Research Report DFE-RR145

Individual budgets for families with disabled children

Final evaluation report: The IB process

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Department for Education

This research report was commissioned 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Government policy and may make reference to the Department for Children, Schools and Families (DCSF) which has now been replaced by the Department for Education (DFE).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

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, acted as the Project Director of the Evaluation.

Meera Prabhakar, a Senior Consultant at SQW, 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.

1: Introduction

Purpose of this report

1.1 This report is one of three volumes containing the findings from the first two years of the Individual Budgets for disabled children pilot programme. The three volumes cover:

- ***The IB process evaluation****,* which described the approaches adopted to implement the pilot and the lessons emerging – **these issues are contained in this volume**
- *The Family Journey evaluation,* which provides an assessment of the outcomes and distance travelled by participating families
- *The Recommendations and Implications,* which draws together the findings of the evaluation and presents recommendations for the future use of the IB approach.

The Individual Budgets programme

1.2 The personalisation of public services has been a consistent direction of policy over the last few years. This has been maintained by the Coalition Government, with the recent Green Paper[1] including a clear expectation of increased choice and control for young people and families. 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] DFE (2011) *Support and aspiration: A new approach to special educational needs and disability – A Consultation*

1.3 A commitment to pilot IBs for families with disabled children was expressed in Aiming High for Disabled Children[2]. This led the then Department for Children Schools and Families to commission SQW 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, suggested the need to pilot the IB approach for families with disabled children.

1.4 *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 that:

- A series of pilots should be established to test the IB approach
- The activities of the pilots should be guided by a Common Delivery Model (CDM) which set out ten key elements to be addressed by the pilot sites (see Table 1 below for a summary of the elements and refer to Annex A for a detailed description of the CDM).

1.5 Each requirement of the CDM 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.

[2] HM Treasury and Department for Education and Skills (2007) *Aiming High for Disabled Children (AHDC): Better support for families*

Table 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

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

1.6 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 2).

Table 2: IB pilot sites

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

Objectives of the programme

1.7 The IB pilots were originally commissioned to run from April 2009 to March 2011, with a possible extension beyond this period, subject to available funding. Sites received between £200,000 and £280,000 in grant funding over the two years to deliver the pilots.

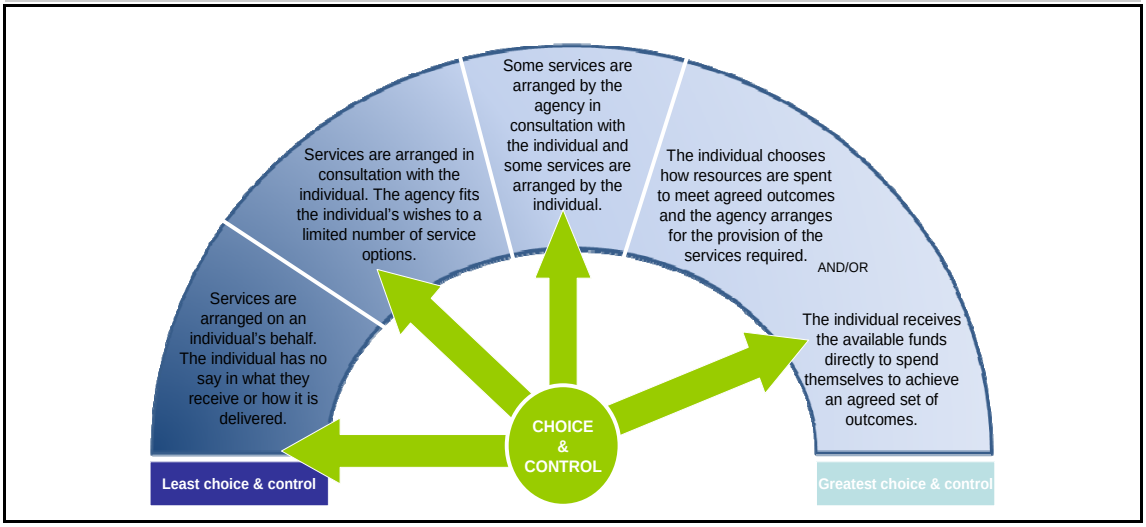
1.8 The activities of each site fed into the national pilot programme, which was set up to establish if an IB:

- Enabled disabled children and their families to have more choice and control over the delivery of their support package
- Improved outcomes for some, or all, disabled children and their families.

1.9 The sites also sought to:

- establish whether or not the IB pilots resulted 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 3, 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 PCTs of implementing IBs for disabled children and the costs of providing services through current arrangements.

Figure 3: Spectrum of choice and control



Source: IB Application Pack

1.10 Individual budgets require a family-centred approach which calls for partnership and integrated service delivery between providers. Therefore each pilot site was set up to be delivered by both local authority and PCT partners. Each local authority was also encouraged to develop their assessment procedures and resource allocation and funding mechanisms. In conjunction with this, the sites were also asked to determine

the exact scope of their funding, where there was an expectation that sites would incorporate as wide a range of service provision and funding streams as possible (i.e. move beyond the devolution of just social care funding) with the exception of school based education funding, which was to be excluded.

An introduction to the evaluation

1.11 The pilots were commissioned to test whether the IB concept and approach worked in practice, and to what extent the approach was cost-effective. This evidence in turn would help to inform any decision on rolling out of IBs. Therefore the evaluation, which sought to assess the progress made during the original two year pilot programme, was to provide an evidence base for both the Department and others wishing to facilitate the provision of IBs to families with disabled children.

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

- evaluate whether provision secured through an IB improved outcomes for some, or all, disabled children and families compared with provision secured through existing routes to accessing services
- test whether the IB pilots resulted 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.

1.13 Thus, the evaluation sought to capture evidence on:

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

1.14 This report seeks to present a detailed assessment of the *process related* progress made by the pilot sites over the original two year pilot programme. As such, the report focuses on the means by which the pilots were set-up and delivered, and the resource and infrastructure requirements associated with the IB approach, where progress is measured against the ten elements of the Common Delivery Model.

1.15 The remainder of the report is structured as follows:

- **Chapter 2: An introduction to the IB Approach and the pilot sites** – presents a summary discussion of the contextual policy landscape and an introduction to the IB pilot sites
- **Chapter 3: Organisational engagement and cultural change –** reviews the actions taken and progress made by the pilot sites against elements 1 (staff and organisational engagement), 2 (change management), 9 (market development) and 10 (engagement of all parties in the development of the pilot) of the CDM
- **Chapter 4: Engaging and involving families** – provides an account of progress made against elements 3 (awareness raising with potential families) and 5 (peer support) of the CDM
- **Chapter 5: Setting up the infrastructure pt I - resource allocation –** provides a detailed description of the development and implementation of element 7 of the CDM - resource allocation – and a comparative analysis of the IB package costs relative to the traditional care packages
- **Chapter 6: Setting up the infrastructure pt II – support planning and the family journey –** describes the mechanics of support planning process (element 4 of the CDM) and then draws both resource allocation and support planning together to illustrates the family journey facilitated in each of the pilot sites. The chapter subsequently sets out progress against elements 6

(development of IT resources) and 8 (provision of a spectrum of choice for the management of IB funding) of the CDM

- **Chapter 7: 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 8: Pilot inputs and cost –** sets out the financial and in-kind costs involved in setting up and running the two year pilot in each of the sites. The chapter subsequently estimates both the set up and running costs that may be associated with an extension of the IB approach to all eligible families with disabled people in the pilot areas
- **Chapter 9: Refining the CDM** – sets out the refined CDM which reflects the experiences and lessons learnt over the course of the IB pilot programme.

1.16 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.

1.17 This report – ***The IB process evaluation report*** – is one of the three main outputs from the study. It should be read in conjunction with:

- *The Family Journey evaluation report,* which provides an assessment of the outcomes and distance travelled by participating families
- *The Recommendations and Implications report,* which draws together the findings of the evaluation and presents recommendations for the future use of the IB approach.

1.18 The main evaluation reports are also accompanied by three sets of additional reports: a set of six case study reports, detailing the activities and progress made by each of the pilot sites; two thematic case study reports, focusing on resource allocation and the means by which safeguarding has been addressed in the IB context; and a technical report, detailing the evaluation approach and a summary of the formal support provision provided to the pilot sites over the two year pilot programme.

Methodology

1.19 The evaluation has gathered information through a number of approaches, as summarised below:

- **Monitoring data** – 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
- **Area case study research** – six pilot specific case studies were undertaken, which sought to explore the context, process and activities of the pilot sites
- **Thematic case study research** – two thematic case studies were undertaken to explore pertinent issues that were highlighted by the pilot sites during the initial stages of the pilot programme. These focused on resource allocation and safeguarding in the IB context
- **Focus groups with participating families** – focus groups were undertaken with a small number of families in each pilot site to gather views on the effectiveness of the process and early service provision
- **Family baseline and follow up surveys** – families were interviewed as close to the point of recruitment on to the pilot as possible to capture their baseline position and subsequently were interviewed again as close to the end of the pilot activity as possible to enable the evaluation to measure distance travelled from the baseline position. In each household, interviews were undertaken with the main carer of the child on the IB pilot programme and the disabled child or young person (CYP) where they were eligible and able to take part - aged 11 or older at the time of the interview and where the main carer and subsequently the CYP gave their consent for the CYP to participate
- **Survey of professionals** – a two-stage professional survey was undertaken in tandem with the family surveys, as a means of producing a comparator set of distance travelled indicators. The survey was completed by the care managers/social workers/relevant professionals who oversaw the pilot families within each of the pilot sites
- **Depth interviews with families that left the pilot** – qualitative in-depth interviews were undertaken with families who had left the pilot to explore their experience of the pilot in more detail and to understand the reasons why these families had left the pilot.

1.20 The methods adopted are descried more fully in the accompanying Technical Report.

2: An introduction to the IB approach and the pilot sites

2.1 This chapter sets out the origins and policy context within which the IB pilot programme was set-up, the direction of travel since that point and draws out the primary messages from the recent DfE SEND Green Paper, which included a future commitment to expand the IB approach. The chapter also provides an introduction to the IB approach and the six pilot sites.

The origins of the IB pilot programme and the policy landscape

2.2 The origins of the IB pilot programme date back to commitments made by the previous Government, which pledged to trial the IB approach for families with disabled children. That is, *Improving Life Chances for Disabled People*[3] originally recommended that IBs should, in principle be extended to families with disabled children and the subsequent *Aiming High for Disabled Children (AHDC)*[4] strategy sought to take forward this recommendation. As such, the IB pilot programme formed one of the multiple work strands of AHDC and was framed to align with the growing social care driven personalisation agenda for disabled children and adults.

Existing approaches used to deliver personalised services

2.3 Personalisation within the children's social care sector originated in the move from institutional care to care in the community. It had been stimulated through a number of approaches prior to the piloting of IBs, which included: direct payments, the budget holding lead professional approach and the use of personal budgets. Each of these formed a pre-cursor to the IB pilot programme and is described in more detail below:

- **Direct Payments** (DP) are available to those with parental responsibility for disabled children and disabled 16 and 17 year olds. Direct payments were introduced by the Carers and Disabled Children Act 2000. The current law concerning direct payments for children can be found in section 17A Children Act 1989, this clause was inserted by the Health and Social Care 2011. This legislation gives local authorities the power to offer a direct payment as long it continues to safeguard and promote the welfare of children

[3] Prime Ministers Strategy Unit (2005) *Improving Life Chances for Disabled People*
[4] HM Treasury and Department for Education and Skills (2007) *Aiming High for Disabled Children (AHDC): Better support for families*

- The **Budget holding lead professional** (BHLP) approach was established following the publication *Support for Parents: The Best Start for Children*[5] which made a commitment to support the increased personalisation of services through the piloting of BHLPs. The approach was proposed to support early intervention for children with additional needs and was based around the *Team Around the Child (TAC)* model, which brought together a range of different practitioners to help and support an individual child. It involved the allocation of low level funding to support the development of a child via: assessment; development of a support plan; and costing and purchasing of services by the BHLP

- **Personal budgets** (PB) allow individuals entitled to social care funding to choose whether they take their budget as a Direct Payment or prefer a local authority officer 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 in its *Vision for adult social care: Capable communities and active citizens*[6] envisaged that by 2013 every adult in receipt of social care will have the opportunity to have a personal budget.

2.4 Each of these approaches sought to embed a person or family-centred approach to service provision, where individuals were put at the centre of the process and therefore were able to influence the types of social care support they received. The IB pilot programme sought to build on the learning derived from these approaches to improve outcomes for families with disabled children.

The IB approach

2.5 The IB approach was built on the premise that it offered:

> *Greater choice and control to families with disabled children…through the drawing together of a series of funding streams and use of an outcomes-based approach…to enable the development and delivery of a holistic and family-led support plan…whose associated funding can be managed in a variety of ways (SQW).*

2.6 It has become increasingly clear that the provision of IBs should be viewed as a form of 'approach' as opposed to an end product, reflecting that it can work across a range

[5] HM Treasury and Department for Education and Skills (2005) *Support for Parents: The Best Start for Children*
[6] Department of Health (2010) *Vision for adult social care: Capable communities and active citizens*

of budgets and includes a series of stages. The IB approach therefore sought to widen the scope of choice and control by drawing together a series of funding streams (i.e. social care plus additional funding streams) to which a child was entitled, to enable the development and delivery of a holistic and user-led support plan which would tailor the support they receive to meet their needs as a whole, rather than being provided with compartmentalised and fragmented support.

Complementary programmes

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

2.8 Lord Darzi announced in the NHS Next Stage Review[7] 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.

2.9 Seventy sites across England were awarded provisional pilot status for personal health budgets. Of these, twenty were selected to participate in 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 currently underway and will run for three years until 2012[8].

2.10 Similarly, through the December 2008 Department for Work and Pensions White Paper [9], the Government set out plans to introduce a right to an individual budget for disabled adults. Under the right, disabled adults who accessed the right to control would be told the monetary value that they were entitled to receive in eligible state support and be able to choose how that money was used to achieve agreed outcomes. The following support services were to form part of the IB packages:

- Access to Work
- Work Choice
- Supporting People
- Disabled Facilities Grants

[7] Department of Health (2008) *High quality care for all: NHS Next Stage Review final report*
[8] Please refer to the Department of Health website for more details http://www.dh.gov.uk/en/Healthcare/Personalhealthbudgets/index.htm
[9] Department for Work and Pensions (2008) *Raising expectation and increasing support: reforming services for the future*

- Community Care Services
- Independent Living Fund.

2.11 The **Right to Control** programme is being trialled for disabled adults in seven local authority areas in England, which are referred to as *trailblazer sites*. Each of these sites falls under the remit of legislation that came into force in 2010, which provides disabled people taking part in the programme with the right described above. Evaluation of these sites will be used to inform decisions about wider roll-out.

Current Government policy

2.12 The commitment to improve the outcomes for families with disabled children was carried forward by the new administration, which from its outset pledged to progress the personalisation agenda for both families with disabled children and disabled adults[10].

2.13 In addition, the Department for Education published a Green Paper - *Support and aspiration: A new approach to special educational needs and disability* - in March 2011, which furthered its commitment to the personalisation of services for families with disabled children. More specifically, the Green Paper highlighted the Government's wish to:

- Give parents the option of a personal budget by 2014, linked to the new 'education, health and care plan', to give them greater control over their child's support, with trained key workers helping them to navigate different services
- Recruit a set of pathfinders to test the best ways to provide a personal budget to children with SEN and/or disabilities, linked to the new plan, building on findings from the current IB pilots.
- The IB pilots have been awarded an additional year of funding to explore how education and health based funding could be incorporated into an Individual Budget for families with disabled children during 2011-12.

[10] *Government Response to the Health Select Committee Report on Social Care* (Third Report of Session 2009-10) to the Health Select Committee; Page 17

The IB pilot sites

2.14 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 delivering this form of activity
- With the capacity and capability to meet the requirements of the pilot within the timescales of the activity.

2.15 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 identified in the sites' applications to become pilots 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 could 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 were expected to explore how an IB package was used by this group and how it compared to existing service users.

2.16 Table 4 sets out the target number of families with disabled children each site proposed to recruit and their chosen target group for the pilot.

Table 4: 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

2.17 The sites provided three primary motivations for their choice of target group: the first related specifically to transition, where the relevant sites 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?

2.18 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. Looking at the position of the pilot sites prior to enrolling on the IB programme, it was evident that all sites had at least 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. Previous relevant experience included:

- Delivery of national programmes – including direct payments and the Short Breaks Pathfinder

- Delivery of pilot initiatives – including the In-Control Dynamite and Taking Control pilots, Budget Holding Lead Professional pilots, the Macintyre Care My Way Project and the Department of Health Adult IB pilot
- Locally based personalisation activities – including the use of person centred planning and lead professional teams.

2.19 The majority of the above experience was 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, the systems set up for adults were often not directly suitable for children as a result of different regulatory frameworks. Therefore, this experience should be used with caution, with an explicit understanding that an adult based system cannot simply be transferred to children.

Why did sites bid to become pilots?

2.20 The sites' rationale in applying to become a pilot 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 approach. 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.

2.21 Looking across the sites, it was evident that they all intended to build on their existing personalisation work/initiatives, which had 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 child-related personalisation activities had better 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.

2.22 Sites had both short and long term objectives for their pilot, which are illustrated in Table 5.

Table 5: 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

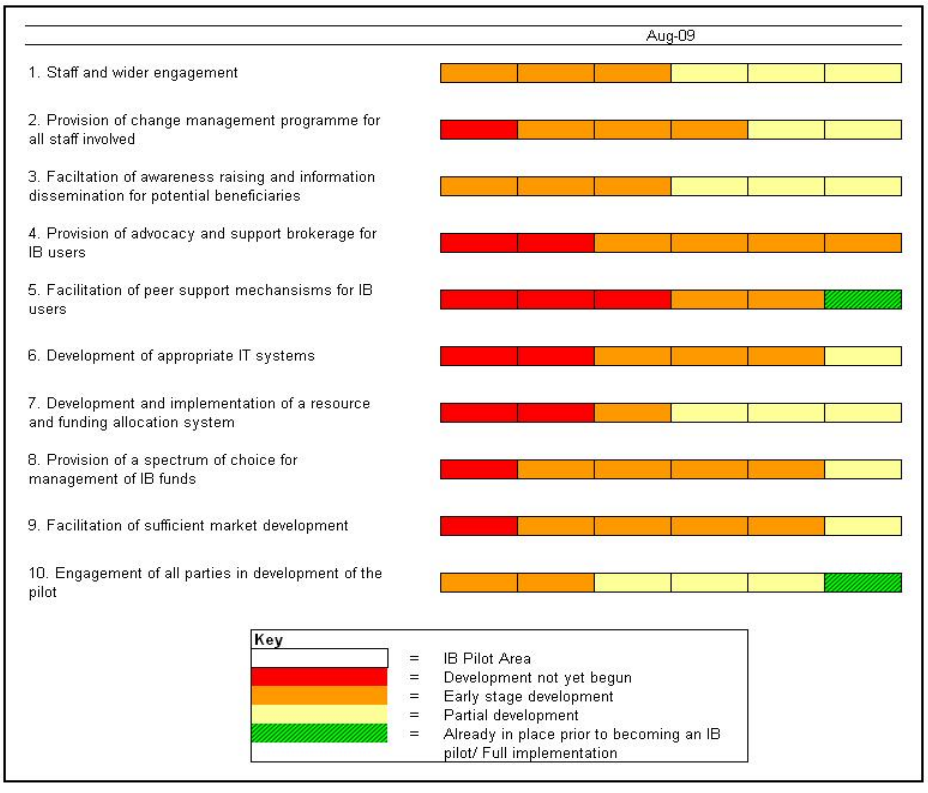
Source: SQW case study research

2.23 The set of objectives indicated 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 needed 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 were to be made following the collation of evidence on its effectiveness.

