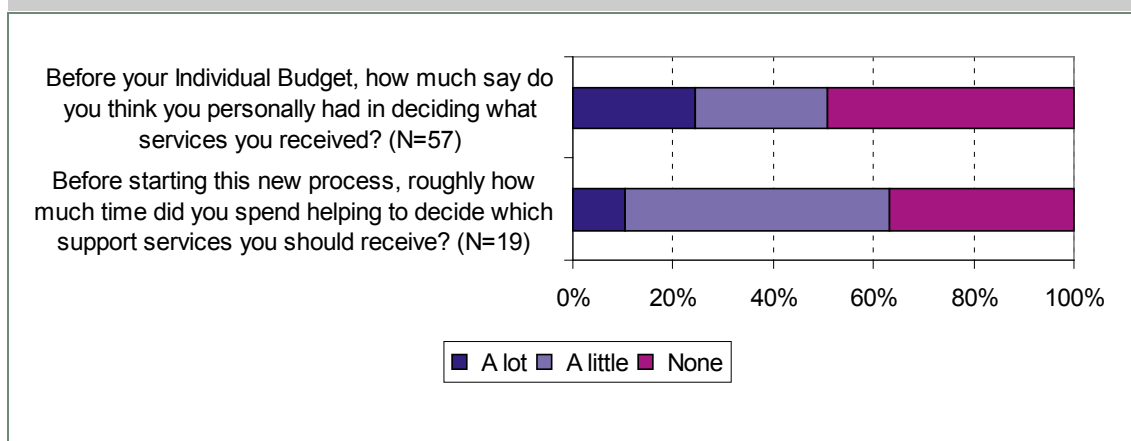


Source: SQW Consulting, Ipsos MORI, Baseline Survey of Disabled Young People

10.20 As illustrated in Figure 10-15, approximately half of the young people consulted (51%) felt they had some level of control over their provision prior to enrolling on the IB programme. The remaining 49% felt they had no control over their previous service provision. Analysis by age showed that a small minority (11%) of young people aged 16 or over spent ‘a lot’ of time helping to decide which support services they should receive prior to enrolling on an IB.

10.21 The majority of respondents (53%) reported that they spent ‘a little bit’ of time deciding which support services they should received, but 37% had spent ‘no time at all’ contributing to the decision making process (see Figure 10-15).

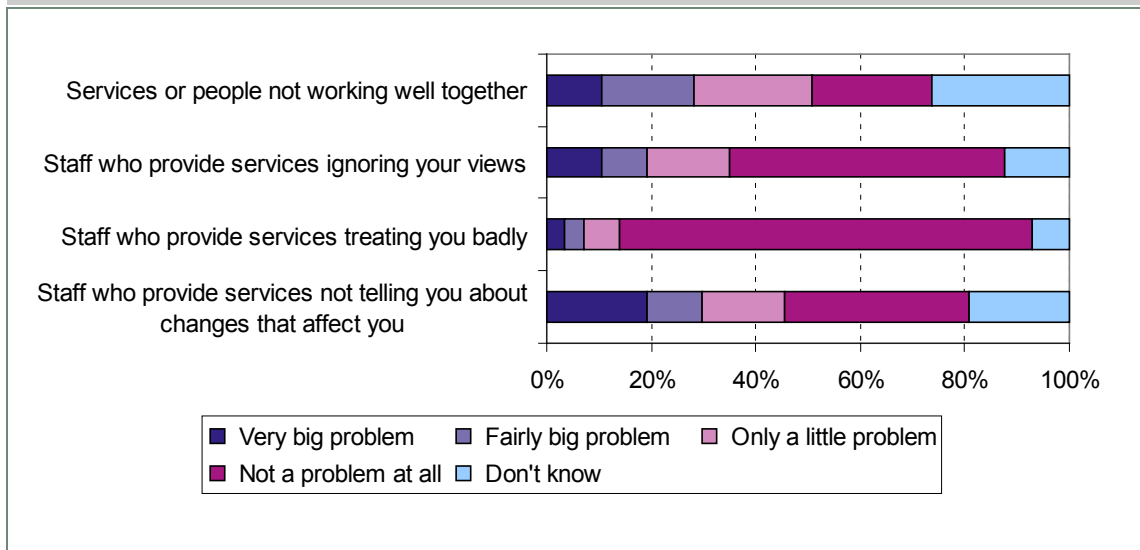
Figure 10-15: Level of control young people had over their provision, prior to enrolling on an IB



Source: SQW Consulting, Ipsos MORI, Baseline Survey of Disabled Young People.

10.22 For the most part, young people were positive about the support that they had received in the past year prior to enrolling on the IB pilot. In line with the perceptions of parents, 82% of whom felt that staff providing services listened to what they said, young people tended to believe (in 53% of cases) that staff did not ignore their views. However, 20% of young people felt that staff not communicating service changes that affected them to be a ‘very big problem’ prior to IB (see Figure 10-16).

Figure 10-16: Problems for disabled young people which have occurred in the last year



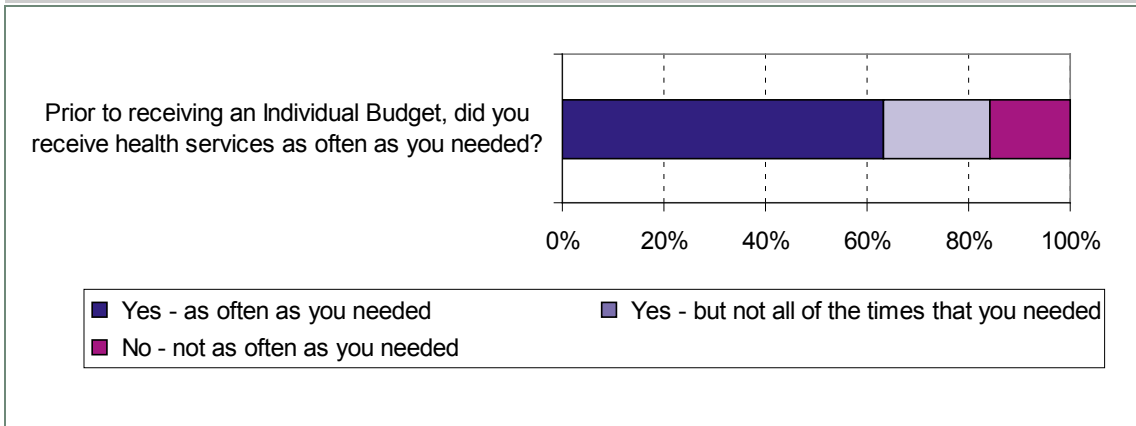
Source: SQW Consulting, Ipsos MORI, Baseline Survey of Disabled Young People

### Health provision

10.23 Although the majority (63%) of young people felt that they received all the health services they needed prior to enrolling on the IB pilot, the remaining 37% were not completely satisfied with the provision of health services (see Figure 10-17). The dissatisfaction was expressed as a result of the young person either not receiving health services as often as they needed them or that they did not receive health services at all of the times that they were needed.

10.24 These opinions align relatively well with the parents attitudes on access to health services. Parents felt that access was provided to at least 'some' of the health services their child/young person required in 79% of cases, although parents were less positive about access to all the health services required; with 25% of parents feeling that their disabled child/young person had access to all the health services they required.

Figure 10-17: Access to health services prior to enrolling on an IB

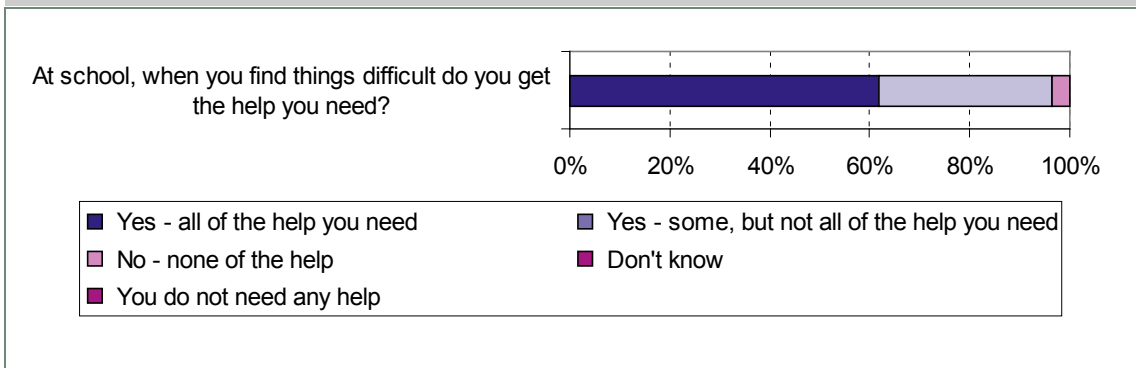


Source: SQW Consulting, Ipsos MORI, Baseline Survey of Disabled Young People

### Education support

10.25 In terms of support while at school, 96% of the young people felt there was at least some help available for when they found things difficult, either through a teacher, another adult or friends in the class. However, although only 4% (two of the young people) felt that there was no help available, 35% felt that although some help was in place, they felt they required further help (see Figure 10-18).

Figure 10-18: Judgement on the support received at school



Number of respondents: 55

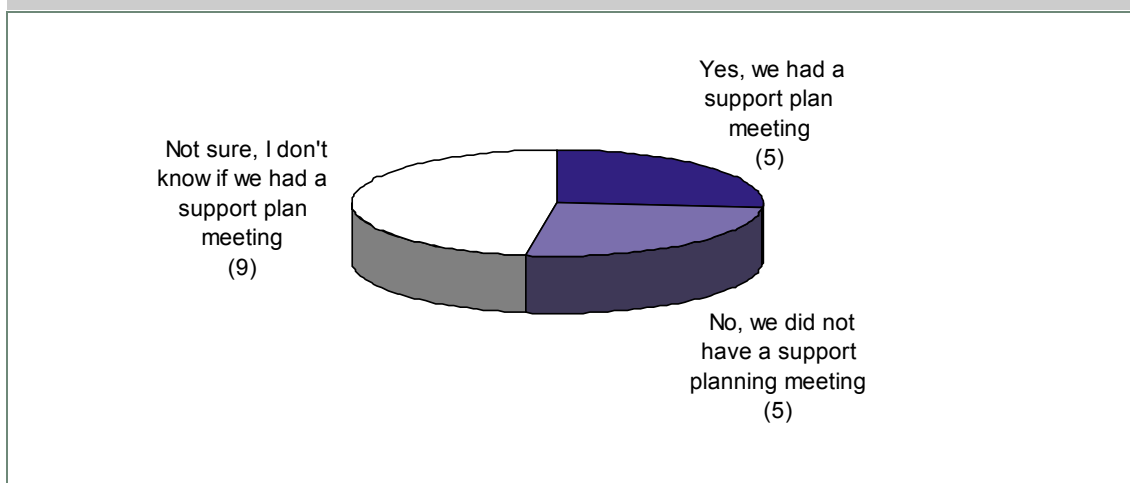
Source: SQW Consulting, Ipsos MORI, Baseline Survey of Disabled Young People

### Early findings on support planning

10.26 At the time of the survey, the support planning processes of the individual pilot sites were still in their relatively early stages. As a result only 19 (33%) of the 57 families where both a parent and young person participated in the survey reported (through the parent/carer) that they had begun to develop their support package. Therefore, 19 young people were asked about their views of the support planning process. This found varying degrees of awareness that the process had or was taking place. That is, only five of the young people (26%) were aware that there had been a support

planning meeting, a further five young people said that they had not had a support planning meeting and the remaining nine were unsure (see Figure 10-19).

Figure 10-19: Knowledge of support planning meeting



Number of respondents: 19

Source: SQW Consulting, Ipsos MORI, Baseline Survey of Disabled Young People

### Summary

- 10.27 The survey gathered information to identify a baseline of the position of responding young people near the start of the pilot, and, where possible, on their experience and understanding of the support planning process. Of the relatively small proportion of young people at least part way through the support planning process, few were aware of support planning meetings.
- 10.28 Young peoples' participation in activities and their perceptions of social inclusion varied across the sample. The majority of young people surveyed were in education, and had positive views on school, corresponding with the views expressed by the parents/carers.
- 10.29 Young people appear to have been relatively more content than parents/carers with respect to the support they had received prior to enrolling on an IB, where in most cases they stated that their needs had been met. The main exception to this finding was felt to be a lack of access to 'money to pay someone to help the young person do the things they want to do'. As early findings show that the most common form of change in service provision was likely to be an increased dependence on personal assistants, this need may be addressed through the provision of an IB and will be monitored during Year two of the evaluation.



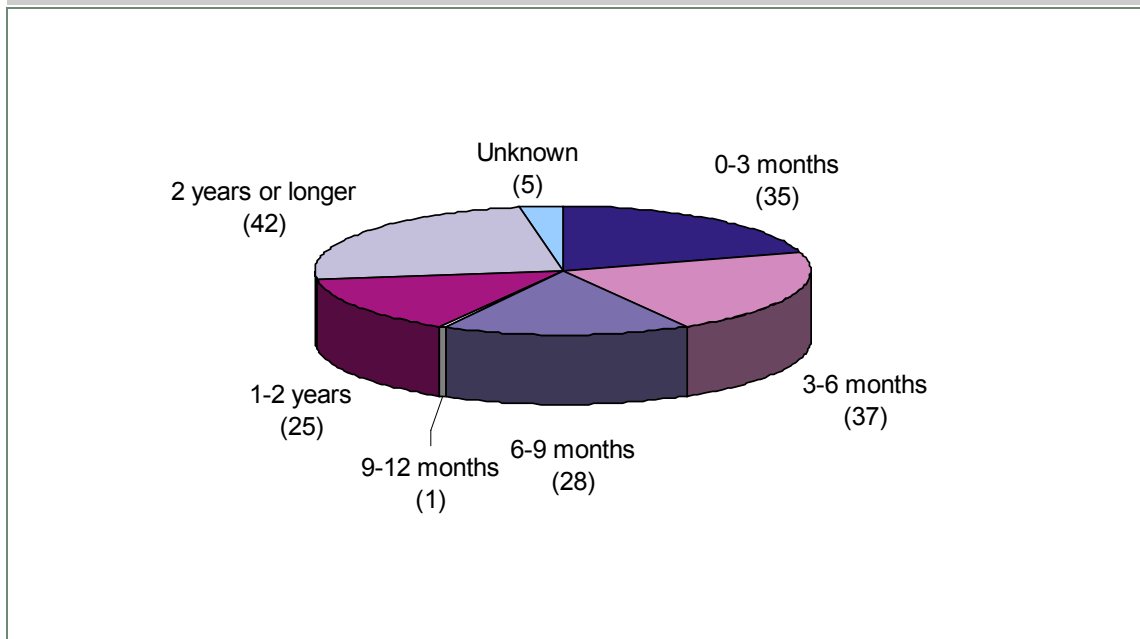
## 11: Professional survey

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### Introduction

- 11.1 The following chapter sets out the findings of the survey of professionals, which sought to collect an external view on the position of the families prior to their enrolment on an Individual Budget (IB). The professional assessments provide insight into the characteristics of the families, their position prior to enrolling on the pilot, and a judgement on the expected changes in service delivery and outcomes as a result of the IB. A follow-up assessment will be undertaken towards the end of the pilot, to examine the actual outcomes and measure distance travelled for each family.
- 11.2 The survey was intended to be completed by professionals with good knowledge of the disabled child/young person and their families; including knowledge of their situation prior to the pilot and of how enrolling on an Individual Budget may affect their provision. Fifty eight professionals completed the survey on behalf of the 173 families engaged in the pilot as of 1<sup>st</sup> March 2010. Nearly 40% (67) of the families had been working with their professional for over a year, and only 20% (35) had known their professional for less than three months when the survey of professionals was conducted (see Figure 11-1). However, over half of these 35 families were from one pilot site, which had recruited a new social worker to work with pilot families and had also experienced turnover of existing staff. This lack of long-term familiarity with the position of the families prior to IB has resulted in a relatively large number of 'don't know' responses at points in the survey. However, as these are focussed mainly in one pilot site the broad approach can still be expected to produce valid results around impact in Year two.

Figure 11-1: Length of time professional has been working with the family

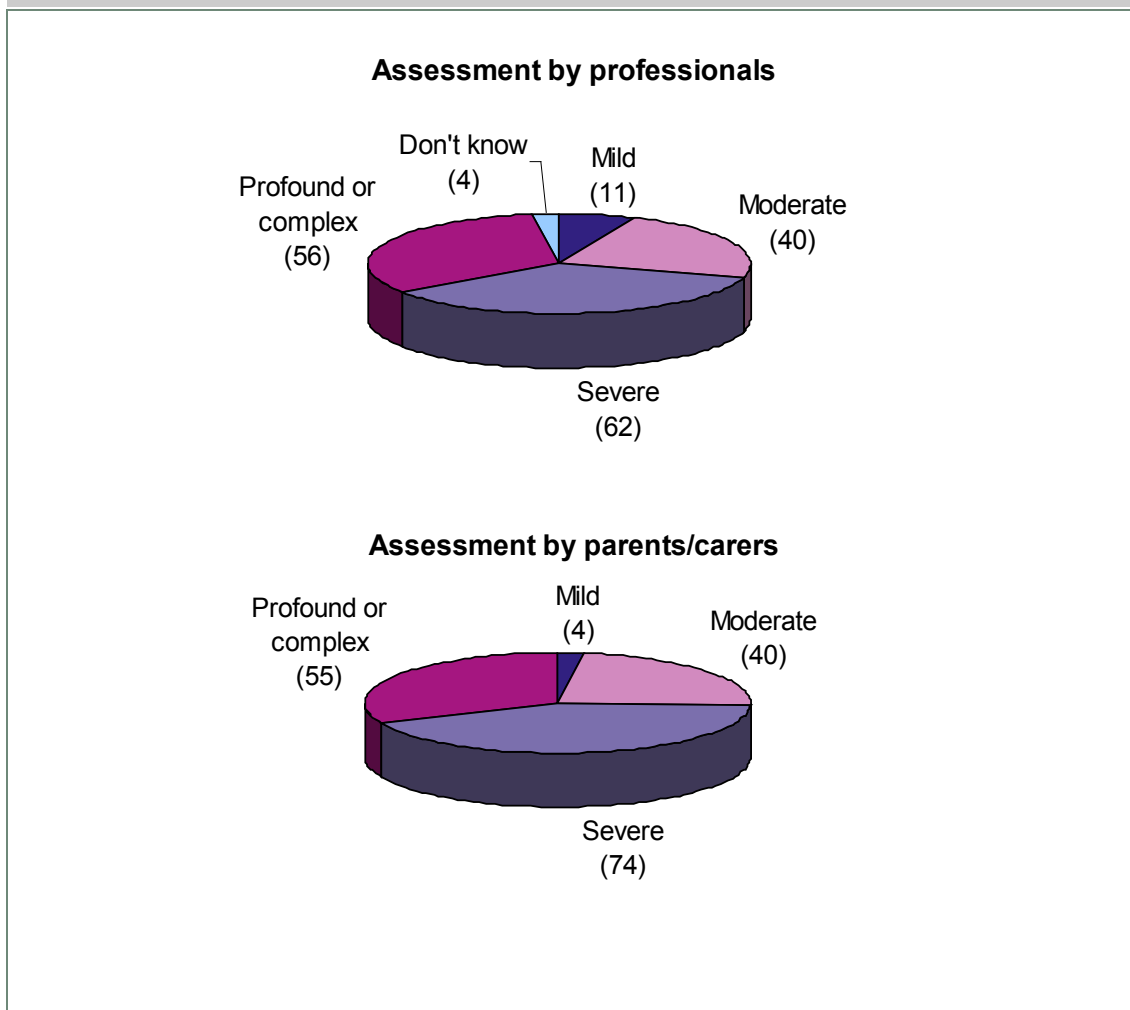


Source: SQW Consulting, Baseline Survey of Professionals

### Characteristics of the participating disabled children and young people

- 11.3 The majority of disabled children and young people enrolled in the IB process had relatively severe or complex needs (see Figure 11-2). That is, over two thirds of those participating (118) were reported by professionals to have severe, profound or complex needs, while only 6% (11) were reported to have mild disability. Professionals and parents/carers tended to have similar views on the severity of disability experienced by enrolled children/young people, although the families were slightly more likely to report greater need, where an additional 12 families stated their child had severe needs and seven fewer families reported their child as having mild needs. Of the 11 children/young people felt by professionals to have mild conditions, two were previously unable to access service provision prior to enrolling on the pilot as they fell below the threshold for statutory social work intervention.