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

2.24 Figure 6 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 6, which illustrates that overall the 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.

Figure 6: Level of implementation against each element of the CDM, August 2009



Source: SQW pilot monitoring returns

2.25 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.

2.26 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?

2.27 During the application process, each prospective site was asked to illustrate the activities that 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 post-16 education funding
- stimulation of the provider market, which was to be asked to increase the flexibility of provision to families with disabled children.

2.28 The development was intended to take placed in a staged way, where emphasis would be first placed on building staff capacity and the appropriate pilot delivery team, followed by development of the required infrastructure in conjunction with gaining buy-in from partners and the pooling and aligning of relevant funding streams.

Summary

2.29 The IB pilots formed one of a range of activities funded by the Government under the *Aiming High for Disabled Children's (AHDC)* transformation programme, which was delivered from 2008 to 2011 and sought to improve services for families with disabled children. IBs delivered in accordance with the CDM provided a means to test 'how' the IB approach could contribute to meeting the aims of the programme and the wider personalisation agenda.

2.30 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 six 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.

2.31 All of the 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, they intended to build on their existing personalisation work/initiatives that had largely been led by the social care divisions of the relevant local authorities.

2.32 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 needed to evolve to facilitate increased choice and control
- Assess the effectiveness of the IB approach to inform a decision on roll out.

3: Organisational engagement and cultural change

3.1 The IB Scoping Study identified that the effective delivery of an IB approach would be dependent on the commitment of a set of core staff. This group was expected to comprise of both a dedicated pilot delivery team and a set of wider stakeholders, which in combination would: develop and drive the IB approach; champion and communicate the benefits of the approach; promote the necessary cultural change associated with the new form of service provision; and facilitate sufficient development of the provider market, including making any required changes to internal commissioning arrangements within both the local authority and PCT.

3.2 Issues around the *organisational engagement and cultural change are covered by elements 1, 2, 9 and 10 of the CDM*. This chapter reviews the actions taken and progress made by the pilot sites against these elements of the CDM. It also reflects on the actions that are likely to be required as the pilots move beyond the two year programme.

Progress against elements 1, 2, 9 and 10 of the CDM

Element 1: Adequate staff and organisational engagement

3.3 All sites had recruited the majority of their IB-pilot specific staff teams by the end of November 2009. The pilot team comprised 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 also funded contributions from the commissioning, IT, finance and legal teams, to ensure that the pilots were able to draw on particular forms of expertise as and when required.

3.4 Dedicated pilot staff were in the main resourced through secondments and associated back-filling from other parts of the local authority, as a means of drawing on existing expertise and to ensure the sustainability of the IB approach in the event that it proved to be effective. Exceptions to this trend included one site which externally recruited their pilot manager on a fixed term contract, and as a result experienced the loss of this individual a month before the end of the pilot.

3.5 One site recruited a dedicated health IB project officer to oversee the development of the pilot and cultural change within the PCT. This led to the undertaking of health-specific IB scoping activities (these are described in more detail in Chapter 5 of the report).

3.6 A number of the sites suffered delays in recruiting staff, which was caused by two main reasons. The first related to challenges in recruiting appropriately qualified/skilled staff to manage and facilitate the pilot activities. The second reason for delayed staff recruitment related to sluggish or restrictive local authority and PCT recruitment processes.

3.7 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. Moreover, 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.

3.8 Following the recruitment of the 'core' delivery teams, some sites expanded their teams during the course of the pilot to increase their delivery capacity, most often to enable the resource allocation and support planning stages of the process. This involved contributions from social workers, project officers or lead professionals in the main and illustrated a need for significant 'frontline' staff contributions at key stages of the development/delivery process.

3.9 All sites set up appropriate governance structures within the first six months of the pilot, which involved the creation of a pilot specific project board. The project board in turn generally reported to the relevant existing local authority structures, which included: 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.

3.10 Two scenarios of future activity had been considered by the sites beyond the two year pilot programme. These were to: sustain the current pilot activities and therefore honour the arrangements that had been set up for participating families; and to extend the IB approach to a wider group of families. Both scenarios were felt to

require dedicated staff resource of either a similar or smaller nature to that used during the pilot.

Summary

3.11 Table 7 presents a summary of the progress made against element one of the CDM.

Table 7: Progress made on the recruitment of adequate staff and organisational engagement

Summary findings and lessons
• All sites had recruited the majority of their IB-pilot specific teams within the first 6-7 months of the pilot • Some sites experienced delays in recruiting pilot staff as a result of either restrictive internal recruitment processes or shortages of appropriately skilled staff • The sites set up appropriate governance structures, which generally reported 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 more staff at the beginning of 2010 to deliver the resource allocation and support planning stages of the process, as they required significant time inputs from 'frontline' staff.
Actions moving forward beyond the two year pilot
• Sustaining current pilot activities and potential extension of the IB approach to a wider group of families was likely to require dedicated staff resource of a smaller or similar scale to that used during the pilot • It was generally felt that the pilot manager and project officers in particular should be retained beyond the programme, albeit in different roles, which focused on embedding the IB approach and associated learning into existing structures.

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

3.12 The management of cultural and organisational change was acknowledged by the majority of pilot sites as a key challenge at the outset of the programme. The rationale for this was two-fold:

- as the means by which the pilot was to be delivered was yet to be explicitly defined by each site at the beginning of the programme, it was difficult to anticipate the scale and extent to which cultural change activities would be required
- although the pilot teams had senior level buy-in from their social care colleagues, the extent to which health and education colleagues were engaged in the personalisation agenda was in most cases unclear to the pilot delivery teams.

3.13 As a result all of the sites undertook some form of change management process which had involved awareness raising and information sessions. The activities

varied considerably and were heavily dependent on the starting point of each site. That is, sites with more experience of child-related personalisation tended to adopt more informal processes, as the required cultural change was perceived to have begun prior to the pilot. Other sites had delivered more formal training sessions, which included the development and dissemination of written guidance, the facilitation of resource allocation and support planning training and meetings with key budget holders and service leads.

3.14 The sites focused their efforts on engaging the teams and individuals that were 'more accessible' during the first year of the pilot. This meant that the majority of the change management activity that took place over this period focused on the social care workforce and pilot delivery teams.

3.15 During the second year of the pilot, the sites widened their engagement strategies and sought to gain 'buy-in' from additional stakeholders, which included the PCT and pre and post 16 education colleagues. This involved discussion between the pilot team and relevant stakeholders, the majority of which were ongoing at the end of the two year programme. As such, this engagement had proved challenging in most cases, where it was felt that engagement from both PCT and education colleagues had been limited as a result of:

- The small scale and uncertain future of the pilot
- Personalised approaches being taken forward at different times in other policy areas which meant they had been introduced to the concept much later than their social care colleagues and therefore led them to be more risk averse in relation to the IB pilot
- A lack of capacity and resource to engage in a meaningful way due to more immediate priorities within their own policy area.
- As such, staff in other service areas generally had a less developed understanding of the objectives of the IB programme and were 'less willing to engage'.

3.16 When asked about the effectiveness of the change management activities that had been facilitated, 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 an ongoing

challenge. For example, one site stated it had found that the general perception amongst the area's social workers was that the IB approach was more labour intensive than traditional approaches 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 implied that the process of change management needed to be undertaken in stages and specifically tailored to meet the needs of the particular audience, which may require different approaches and intensity of approach being used for different staff groups/teams.

3.17 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 had facilitated increased joint-working and a shared understanding of the pilot.

3.18 Looking beyond the two year pilot programme, the majority of the sites were seeking to use the evidence and learning produced from their activities to engage additional budget-holders and operational teams. The sites added that the recent DfE Green Paper, which had committed to extending the remit of the IB pilot programme to include education funding and more effective engagement from health, would support them in doing so.

Summary

3.19 Table 8 presents a summary of the progress made against element two of the CDM.

Table 8: Progress made on the provision of a change management programme for all staff involved in the pilots

Summary findings and lessons
• All sites adopted formal, informal or a mixed approach to change management, which 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 focused their initial efforts on engaging and raising awareness in the teams that were the most accessible during the first year of the programme. This included the children's social care team and excluded the PCT and education delivery teams in the main • During the second year of the pilot, the sites widened their engagement strategies and sought to gain 'buy-in' from additional stakeholders, which included the PCT and pre and post 16 education colleagues. This involved discussion between the pilot team and relevant stakeholders, the majority of which were ongoing at the end of the two year programme. As such, this engagement had proved challenging in most cases, where it was felt that engagement from both PCT and education colleagues had been limited as a result of: the small scale and uncertain future of the pilot; difference in policy approaches to personalisation, which led them to be more risk averse in relation to the IB pilot; and a lack of capacity and resource to engage in a meaningful way. • The experience of the sites implied that the process of change management needed 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.
Actions moving forward beyond the two year pilot
• Looking beyond the two year pilot programme, all sites were seeking to use the evidence and learning produced from their activities to engage additional budget-holders and operational teams. The sites added that the recent DfE Green Paper, which had committed to extending the remit of the IB pilot programme to include education funding and more effective engagement from health, would support them in doing so.

Element 9: Facilitation of sufficient market development

3.20 Prior to the inception of the IB programme, demand-led development, i.e. market development that had been led by families as opposed to professionals, had been stimulated through the general evolution of the AHDC strategy and associated programmes including the Short Breaks Pathfinder programme. Therefore, although

it was widely recognised that market development or provider-related cultural change was likely to be limited as a result of the small size of the pilots, sites intended to build on the existing development that had been undertaken. As such, the challenge was to ensure that providers were prepared for the future and in a position to be better able to support people if the pilot was rolled out.

3.21 The majority of the sites begun to focus their attention on developing the market during the second year of the pilot to ensure that the required forms of provision were available for participating families as they moved through support planning. In most cases this development was intended to be undertaken in response to emerging demand whereby families suggested and developed ideas during the support planning stage and the sites subsequently investigated ways to stimulate the market.

3.22 Each of the sites was asked to provide their reflections on the willingness of providers to respond to user demand. They reported that this had begun to occur prior to the IB pilot as a result of the work of the Short Breaks Programme in particular. A number of local providers were beginning to offer services in a more individualised manner. However, this ongoing change had been exhibited mainly by providers of Short Breaks, as opposed to in more universal or community based settings.

3.23 Therefore, provider-related cultural change in the IB context involved a focus on the development of community capacity to enable families to access local and universal services, as a means of enabling 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.

3.24 Community-based provision was developed using a variety of methods including:

- the facilitation of provider forums, where the concepts of personalisation, individual level commissioning and inclusion were introduced and discussed
- the use of inclusion workers, who went out into the community to build capacity within individual organisations and to source the services that families would like to access
- the provision of pump priming funding to organisations to build capacity to deliver services for disabled children; and through CVS hubs within a locality.

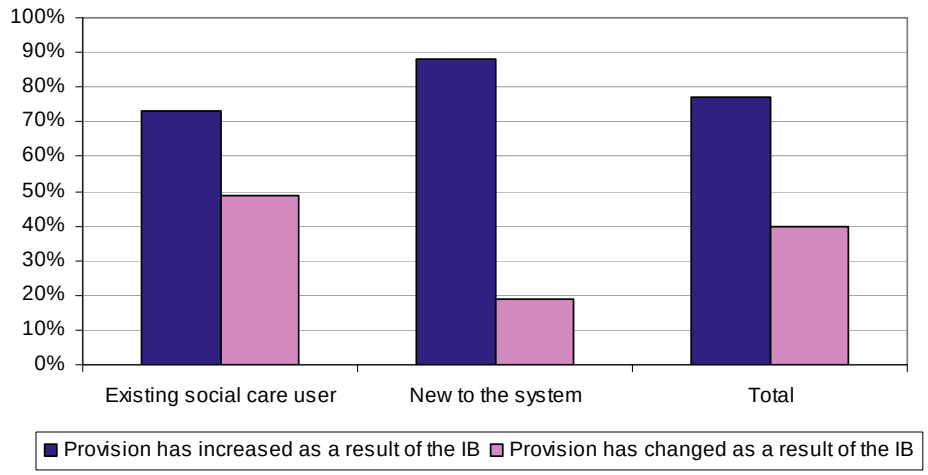
3.25 The need to develop community based services was informed by the demands of families, albeit with differing demands originating from families that had previously accessed social care services and families that were newcomers to the social care system. A number of these demands focused on a desire to recruit an appropriate Personal Assistant (PA) to provide support to enable the child/young person to take part in mainstream activities that they had been previously unable to access.

3.26 Figures 9 and 10 use data gathered from the follow up parent/carer survey, to understand the changes in service provision that were made as a result of the provision of an IB. The first of these figures shows the means by which families chose to modify their use of PAs as a result of their IB (where 55% of families that were in receipt of their IB funding had modified this activity). Of this group, 77% increased their use of PAs and 40% chose to use PAs in a different way, which included sourcing more age appropriate PAs (which were closer in age to the disabled child or young person) and using PAs to support the relevant children/young person to undertake new forms of activity.

3.27 Figure 9 demonstrates that newcomers to the system were more likely to increase, but less likely to modify their use of PAs. This reflects that newcomers were much less likely to have been receiving these services previously. Interestingly, 19% and 49% of newcomers and existing users respectively chose to change their use of PAs as a result of their IB, which implies an increase in flexibility and tailoring of this form of support.

3.28 Anecdotal evidence from the sites also implied that existing service users had tended to either increase the amount they spent on Personal Assistants (PAs) or change the way they used PAs, with less spent on overnight residential care relative to their previous/traditional care package; whereas newcomers had spent comparatively less on PAs and more on universal services than existing service users.

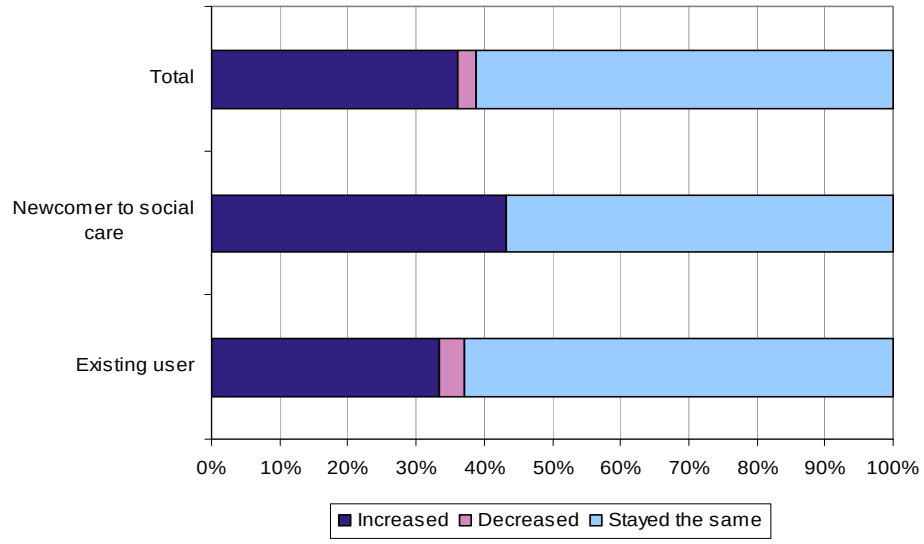
Figure 9: Differences in the use of Personal Assistants as a result of the IB



N=53
Source: SQW and Ipsos MORI Follow up Parent/Carer Survey

3.29 Figure 10 confirms the perceptions of the pilot sites, in that newcomers to the social care system tended to increase their use of mainstream and community resources more than existing users (43% and 33% respectively).

Figure 10: Changes in the use of mainstream and community resources as a result of the IB



N=111
Source: SQW and Ipsos MORI Follow up Parent/Carer Survey

3.30 Examples of the ways in which families used PAs to support their child to access mainstream and community resources accessed are illustrated in Figure 11.

Figure 11: Examples to illustrate how PAs were used by participating families

- PA hired to take Child A to the cinema and bowling with their friends every fortnight
- A PA was employed to help Child B to explore the outside world and gain new experiences, which included weekly special needs swimming and trampolining activities, horse riding and day trips
- PA hired to support family to go on holiday
- PA hired and season ticket funded for PA to support Child C to regularly attend their local football team matches
- PA recruited to help Child D attend dance lessons at the local leisure centre
- PA recruited to help Child E attend the local gym on a regular basis

Source: Support plans of participating families

3.31 Further examples of the inclusion of community resources in support plans are presented in Figure 12.

Figure 12: Examples of wider use of community facilities

- Participate in swimming sessions at local pool to help exercise and stay healthy
- Attend youth club for enjoyment, and to help the young person get involved in their local community
- Visit railway museum and local model railway exhibitions to feel included in the community and pursue interest in trains and railways
- Access local allotments to pursue interest and develop skills in gardening, make the young person feel included in the local community and positively impact his overall health
- Bowling at bowling alley – to help the young person stay healthy and participate in activities outside of the home

Source: Support plans of participating families

3.32 The majority of sites confirmed that there had been a drop in demand for overnight residential care amongst participating families. However, given that the pilots only involved a small number of families, this reduction had little impact on reducing overall demand for this form of service in the short term. When considering longer term implications, the sites added that in the event that the IB approach was rolled out across an area, residential facilities would most likely experience a reduction in demand and that this change would imply a need to increase the speed at which changes to the commissioning processes were taking place. For example, several of the sites had begun to transition from block contracting to the use of framework or more flexible contracting arrangements as a result of the Short Breaks Programme. In some cases this led a small number of services to be decommissioned. As such, sites may need to consider the decommissioning of more services if roll out takes place or to work with providers to help them amend their offer to better meet the demands of families.

3.33 Focusing now on challenges faced in accessing the required provision, most sites had experienced problems in sourcing sufficient and suitable PAs, which in some cases had led to significant delays in getting the appropriate support up and running. This was in the main a result of a shortage of PAs aged 16-25 years old (the preferred age group cited by participating young people), with the appropriate skills to provide the required support.

3.34 Sites therefore considered how best to stimulate growth in the supply of PAs and how to support their skill development. For example, one of the sites worked with their Adult Social Care team to embed a new pay structure for PAs based on service provision to address issues relating to low pay which had translated into an insufficient supply of PAs. In addition the site had introduced an e-learning option for any PA currently employed by one of the families participating in the pilot to stimulate and sustain the skills development of the relevant individuals.

3.35 Contribution of health monies in one of the sites was seen to have encouraged creative solutions to promote health and well-being in ways that had not been available from the traditional service provision. Examples of how the health money was spent included: gym membership, alternative therapies, day trips, exercise and sporting equipment, gardening, horse riding and one-to-one swimming lessons.