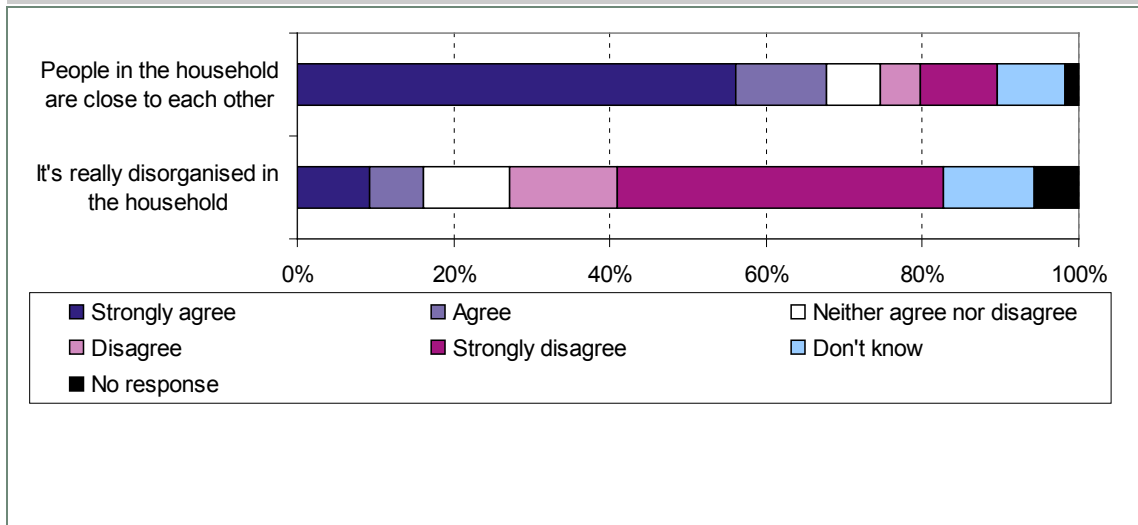
Figure 11-2: Severity of the child/young person's disability



Source: SQW Consulting, Baseline Survey of Professionals

11.4 Most of the disabled children/young people enrolled in the IB programme were judged to be raised in a strong family environment (see Figure 11-3). Professionals strongly agreed that the majority (56%) of family households were close to each other, with a further 12% agreeing it to be the case. In addition, only 16% (26) of households were felt to be 'really disorganised'. These findings were in line with the responses given by the parents in the parent/carer baseline survey.

Figure 11-3: Judgements on the household within which the disabled child/ young person is living

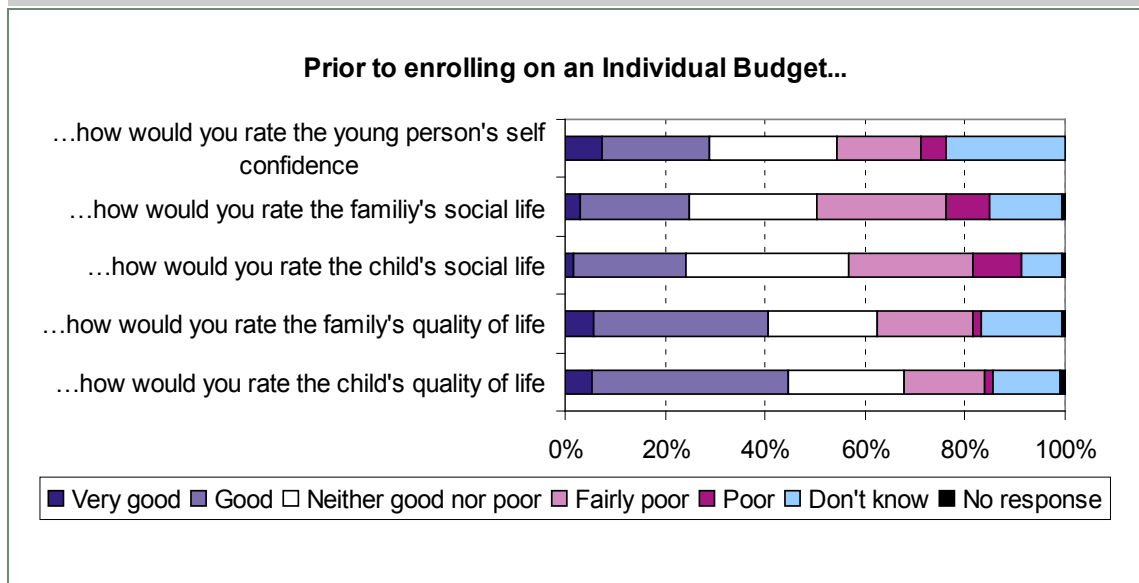


Source: SQW Consulting, Baseline Survey of Professionals

### Prior to IB

- 11.5 Professionals reported that around 40% of the children/young people and their families had 'good' quality of life, with only a few of the children/young people or families (5% and 6% respectively) reported to have a 'very good' quality of life (see Figure 11-4). Professionals and parents both judged the children/young people to have a better quality of life than their family as a whole. However, parents tended to rate their child's quality of life more highly, with 62% of parents rating their child's quality of life as good (either fairly good or very good), while 45% were rated good or very good in the survey of professionals.
- 11.6 Perceptions of the children/young people's self confidence prior to IB were mixed, although almost half (83) of this group were felt to not find school enjoyable, with this being felt strongly in 44 cases, the majority (55%) of whom had profound or complex needs. This contrasts with the views expressed by parents, 80% of whom felt their child/young person finds school enjoyable and 77% of whom felt that, taking into account their disabilities, the children were doing well at school or college.
- 11.7 More children and families were felt to have a 'poor' or 'fairly poor' social life than a 'good' or 'very good' one, and over a third of parents were felt to be at least 'somewhat constrained' in their employment choices by their child's condition, including 37 who were felt to be 'very constrained'. Parents of disabled children/young people with severe, profound or complex needs were thought to be particularly likely to be constrained in their employment choices.

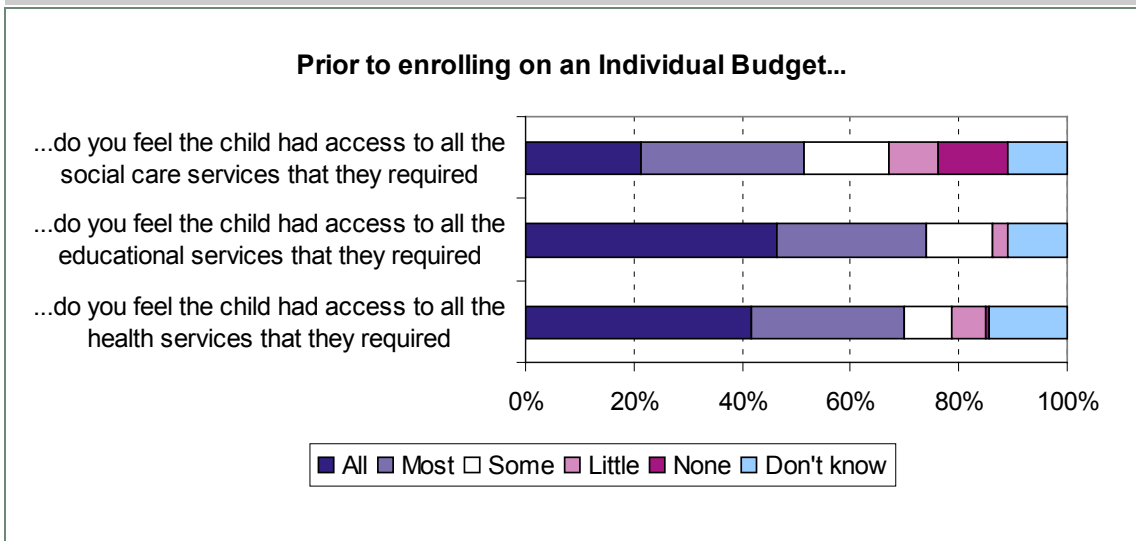
Figure 11-4: Quality of life of the disabled children/young people and parents prior to enrolling on the pilot



Source: SQW Consulting, Baseline Survey of Professionals

- 11.8 Professionals tended to be positive about the provision of services that the child/young person received prior to enrolling on the pilot, and over their ability to access the services they required (see Figure 11-5). The majority of children/young people were felt to have access to 'all' or 'most' of the health and education services they required, a view which was in the most part corroborated by the parents' views set out in Chapter 9. However, professional perceptions relating to access to social care were less positive, with just 51% of children/young people felt to have access to 'all' or 'most' social care. Parents were even less content with access to social care; only 21% of parents felt they had access to 'all' or 'most' of the social care services they required. This suggests that parental dissatisfaction with previous services had not been fully appreciated by professionals. In time this could mean an increased pressure to change services as families gain greater influence.
- 11.9 As would be expected, 43% (12) of children/young people in the pilot site which sought to target newcomers to the system, had accessed 'none' of the social care services they required prior to enrolling on an IB.