3.36 **Summary**

3.37 Table 13 presents a summary of the progress made against element nine of the CDM.

Table 13: Progress made on the facilitation of market development

Summary 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 begun to focus their attention on developing the provider market during year two of the programme, to ensure that the required forms of provision were available • Provider-related cultural change in the IB context involved a focus on the development of community capacity to enable families to access local and universal services • Community-based provision was developed using a variety of methods including: the facilitation of provider forums, where the concepts of personalisation, individual level commissioning and inclusion were introduced and discussed; the use of inclusion workers, who went out into the community to build capacity within individual organisations and to source the services that families would like to access; and the provision of pump priming funding to organisations to build capacity to deliver services for disabled children; and through CVS hubs within a locality • The IB pilots illustrated a trend towards the use of more PA related and universal/community based provision relative to overnight residential care provision. In addition, the evaluation evidence showed that existing service users tended to increase the amount they spent on PAs, with less spent on overnight residential care relative to their previous/traditional care package, whereas newcomers had spent comparatively less on PAs and more on universal services than existing

service users

- Personal Assistants (PAs) were in the main recruited to provide support to enable the child/young person to take part in mainstream activities that they had been previously unable to access
- Most sites had experienced problems in sourcing sufficient and suitable PAs, which was in the main a result of a shortage of PAs aged 16-25 years old (the preferred age group cited by participating young people), with the appropriate skills to provide the required support.

Actions moving forward beyond the two year pilot

- The majority of sites reported a drop in demand for overnight residential care, which had not impacted significantly on the market given the small number of families participating in the pilot. However, the implications of a transition away from overnight residential care provision will need to be carefully considered if the IB approach is extended to incorporate more families.

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

3.38 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. However, progress against this element varied considerably across the pilot sites.

3.39 Looking first at wider stakeholders, it was evident that a few 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 at the end of the two year programme, 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.

3.40 In addition, sites reported specific difficulties in engaging PCT and education colleagues for reasons of a similar nature to those described above around element 2 of the CDM. They added that there was a general sense that the IB pilot or indeed future roll out of the IB approach was unlikely to become a priority for health in the near future as the health structures were facing significant reorganisation. Similarly, they expressed an ongoing concern relating to a general mismatch between education and social care, both of which were largely inwardly focused and therefore did not use joined up approaches.

3.41 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. For example:

- One site noted that working relationships between their Children's and Adult social care teams had been considerably strengthened through the joint working undertaken as part of the pilot, which was proving valuable for both services, particularly in relation to transition-related work
- Another site had successfully engaged three local special schools, which had provided in-kind support to the pilot and enabled a school-based form of advocacy for the IB pilot within the relevant schools
- Another site reported that although their Adult service colleagues had been less engaged than originally anticipated, their previous experience in delivering personalised approaches was becoming more valuable as the pilot developed and had assisted them during development of IB-specific guidance, as well as enabling them to extend existing infrastructure and support services to meet the needs of families with disabled children
- And another site worked alongside their Raising Participation Age (RPA) pilot, which provided funding to explore ways to support young people to continue in education or training. This was an important and significant development for both the pilot site and the relevant education service, as it provided a lever to bring together pilot and education colleagues and therefore created a valuable opportunity to consider and test the ways in which young people with disabilities could be supported in a variety of ways to fulfil the Authority's responsibility to engage young people in education and employment with training until the age of 17 by 2013 and 18 by 2015.

3.42 Effective engagement of wider stakeholders 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).

3.43 It was evident that the sites had used both formal and informal mechanisms to facilitate the *engagement of parents and disabled children*. For example, several of the sites had formally appointed a parent representative onto the IB pilot project board to enable co-production of the pilot. This was felt to have provided a valuable 'reality check' to some of the discussions. Similarly, another site had engaged their parent council and was accessing resources through this group to feed into the development of their pilot.

3.44 More informal approaches included: the facilitation of ongoing dialogue as a means of gathering feedback from participating families; attendance by some families at support planning approval panels; and peer support/focus group sessions involving disabled young people, which sought to understand their pilot experiences. Information gathered from these approaches was used to review and refine the relevant pilot processes and helped to inform organisational cultural change.

3.45 The pilot sites were aware that they would need to sustain their efforts to widen engagement as they moved beyond the two year programme. They added that as a result of the emphasis on inclusion of education in the recent DfE SEND Green Paper, this was likely to involve a focus on gaining buy-in from both pre and post 16 education colleagues.

3.46 Table 14 provides a summary of progress against CDM element ten.

Summary

Table 14: Progress made on the engagement of all relevant parties in the development of the pilot

Summary 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 was facilitated through both formal and informal mechanisms, which included the appointment of a parent representative onto the IB pilot project board, active engagement of the parent council/forum and the gathering of informal feedback throughout the duration of the pilot • Engagement of disabled young people was facilitated through informal approaches, which involved gathering feedback through informal discussions and/or focus group sessions to understand their pilot experiences.
Actions moving forward beyond the two year pilot
• The pilot sites were aware that they would need to sustain their efforts to widen engagement as they moved beyond the two year programme. They added that as a result of the emphasis on inclusion of education in the recent DfE SEND Green Paper, this was likely to involve a focus on gaining buy-in from both pre and post 16 education colleagues.

Safeguarding

3.47 The IB pilot sites raised the issue of safeguarding as a key delivery challenge early in the programme. The majority of concerns raised related to two main issues: concern around how best to manage the shift in control from professionals to families brought about by personalised approaches in combination with an authority's duty to safeguard this group; and uncertainty around the legal framework governing

personalised approaches. It was also apparent that the challenges discussed were not new concerns, as they had been previously raised in relation to direct payments.

3.48 As such, the sites carefully considered how to ensure sufficient safeguarding processes were in place. This resulted in the sites building on existing local authority practices, e.g. direct payment guidance, to ensure that safeguarding and the assessment of risk was a running theme through all IB-related activities.

3.49 Emerging practice therefore included recognition of a 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 led the sites to develop several safeguarding mechanisms, which fell broadly under the following themes:

- Raising awareness of safeguarding issues with families including the strong promotion of the use of CRB checks when employing individuals and the use of registered organisations
- Raising awareness of safeguarding issues in the community and with service providers
- Ensuring that risk assessment was built into all stages of the IB approach and its associated process.

3.50 Each of the above themes is described in more detail in the *Safeguarding Thematic Case Study.*

3.51 As such, it was evident that the sites sought to embed safeguarding and risk assessment across the spectrum of their pilot activities. Moreover, although safeguarding was not explicitly covered in the original Common Delivery Model (CDM)[11], which was used to inform the development of the IB approach, it has emerged as an important consideration and therefore features in the refined version of the CDM (see Chapter 9 for more details).

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

4: Engaging and involving families

4.1 Evidence gathered as part of the IB Scoping Study indicated that some of the barriers associated with direct payments, had continued into the delivery of personal budget approaches. These included the difficulties faced by some service users in engaging with and understanding the process, which had been amplified by a failure by professionals to sufficiently promote the advantages of personalised approaches to service provision. As such, the IB pilot programme sought to learn from and address these challenges to ensure that the approach was effectively championed and therefore was accessible to a wide range of families with disabled children.

4.2 This chapter sets out the means by which the pilot sites sought to *engage and involve families* in the activities of the pilot and therefore provides an account of *progress made against elements 3 and 5 of the CDM*. This includes feedback gathered during a set of focus groups which sought to explore the experience of participating families. It also evidences the engagement profile of the pilot sites.

Progress against elements 3 and 5 of the CDM

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

4.3 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.

4.4 As such, information was 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.

4.5 Personal one-to-one contact and speaking to families in their ‘own language’ was widely seen by staff as the most effective form of engagement, particularly for those

families from more deprived backgrounds. 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 reiterated the need for considered recruitment of the pilot delivery teams, as a means of ensuring that effective family engagement can be undertaken.

4.6 This form of approach had in most cases proven to be more resource intensive than originally anticipated and had 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. As such, 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.

Feedback from participating families

4.7 Families provided a range of reasons as to why they had signed up to take part in the IB pilot. These included the IB approach providing the potential to:

- increase the flexibility of service provision
- provide a more tailored service for the relevant child, which could lead to increased independence for young people
- increase the family's ability to influence the form and frequency of service provision
- try something new, as traditional service provision was not proving to be effective.

4.8 Some families also added that their decision to participate in the pilot had been led by professional suggestions that the pilot would provide a valuable opportunity for the family.

4.9 The majority of parents that participated in the focus groups stated that they had no real concerns relating to signing up to the IB pilot. They instead expressed their

excitement about the pilot and explained that they felt their participation would provide them with an alternative to the traditional service, which to date had not been as flexible as they had hoped. However, although no major concerns were raised, parents had felt anxious about the impact the IB approach may have on their child's existing support and funding allocation, the responsibility and time associated with managing their own budget and in the cases where a PA was to be used, becoming an employer.

4.10 Looking specifically at the support and information provided at the outset of the pilot, most parents reported that they had received a good level of information and support, where the IB pilot managers in particular were cited as being very helpful and supportive. They added that the individual face to face contact approach had proved invaluable. In addition, parents that had attended initial information events had in the main found these helpful and stated that they had provided a useful opportunity to meet and share ideas with other families.

4.11 The main exceptions to the generally positive views relayed above, which were recommended by families in hindsight, related to a need to:

- **More effectively manage the expectations of the families in terms of the timescales associated with the process** - families had expected to be in receipt of their IB funds within a few months, whereas in reality this had often taken 6 months or longer. As such, parents reported that the IB approach should in future seek to work in a more timely fashion to accommodate the immediate needs of a family.
- **Explain the resource allocation process and the potential for a family's funding allocation to either increase or decrease** – many families had assumed that their funding allocation would remain the same or increase as a result of signing up to the pilot and therefore had not expected their IB allocation to be lower than their existing allocation.

4.12 Parents also added that there needed to be a balance struck between the provision of appropriate and comprehensive information and overburdening parents at the outset of the process, as the latter may hamper their outlook.

Achieved engagement profile

4.13 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.

4.14 The invitation to participate in the pilot was therefore 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 both cases, 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.

Families actively engaged in the pilot

4.15 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.

4.16 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.[12]

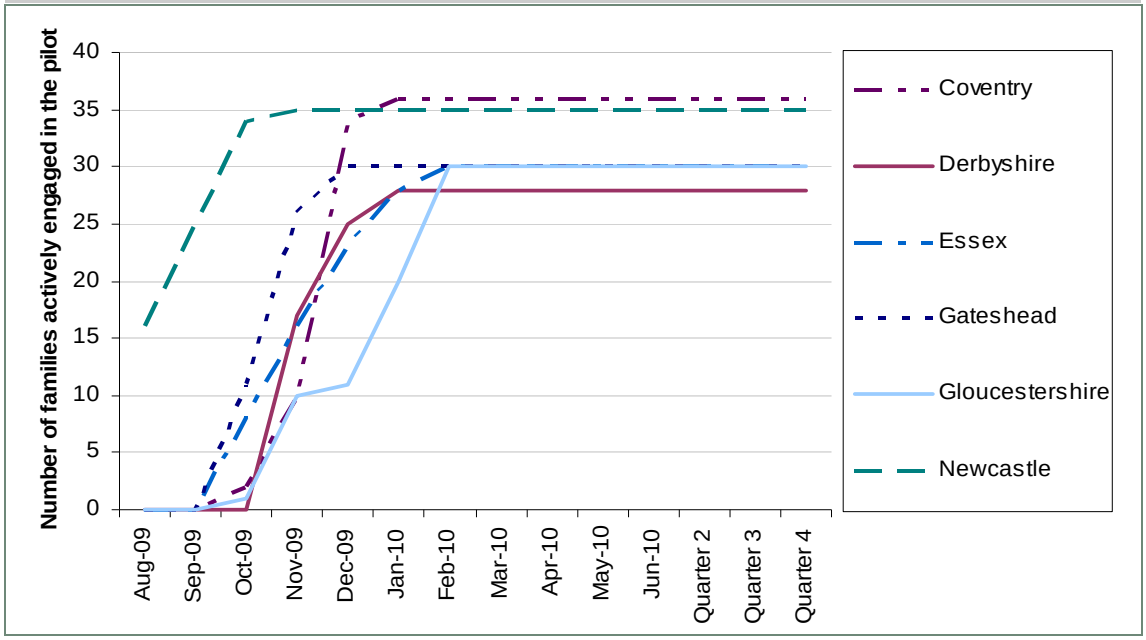
4.17 This achievement reflected the significant efforts made by the pilot sites and indicated an apparent level of demand from families to take up the IB offer. However, to draw out this demand took considerable effort and required to be delivered in an appropriate way as described above.

[12] 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 a further extension.

4.18 Looking across the programme as a whole, the pilot sites engaged 189 families, which exceeded the target of 185 families. The aggregate engagement figure included 14 families that had been engaged over and above the target number in three of the pilot sites.

4.19 Figure 15 sets out the engagement profile by site for the programme. This shows 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 demonstrate how quickly demand could be built in some areas.

Figure 15: Families engaged at each stage of the Individual Budget pilot



N=189
Source: SQW pilot monitoring returns

4.20 Table 16 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 34% 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.

Table 16: Recruitment from target groups

Pilot site	Target group	Proportion of engaged families from target group
1	Young people in transition	89%
2	Young people in transition	86%
3	Young people in transition	34%
4	Age range 0-16	97%
5	Newcomers to social care system	63%
6	Young people in transition	80%

Source: SQW pilot monitoring returns

Summary

4.21 Table 17 presents a summary of the progress made against element three of the CDM.

Table 17: Progress made on the facilitation of awareness raising and information dissemination for potential families

Summary findings and lessons
• The sites used a variety of mechanisms to raise awareness and share information with prospective families with disabled children • The most effective mechanism was 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 reiterated the need for considered recruitment of the IB delivery teams, to ensure that effective family engagement can be undertaken • More time had been spent engaging and supporting harder to reach families, as they required tailored information and more reassurance to engage them in the pilot • Most families that participated in the focus groups reported that they had received a good level of support and information and added that the pilot managers in particular had been very supportive. The only exceptions to the generally positive views related to a need to more effectively manage the expectations of families in terms of both the timescales associated with the process and the potential for a family's funding allocation to increase or decrease as a result of the IB approach • Although the pace of family engagement varied by site, all sites successfully engaged a cohort of families to take part in the pilot. This indicated an apparent level of demand from families to take up the IB offer in the event that the approach was made to them in the appropriate way.
Actions moving forward beyond the two year pilot
• Personal one-to-one contact had proven resource intensive and 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

Element 5: Facilitation of peer support mechanisms

4.22 All six of the pilot sites had committed to ensure that appropriate support mechanisms were supplied for participating families. As such, they initially asked

their families whether they wanted to take part in formal peer support groups/settings and in that sense had enabled families to inform the development of this element. In three out of the six sites this initial exercise illustrated that families were happier to network informally amongst themselves and therefore no formal mechanisms were set up.

4.23 Three sites had adopted formal mechanisms to support families. These included:

- externally commissioning a special needs network to coordinate peer support for families engaged in the pilot, which had led to the delivery of sessions on support planning and community mapping
- the opportunity for participating families to attend an existing parents' forum
- holding parent focus groups to allow parents to share their real life experiences.

4.24 Each of these mechanisms has generally been taken up by a small number of parents (between 5-7 in each site) in each of the sites, which reflected the differing desire to participate in this form of peer support.

4.25 Feedback from the focus groups with participating families illustrated the value of informal networking that had taken place between some of the families. For example, parents discussed how they had shared ideas about the types of services/support they might access during their support planning activities, which had led them to consider a wider range of options than they may have done in the absence of peer support. It was also evident that parents had in some cases supported each other to understand how to effectively manage their IB funding allocation.

4.26 Two of the sites had considered the provision of peer support for the young people participating in the pilot. The first site had considered setting up a Facebook group to provide a discussion forum for their young people, but having assessed the risks associated with this and the diversity of the young people, had decided the option was inappropriate. The second site contracted an external organisation to run peer support events for young people but had to date struggled to engage many young people in these activities. This lack of engagement was felt to be a result of the young people not feeling sufficiently comfortable to engage in discussion-related activity, which was felt to be unfamiliar. As such, the site has started to run activity taster sessions as opposed to peer support/discussion groups, to encourage their young people to experience different forms of potential service/support provision.

4.27 In the event that the IB approach is rolled out to a wider group of families, sites felt that they would need to extend their offer of peer support to ensure a wider range of mechanisms were facilitated. Sites also emphasised the need to ensure that all forms of peer support were accessible to as many families as possible.

Summary

4.28 Table 18 presents a summary of the progress made against element five of the CDM.

Table 18: Progress made on the facilitation of peer support mechanisms

Summary findings and lessons
• Peer support mechanisms were family led in the main and as a result varied in scale, nature and formality • Informal parent peer support occurred through general networking between families outside of the formal confines of the pilot. Conversely, formal parent peer support included the facilitation of tailored focus groups and the use of existing parent forums/groups which provided an opportunity for families to discuss their experiences • Support for participating young people was less developed and proved more of a challenge as a result of the group's very differing needs and desires.
Actions moving forward beyond the two year pilot
• Sites stated that they would need to extend their offer of peer support to include a wider range of engagement mechanisms in the event that the IB approach was rolled out to more families.

5: Setting up the infrastructure pt I – resource allocation

5.1 *Elements 4, 6, 7 and 8 of the CDM* covers the *infrastructure required* to deliver the IB approach. The sites ploughed much of their energies into meeting these requirements during the initial stages of the pilot programme and subsequently into using the infrastructure to deliver the pilots.

5.2 This chapter of the report provides a *detailed description of both the development and delivery stages associated with element 7 of the CDM* – resource allocation – and a comparative analysis of the IB package costs relative to the traditional care packages. Feedback on the effectiveness of the resource allocation models is also described from both a pilot site and family perspective. The subsequent chapter provides a similar discussion of elements 4, 6 and 8.

5.3 It is important to note that the IB process began after a family's needs had been assessed and their eligibility for service provision determined. Therefore, the IB approach piloted did not seek to modify the assessment processes used within each of the sites and instead sought to understand how best to allocate resource to meet the required need.

Progress against element 7 of the CDM: resource allocation

5.4 The IB pilots are one form of personalised budget. Across any form of personalised budget a key question is the value of resource allocated to each individual case. Resource allocation provides a way of calculating this amount in relation to assessed need. The allocation of resource has to reflect the needs of the individual and the constrained budgets of funders, and the resource allocation system acts as a way of balancing these two factors.

5.5 It is also important to note that the statutory duties placed on local authorities mean that the use of a resource allocation approach can only produce an 'indicative' budget. Authorities are then required to ensure that the level of budget allocated is sufficient to meet user needs[13], which in process terms is generally confirmed on completion of the associated support planning stage.

5.6 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 was used for different age groups). A basic description of each of these models is presented below (for a more detailed description of the different models, please refer to the associated *Resource Allocation Thematic Paper*).

In-Control RAS version 4

5.7 An adapted version of the RAS 4 and Taking Control RAS questionnaire was used by two of the sites. Development within these sites was undertaken using the following steps:

- A RAS questionnaire was developed by the pilot teams, which was based on the Every Child Matters (ECM) outcomes framework and reflected the team's understanding of service provision and associated unit costs
- A sample of current service users were selected and scored against the RAS questionnaire
- For the same users,
  - the total monetary value of their current packages of support were aggregated to give the total value of support, which was divided by the total points score of the group of users to produce the price point

[13] "The judgment of the Court of Appeal in *R (Savva) v Kensington and Chelsea* makes clear that while RAS schemes may be used as a 'starting point' to give an indication of the level of funding which may be required, they cannot dispense with a local authority's 'absolute duty' to meet assessed needs through services or direct payments once it has concluded that such services are necessary" from 'Cemented to the floor by law': Respecting legal duties in a time of cuts[13] Steve Broach, Barrister, Doughty Street Chambers

  - ➢ OR the monetary value associated with the largest current package of support was identified, which was divided by the maximum number of points that could be obtained in the RAS questionnaire, which produced the price point[14]

- Indicative IB allocations were calculated by multiplying the RAS assessment scores by the relevant price point.

5.8 As such, the sites did not work within a ring-fenced 'pot' of IB funding as others did (see para 5.12) and instead sought to develop a price point on the basis of analysis of between 60-100 existing cases. Funding allocations were subsequently drawn down from the relevant core budgets.

5.9 In one of these sites, it was clear that the site had significantly modified the original Taking Control 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. This resulted in the development of a questionnaire based on a set of 26 'positively' framed outcome statements. The statements were structured around the five Every Child Matters (ECM) outcomes and were developed to reflect the most common needs and outcomes of families that were in receipt of services in the site.

5.10 Table 19 provides a detailed example of the modified model used in the site. This shows that each outcome statement was associated with a traffic light system, which sought 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.

5.11 This two stage approach differed from that of the original RAS questionnaire, as did the categorisation of four levels of support relative to three categories (no support, some support and lots of support) in the original questionnaire.

[14] This process assumed that the pilot cohort of families would be similar in nature to the existing cases used to develop the model, with the exception of a few anomalies.

Table 19: Example of the enjoy and achieve outcome in the model

The enjoy and achieve outcome was 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 was measured by the parent/carer and the child/young person (where appropriate) answering statements using a traffic light system, where each colour represented the following answers:

No, not at all	Partly/sometimes/not enough	Yes always/completely/not an issue

The parent/carer and child/young person (where appropriate) was then asked to decide whether support was needed to achieve the statement, and where support was required, the level of support needed:

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

Each statement was allocated a maximum number of points, which were weighted to reflect the costs of provision to achieve the relevant outcome statement. The associated support needs for each statement then broke down these points, providing more points for higher needs. The individual point score for each support need was then aggregated to produce a total score, which was 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 was 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

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

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

5.12 A RAS guidance document was also produced and disseminated to the relevant pilot team to ensure consistent delivery of the RAS. Table 20 provides an illustration of this guidance.

Table 20: Example of guidance for the enjoy/achieve outcome from one of the pilot sites

a. My child is able to communicate			
Specialist support	**Lots of help**	**Some extra help**	**No extra help**
Uses specialist electronic (or other) communication tools. All carers need training	Is unable to use communication tools but is able to convey needs etc by other means Non English speaking – translator needed	Uses makaton, PECS and/or signing	
b. My child has interests/activities out of school and in holidays or at weekends			
Specialist support	**Lots of help**	**Some extra help**	**No extra help**
Can only attend activities with carer who can offer nursing support/medication etc Needs to take oxygen/tube feeds etc Minimum 1:1 support to manage challenging behaviour	Requires close supervision during activities due to health and/or behaviour issues 1:1 support during activities (PA or inclusion grant) Financial contribution towards accessing resources	Transport Information and advice regarding activities etc	

Source: IB pilot site

In-Control RAS version 5

5.13 Two sites adapted RAS 5 for use in their IB pilot. This approach apportions IB funds on the basis of a percentile distribution as opposed to using a price point system. This was facilitated via the following stages:

- Each site costed the existing service packages of all the families that had been recruited to take part in the pilot and the total value of these packages subsequently formed the basis of an 'IB pot' of funding, which was to be distributed to the families
- The RAS questionnaire, which was again based on the five ECM outcomes, was undertaken with each family to produce a score for each family

- The RAS scores for each family were organised from high to low and allocated to percentiles, e.g. the top percentile was based on the highest scored need and the 50% value equated to the median value of the cohort of families
- The value of the families' existing care packages was similarly ordered from high to low and in percentiles
- An indicative allocation table was created through the alignment of the RAS scores and package values from the same percentiles, i.e. the 75th percentile RAS score was allocated the package value from the 75th percentile.

5.14 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 (see Table 21).

Table 21: Example of the Be Healthy outcome in the model

Be Healthy

To be as fit and healthy as I can be.
What level of support does the child need to achieve this?

0	1-2	3-6	7-9	10-12
No Support	**Small Support**	**Some Support**	**Lots of Support**	**Exceptional Support**
	The band for scoring within this question is 1-2 points	The band for scoring within this question is across three points thus offering a bottom, middle and top of the scale		

Source: IB pilot site

Alternative approaches to resource allocation

5.15 Three of the pilot sites used models which allocated resources in a different way to those described above. That is, they instead developed approaches which were based around the costing of particular services.

5.16 In one of the three models (referred to as *alternative model 1)* initial work was undertaken to review the assessment and existing care plans of the family. Subsequently, the families were contacted and an initial discussion held to discuss what outcomes the family and child/young person would like to achieve. The identified outcomes were then costed by the professionals on the basis of the costs of standard services being provided in the current, traditional system as proxies for service provision that would be required to achieve the outcomes. The sum value of these services was then called the indicative budget.

5.17 The second model sought to develop an outcome-based questionnaire, similar in nature to that used by the In-Control RAS models, which asked families to consider the level of support (none, basic, standard or enhanced) that would be required to achieve each of the stated outcomes. Financial values were attached to each level of support and therefore indicative budgets were calculated on the basis of the aggregate level of support required.

5.18 In the other area an early intervention approach was facilitated through lead professionals (referred to as *alternative model 2)*, who initially visited the family to identify needs and desired outcomes, following which a 'Team Around the Family' meeting was held. Following agreement of the needs/outcomes, support planning took place and the individual budget was calculated on the basis of the chosen services/activities.

5.19 As such, the main differences between the RAS based models and alternative models appear to lie in: the sequencing of resource allocation in the family journey (see Chapter 6 for more details); and the degree of systematisation through which the scale of resource was decided.

Reflections on resource allocation

Feedback from the pilot sites

The development stage

5.20 All sites recognised from the outset of the pilot that resource allocation was in no way an 'exact science' and that any model would require 'room for manoeuvre' to ensure differing circumstances could be taken into account, especially as their approaches were somewhat developmental. Development of the relevant resource allocation model was subsequently reported to have required dedicated and intensive 'thinking time' from the pilot delivery teams and other involved parties. This often involved several 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 and consistently use the model.

5.21 It was clear that *all sites had aimed to develop an equitable and transparent model*. However, it was evident that transparency had been interpreted in different ways. Although all sites interpreted transparency to include the use of an inclusive and well-defined process that provided sufficient information and explanation to families, those sites using the RAS also felt that transparency should include the provision of an up-front indicative budget allocation to families at the beginning of the support planning process, along with their relative traditional service budget associated with the child/young person. Whereas, of the sites that used an alternative model: one site had chosen to provide just the initial indicative budget to the families, but not the relative traditional service provision budget; the alternative model used in the second site was aimed at newcomers to the social care system (and therefore were not associated with previous service provision) and was facilitated through a budget-holding lead professional approach, which did not offer an up-front indicative budget; and the remaining alternative model site used a similar interpretation to that of the RAS sites.

5.22 As such, 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 (see the sequencing of resource allocation in the family journey in Chapter 6 for more details).

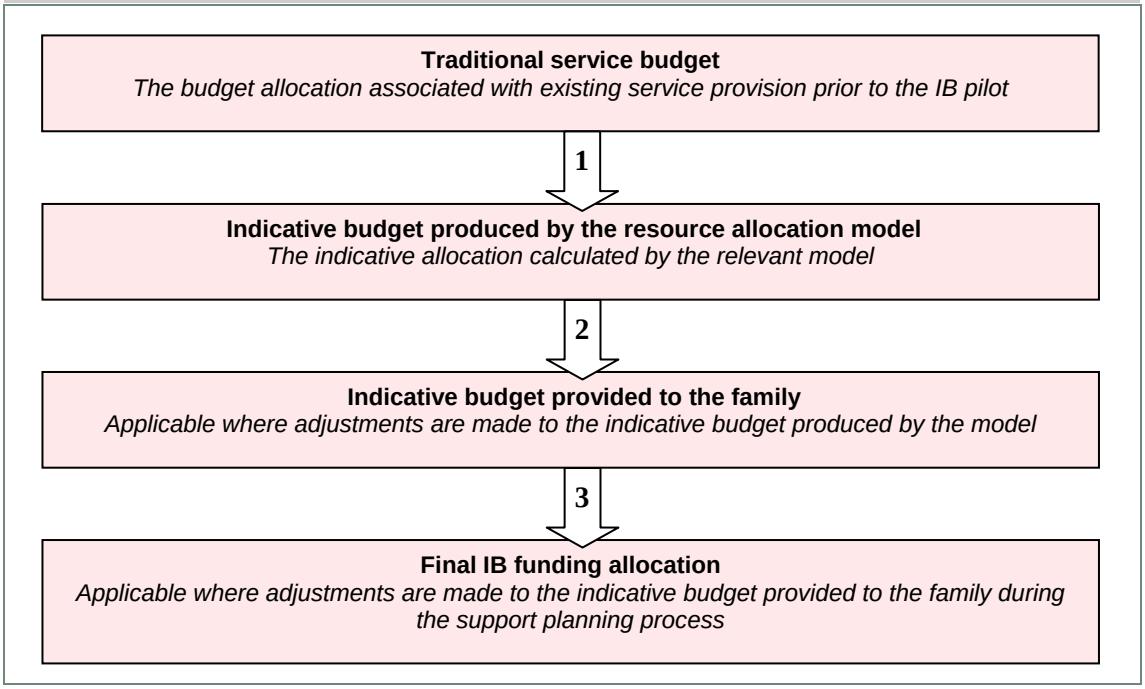
5.23 In addition, most sites created a contingency budget, which was formed by holding back a proportion of either the overall IB pot or a proportion of each IB funding allocation outside of the existing service packages offered. This implied that sites had in effect double funded their contingency and as a result had slightly lowered the value of packages across their cohort.

The implementation stage

5.24 The RAS assessments were undertaken by members of the individual pilot teams, which comprised of social workers and lead professionals in the main. The majority of these individuals had been involved in the development of the relevant model and/or RAS-specific training sessions and as such, had built a good understanding of the workings of the model. All pilot sites also developed RAS guidance to ensure resources were allocated on as consistent a basis as possible across the participating families.

5.25 Figure 22 sets out the stages at which an IB funding allocation may have been subject to change and/or moderation as a result of the IB approach. Each site facilitated at least one stage of the illustrated budget moderation, which was dependent on the differing mechanics, sequencing and levels of professional judgement associated with the different resource allocation models. That is, for those sites using the RAS, although the completion of the initial RAS questionnaire was subject to some professional judgement, subsequent derivation of the RAS-based indicative budget was based on the mechanics of the RAS itself. This derivation process was in some cases viewed as mechanistic in its nature and as a consequence, the majority of the sites using the RAS subsequently moderated (using professional judgements) the model-based indicative budgets prior to communicating these budgets to the families.

Figure 22: Stages at which an IB allocation may have been subject to change and/or moderation



Source: SQW

5.26 In the sites using alternative resource allocation models: one site relied more heavily on professional judgement to derive their indicative budgets, which essentially cut out any derivation of a model-based indicative budget; another site sought to derive the budget on the basis of the services selected during individual support planning exercises and therefore did not involve the indicative budgeting stage; and the third site facilitated a similar process to that of the RAS sites. As such, it would appear that these sites relied heavily on professional judgement to derive their indicative budgets.

5.27 Evidence gathered from the sites using the RAS showed that where applicable, sites tried to minimise significant differences between the traditional (existing) service budget and the indicative budget provided to the family. This moderation was undertaken to assist the transition families were making from the traditional service model to the IB model, i.e. moderation at stage 2 in Figure 22.

5.28 The extent and frequency of moderation varied considerably between the sites, where for example, one site modified a small number of the budgets produced by the RAS, whereas another site felt that the indicative budgets produced by the RAS were unreliable across the board and therefore all cases were modified prior to the budgets being communicated to the families. These findings reflect a lack of confidence in the model-based indicative budgets in some sites, combined with a

desire to minimise the number of families who left the pilot following receipt of their indicative budget.

5.29 Although the alternative models produced indicative budgets that differed from the relative traditional service budgets, these budgets were not subject to the interim stage 2 moderation. This appeared to be a result of the sequencing and methods by which the indicative budgets were derived.

5.30 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.

5.31 Stage 3 moderation was undertaken in all the sites in the cases where support planning resulted in the need to decrease/increase the indicative budget to support the achievement of family's identified outcomes. Examples of cases where this moderation was required included: instances where families had opted to include one off purchases in their IB packages e.g. capital equipment or housing adaptations, which would only be required once and therefore skewed the budgets; and to manage age-related discrepancies where for example, older children required more funding to facilitate leisure activities relative to their younger counterparts.

5.32 The final stage of moderation (i.e. stage 3) was felt by some sites to be associated with a significant financial risk. That is, those sites that were reliant on a 'finite' pot of IB funding felt that they exposed themselves to the risk of spending more funding than was available in the pot. As such, some of the pilot sites used contingency funding (see paragraph 5.22) to meet any additional costs that arose during the support planning stage.

5.33 Additional site-based reflections on the resource allocation models included an ongoing need to refine the models and assessment processes to take the following into account:

- The wider service offer associated with each child/young person (e.g. significant health packages) which can provide complementary benefits for the individual and their family and so may reduce the need for support via the IB. This implies a need to either:

- Embed a single assessment process which integrates all relevant assessments (e.g. social care, health and education) with subsequent resource allocation processes, thereby creating a holistic process which ensures that all needs/outcomes are identified at the initial stage and can therefore be fed into resource allocation and subsequent support planning decisions

OR

- Consider the service offer being provided by other agencies (e.g. health and education) at the outset of the IB approach and seek to offer additional services through the IB to meet any additional unmet need.

- Accessibility of services and therefore the travel costs associated with access, which are often higher for those families that live in remote areas and therefore have to travel greater distances to access services
- Changes in the weighting of the RAS questionnaire scores to more accurately reflect the associated costs of new and emerging local service provision required to meet specific need
- Age specific questions to reflect differing needs e.g. the model needed to recognise the differing needs of the 14+ year age group relative to the 0-5 year age group, where the former would spend more on undertaking independence related activities.

5.34 The reflections confirm the views set out in the Interim Evaluation Report. That is, that the pilot programme has enabled the sites to develop and deliver a range of resource allocation models, all of which remained a 'work in progress' and would require refinement for further use.

Strengths and weaknesses of the individual resource allocation models

5.35 Table 23 sets out a summary of the critique of the strengths and weaknesses of the resource allocation models that was undertaken as part of the *Resource Allocation Thematic Case Study.*

Table 23: Identified strengths and weaknesses of the individual models

Strengths	Weaknesses
In-Control RAS version 4	
• Was relatively simple to understand and so local authorities were able to explain the steps involved to families and thereby engage the family fully in the assessment process • Focused on outcomes and so provided the basis for a budget based on need rather than from a predetermined mix of services • Was comprehensive in seeking to cover all needs and so provided an option to value needs on a common basis[15].	• The initial price point developed was strongly related to the previous value of packages (especially because pilots often restricted themselves to the total value of the budgets allocated previously to the pilot families), which may not have been appropriate • The conversion of the RAS assessment scores into 'indicative budgets' was dependent on the weightings that had been developed by the professionals in each of the relevant pilot site. This may be difficult to replicate in a robust way in any large scale roll out. • The model tended to favour families that needed a breadth of support over a range of issues rather than extremely high levels of need on a few questions, simply because it added the scores from each question together.
In-Control RAS version 5	
• The strengths identified were similar in nature to version 4 of the RAS , especially around comprehensive and outcome focussed nature of the assessment. • However, RAS 5 also avoided significant change in the cost curve by allocating resources based on the previous profile.	• One of the pilot sites that used this model struggled to understand how it operated, which in turn made it difficult to explain to participating families. This issue led to a lack of confidence in the results produced by the model • The nature of the conversion in this model meant that budget allocations could at points be very sensitive to the RAS score, which introduced a greater level of risk around the accuracy and quality of completion of the RAS questionnaire • Indicative budgets were based on old care package values, where it was recognised that these may not be accurate in reflecting need. The nature of the conversion, which can move an allocation from one family to another may amplify this issue.
Alternative models 1 and 2	
• The budget follows agreement of the service package by the professional/family and so the process was felt to be easy for families to understand.	• (Indicative) budgets were derived using professional judgement of what a family would have received in the traditional system. Therefore, this model risks being more open to variation in associating need to budget because of the additional step of first converting need to support rather than focussing on outcomes. Moreover, the strong professional; involvement also creates the possibility of variation in deciding what the family would have received.

Source: SQW case study research

[15] ADASS's Common Resource Allocation Framework (2009) recommends that Councils should not exclude very high levels of need from their allocation framework

5.36 Sites that allocated IB funding using an In-Control RAS and based on a specific 'IB Pot' (i.e. the total budget for the pilot came from the sum of the previous packages of the families that agreed to take part) experienced an additional issue. That is, as some families left the pilot the relevant sites were left with a potential liability. This issue was amplified where those families that had left the pilot had been calculated through the RAS to have a reduced budget, leading the overall budget pot to be less than the sum of the individual allocations for the remaining families. When families left the pilot and maintained their existing budget the pilot manager then faced a choice of:

- Recalculating the price point and package values for remaining families – yet this was not practical where they had completed support planning and had an agreed plan; or
- Managing any deficit through a contingency fund.

5.37 Sites reflected that this issue would decrease in the event that the voluntary IB approach was extended to include more families, as this would move the resource allocation exercise closer to a whole budget approach whereby the total points would be set against the local authority's total budget rather than that of a sub-set of families. They also noted that this whole budget calculation would increase set up costs as more reviews would be required to calculate the price point.