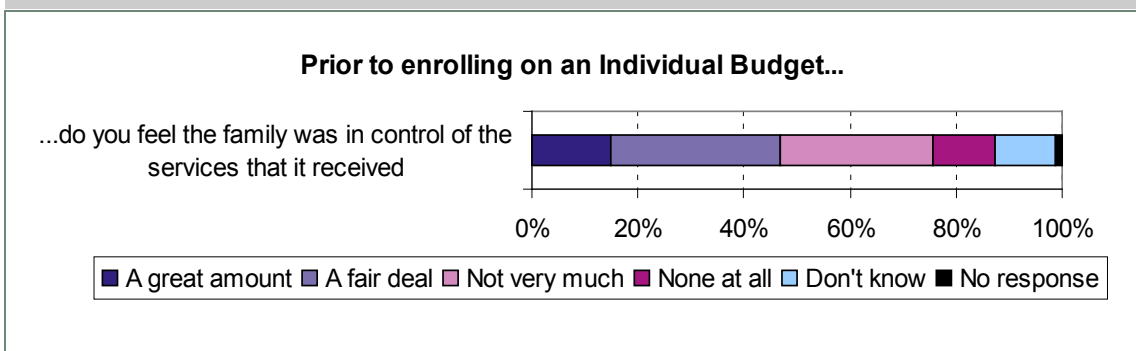
Figure 11-5: Provision prior to enrolling on an Individual Budget



Source: SQW Consulting, Baseline Survey of Professionals

11.10 As Figure 11-6 illustrates, there was considerable variation in the perceived level of control families had over the services that they received prior to enrolling on an Individual Budget.

Figure 11-6: Control over services prior to enrolling on an Individual Budget

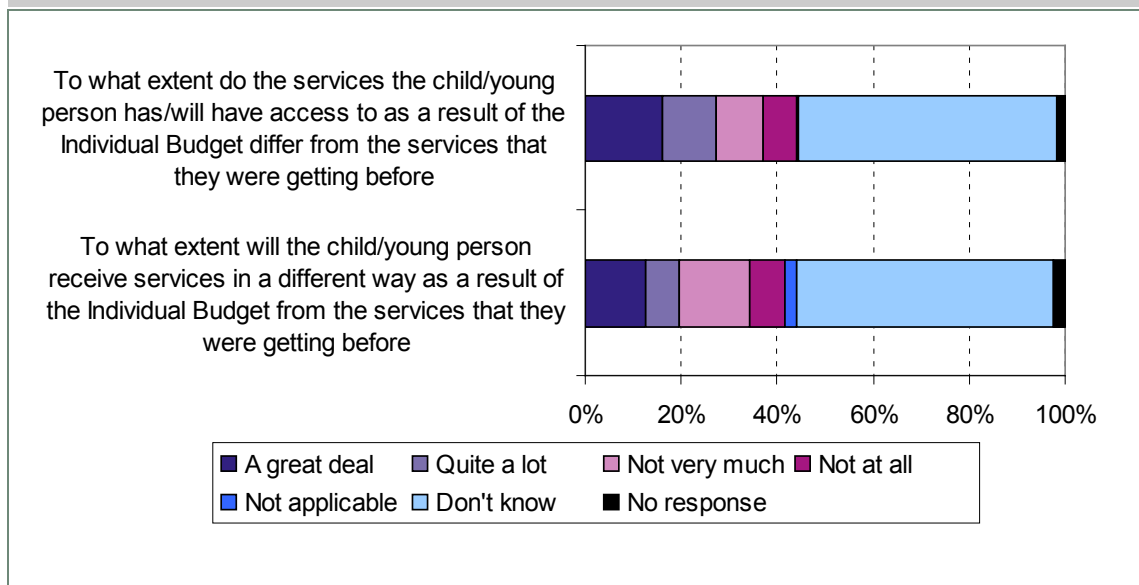


Source: SQW Consulting, Baseline Survey of Professionals

### The IB Package

11.11 As the baseline survey was conducted during the early stages of Individual Budget pilot programme, there was a great deal of uncertainty amongst professionals over how the provision of support/services to participating disabled children/young people and their families would vary from traditional services (See Figure 11-7). For the majority of children/young people, professionals 'didn't know' the extent to which the services available and the way these services would be accessed would vary as a result of the IB offer.

Figure 11-7: Changes in provision as a result of enrolment on an Individual Budget



Source: SQW Consulting, Baseline Survey of Professionals

11.12 The key changes professionals expected to result from IB provision were:

- **Increased variation and flexibility of the offer.** This includes a number of families who were previously unaware of some of the services available to them
- **More appropriate provision,** to better meet the needs of the families
- **New provision** for families not previously in receipt of services.

11.13 Examples of how these changes could come about included: one child prior to their IB did not have access to activities outside their school day, but now has access to a range of services which allow them to interact with their peers; and one young person has had more opportunities to enjoy outings with their family, and visit their grandparents who live abroad, through the provision of an IB.

11.14 Figure 11-8 shows the number and proportion of families expected to experience improvements as a result of IB, by the severity of their disability. It reveals that a higher proportion of children/young people with profound or complex needs were expected to benefit from improved choice over how they run/live their lives, improved choice of service providers, coordination of services and quality of care as a result of their Individual Budget (compared to individuals with other levels of need). More generally, the main improvements were expected to be in terms of :

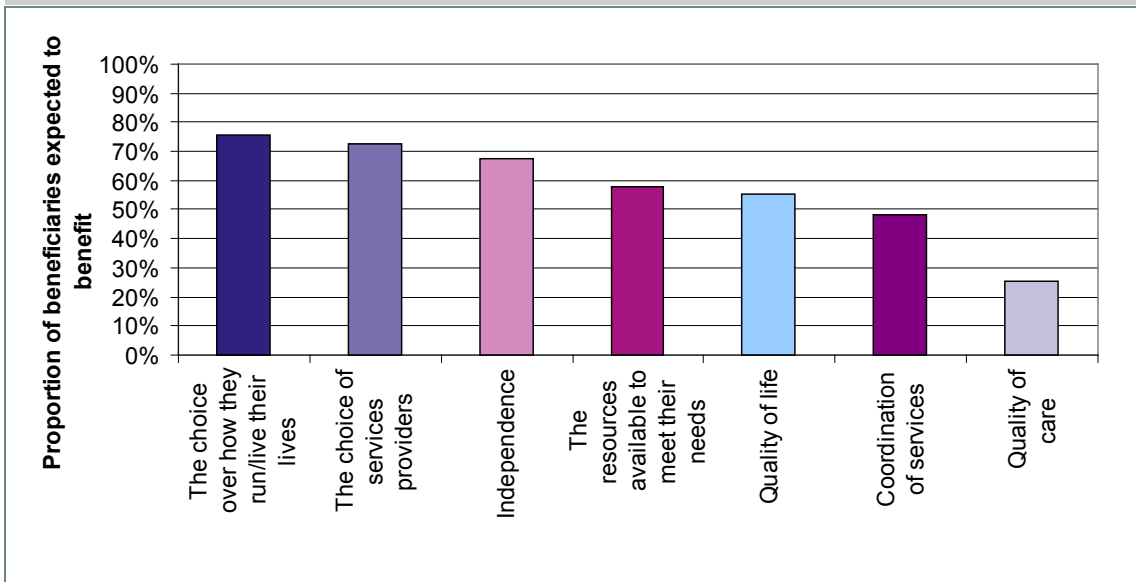
- the choice over how they run/live their lives (professionals felt 77% of families would see improvement in this area)

- the choice of service providers (75% families)
- independence (70% families) (see Table 11-1).

11.15 It was felt that quality of life would improve for the majority of families (96 or 59%) as a result of the IB, and a much smaller number (44 or 25%) were expected to benefit from improved quality of care, perhaps because of the relatively high proportion of children/young people already felt to be accessing the services they required prior to enrolling on an IB.

11.16 The professional opinions on the areas families were expected to benefit as a result of the IB vary considerably from the benefits the families themselves perceive they will achieve (according to the baseline parent/carer survey). Families are much less likely than professional to believe that the choice over how they run/live their lives, the choice of service providers and independence will improve as a result of the IB. That said, the proportion of professionals and families who perceived that there would be an improvement in quality of life and resources available to meet their needs is comparable. These differences may reflect differences in the perspectives of both groups and it will be important to track how the views of both groups evolve through Year two of the evaluation.

Figure 11-8: Areas in which the families are expected to benefit as a result of the Individual Budget



Source: SQW Consulting, Baseline Survey of Professionals



Table 11-1: Expected improvements as a result of IB, by severity of disability

	Mild	Moderate	Severe	Profound or complex	Don't know	Total
<b>Number of families</b>	<b>11</b>	<b>40</b>	<b>62</b>	<b>56</b>	<b>4</b>	<b>173</b>
The choice they have over how they run/live their lives	8 (73%)	20 (53%)	51 (84%)	49 (88%)	3 (75%)	131 (77%)
The choice of service providers	8 (73%)	19 (50%)	50 (82%)	47 (84%)	3 (75%)	127 (75%)
Independence	10 (91%)	22 (58%)	43 (71%)	40 (73%)	3 (75%)	118 (70%)
The resources available to meet their needs	8 (73%)	21 (55%)	35 (57%)	36 (64%)	0 (0%)	100 (59%)
Quality of life	8 (73%)	16 (42%)	38 (62%)	31 (55%)	3 (75%)	96 (57%)
Coordination of services	6 (55%)	14 (37%)	29 (48%)	34 (61%)	0 (0%)	83 (49%)
Quality of care	2 (18%)	8 (22%)	14 (23%)	20 (36%)	0 (0%)	44 (25%)

*Percentages are of the proportion of children expected to benefit by the population with each level of severity of disability.*

*Source: SQW Consulting, Baseline Survey of Professionals*

## Summary

11.17 The survey of professionals sought to collect an external view on the position of families prior to their enrolment on the pilot. The professionals provided a mixed reaction when asked to rate the existing quality of life of the disabled children/young

people and their parents, where they reported around 40% of the children/young people and their families as having a 'good' quality of life. In contrast, most families were judged as providing a stable environment.

- 11.18 The majority of children/young people were felt to have access to 'all' or 'most' of the required health and education services, with slightly fewer families having sufficient access to the required social care services. This supports findings from the survey of parents/carers.
- 11.19 There was a great deal of uncertainty amongst professionals on how the IB provision would vary from traditional service provision, which was to be expected in a baseline survey. However, it was also evident that the children/young people most expected to experience a 'great deal' of change in their service offer (or the way the services were delivered) were those with profound or complex needs.