5.38 Conversely, sites that did not use an 'IB pot' did not experience this set of issues. That is, they derived their indicative budgets based on a large sample and then took the necessary funding from the overall budget rather than a ring fenced IB pot, which provided a greater degree of freedom to deal with families that left the pilot and anomalies

Feedback from the family focus groups and survey

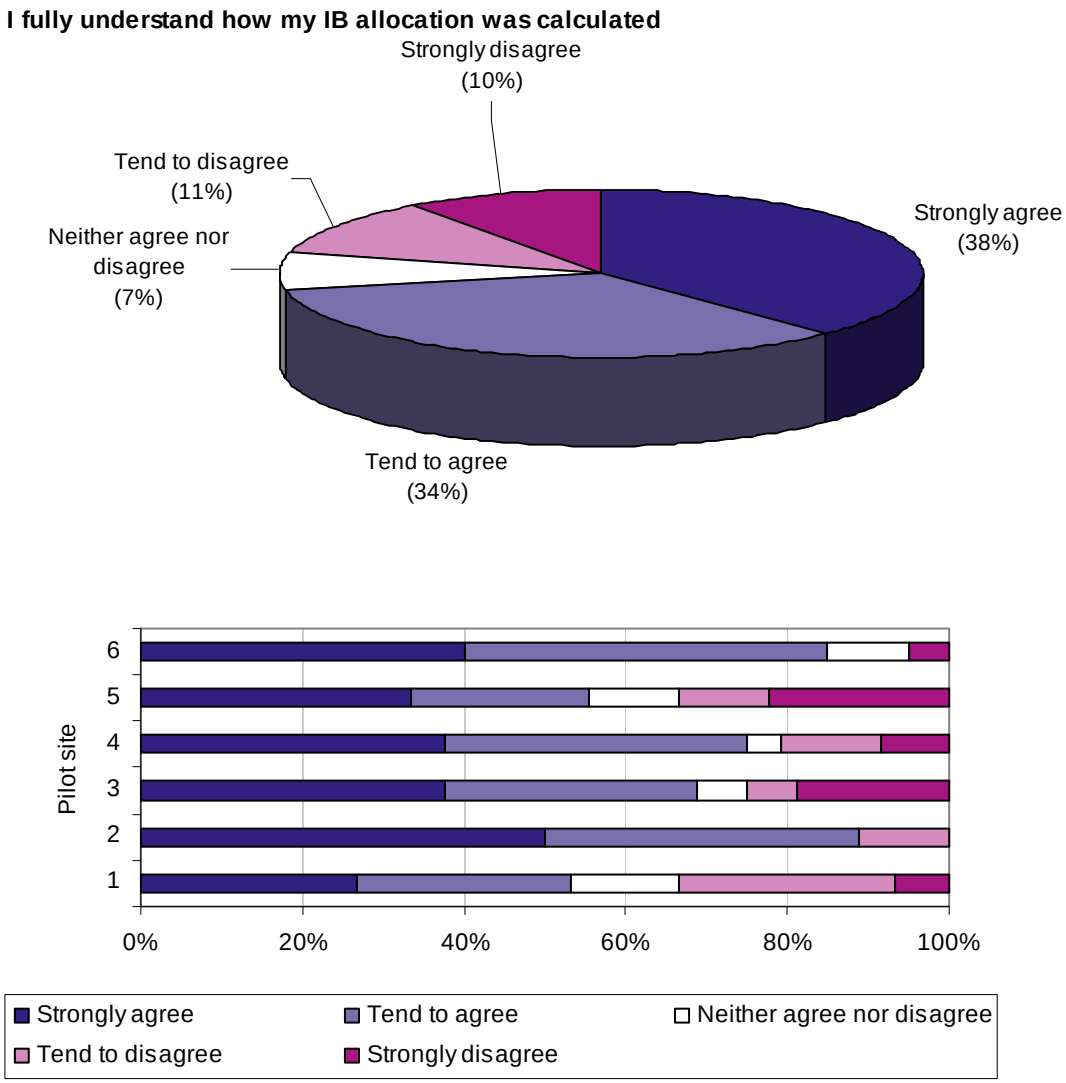
5.39 Families were asked to reflect on their experiences of resource allocation during a set of focus groups which were conducted in each pilot site. This illustrated that the majority of families that had had the experience of an up-front indicative budget had felt that this gave them a stronger basis upon which to plan their support. They also highlighted that comparisons between their indicative budgets and the costs of services/support helped them to understand the trade offs associated with different packages of support, thereby strengthening their decision making process.

> *'It was really empowering to know about the money and I was able to understand the support I could buy when I related it to the money'*
>
> *'By turning it into money, that makes it more flexible in itself…and you can think I could use that smarter and make it work harder'*
>
> *'Better knowing how much you got…you could then fit your plan into the money'.*
>
> *Quotes from the focus groups*

5.40 Focusing more closely on the mechanics used to derive the budgets, the focus groups highlighted mixed levels of awareness in relation to how budgets had been calculated. That is, it was clear that some sites had been more successful in delivering a transparent and clear resource allocation process, whilst other sites had left families feeling confused as they had been unable to comprehensively explain how their indicative budgets had been derived. This latter group of families expressed a desire to improve their level of understanding, thereby implying a need for some sites to improve their communication around resource allocation.

5.41 Supporting evidence from the parent/carer follow-up survey reiterated the above point (see Figure 24). That is, although the majority of families (72%) either 'strongly agreed' or 'tended to agree' that they had fully understood how their IB allocation had been calculated, variation in understanding between the individual pilot sites was apparent. For example, whilst only 5% and 11% of families that responded to the follow-up survey in sites 2 and 6 reported that they either 'tended to disagree' or 'strongly disagreed' that they had fully understood how their IB was calculated, 33% of comparative families in sites 1 and 5 provided the same response.

Figure 24: Understanding of how the IB allocation was calculated



N=111
Source: SQW and Ipsos MORI Follow Up Parent/Carer Survey

5.42 Many parents had also assumed that their indicative budget would be the same or more than what they had received previously, as there was a general feeling that service provision had been insufficient to date. As such, those families which experienced a decrease in their budget had been surprised and in some cases had left the pilot. However, although this finding implied a need to better manage funding related expectations at the beginning of the pilot, a number of families that had received a lower indicative budget than their traditional service provision budget were still taking part in the pilot. This 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, which was recognised by some of the parents that participated in the focus groups:

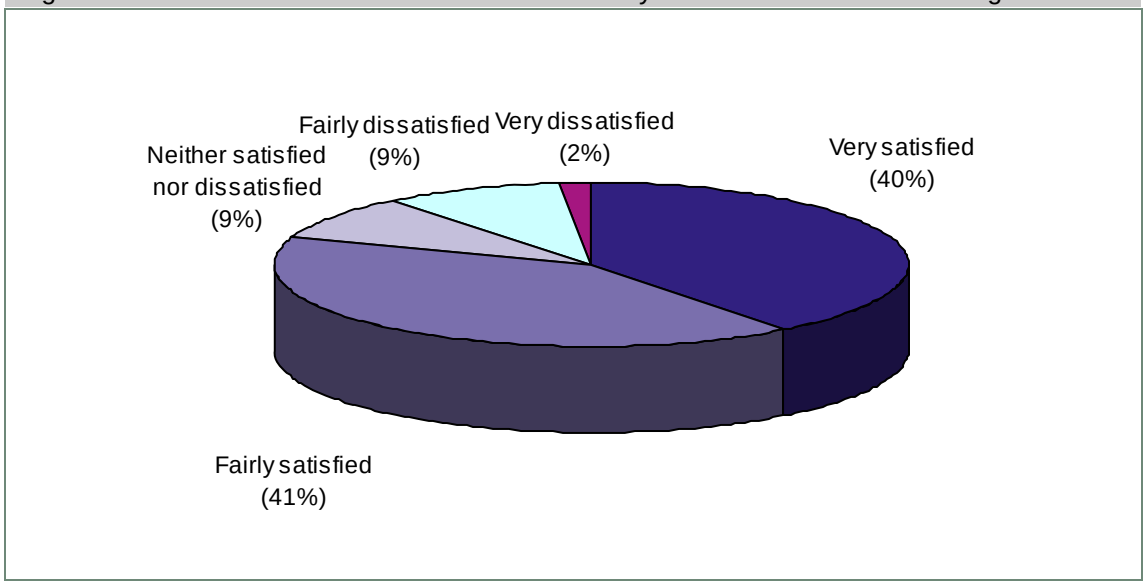
'…it wasn't the amount that mattered… it was being able to choose how to spend it and not being tied to set services'

'I expected to get access to more stuff, services and things, rather than money…saw money more as a mechanism to obtain the required services which were not previously available via council commissioned provision'.

Quotes from the focus groups

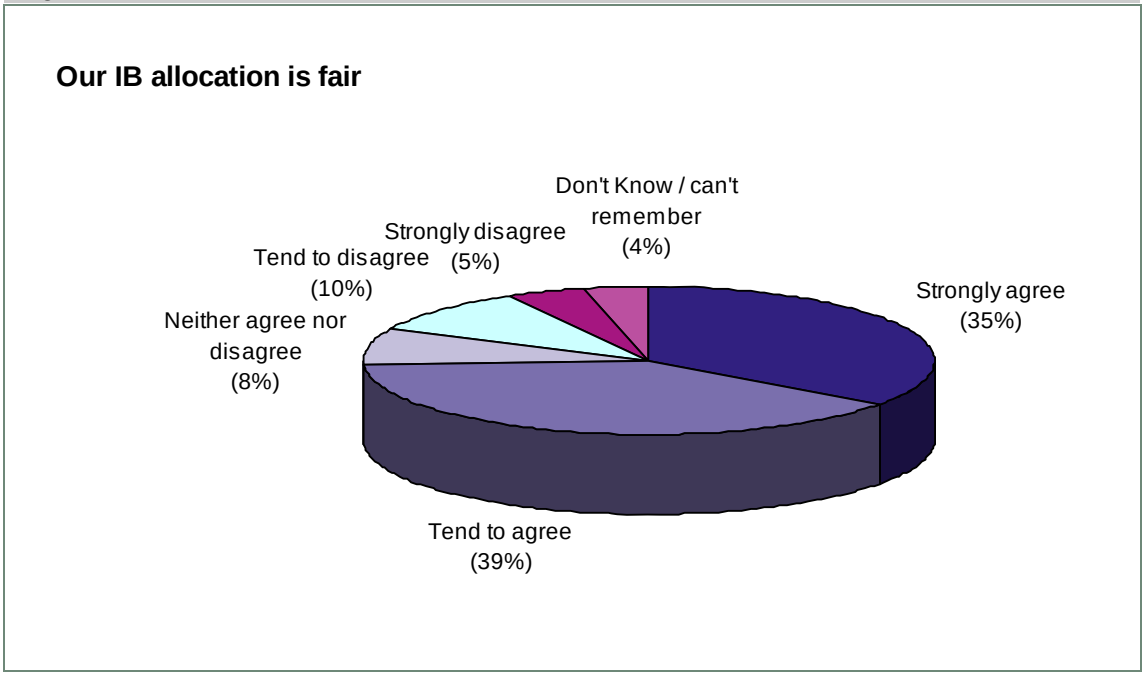
5.43 Figures 25 and 26 illustrate some of the findings from the parent/carer follow-up survey, which asked participating families to state both how satisfied they were with their IB funding allocation and how fair they felt it was. These show that 40% of families were very satisfied and an additional 40% were fairly satisfied with their IB allocation. And similarly, that 35% of families strongly agreed and 38% tended to agree that their IB allocation was fair. Interestingly.

Figure 25: Parent/carer satisfaction with the monetary value of their Individual Budget



N=111
Source: SQW and Ipsos MORI Follow Up Parent/Carer Survey

Figure 26: Parent/carer views on fairness of their IB allocation



N=111
Source: SQW and Ipsos MORI Follow Up Parent/Carer Survey

5.44 As such, those families that remained part of the pilot were largely positive about their IB allocations. However, this finding should be interpreted with caution, as it does not include the views of those families that left the pilot and the majority of the families that took part in the survey had volunteered to take part in the pilot and therefore may be more open to the budgeting nuances introduced through the IB approach.

Looking to the future

5.45 In the event that the IB approach is rolled out beyond the pilot cohort of families, it is likely that sites will need to further refine their resource allocation models and consider the following ongoing issues:

- Increased staff resource required to 'scale-up' the number of professionals that are able to support families to complete the resource allocation model
- Consideration of how best to incorporate children and young people of differing age (as some sites had focused on the transition group in the main) – this may means specific questions or revised guidance to tailor how the tools are used
- How to better align the resource allocation process to fit alongside equivalent activities in other service areas.

Comparative analysis of the derived budgets

5.46 The following analysis shows the extent to which a family's budget allocation changed at each of the stages of budget moderation (see Figure 22). It also sets out the values of the average IB packages for both existing service users and newcomers to the social care system and compares the former with the previous traditional care package values.

5.47 It is important to note that the analysis presented below should be treated with caution it is derived from only a small number of cases and in some instances are skewed by one or two families that experienced a significant change in the value of their package. As such, the figures should be interpreted as illustrative.

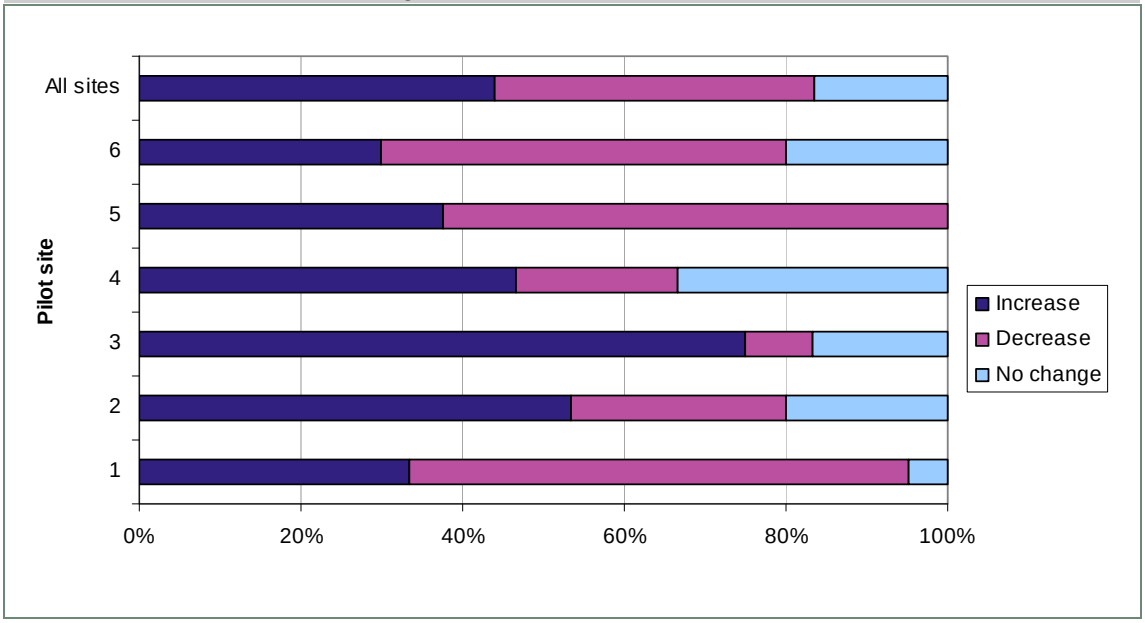
Analysis of budget moderation

Moderation stage one: from traditional to indicative budget produced by the model[16]

5.48 Figure 27 illustrates the extent to which the indicative budgets produced by the models (i.e. the first indicative budgets produced in each area before any negotiation) in each site differed from the comparative existing traditional service budgets. This shows that on average across the sites, 44% of the model-based increased, 40% decreased and 16% were unchanged relative to the traditional service budget. Breaking these findings down by site, the data shows considerable variation between the sites. For example, only 8% of the model based indicative budgets were lower than their traditional service comparators in site 3, whereas 62% of the relevant budgets decreased in site 1.

[16] This analysis assesses differences in package values for existing users of the social care system only. Please also note that the indicative budgets derived through the alternative models have been included for the purposes of the analysis, with the exception of the early intervention model (alternative model 2), which did not involve the derivation of an indicative budget.

Figure 27: Moderation from traditional to indicative budget produced by the model for existing service users – direction of change



N=91
Source: SQW pilot site monitoring returns, all sites

5.49 Table 28 shows the average proportionate change in budget experienced across the sites, which highlights that model based resource allocation led to an average decrease of nearly 15% relative to the traditional service budget. However, this figure should be interpreted with caution as it masks both the sizeable range of change (from -91% to 1027%) and the considerable difference in average proportionate change experienced within each of the sites.

5.50 These changes appear to have happened independently of the model adopted, as even where sites adopted a similar approach they ended up with very different results. This would suggest the variation in implementation and local practice can have a much larger impact than anything mechanistic in the approach.

Table 28: Moderation from traditional to indicative budget produced by the model for existing service users – average proportionate change

Pilot site	Average % change	Range
1	-40%	-91% to 1027%
2	-3%	-24% to 145%
3	93%	-11% to 733%
4	12%	-58% to 453%
5	-19%	-62% to 75%
6	-6%	-83% to 226%
All sites	**-5%**	**-91% to 1027%**

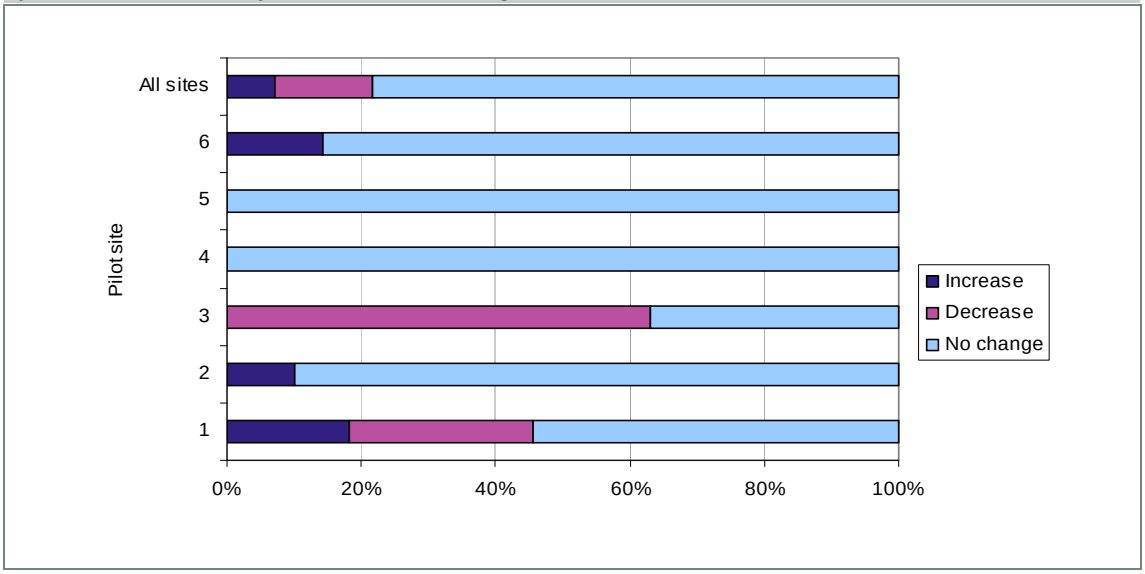
N=91
Source: SQW pilot site monitoring returns, all sites

Moderation stage two: indicative budget from the resource allocation model to indicative budget provided to the family

5.51 Analysis of the stage two moderation process confirms that some sites did not change the indicative budgets produced by the relevant resource allocation models and instead passed on the model based indicative budget to the family as the basis for discussion (see Figure 29). Interestingly, this included both sites that used an alternative resource allocation model and those that used the RAS, which indicated a desire to 'test' the accuracy of the model based budgets.

5.52 Similarly, for those sites that chose to moderate the indicative budgets produced by the resource allocation models, it was clear that the level of moderation varied between sites. The cause of this variation most likely reflects differing levels of confidence in the budgets produced by the models and a desire to assist the transition families were making from the traditional service model to the IB model.