## 12: Findings to date and next steps

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- 12.1 This report comes at the end of the beginning for the pilots: the first families have been recruited and as a group are at various stages of support planning. Therefore, the real tests around the satisfaction of families with the process, and the resultant outcomes are not yet apparent. However, the experiences to date do suggest a number of emerging findings, both in terms of what has gone well, and areas that require further refinement before a robust delivery model emerges.
- 12.2 This final chapter sets out our reflections on the first year of the pilots. It covers the achievements and issues faced by the sites, and so identifies some of the learning that is beginning to emerge at this stage in the process. The final section considers how the next stages of the evaluation will enhance this learning.

### Reflections on the first year of the pilots

#### ***What has worked well***

- 12.3 Taking first those things that have gone well, it is apparent that the sites came to the pilot from very different starting points, but each recognised that it faced considerable challenges in developing an approach to each of the elements of the CDM. Moreover, there was considerable nervousness about the fairly tight timescale within which processes had to be established and families recruited to the pilot.
- 12.4 Each site has travelled some distance over the first year of the pilot. They now have a series of processes in place. The sites appear to have used the elements of the CDM to structure much of their thinking and activities. The framework provided appears to have been helpful in enabling sites to structure their thinking. At the same time the flexibility in the framework has enabled a range of different approaches to develop at area level. This diversity of approach has already thrown up some learning across sites, and indeed some of the later sites have adapted their behaviour based on the experiences of others which might have been one or two months ahead.
- 12.5 The sites have recruited in excess of 180 families to take part in the pilot. The numbers recruited are, in aggregate, in line with the original targets set. The timing of recruitment was close to that envisaged in the design of the pilots. The sites are to be commended for moving with this pace.

- 12.6 The survey results illustrate a good range of diversity between participants in relation to socio economic groups, severity of the child/young person's disability and previous use of personalised approaches (e.g. Direct Payments). This implies that IBs can be attractive to a wide range families if, as has happened through the pilots, the potential advantages are explained fully to them.
- 12.7 The results also suggest that a number of families are struggling to cope with their circumstances and expressing a degree of dissatisfaction with their existing support packages. This suggests that there is the potential for IBs to improve satisfaction and outcomes for these families, if IBs work as hypothesised.
- 12.8 A key part of delivering benefits is the support planning process through which families decide how best to spend their budget. This is at an early stage, but the initial feedback is encouraging. A number of families are reported to have changed considerably the nature of their care packages, and in some cases this has been a direct result of the young person themselves being actively involved in the process.
- 12.9 In a number of cases families have received a lower budget allocation through the pilot, than was attached to their previous support package. While some of the families have then dropped out of the pilot others, through the work of the sites, have remained part of the pilot and engaged in detailed support planning through which they anticipate achieving greater outcomes for less resource.
- 12.10 One issue which is coming through in the initial support packages is of support planners seeking to draw more explicitly on community resources to augment more traditional services and other activities that require funding. Sites have been seeking to develop community capacity to enable families to access local and universal services, which introduces new providers into the mix, creates new forms of service provision for families and will help to re-shape the market over both the short and longer term.

***What has worked less well***

- 12.11 However, this progress has been far from straightforward, and in most cases although processes are in place there is a recognition that the same approaches would not be used to facilitate some key elements of the CDM in a second round of recruitment. In part this is the inevitable challenge of developing a new approach in such a complex field. For example:

- although IT systems have been developed / adapted there is limited integration with other systems. In some cases the current 'fixes' do not look sustainable for larger scale of activity
- the range of approaches to resource allocation have thrown up a range of issues, including about accuracy, fairness and transparency, to highlighting issues with previous funding allocations. The combination of these issues has raised budgetary issues for the pilots and to some families declining to take forward an IB on financial grounds regardless of any change in control
- the sequencing of support planning alongside resource allocation is a cause for considerable reflection amongst the sites. In particular there is uncertainty as to when or if the value of the package should be communicated to the family for fear this then skews planning away from outcomes
- uncertainties around the legal position and responsibilities of local authorities on certain issues. This can understandably lead to caution on the part of sites
- several sites expected to gain much from the experience of their council colleagues in adult social care, which was also anticipated to support the transition group. However, in practice these links have often been less beneficial than expected due to issues around joint working and the different legal responsibilities and funding streams associated with young people
- the market development elements have been limited, reflecting the scale of the pilot and the uncertainty of future arrangements; although some innovative actions have been included in a number of support plans.

12.12 Sites have faced a range of issues in obtaining other funding streams, and while some have achieved more than others, there is much more to be done. Attempts to draw in travel and support budgets from education have proved difficult and approaches to PCTs have received very mixed responses, most often with a restricted and fairly small amount of money being made available. However, progress in this area is below what might have been expected, especially given the former DCSF's and the Department of Health's co-sponsorship of the programme and that each site application had to be co-signed by the PCT and the local authority.

12.13 This list of issues is not intended to imply that the pilots have been problematic. Rather, it demonstrates the distance that still requires to be travelled and the issues

to be resolved before we as evaluators or indeed the sites as practitioners would be comfortable in recommending specific approaches within the CDM framework. Further refinement and reflection is required, augmented by evidence from beneficiary families as to what worked or not for them. This will inform a revised CDM to be presented at the end of year two.

### ***Looking to the future***

- 12.14 Several of the areas of less progress listed above reflect at least in part issues of ambition. The sites appear to have focussed on delivering the core elements and doing so in a way that could have been achieved in the timescale available. Moreover, other local authority departments or other public agencies have engaged to very different and often limited extent with the pilots, with some seeking to find ways to engage and providing flexible resources and others declining to do so often on grounds of wider pressures that they faced. This highlights the difficulties of trying to bring together resources from across agencies in a voluntary way and with an apparently limited amount of influence being exerted from the centre of government.
- 12.15 Similarly, while the families have used the opportunity to change elements of their support packages, the anecdotal perceptions of some support planners is that they are trying out new things and may become more radical over time if their initial choices work as they hope. This in turn would further impact on the supplier market.
- 12.16 As such it appears that while much has been achieved there is much that still requires to be learned around implementation. The second year of the pilots will provide an opportunity to more fully understand the successes or otherwise of the structures put in place to date, as we describe in the following section on evaluation.
- 12.17 Year 2 will also give sites the opportunity to make progress on some of these issues. However, the scope for radical changes may be limited by uncertainties of what may happen beyond the planned life of the pilot in 12 months time. Moreover, only limited recruitment is planned in year two and several of the key issues highlighted above would need a further round of recruitment to more fully test any new approaches developed, for example around resource allocation.

### ***Summary of progress to date***

- 12.18 Table 12-1 summarises the key points around the achievements and issues of the first year of the pilots.

Table 12-1: Summary of progress to date

#### What has gone well

- The sites have progressed broadly in line with the speed and scale envisaged in the pilot design. They have now recruited a cohort of families, who in turn are proceeding through support planning.
- The range of families involved suggests that, if explained properly, IBs can be attractive across the social spectrum and to families with young people facing a wide range of disabilities
- The families include a number who are both satisfied and dissatisfied with their current support and so the evaluation will be able to test how levels of satisfaction change, if at all, from different starting points
- The early feedback from resource allocation and support planning suggests that some families have used the opportunity to significantly change their support package (even in some cases where they have been allocated fewer resources)

#### What has worked less well

- The sites have put in place a series of processes, but having now tested these with a first cohort of families recognise the need for substantial refinement and adaptation
- There is discomfort around the robustness of the resource allocation process and then with its fit to support planning
- An important barrier for the sites has been around their linkages to other parts of their own authority. For example, there have been compatibility issues around the of IT systems, or of transferring the experience of adult social care to the very different environment of young people
- The sites have made some progress in attracting funding streams outside social care, but this has been difficult and so further efforts will be required in Year two.

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*Source: SQW Consulting*

#### Reflections on the evaluation

12.19 A key challenge for the evaluation in the first year has been to operate in a way which has been flexible to the development of sites, but at the same time could ensure that as robust data as possible was generated in the timescale available. Key in this has been the issue of time, to:

- understand the development of each and log the issues faced as they came up, so that we could return and ask how they were being resolved
- baseline the families as near as possible to them joining the pilot, which given recruitment has been spread over several months in six locations was not straightforward
- encourage sites, through the support team, to recognise the timescales involved and to recruit on target to allow sufficient time for families to experience the IB and report on outcomes.

- 12.20 Having worked through these issues, the evaluation is now well placed to deliver a range of results in twelve months. In particular we have in place good relationships with each of the sites to enable us to continue to gather information on their costs and processes as they move now to complete the support plans for the participating families and then to monitor and review these over the coming year. We also anticipate that further funding streams will be drawn in to the packages in some areas, and this will further enhance the variety of experience for the participating families. The planned further area based case study work alongside the more detailed thematic case studies will enable more to be learned about these implementation issues.
- 12.21 When the evaluation reports in 12 months time it will contain feedback about families who will have had their IB live for a period of around eight months. This update of the baseline data reported above from parents and young people will enable any changes in key outcomes to be assessed from a number of perspectives and on the basis of distance travelled. This in turn can be assessed against the cost involved to provide a view on cost effectiveness.
- 12.22 The range of family types, of disabilities faced and approaches should provide some scope to differentiate the circumstances in which the IB leads to improved outcomes. Similarly, it will be intriguing to see in what ways outcome change in relation to the comparative monetary value of the IB to previous provision, and to previous satisfaction with the support received.
- 12.23 We would also caution that the overall number of families participating is relatively small and so the amount of conclusive analysis by sub-group may be limited. This will depend on the frequency of any shifts that are observed. Similarly, any changes observed will of course be only short term. Building on the points around ambition above, it is possible that more refined packages will develop over time, or that wider family outcomes, say in terms of employment, will only become apparent once certain prior conditions around satisfaction with care have been addressed. Such issues have been recognised since the beginning of the pilot programme and could only be resolved by an extended study period.
- 12.24 Overall however the good progress made by sites in the first year, the on-going relationships between the sites and the evaluation team, and the coverage and inferences of the baseline survey data suggest that the overall pilot programme is well placed to provide further and much deeper insights in March 2011. This in turn should provide a much more robust evidence base for policy makers to refine their



thinking around the IB approach as an appropriate means to deliver much needed, high quality support to families with disabled children.