Figure 29: Moderation from indicative budget produced by the model to indicative budget provided to the family – direction of change

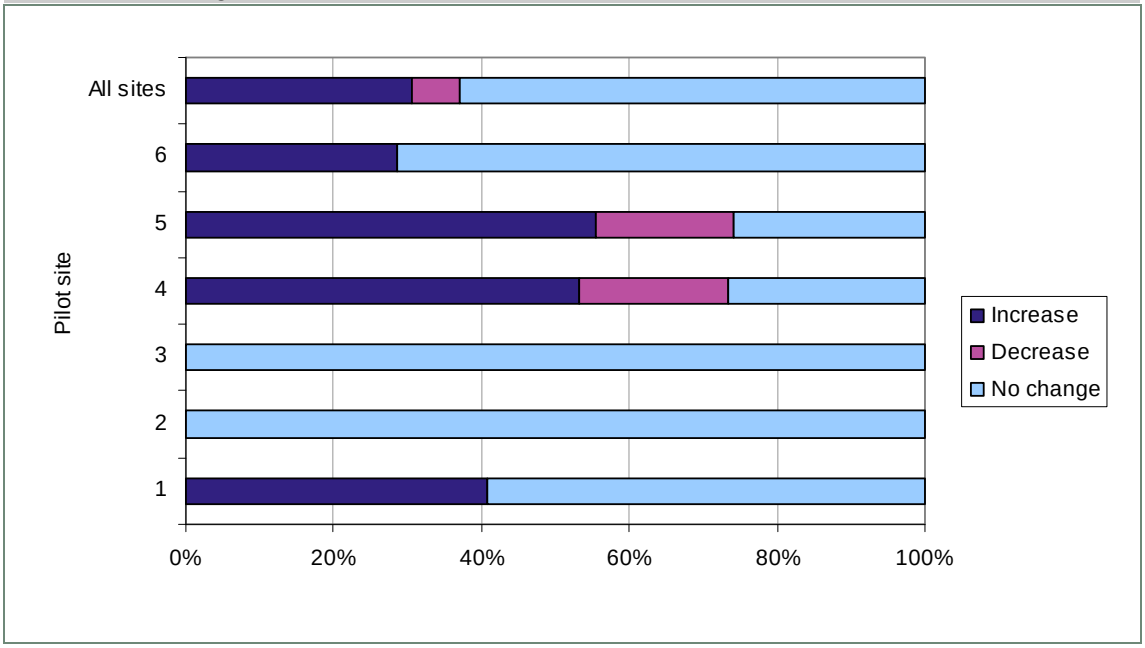


N=124
Source: SQW pilot site monitoring returns, all sites

Moderation stage three: indicative budget provided to the family to final IB funding allocation

5.53 Looking finally at the extent of change that occurred during the stage three moderation process, it was again clear that some sites did not deviate from the indicative budget provided to the family and as such, that they felt that the relevant need could be met within this budget (see Figure 30). That is, sites on average moderated 37% of the indicative budgets provided to families to form the final IB funding allocation. However, the analysis also showed sizeable levels of moderation in other sites, where for example, nearly 75% of the indicative budgets provided to families were either increased or decreased as a result of the support planning process in sites 4 and 5.

Figure 30: Moderation from indicative budget provided to the family to final budget allocation – direction of change



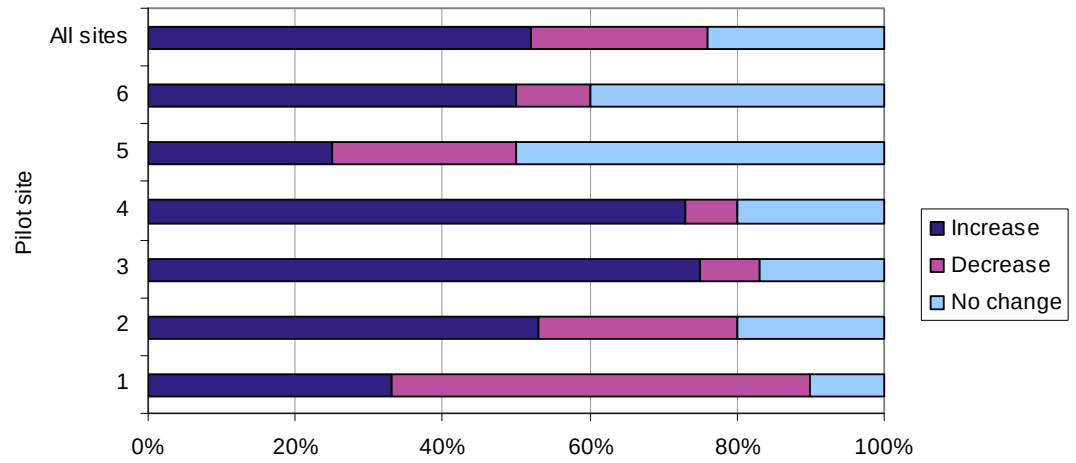
N=124
Source: SQW pilot site monitoring returns, all sites

Final IB funding allocation vs. traditional service budget - existing service users

5.54 The resource allocation process produced significant changes in the distribution of funding between families. This resulted in more families experiencing an increase in their funding allocation relative to the traditional service budget (see Figure 31). That is, 52% of families experienced an increase in their funding, 24% experienced a decrease in their funding and 24% were defined to have experienced no change (defined as variation of less than 10%) in their package value. Similarly, the data shows considerable variation in the extent of change between the sites, where for example, 33% and 57% of families in site one experienced an increase and decrease in their budgets respectively, in comparison to 75% and 8% of families in site three. 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.

5.55 Sites were willing / able to bear this variation because of the scale of the pilot. The implications of such changes however, would need to be assessed and managed much more carefully if any rollout was to proceed.

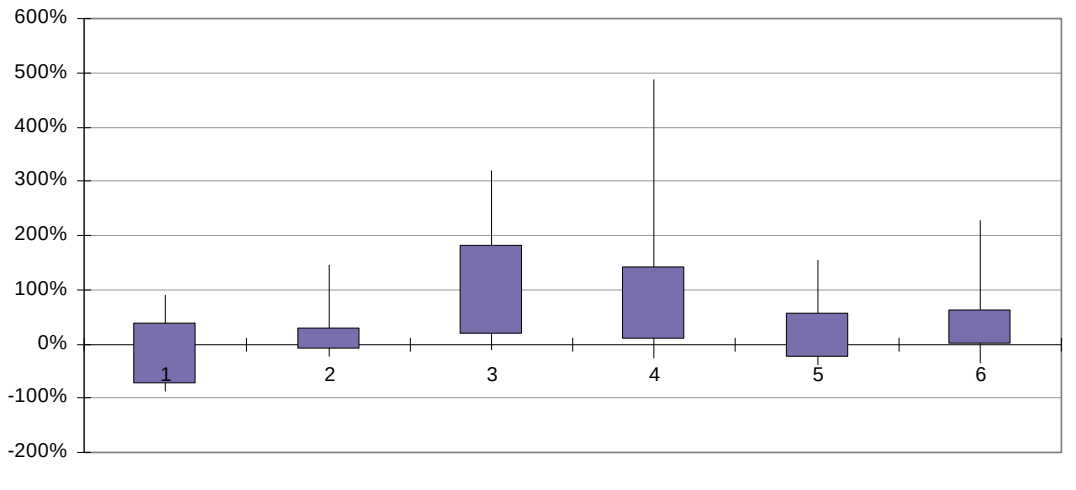
Figure 31: Moderation from traditional service budget to final IB funding allocation



N=91
Source: SQW pilot site monitoring returns, all sites

5.56 Figure 32 illustrates the distribution of budgetary change experienced by each of the sites. The 'boxes' on the diagram illustrate the distribution of the proportionate change in budgets for those families that experienced a change that lay between the 25th and 75th percentile of the site specific distribution. It shows that the range of change for this middle 50% of budget allocations in sites 2 and 6 was between 40-65%, whereas for site 3 the range of change experienced by this group of families was nearly 170%. Similarly, the whiskers on the figure show the maximum and minimum changes in budget allocations as a result of the IB process, which again illustrates large variation between the sites.

Figure 32: Proportionate change between the final IB final funding and traditional service allocations



N=91
Source: SQW pilot monitoring returns, all sites

5.57 Table 33 sets out the average and median values of both the IB packages and traditional service packages for families that were existing social care users. This shows that average IB package costs ranged from £1,700 to £16,500 per annum across the sites as compared to average traditional service packages of £1,700 to £15,100 per year. And similarly, that the median IB package costs ranged from £1,600 to £12,700 per annum across the sites as compared to median traditional service packages of £1,700 to £12,900 per year. As such, the evidence shows that final IB package values lay in a similar range to the comparative traditional service packages.

5.58 The data showed large variation between the sites. The overall level of spend across the IB cohort when comparing old and new packages remained close to cost neutral.

5.59 For example, site one produced final IB allocations that were on average 40% lower than the comparative traditional funding allocation, whereas site 3 allocations were on average 61% higher (see Table 33), where the latter increase was felt to largely reflect a meeting of previously unmet demand, which could not be met through traditional service provision. These figures should be treated with caution as they illustrate the average of only a small number of cases in each site and in some instances are skewed by a number of families that experienced a significant change in the value of their package. For example, in several cases the percentage level of change was over 100% of the budget, although this often reflected a big change on a small budget; while a handful of usually larger budgets changed by more than £20,000.

5.60 As such, an analysis based on the median package values is likely to more accurately reflect the true extent of budgetary change experienced by families' as they transitioned from the traditional service to the IB approach. This analysis showed that *across the programme, families experienced a 17% increase in their budget as a result of the IB approach*.

5.61 Site differentials in the average and median IB package costs can partially be explained by:

- **Inclusion of different funding streams in the package** - where for example some sites included additional health and education monies in the IB packages
- **Exclusion of particular social care services within the IB allocations** - where for example one site chose to exclude the provision of specialist services in their IB packages and instead drew in this provision over and above the IB in cases where it was required
- **Extent to which the pilot team sought to 'steer' their families towards more community and mainstream services** as opposed to specialist services - which were more expensive in their nature.

Table 33: Comparisons of average IB package vs traditional service package for existing service users by site

Pilot site	Range of IB package costs	Average IB package	Median IB package	Range of traditional service package costs	Average traditional service package	Median traditional service package	% change in average package value	% change in median package value
1	£2,500 to £25,200	£7,600	£6,200	£600 to £38,500	£12,600	£10,400	-40%	-41%
2	£2,000 to £65,000	£10,500	£5,400	£1,600 to £72,600	£10,800	£3,000	-3%	82%
3	£6,600 to £13,700	£10,700	£11,900	£1,600 to £14,800	£6,700	£5,700	61%	109%
4	£1,600 to £19,500	£9,700	£10,400	£300 to £17,200	£7,000	£6,600	38%	58%
5	£1,100 to £3,000	£1,700	£1,600	£700 to £2,800	£1,700	£1,700	3%	-3%
6	£2,400 to £45,700	£16,500	£12,700	£1,500 to £44,800	£15,100	£12,900	9%	-1%
All sites	**£1,100 to £65,000**	**£10,200**	**£7,700**	**£300 to £72,600**	**£10,200**	**£6,400**	**0%**	**17%**

Source: SQW pilot site monitoring returns, all sites n= 92, average package costs reflect annual budgets

Newcomers to the system

5.62 Analysis of the thirty-three families that were newcomers to the social care system[17] and in receipt of their IB funding at the end of the two year programme again reflected a range of need which was to be met using budgets ranging from £240 to £14,700 per year. This group of families also appeared to receive lower average IB budgets than families that were existing users of the social care system in the main, which in part could be explained by the fact that they had been picked up shortly after diagnosis and had less complex needs. Exceptions to this trend, i.e. those cases that were allocated relative high IB funding packages, may have been made up from families that had previously been assessed as eligible for social care but did not take up the traditional service offer as it was deemed inappropriate.

5.63 As the figures are made up from only a limited number of newcomers to the system, they cannot be used to estimate latent demand. However, they provide a useful illustrative example of the potential size of the costs that may arise per family as the IB approach is extended to include more families from this group.

Table 34: Value of the average IB packages for newcomers to the social care system

Pilot site	Range of IB package costs	Average IB package
1	£2,300	£2,300
2	£240 to £14,700	£4,400
3	£5,000	£5,000
4	£1,000 to £13,400	£4,500
5	£700 to £4,600	£2,100
6	£1,200	£1,200
All sites	**£240 to £14,700**	**£3,400**

Source: SQW pilot site monitoring returns, average package costs reflect annual budgets

Summary

5.64 Table 35 presents a summary of the progress made against element seven of the CDM.

[17] This group is made up from both families that had previously been assessed as eligible for receipt of social care services but had chosen not to take up the traditional service offer and those families that had only recently had their first contact with social care services.

Table 35: Progress made to date against elements seven of the CDM

Summary findings and lessons

- 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 was used for different age groups).
- The main differences between the RAS based models and alternative models appear to lie in: the sequencing of resource allocation in the family journey (see Chapter 6 for more details); and the degree of systematisation through which the scale of resource was decided
- 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, which had often involved training to ensure that all parties were able to effectively and consistently use the model
- All sites had aimed to develop an equitable and transparent model, which included the use of an inclusive and well defined process that provided sufficient information and explanation to families. Findings from the family focus groups illustrated that some sites had been more successful in delivering a transparent and clear resource allocation process
- 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. This finding was supported by feedback from families, which illustrated that the majority of families that had had the experience of an up-front budget had felt that this gave them a stronger basis upon which to plan their support
- Many parents had assumed that their indicative budget would be the same or more than what they had received previously, as there was a general feeling that service provision had been insufficient to date. As such, those families which experienced a decrease in their budget had been surprised and in some cases had left the pilot. However, the incidence of drop out from the pilot was minimised in some sites via effective communication of the indicative budgets, which included suggesting to families that the greater flexibility of an IB might outweigh the loss of resource
- The extent and frequency of budget moderation varied considerably between the sites, which was dependent on the differing mechanics, sequencing and levels of professional judgement associated with the different resource allocation models. This moderation was undertaken at a minimum of one of the following three stages: moderation from the traditional service allocation to the indicative budget produced by the resource allocation model; moderation from the indicative budget produced by the model to the indicative budget provided to families; and moderation from the indicative budget provided to families and their final IB funding allocation
- It was clear that sites that had used the RAS model relied heavily on the mechanics of the model itself, with some additional professional judgement. Whereas sites that used an alternative model relied more heavily on professional judgement to derive their indicative budgets
- The resource allocation process produced significant changes in the distribution of funding between families. This resulted in more families experiencing an increase in their funding allocation relative to the traditional service budget, where analysis of the median package values showed that across the programme, families experienced an increase of 17% in their budget as a result of the IB approach
- The data showed large variation between the sites. The overall level of spend across the IB cohort when comparing old and new packages remained close to cost neutral.
- Findings from the follow up parent/carer survey showed that 80% of responding families were either very satisfied or fairly satisfied with their IB funding allocation. The survey also showed that newcomers to the social care system tended to be more positive than existing users of the social care system, which was likely to partially reflect the fact that the former group did not have an preconceived notions about the value of their IB funding allocation
- At the end of the two year programme, all resource allocation models were viewed as a 'work in progress' and would require refinement for further use.

Actions moving forward beyond the two year pilot

In the event that the IB approach is rolled out beyond the pilot cohort of families, it is likely that sites will need to further refine their resource allocation models and consider the following ongoing issues:

- Staff resource required to 'scale-up' the use of the resource allocation model
- Consideration of how best to incorporate children and young people of differing age (as some sites had focused on the transition group in the main)
- How to either effectively incorporate additional funding streams/services into the resource allocation model or align resource allocation models used by different agencies.

Average package values derived for families that were newcomers to the social care system provide a useful illustrative example of the potential size of the costs that may arise per family as the IB approach is extended to include more families from this group.

6: Setting up the infrastructure pt II – support planning and the family journey

6.1 Over the first year of the pilots, it became increasingly clear that resource allocation and support planning were integrally linked. This meant that development of these strands was undertaken simultaneously and resulted in the creation of a single process in each site, through which families progressed. This Chapter *describes the mechanics of the support planning process and then draws both the resource allocation and support planning processes together to illustrate the journey through which families proceeded in each of the pilot sites*. Reflections on the effectiveness of these processes are then presented from both the pilot site and family perspectives.

6.2 The chapter subsequently sets out progress against elements 6 and 8 of the CDM (development of IT resources and a spectrum of choice for the management of the IB funding), both of which also formed part of the infrastructure requirements of the IB approach.

Progress against CDM elements 4, 6 and 8

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

6.3 All six sites developed and embedded a support planning process through which professionals could assist families to decide how bets to meet their needs using the resources that they had available and were allocated. This was delivered through a variety of mechanisms, each of which is described below in conjunction with the rationale for selection:

- **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
- **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 used this expertise to facilitate the required provision

- **mixed forms of provision that combine both internal and external provision –** as there was no conclusive evidence to support the effectiveness of any one form of support planning, a number of the sites facilitated both internal and external provision to test the effectiveness of the different processes.

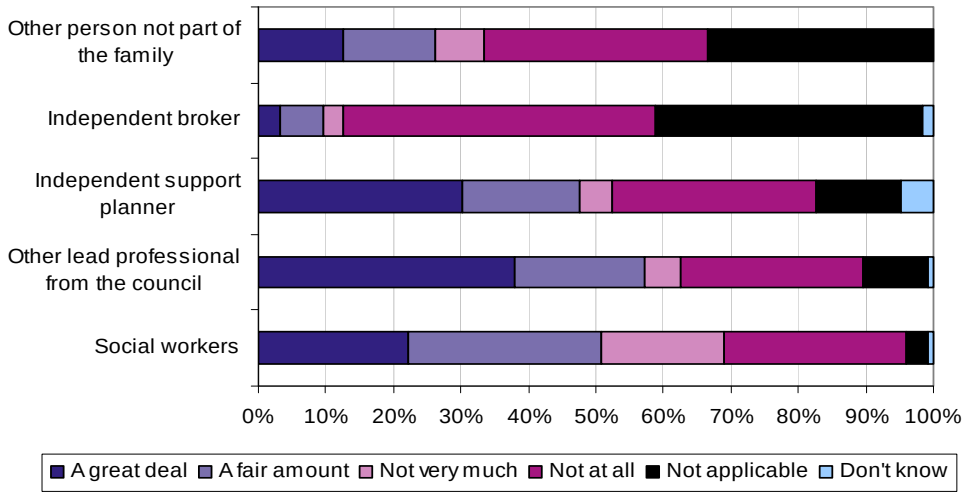
6.4 The approaches and tools used in some cases drew on previous experience of Person Centred Planning. This appears to have offered professionals a sound basis from which to engage in the support planning process around IBs. People with these skills may provide an important resource to deliver suitable support to families in any expanded IB offer.

6.5 Two supplementary forms of support planning were used by a number of the pilot sites. The first of these related to the use of the Planning Live approach[18]. This provided a means by which families and their supporters could plan together as a group via the help of trained facilitators. The second related to the facilitation of 'self support planning', whereby the family and disabled child draft the planned themselves, with support provided as and when required.

6.6 Figure 36 from the parent/carer follow-up survey reflects the extent to which different types of professionals were involved in the support planning process. This shows that approximately half of the families reported that a social worker, lead professional or independent support planner had been involved either a 'great deal' or 'a fair amount' in the development of their support plan.

[18] Planning Live has been provided in some sites by Helen Sanderson Associates as part of the support provided through DfE funding to the pilots.

Figure 36: Extent to which different professionals contributed to the development of the



N=126
Source: SQW and Ipsos MORI parent/carer follow-up survey

6.7 Support planning guidance was developed by the majority of the sites. Figure 37 provides an example of the guidance used in one of the sites.

Figure 37: Example of support planning guidance 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

6.8 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'[19], was also commissioned by the majority of sites as a means of assisting families during the support planning process. This was delivered through the use of external advocacy services which were experienced in offering support to families.

[19] Definition adapted from the National Standards for the Provision of Children's Advocacy Services, Department of Health 2002

The 'family journey'

6.9 Traditional approaches to service provision for families with disabled children have to date been led by professionals that have developed care packages using the services commissioned or endorsed by the relevant local authority or agency. As such, the family and disabled child have had relatively little influence over the support provided to them. The IB approach was introduced to test whether the provision of more family-led choice and control could lead to more appropriate service provision and subsequently to enhanced outcomes. The family-led models used by each of the sites are detailed below.