## Annex A: The Common Delivery Model (CDM)

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A.1 The common delivery model provided recommendations on ten essential requirements for the forthcoming pilots. Each requirement was 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**

A.2 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.

A.3 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***

A.4 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.

A.5 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***

A.6 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.

A.7 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**

- A.8 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.
- A.9 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.
- A.10 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**

- A.11 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.
- A.12 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.
- A.13 We recommend that each pilot site facilitates some form of peer support for their IB users.

## **6. Development of appropriate IT systems**

A.14 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.

A.15 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**

A.16 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.

A.17 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**

A.18 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.

A.19 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**

A.20 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.

A.21 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**

A.22 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.

A.23 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.

A.24 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.



## Annex B: The evaluation framework

B.1 Table B-1 sets out the *IB process* component of the framework

Table B-1: IB process evaluation framework

		Core objectives (from the ITT - shown in capital letters) and associated research questions	Method/tools
Evaluation framework component	Context	<p><b>Key contextual conditions</b></p> <ul style="list-style-type: none"> <li>• What are the key contextual conditions in the pilot sites?</li> </ul>	<ul style="list-style-type: none"> <li>• Secondary and administrative data collation</li> </ul>
		<p><b>Pre-IB pilot position – what was the situation prior to the IB pilot?</b></p> <ul style="list-style-type: none"> <li>• What existing activity is/was previously undertaken by each pilot site to promote greater user control?</li> <li>• How were local authority/PCT officers involved in the prioritisation and selection of services/support for families with disabled children prior to the pilot?</li> <li>• How were families with disabled children involved in prioritising their needs and selecting their own service/support provision prior to the pilot?</li> <li>• Were resources devolved to families with disabled children prior to the IB pilot? And if so, which funding streams were devolved and what restrictions were imposed on their use?</li> <li>• To what extent did local authority/PCT staff promote or resist greater user control?</li> <li>• What prior knowledge did local authority/PCT staff have of IB provision and what were their attitudes towards this form of provision?</li> <li>• How willing were providers to respond to user-led provision?</li> </ul>	<ul style="list-style-type: none"> <li>• Case study research</li> </ul>
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		<b>Core objectives (from the ITT - shown in capital letters) and associated research questions</b>	<b>Method/tools</b>
<b>Objectives</b>	<p><b>Local objectives:</b></p> <ul style="list-style-type: none"> <li>• What was the rationale for becoming an IB pilot?</li> <li>• What are the main objectives of each pilot site?</li> <li>• How many beneficiaries and which target group (or theme) does each pilot site intend to recruit?</li> </ul>		<ul style="list-style-type: none"> <li>• Pilot site delivery plan</li> <li>• Case study research</li> </ul>
	<p><b>Assessment of each pilot site against the CDM</b></p> <ul style="list-style-type: none"> <li>• To what extent does each of the pilot areas already comply with the CDM, i.e. what is the starting point of each area?</li> <li>• What was the rationale for implementing the relevant components of the CDM model prior to the inception of the IB pilot?</li> <li>• How does each pilot intend to implement each component of the CDM and why have they chosen the relevant methods of implementation?</li> <li>• Which of the components of the CDM are likely to be the most challenging to achieve and why?</li> <li>• Which of the components of the CDM are likely to require significant resources to achieve and why?</li> </ul>		<ul style="list-style-type: none"> <li>• Pilot site delivery plan</li> <li>• Case study research</li> </ul>
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	Core objectives (from the ITT - shown in capital letters) and associated research questions	Method/tools
<b>Inputs</b>	<p><b>What were the main financial inputs to the process? (see chapter 4 for more details)</b></p> <p><i>Pilot and additional funding:</i></p> <ul style="list-style-type: none"> <li>• How much funding was awarded by the former DCSF to deliver the pilot?</li> <li>• How much additional funding was required to deliver the pilot and what was the source(s) of this funding?</li> </ul> <p><i>Implementing the CDM:</i></p> <ul style="list-style-type: none"> <li>• How much did it cost to implement the CDM? What were the costs for the individual elements of the CDM and how these were used.</li> <li>• What other costs were incurred during the set-up of the pilot?</li> </ul> <p><i>Existing services:</i></p> <ul style="list-style-type: none"> <li>• Is the provision of an IB associated with additional costs/savings relative to traditional service provision – consideration should be given to the fixed costs of delivery, the cost associated with engaging a beneficiary and the cost associated with the particular form of service provision?</li> </ul> <p><i>Ongoing costs:</i></p> <ul style="list-style-type: none"> <li>• How much per year does/will the IB pilot cost to run e.g. salaries, training, ongoing provision of advocacy and brokerage services etc.?</li> <li>• How will the ongoing costs be used?</li> <li>• How does this compare to existing arrangements?</li> </ul> <p><i>Funding streams pooled/aligned/integrated:</i></p> <ul style="list-style-type: none"> <li>• Which funding streams/sources/notional services have been drawn together to form IB packages? What restrictions have been imposed on the use of each funding stream? Will this arrangement change over time, for example, to include more funding streams?</li> <li>• How does this compare to existing arrangements?</li> </ul>	<ul style="list-style-type: none"> <li>• Process monitoring tool</li> <li>• Case study research</li> </ul>
	<p><b>What were the main non-financial inputs to the process?</b></p> <ul style="list-style-type: none"> <li>• Who else has been involved in helping to set up and manage the delivery of the pilot? And to what extent have they been involved?</li> <li>• Which other initiatives have provided in-kind contributions to help set up and manage the deliver of the pilot e.g. the Short Breaks Programme?</li> </ul>	<ul style="list-style-type: none"> <li>• Process monitoring tool</li> <li>• Case study research</li> </ul>
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		Core objectives (from the ITT - shown in capital letters) and associated research questions	Method/tools
<b>Process and activities</b>	<p><b>Implementation of the CDM</b></p> <ul style="list-style-type: none"> <li>• Did the IB pilot work build on existing user control mechanisms/interventions? If so, how?</li> <li>• How have each of the ten components of the CDM been implemented? For example, how were IB funds allocated and did the allocation take account of both the needs of the disabled child and their family?</li> <li>• How were beneficiaries recruited to take part in the pilot and why was this process chosen? Were all families with disabled children eligible to take up the IB offer or did the pilot site develop eligibility criteria?</li> <li>• What additional activities/mechanisms have been set-up to deliver the pilot and why?</li> </ul>	<ul style="list-style-type: none"> <li>• Case study research</li> </ul>	
	<p><b>Partnerships and networks</b></p> <ul style="list-style-type: none"> <li>• What partnerships and networks have been set up as a result of the pilot?</li> </ul>	<ul style="list-style-type: none"> <li>• Case study research</li> </ul>	
	<p><b>Requirement for existing services</b></p> <ul style="list-style-type: none"> <li>• What traditional service provision is running in parallel to IB provision in each of the pilot sites? And which components of this provision would remain beyond the lifetime of the pilot to avoid double funding?</li> </ul>	<ul style="list-style-type: none"> <li>• Case study research</li> </ul>	
	<p><b>Auditing and accountability</b></p> <ul style="list-style-type: none"> <li>• What auditing/reviewing processes was the family/manager of the IB funds required to undertake? And how frequently were these undertaken?</li> <li>• How did the pilot sites verify the auditing process? And how were disputes/appeals dealt with?</li> </ul>	<ul style="list-style-type: none"> <li>• Case study research</li> </ul>	
	<p><b>IDENTIFY ANY CRITICAL BARRIERS EXPERIENCED BY THE PILOT AUTHORITIES AND PCTS TO THE SUCCESSFUL IMPLEMENTATION OF IBs, AND RECORD SUCCESSFUL APPROACHES TO ADDRESSING THOSE BARRIERS</b></p> <p><b>Barriers and critical success factors</b></p> <ul style="list-style-type: none"> <li>• What are the main barriers to the set-up and delivery of IBs? What evidence is there of these barriers and how have these been addressed?</li> <li>• What critical success factors are necessary to ensure the effective delivery of IBs? What evidence do you have to illustrate your view?</li> </ul>	<ul style="list-style-type: none"> <li>• Case study research</li> </ul>	

Core objectives (from the ITT - shown in capital letters) and associated research questions		Method/tools
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<b>Results/outputs</b>	<p><b>Implementation of the CDM</b></p> <ul style="list-style-type: none"> <li>• How has the pilot site implemented the 10 components of the CDM:</li> <li>➤ Set up appropriate governance and management structures, including local authority, health, education and adults services staff?</li> <li>➤ Implemented an effective change management programme?</li> <li>➤ Undertaken sufficient and effective awareness raising/information dissemination exercise(s) for potential beneficiaries?</li> <li>➤ Set up effective advocacy and/or support brokerage mechanisms for their IB users?</li> <li>➤ Facilitated peer support for their IB users?</li> <li>➤ Developed appropriate IT systems to monitor and review the activities of the pilot?</li> <li>➤ Developed an effective resource and funding allocation system?</li> <li>➤ Provided a range of deployment options for the management of IB funds?</li> <li>➤ Stimulated the provider market to respond to the needs of the IB users?</li> <li>➤ Engaged providers and parents/disabled young people in the development of the pilot?</li> <li>• If all 10 components have not been implemented, which components are absent, what are the reasons for this and what has been done instead?</li> </ul>	<ul style="list-style-type: none"> <li>• Case study research</li> </ul>
	<p><b>Effectiveness of the recruitment process</b></p> <ul style="list-style-type: none"> <li>• How many potential families expressed an initial interest in taking part in the pilot e.g. how many potential beneficiaries attended awareness raising/information sessions?</li> <li>• How many families are actively engaged in the process?</li> <li>• How many support plans have been developed and finalised and in what timescales were they completed (measure of intermediate retention)?</li> <li>• How many families are in receipt of an IB relative to the target number and in what timescales did this occur (measure of sustained retention)?</li> <li>• How many families have dropped out of the Programme, at what point did they drop out and why?</li> </ul>	<ul style="list-style-type: none"> <li>• Family monitoring tool</li> <li>• Family survey</li> </ul>

		Core objectives (from the ITT - shown in capital letters) and associated research questions	Method/tools
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<b>Outcomes</b>		<p><b>ASSESS THE RELATIVE IMPORTANCE OF THE 10 FACTORS OF THE COMMON DELIVERY MODEL TO THE SUCCESSFUL IMPLEMENTATION OF IBs</b></p> <p><b>Effectiveness of the CDM</b></p> <ul style="list-style-type: none"> <li>• How have each of the components of the CDM supported the effective and successful delivery of the pilot? Which components have been essential to the process? – <i>assessment of this question will be linked to the number of beneficiaries who are in receipt of an IB and number of beneficiaries who have dropped out of the process</i></li> <li>• How satisfied were beneficiaries with the individual elements of the CDM? – <i>this question also features in the family journey framework</i></li> <li>• How has the process changed the behaviour of those directly and indirectly involved? <i>This may include:</i> <ul style="list-style-type: none"> <li>➤ Staff more willing to promote IBs to potential beneficiaries</li> <li>➤ Improved understanding of IBs has increased staff confidence to support the facilitation of IBs</li> <li>➤ Increased partnership working</li> </ul> </li> <li>• How has the process changed the way in which services are provided to families? <i>This may include:</i> <ul style="list-style-type: none"> <li>➤ Providers have changed their perceptions/attitudes towards user-led provision</li> </ul> </li> <li>• Has the process helped to improve safeguarding, e.g. by helping to identify families that could be at risk at an earlier stage?</li> </ul>	<ul style="list-style-type: none"> <li>• Case study research</li> <li>• Family focus groups</li> <li>• Family monitoring tool</li> </ul>
<b>Impact</b>		<ul style="list-style-type: none"> <li>• How has the process changed the way in which services are provided to families over the longer term? <i>This may include:</i> <ul style="list-style-type: none"> <li>➤ Providers have increased their flexibility and capacity to respond to user-led service provision</li> <li>➤ Formation of new providers and services</li> <li>➤ Assessment processes are now integrated</li> <li>➤ Improved and increased pooling of funding</li> <li>➤ Quality of provision has improved</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Case study research</li> </ul>

	<b>Core objectives (from the ITT - shown in capital letters) and associated research questions</b>	<b>Method/tools</b>
	<ul style="list-style-type: none"> <li>➤ Local authority/PCT has undergone a system transformation/significant cultural change</li> <li>➤ Local authority/PCT have developed plans to continue/develop their IB provision</li> </ul>	

B.2 Table B-2 sets out the *family journey* component of the framework:

Table B-2: IB family journey evaluation framework

		Core objectives (from the ITT - shown in capital letters) and associated research questions	Method/tools
Evaluation framework component	Context	<ul style="list-style-type: none"> <li>• What are the characteristics of the families?</li> </ul>	<ul style="list-style-type: none"> <li>• Family registration form</li> </ul>
		<p><b>Pre-IB pilot position – what was the situation prior to the IB pilot?</b></p> <ul style="list-style-type: none"> <li>• How were families with disabled children involved in prioritising their needs and selecting their own service/support provision prior to the pilot? <i>For example:</i> <ul style="list-style-type: none"> <li>➤ In receipt of a Direct Payment</li> <li>➤ Had support from a Lead Professional</li> <li>➤ Local authority/PCT staff involved family and disabled child in the service-planning process</li> </ul> </li> <li>• What was the baseline position of the family and disabled child/young person in relation to satisfaction with existing service provision and how do they rate themselves against the potential measures of progress set out by the evaluation e.g. control over daily life, level self-confidence etc.?</li> </ul>	<ul style="list-style-type: none"> <li>• Family registration form</li> <li>• Family survey</li> <li>• Survey of professionals</li> </ul>
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		Core objectives (from the ITT - shown in capital letters) and associated research questions	Method/tools
Objectives	Participation objectives:	<ul style="list-style-type: none"> <li>• What do the family/disabled child hope to achieve by taking up the IB offer?</li> </ul> <p><i>For example:</i></p> <ul style="list-style-type: none"> <li>➤ Increased access to appropriate services</li> <li>➤ Increased control over daily life</li> <li>➤ Increased choice of service providers</li> <li>➤ Improved quality of life</li> <li>➤ Greater continuity of care</li> <li>➤ Improved quality of care</li> </ul>	<ul style="list-style-type: none"> <li>• Family survey</li> </ul>
	↓		
Inputs	Time/effort contributed towards setting up and managing the IB	<ul style="list-style-type: none"> <li>• How much time/effort did the family/disabled child contribute towards the set-up process which resulted in receipt of IB funds?</li> <li>• How much time/effort did the family/disabled child contribute towards managing the IB, i.e. accessing appropriate services and implementing the IB support plan?</li> </ul>	<ul style="list-style-type: none"> <li>• Family survey</li> <li>• Case study research</li> </ul>
	PROVIDE A COST COMPARISON OF (A) THE COSTS TO THE LOCAL AUTHORITY AND PCT OF IMPLEMENTING IBS FOR DISABLED CHILDREN AND (B) THE COSTS OF PROVISING SERVICES THROUGH CURRENT ARRANGEMENTS	<p><b>How much funding was allocated to the family/disabled child?</b></p> <ul style="list-style-type: none"> <li>• How much funding was allocated to the family/disabled child? Does the total amount represent the allocation calculated using the resource and funding allocation model or were adjustments made? If adjustments were made, what were they?</li> <li>• How does this compare to existing arrangements?</li> </ul>	<ul style="list-style-type: none"> <li>• Family monitoring tool</li> </ul>
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		Core objectives (from the ITT - shown in capital letters) and associated research questions	Method/tools
<b>Process and activities</b>	<p><b>What activities did the family/disabled child undertake to receive an IB?</b></p> <p><i>For example:</i></p> <ul style="list-style-type: none"> <li>• Meetings with local authority/PCT staff</li> <li>• Attended training to further understanding of IBs and what they could potentially offer</li> <li>• Support planning</li> <li>• Capacity building to understand the potential funding deployment mechanisms that could be used</li> </ul>	<ul style="list-style-type: none"> <li>• Family survey</li> <li>• Case study research</li> </ul>	
	<p><b>How were the IBs funds managed and by whom?</b></p> <p><i>For example:</i></p> <ul style="list-style-type: none"> <li>• Family or disabled young person is paid the budget and manages the money themselves</li> <li>• A third party is set up to act on behalf of the disabled child and their family, which holds and manages the money</li> <li>• The IB is paid directly to a service provider who manages the money through an Individual Service Fund</li> <li>• The care manager or the local authority/PCT acts on behalf of the disabled child and their family and organises services provision based on their allocated budget</li> </ul>	<ul style="list-style-type: none"> <li>• Family survey</li> <li>• Case study research</li> </ul>	
	<p><b>How did the family/disabled child access the appropriate services and implement the IB support plan?</b></p> <p><i>For example:</i></p> <ul style="list-style-type: none"> <li>• Worked through a support broker who supported the family/disabled child to access the appropriate services</li> <li>• Worked through a peer support network who provided information on where to access the appropriate services</li> <li>• Worked through the local authority/PCT to access a preferred provider list who were able to provide the appropriate services</li> </ul>	<ul style="list-style-type: none"> <li>• Family survey</li> <li>• Case study research</li> </ul>	
	<p><b>Auditing and accountability</b></p> <ul style="list-style-type: none"> <li>• What auditing/reviewing processes was the family/manager of the IB funds required to undertake? And how frequently were these undertaken?</li> </ul>	<ul style="list-style-type: none"> <li>• Case study research</li> </ul>	

	<b>Core objectives (from the ITT - shown in capital letters) and associated research questions</b>	<b>Method/tools</b>
	<p><b>IDENTIFY ANY CRITICAL BARRIERS EXPERIENCED BY THE PILOT AUTHORITIES AND PCTS TO THE SUCCESSFUL IMPLEMENTATION OF IBS, AND RECORD SUCCESSFUL APPROACHES TO ADDRESSING THOSE BARRIERS</b></p> <p><b>Barriers and critical success factors</b></p> <ul style="list-style-type: none"> <li>• What were the main barriers to accessing and managing an IB? What evidence does the family/disabled child/local authority/PCT/provider have to illustrate this view?</li> <li>• What critical success factors are necessary to ensure the effective delivery of IBs? What evidence does the family/disabled child/local authority/PCT/provider have to illustrate this view?</li> <li>• How satisfied were families with the individual elements of the CDM and which elements proved to be critical success factors? – <i>this question also features in the IB process framework</i></li> </ul>	<ul style="list-style-type: none"> <li>• Family survey</li> <li>• Family focus groups</li> <li>• Case study research</li> <li>• Depth interviews with beneficiaries who drop out</li> </ul>
	↓	
<b>Results/outputs</b>	<p><b>What were the immediate and measurable results of the pilot?</b></p> <ul style="list-style-type: none"> <li>• How many support plans have been developed and finalised (measure of intermediate retention)?</li> <li>• How many families are in receipt of IB funds relative to the target number (measure of sustained retention)?</li> <li>• How many families dropped out of the pilot and at what point did they drop out? Why did beneficiaries drop out of the pilot?</li> <li>• Which services did families access using their IB funds? Did the families encounter any difficulties in accessing appropriate services?</li> <li>• How has IB provision differed from traditional service provision?</li> </ul>	<ul style="list-style-type: none"> <li>• Family monitoring tool</li> <li>• Family survey</li> <li>• Depth interviews with families who drop out</li> </ul>
	↓	
<b>Outcomes</b>	<p><b>EVALUATE WHETHER PROVISION SECURED THROUGH AN IB IMPROVED OUTCOMES FOR SOME, OR ALL, DISABLED CHILDREN AND FAMILIES THAN PROVISION THROUGH EXISTING ROUTES</b></p> <p><b>TEST WHETHER THE IB PILOTS RESULT IN SOME, OR ALL, DISABLED CHILDREN AND THEIR FAMILIES REPORTING INCREASED LEVELS OF SATISFACTION WITH THE EXPERIENCE OF GAINING SERVICE PROVISION THROUGH AN IB</b></p> <p><b>How has the provision of an IB changed beneficiary perceptions of service performance?</b></p> <ul style="list-style-type: none"> <li>• Increased user satisfaction with service provision (NI 54)</li> </ul>	<ul style="list-style-type: none"> <li>• Family survey</li> <li>• Case study research</li> <li>• Survey of professionals</li> </ul>