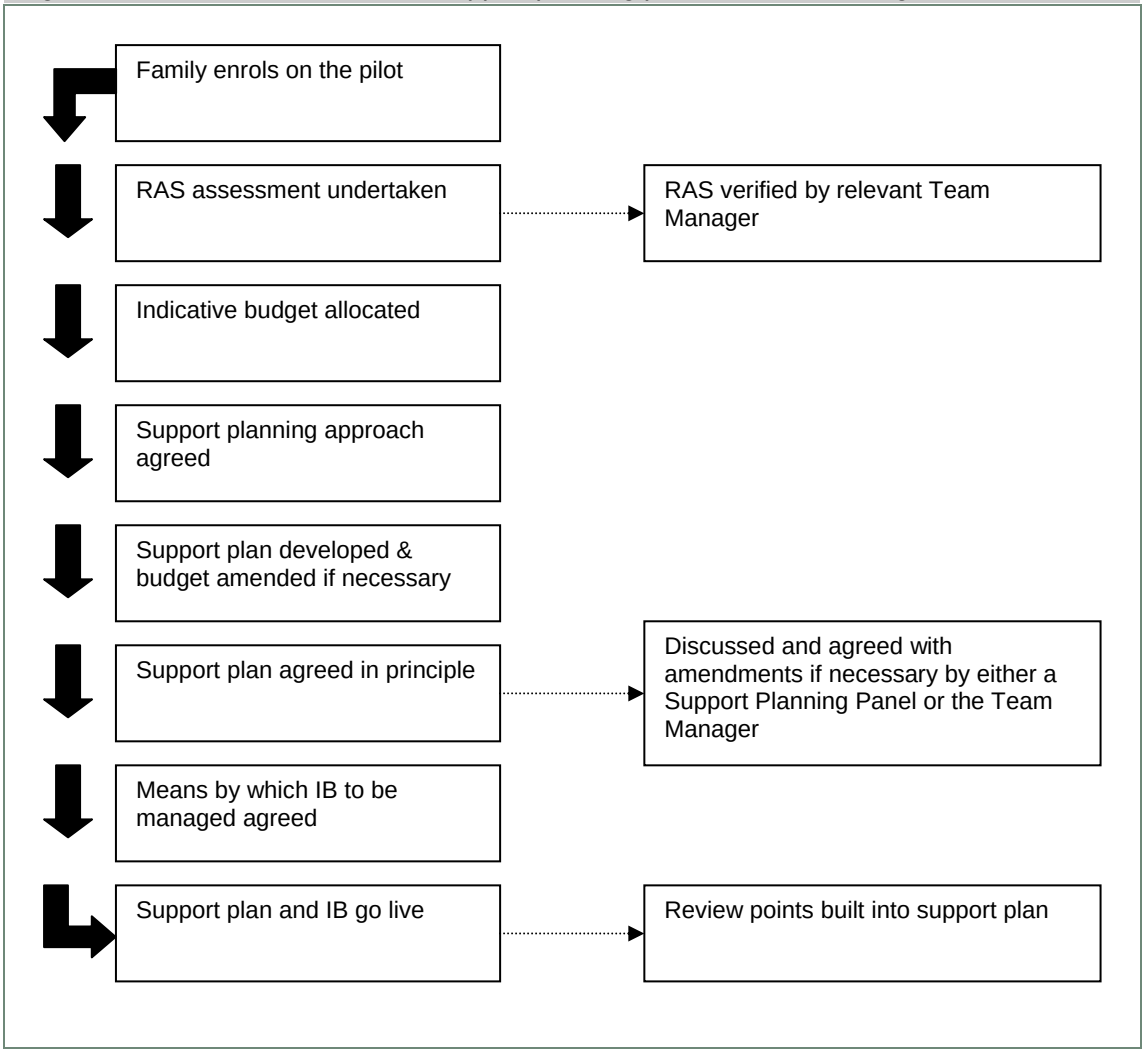
The In Control RAS and support planning

6.10 Combining the RAS and support planning development activities, the resultant process used by the three relevant sites (and the site which used an alternative model similar in nature to the RAS) is illustrated in Figure 38. This shows that once a family had been given their indicative budget, they proceeded onto support planning, where they were given a choice of how they would like to undertake this process (where each of the three sites offered a different set of support planning options). This process was used as a means of enabling the family and their child to identify the outcomes that they wished to achieve using their IB. The support plan was then developed and agreed with the family and child/young person. In some cases this involved the amendment of the indicative budget produced through the RAS to either ensure the funding could accommodate the services/activities required to meet the needs of the family and the child or to reduce the budget in cases where the need could be met using a smaller allocation.

6.11 Once the support plan was agreed the plan was taken to either a support planning panel or the relevant team manager for approval/vetting. This approvals process included the finalisation of both the plan and associated final IB funding allocation.

6.12 In some cases, families were invited to attend the panel where the relevant support plan was discussed. Families were therefore provided with the opportunity to explain the rationale for the individual components of their support plan and have in some cases challenged the decision of the support panel. Alternatively, this process was facilitated between the support planner, the family and the relevant Team Manager. Approvals in both models were subsequently made to both the plan and the final budget allocation.

Figure 38: Resource allocation and support planning process for sites using the RAS

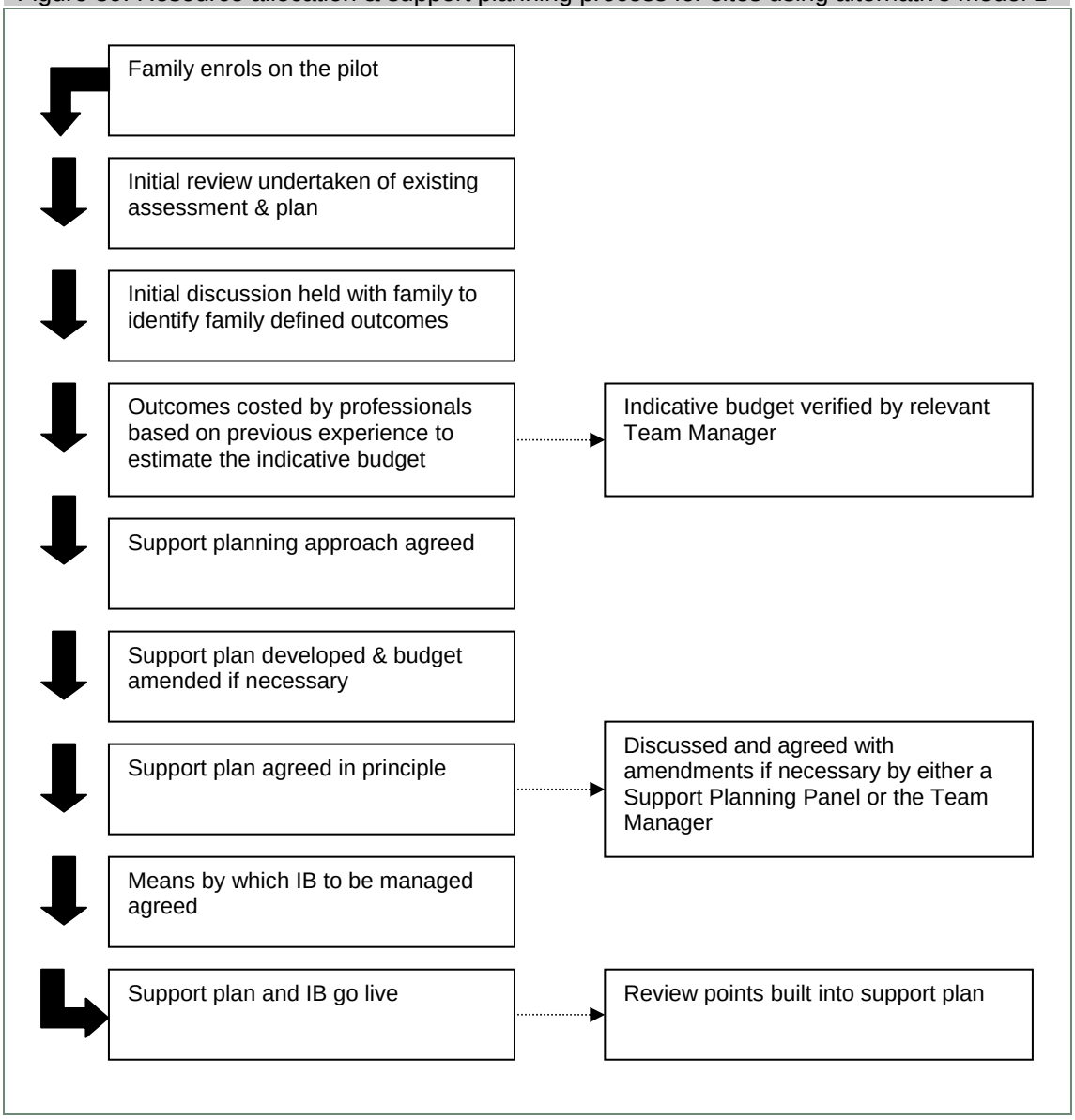


Source: SQW case study research

Alternative forms of resource allocation and associated support planning

6.13 The resource allocation and support planning process associated with the first of the remaining two sites that developed alternative resource allocation models (referred to as *alternative model 1)* is illustrated in Figure 39. In sequencing terms, this shows that following enrolment to the pilot, work was undertaken to review the assessment and existing care plans of the relevant families. The families were then contacted and an initial discussion was held to explore what was and wasn't working in relation to their current service provision and subsequently, what outcomes the family and child/young person wanted to achieve through the IB. Support for the identified outcomes were then costed by the professionals as discussed above to produce an indicative budget. Once the indicative budget was approved by the relevant team manager, the family was informed and the support planning process began, which was facilitated in a similar sequence to that of the RAS sites.

Figure 39: Resource allocation & support planning process for sites using alternative model 1

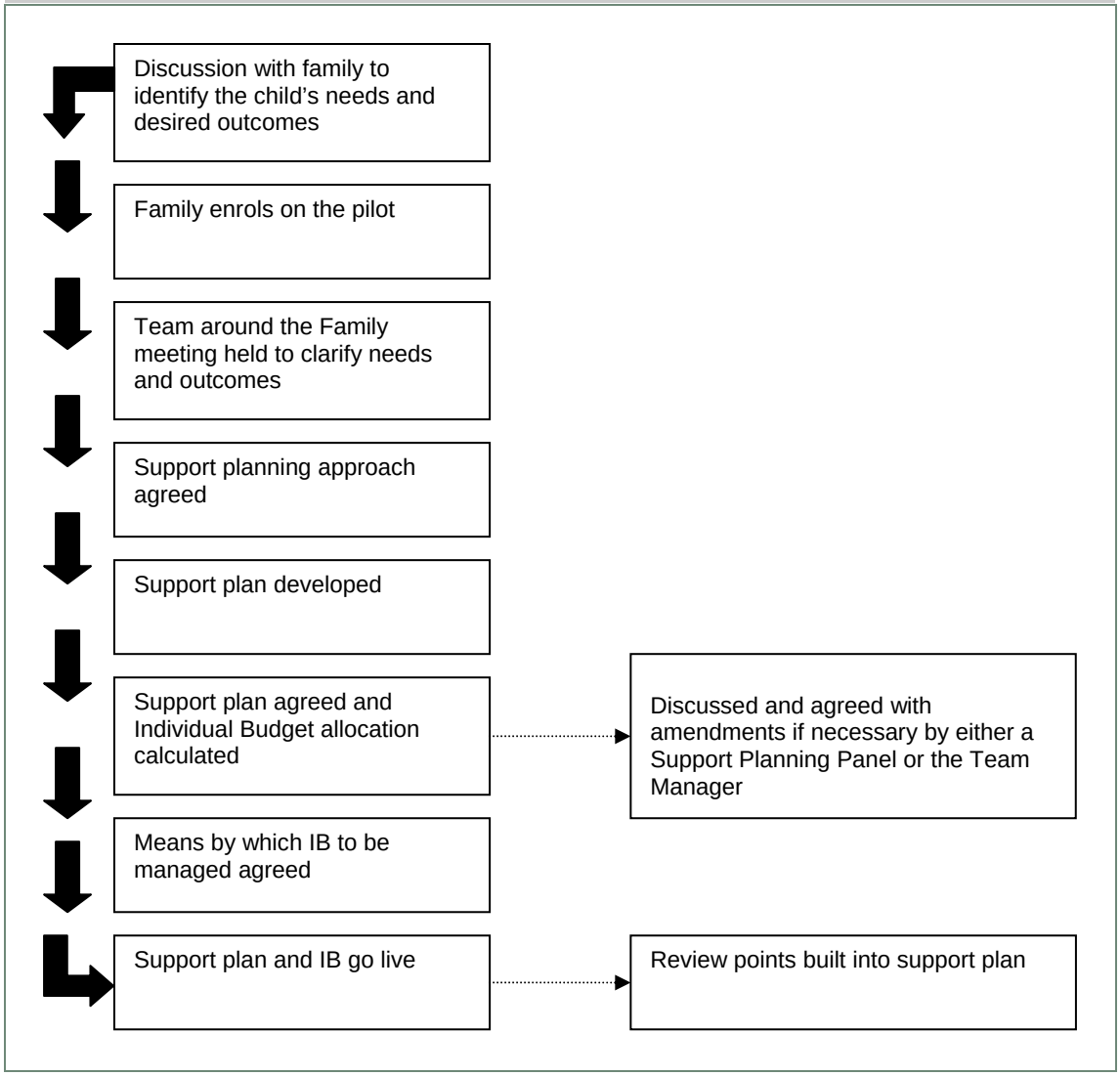


Source: SQW case study research

6.14 The second pilot site which used an early intervention model (referred to as *alternative model 2)* was facilitated through lead professionals who initially visited the family to identify their and their child's needs and desired outcomes, following which a 'Team Around the Family' (TAF) meeting was held to clarify the needs and outcomes of the relevant child and their family. Following agreement of the needs/outcomes, support planning took place and the individual budget was calculated on the basis of the chosen services/activities. The support plan then proceeded through a similar approvals process to that of the other models, after which, the plan and IB went live. This implied that the approvals process in this model acted as the main point at which the budget was checked and reviewed.

6.15 Figure 40 summarises the resource allocation and support planning process used to facilitated *alternative model 2*.

Figure 40: Resource allocation and support planning process for sites using alternative model 2



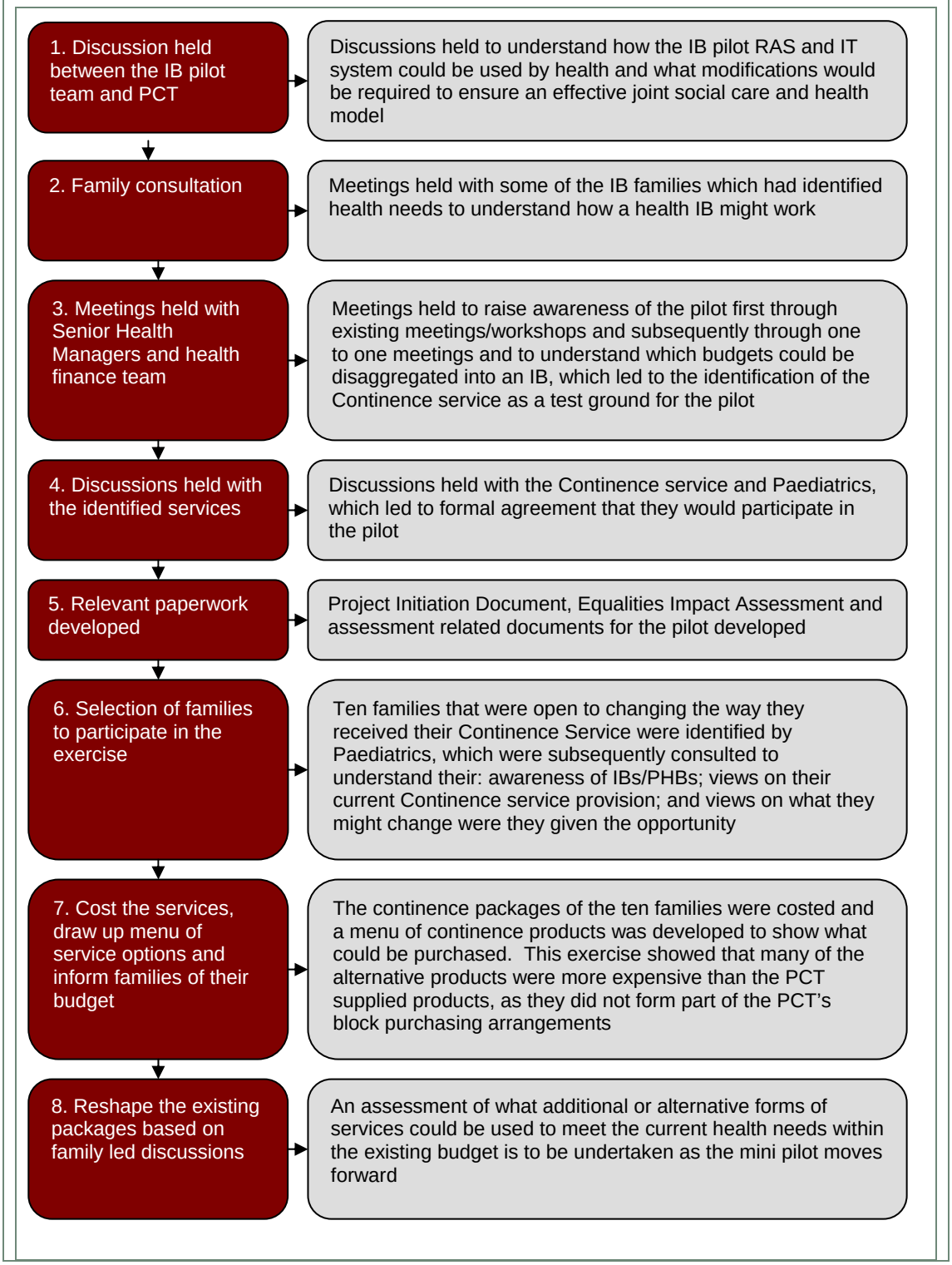
Source: SQW case study research

Health-related support planning

6.16 During the course of the second year of the pilot programme, two of the sites were grated provisional status to participate in the Department of Health's Personal Health Budget (PHB) Programme. The rationale for joining the complementary programme was to formally enhance the workings of the IB pilot through learning from the PHB programme. The progress made by one of these sites is described in Figure 41 below.

Figure 41: Health related planning process in the one of the pilot sites

As the PCT was unable to provide funds to allocate as part of the IB packages, they committed to undertaking a 'hypothetical' planning exercise to further their understanding of what a health related IB may look like for families with disabled children. The model/framework used to undertaken this process is illustrated below.



Source: SQW case study research

Reflections on support planning and the family journey

Feedback from the pilot sites

6.18 All sites reported that they had found the support planning process both rewarding and challenging. Focusing first on why support planners had found the process rewarding, it was clear that in the majority of cases the individuals felt that it had helped families to access more tailored support and so to improve their day-to-day situations. One support planner explained that they felt they were 'making a difference' by translating what each family wanted to achieve into 'tangible support'.

6.19 Looking now at the challenges faced, it was apparent that the majority of families had not in the past been aware of the costs of different services and therefore in many cases they had found it difficult initially to imagine exactly what the budget they were allocated could purchase. This challenge had implications for the time spent supporting the relevant family to understand the cost of existing service provision and other options that they may want to choose, which often included a need on the part of the support planner and family to be both creative and realistic about how the budget could be used and how far the money could be stretched.

6.20 Individuals involved in the support planning process stressed the importance of the exploration and subsequent identification of activities to meet the child/young person's goals through discussion. They added that families tended to assume they could not make choices outside of the norm at the outset of the process, but that given time and sufficient encouragement, the process more often than not facilitated the consideration of alternative options such as community based or mainstream service provision as a means of achieved the designated outcomes.