	Core objectives (from the ITT - shown in capital letters) and associated research questions	Method/tools
	<ul style="list-style-type: none"> <li>• Increase control over daily life</li> <li>• Increased personal costs</li> <li>• Increased access to more appropriate services</li> <li>• Greater continuity of care</li> <li>• Improved quality of care</li> <li>• Fewer unmet needs</li> </ul>	
Impacts	<p><b>How has the provision of an IB changed the behaviour and well-being of beneficiaries and their perceptions of service performance?</b></p> <p><i>Consideration will be given to the effects on both the disabled child/young person and their family.</i></p> <p><i>Outcomes to be explored:</i></p> <ul style="list-style-type: none"> <li>• Increased self-confidence of the disabled child and increased parental confidence</li> <li>• Improved health (self perception measure, which is closely associated with general well being) of both family and disabled child</li> <li>• Improved quality of life</li> <li>• Increased range of social and economic opportunities available to both the family and disabled child</li> <li>• Increased social engagement and participation in the community</li> <li>• Increased opportunities for independent living</li> <li>• Increased sense of safety when undertaking activities both inside and outside of the home/reduced family anxiety associated with child undertaking activities inside and outside of the home</li> <li>• Reduction in family stress levels</li> <li>• Strengthened family units</li> <li>• Increased labour market participation or engagement in non-compulsory education</li> <li>• Increased educational attainment of disabled child/siblings</li> </ul>	<ul style="list-style-type: none"> <li>• Family survey</li> <li>• Survey of professionals</li> </ul>

## Annex C: The activities of the support team

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### Introduction

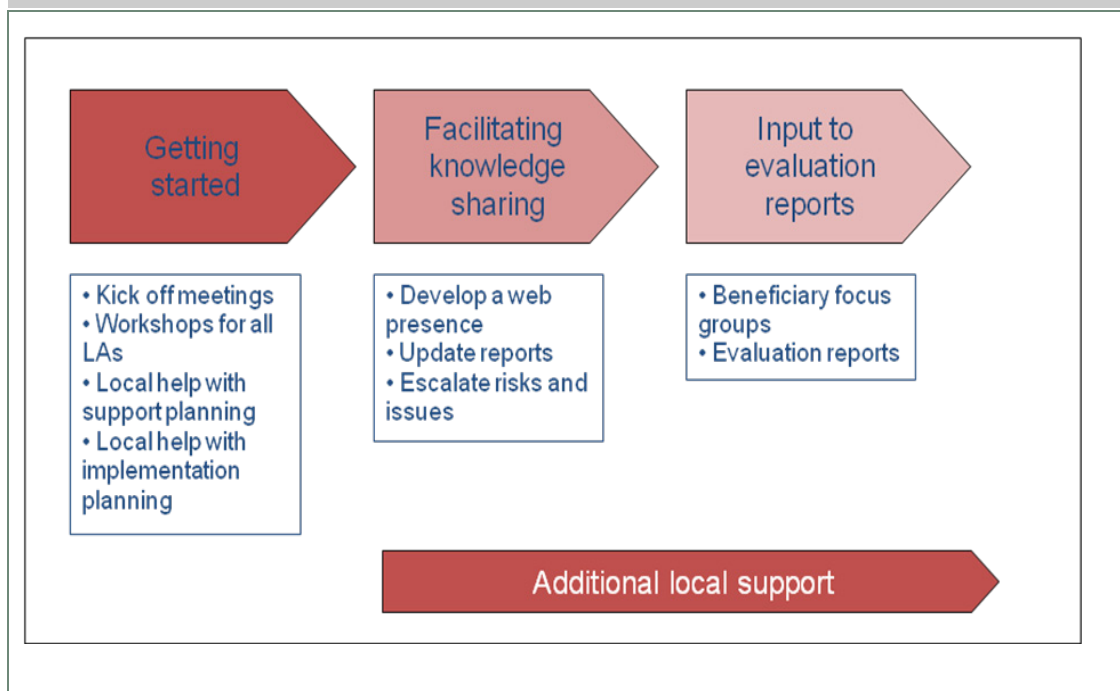
- C.1 The sites taking part in the pilot have received support commissioned by the former DCSF from two external organisations: iMPower and Helen Sanderson Associates (HSA). This annex provides an update on the activities undertaken by the support organisations.

### iMPower

#### **Overview**

- C.2 iMPower have undertaken a 'support and challenge' role as part of the programme. This has been a relatively 'light touch' approach with our contact with sites spread over the full length of the pilot. The original planned approach is illustrated in the Figure C-1:

Figure C-1: Overview of iMPower planned approach



Source: iMPower

- C.3 It became clear during the initial stages that local support and knowledge sharing could be better achieved in the main through a series of workshops where the local authorities could get together to discuss progress, issues and have presentations on relevant topics, rather than the intended series of visits to individual sites. The

latter has instead been used in circumstances where issues have arisen in specific areas.

C.4 iMPower's work split into two distinct phases.

- Support on implementation planning to ensure sites had robust plans in place to develop and deliver their offering; and
- Challenge and knowledge sharing, including providing additional help to those sites who were falling behind schedule and organising workshops.

Specific activities

C.5 The specific activities undertaken by iMPower are as follows.

***Initial workshops***

C.6 iMPower attended the launch workshop in April 2009 where they introduced themselves and their role, as well as meeting the key people from each site. They then ran a further workshop in June 2009 where they introduced the role in more detail and in particular introduced the Implementation Plan template that they had developed.

***Implementation planning***

C.7 iMPower's role in implementation planning was threefold. They:

- Visited each pilot site to work through the template and provided support in completing the template
- Co-ordinated the review of the first draft of plans and fed back to the sites; and
- Carried out an additional visit to one site which needed further support.

***Workshops***

C.8 iMPower has facilitated a series of workshops hosted by the former DCSF and by pilot sites. The agenda of each session varies but has generally included:

- Updates from the former DCSF, SQW and iMPower;
- A presentation by the host site;
- A brief update from each site;

- An external speaker (for example the Children’s Society, Personal Health Budgets team from the Department of Health); and
- A discussion on a relevant topic (for example support planning, commissioning).

***Additional challenge and support***

C.9 iMPower has carried out additional visits to one site where they were behind schedule. These visits provided an additional level of challenge as well as support and advice to sites on how they could catch up.

***Knowledge sharing through the website***

C.10 iMPower set up and administered a knowledge sharing website using the Commissioning Support website. This site uses a ‘social networking’ approach for those involved in the pilot to share and access useful information.

***Ongoing reporting to the former DCSF***

C.11 Since December 2009 iMPower has been providing regular updates to the former DCSF on the progress of each site against the Common Delivery Model. This, linked to the monthly progress reports was developed to provide the former DCSF with assurance about progress of the sites and so the overall pilot programme.

***Adding value***

C.12 iMPower’s involvement in the pilot has added value to the development of the pilots in a number of ways. Examples include:

- Providing support to help the sites think through their implementation plans. The sites presented a mix of experience in this area and in two particular cases iMPower perceive that the additional support enabled these sites to turn initially weak first drafts into structured and detailed plans
- Developing a forum to share knowledge. It was recognised at an early stage that the best use of iMPower’s resource was to facilitate conversations between the sites, and this led to setting up the ongoing series of workshops. As the workshops have taken place iMPower has learned from them and strived to make the content more relevant and to provide useful outputs for the sites.

- Providing extra support where it is required to help sites get up to speed where they have fallen behind. The additional one-to-one support allowed a focus on specific issues and address these.

### ***Lessons learnt***

C.13 There are a number of lessons to be learned from the first year of the pilots in terms of the support and challenge functions:

- Having regular reporting and an escalation process is important to catch issues early and ensure that they are addressed.
- The light touch approach means there can be long gaps between contact with sites. This makes it harder to build a robust relationship with the teams who are implementing the pilots
- As a way of sharing knowledge the website is only as good as the contributions made to it. It has not been easy to get people to use it on a regular basis and this is reflected in a small number of people contributing the majority of information.

### **Helen Sanderson Associates**

C.14 Helen Sanderson Associates (HSA) was engaged to provide specialist support and guidance to sites around support planning.

C.15 All sites were contacted by HSA, to discuss and agree how best they might add value. This process was intended, and has been, led by the sites to ensure that they resource was targeted where it could make most difference in a local context.

C.16 Four sites which have taken up the offer of support from HSA, a range of activities have been delivered. These activities have included:

- Input to guidance and planning documents in several sites
- Attendance and input to events for providers to raise their awareness of the issues that they might face as families exercised choice and control
- A development session with the decision making panel in one area to build their awareness and thinking around IBs and some of the issues that they might face



- Providing support planning training for social workers or others engaged in support planning. One or two day courses for selected groups of staff have been provided in three areas
- Planning Live workshops in two areas which felt that they required support to implement this model.

C.17 In addition, one site has sought additional support through its own resources, in addition to the core former DCSF funded offer. This activity has focussed on very similar activities (Planning Live, provider and family awareness). It reflects an awareness by site staff of the challenges of implementing IBs effectively within their local context.

C.18 Two sites have not taken up this offer of input because they thought that their own staff already had considerable experience of the types of support planning that they wished to offer. In both cases it is possible that further support will be required in year two of the pilots, possibly around planning around health budgets or for groups of social workers with less experience of personalisation approached.

C.19 Some of the other sites have also retained some of their allocation and are in discussions about what further activities might take place next year.

### ***Adding value***

C.20 Across the range of activity described above HSA has been able to add value through:

- Facilitating specific time for practitioners to focus on personalising planning in detail
- Doing much of their training in mixed participant courses resulting in healthy and realistic debates, which in time should assist joint working
- Using their experience of planning to break down tasks and explain how they link together. This should help to ensure that potential planners are fully aware of person centred conversations, how this links to the collation of information and the format of the plans. It should also help planners to aid participants to consider a range of uses for funds.

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