6.21 In the cases where families struggled to suggest activities, support planners often asked the family to provide an indication of where they wanted support and the support planner subsequently used this information to suggest possibilities. This often involved a discussion of how other families had used their budgets to enable the family to recognise the potential of their IB. In essence the support planner was drawing on their experience to help raise awareness amongst families of the possibilities.

6.22 Looking specifically at the differences between the IB support plans and non-IB care packages, the sites felt that the former reflected a change in focus from the provision of specialist services to more community-based and/or mainstream services. One site added that for those families who were existing users of the social care services

a significant proportion of IB funding had been spent on Personal Assistant (PA) time with less on residential care; whereas those families who were newcomers to the social care system seemed to spend less on PA time and more on particular activities. Other sites had also helped families think through solutions that may not necessarily require funding, such as attendance at youth clubs, as a means of broadening the activities they engaged in.

6.23 Site-related feedback on the reactions of families to the support planning process showed that they felt families had in the main found the process challenging and often emotional. However, they also reported that families had really valued the opportunity to shape their plan and had appreciated the balance between the independence the process provided combined with the assistance provided by the support planner. One site also reported that some families had stated that the process had helped them to improve their communication within their family unit, which was likely to result in a reduction in family-related stress levels.

6.24 Sites also highlighted differences in the approaches taken by parents in formulating the relevant support plans. That is, well-informed parents already using the traditional system tended to be more innovative and proactive in identifying activities and making contact with relevant service providers, and were generally more vocal about their needs. Conversely, those new to the system took longer to understand their plans and engage with the process effectively.

6.25 The support planning process was also cited to act as an ‘enabler’ which supported disabled young people to ‘live like other young people’ and to overcome the isolation that some of the participants had experienced. For example, the IB approach and support planning process enabled young people to hire their own PA, rather than a care assistant sent by a care agency, which translated into the recruitment of appropriate individuals, who tended to be close in age to the disabled young person. This change in approach subsequently enabled many of the IB participants to take part in activities with their friends, such as attending social or sporting activities. Other activities that have been purchased through the IB funding have included: camping trips, participation in exercise classes, support to go to the cinema, membership to a local zoo, and summer school/holiday club places.

6.26 Reflections on the time taken to complete the support planning process, revealed considerable variations both across the sites and between families. This variation was caused in part by differing levels of existing support planning experience of the

individual sites, which in cases where processes were already embedded, led to the process being undertaken in a shorter time.

6.27 The duration of the process was also felt to be dependent on: the previous experience of the family, where existing service users were often more informed; and the time spent by the support planner assisting the family to explore local community resources, which often included support to trial some of the activities with the young person. The impacts of the differing levels, duration and quality of support were assessed in the family follow-up survey, the results of which are detailed below in the family feedback section.

6.28 While some sites used a support planning template within which each support plan was populated, others essentially let the family dictate the format of the support plan. The resultant differences between these approaches appeared to be negligible, where sites reported that although it was important to design the plan in a way that the relevant family was comfortable with, the end format had not resulted in noticeable differences in content. They added that clear support planning guidance that was both flexible and inclusive in its approach and an associated written record of the agreed final budget and support plan were critical to the success of the overarching support planning process.

6.29 Table 42 provides examples taken from two of the support plans developed by participating families, which show the set of costed actions that were approved in both cases. These examples highlight the ways in which families sought to combine their own resources with those provided as part of their IB funding allocation.

Table 42: Examples of costed actions in the pilot support plans

Type of provision	Annual cost
Newcomer to the social care system	
2 x 4hour sessions per week at childminder during school holidays (13 weeks per year) @ £5 per hour	£520
Annual family membership at a summer mainstream play scheme	£47
2 sessions per week at a local childminder (within walking distance)	£215
Transport to special school play scheme during summer holidays provided until parent passes driving test @ £10 per journey	£60
TOTAL	**£842**

Type of provision	Annual cost
Existing user of social care services	
Trip to a concert/entertainment event	£35
Transport to work experience	£100 (with additional £100 contributed from the school)
Residential break	£300
Participation in football activities	£133 (includes attendance fee and one way transport, where the parents will facilitate return transport)
Participation in day trips	£200 for trip fees and £96 to cover transport costs (where transport was to be shared between the family and the IB)
Attendance and participation in sessions and events run by a day centre	£1160
Hosting an evening with friends	£0
Contingency to be spent as and when needed or released at the end of the year	£296
TOTAL	**£2,320**
Existing user of social care services	
PA Support during term times: 39 weeks	£4,095
Employers Liability insurance	£135
Monthly Weekend respite (21 hrs per weekend)	£2,700
Holiday respite 2 days a week over 12 weeks	£2,700
Holiday placement at Camp for1 week	£225
PA support costs for holiday time (3 hours p/w for 13 weeks	£ 409.50
Other holiday respite activities (since term time activities cease) e.g. attend day trips, overnight camp	£ 836
Entrance fees, snacks and PA expenses for 52 weeks	£ 780
After school activities / Saturdays in term time	£696.50
Family Break – additional costs: Cost of 3 bed instead of 2 bed accommodation and for closer proximity to amenities and PA cost	£301
One off equipment including supportive software	£ 415
Contingency Costs	£285
TOTAL	**£13,578**

Source: Pilot site support plans

6.30 As such, the support planning processes have in the main been perceived as both a learning process and a success by the sites.

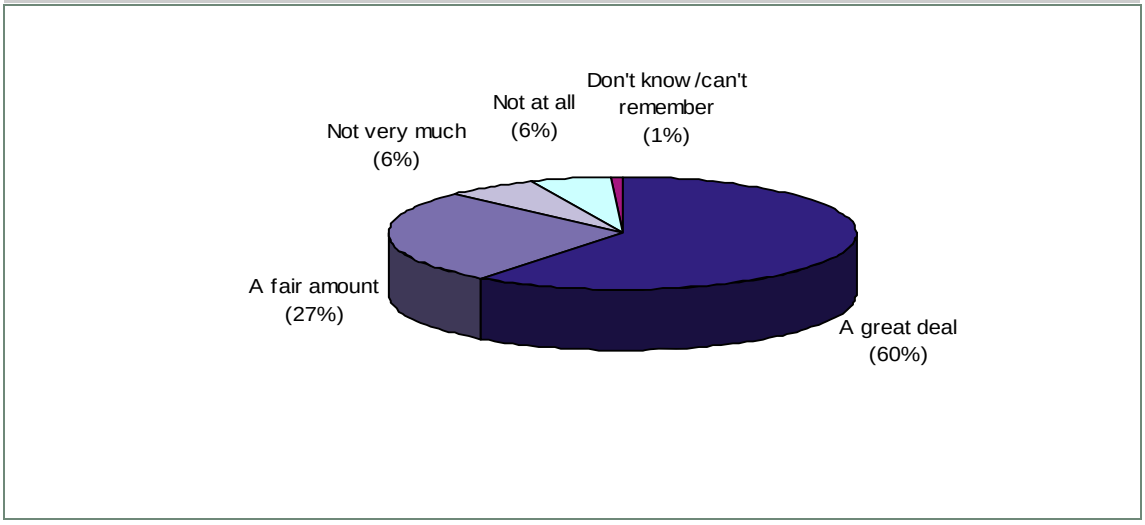
Feedback from the family focus groups and survey

6.31 Families at the focus groups echoed much of the positive feedback expressed by the pilot sites. For example, they highlighted the 'empowering' nature of the process, where they explained that they felt they had been 'listened to' for the first time and that their 'views had been taken into account'.

> *'We were used to being 'done to' by professionals rather than actually having our voices heard and taken into account…and we now feel like we have a right to say what we would like'*
>
> *'I am as enthusiastic now that I've been through support planning as I was at the beginning of the programme. I have been able to create something for my son for the first time from us rather than an outside agency recommending what should happen'.*
>
> *Quotes from the focus groups*

6.32 This finding was reinforced by results from the parent/carer survey, which showed that the majority of families (87%) felt that their views had either been taken into account to a 'great extent' (60%) or 'a fair amount' (27%) when developing their support plans (see Figure 43).

Figure 43: To what extent do you feel your family's views were taken into account in developing the support plan



N=126
Source: SQW and Ipsos MORI Follow Up Parent/Carer Survey

6.33 The flexibility of the planning process was also identified as one of the critical success factors. For example, the IB approach had enabled families to choose a PA who was age and gender appropriate, which was reported to have helped increase the independence and socialisation of the relevant disabled children/young people.

'It's more flexible than Direct Payments ever was, what I've got incorporated in it…the fact that rather than going into respite at xxx, which is all there was, she can go and stay with someone for a weekend, and we can choose who she goes to…and that for us is a much better way for xxx'

'I am glad we did it as we had greater flexibility, new ideas and met other people to pinch ideas from'

'I've managed to find a PA for xxx who is male and an ex-royal marine, so he's really active and a really good role model. It's meant that xxx has got back on his feet, to the standard he was before…and I don't think he would have done that if he'd just had a standard council employee'

'The female PA xxx got is only 19! She's young and still at university…and has to the extra energy to keep up with xxx'

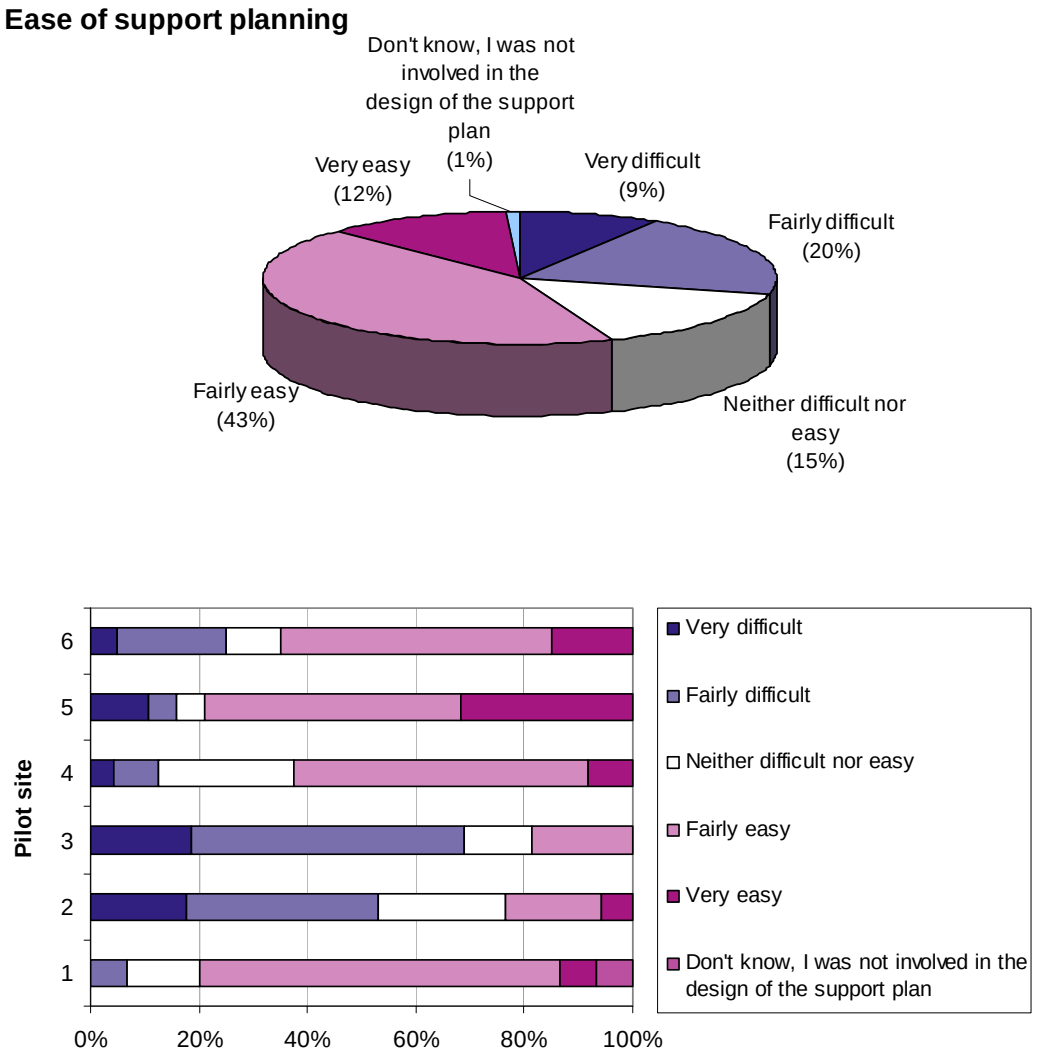
'The PA's young and gels like that with xxx, which is absolutely fantastic…it's great, xxx is going 'yes! I'm going out with my PA today''

Quotes from the focus groups

6.34 Supporting evidence from the parent/carer follow-up survey showed that the majority of families (55%) had found the design of their support plan either 'very easy' or 'fairly easy' (see Figure 44). Of the remaining 45% of families, nearly 30% had found the process either 'fairly difficult' or 'very difficult'.

6.35 Site level analysis of the same indicator (see Figure 44) highlights considerable variance between the areas, where for example over 50% of families that responded to the survey in sites 2 and 3 reported that they had found the design of their support plan either 'fairly difficult' or 'very difficult'. This finding may reflect the experience and confidence of both the relevant families and support planners and therefore indicate the pilot nature of the process. It was also supported by views gathered at the focus groups, which showed that despite finding the process rewarding, some families had found support planning challenging and time-consuming.

Figure 44: How easy or difficult was the design of the support plan?



N=111
Source: SQW Follow Up Parent/Carer Survey

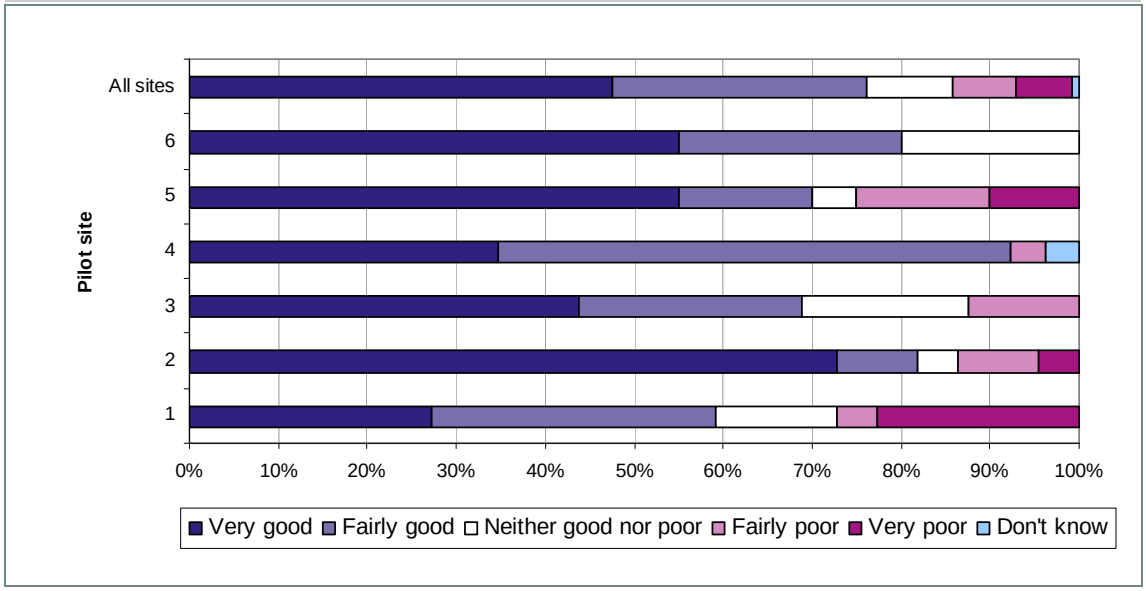
6.36 General consensus also showed that the following elements of the family journey had proven to be effective:

- **Quality and engagement on the part of the IB project officers –** the project officers that had supported the families throughout the process were felt in the main to have been very effective, as a result of their empathetic and understanding nature. There was also a general feeling that these individuals genuinely wanted to support the families as best they could and for that reason, were heavily involved in helping the family to recognise the possibilities that could be achieved through the IB approach. Parents added that it was this quality engagement that had made the real difference to them in comparison to traditional service provision

- **Involvement in support planning as part of the IB approach –** support planning (and the planner themselves) was viewed to have been an invaluable experience, which had helped families to 'think outside of the box'. Parents also agreed that this exercise had helped them to recognise: the resources that could be drawn upon from both within their family and their support network to support their child; and in the cases where the child/young person had participated, to learn more about the desires and wishes of their child.

6.37 These findings were again substantiated by the parent/carer survey, which showed that 77% of families across the sites felt they had had 'very good' (48%) or 'fairly good' (29%) support throughout the family journey (see Figure 45).

Figure 45: Rating on quality of support received through the process of support planning and



N=126
Source: SQW and Ipsos MORI Follow Up Parent/Carer Survey

6.38 Focusing now on what didn't work as well, families at the focus groups raised concerns about the timeliness of follow-up actions post the introductory sessions and sign up to the pilot and reported that progress through the process had been slower than expected. Many families also discussed the need for more timely processing and approvals of support plans, where some families had waited several months to gain approval and had not been informed why the delay had occurred.

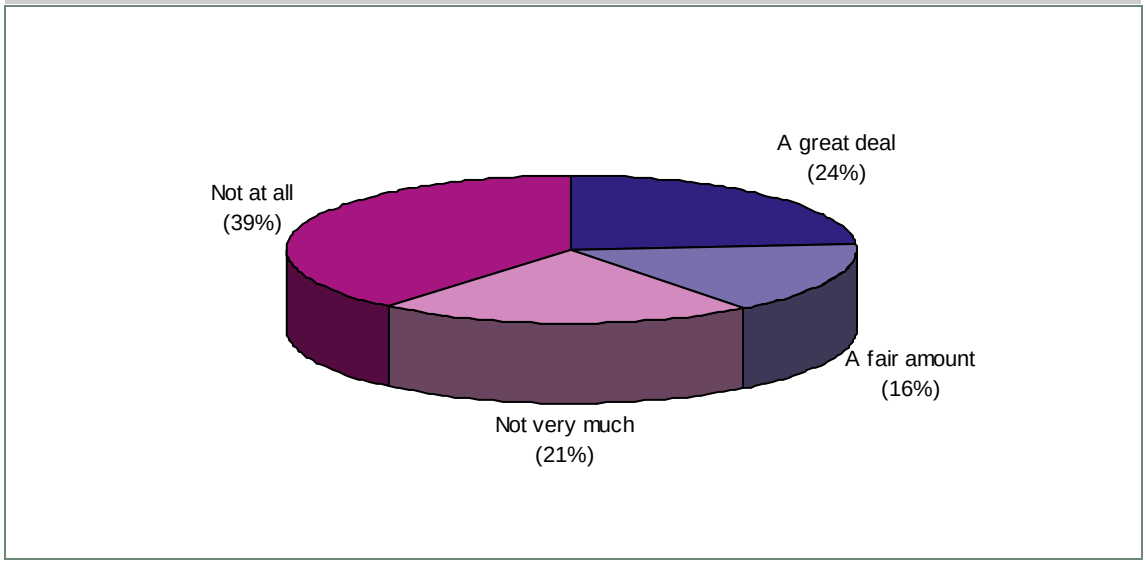
6.39 Interestingly, some parents viewed the IB process as distinct from their involvement with the social care team. These parents added that they felt the IB approach should be integral to the workings of the social care team and that the sites should seek to align the two in the future.

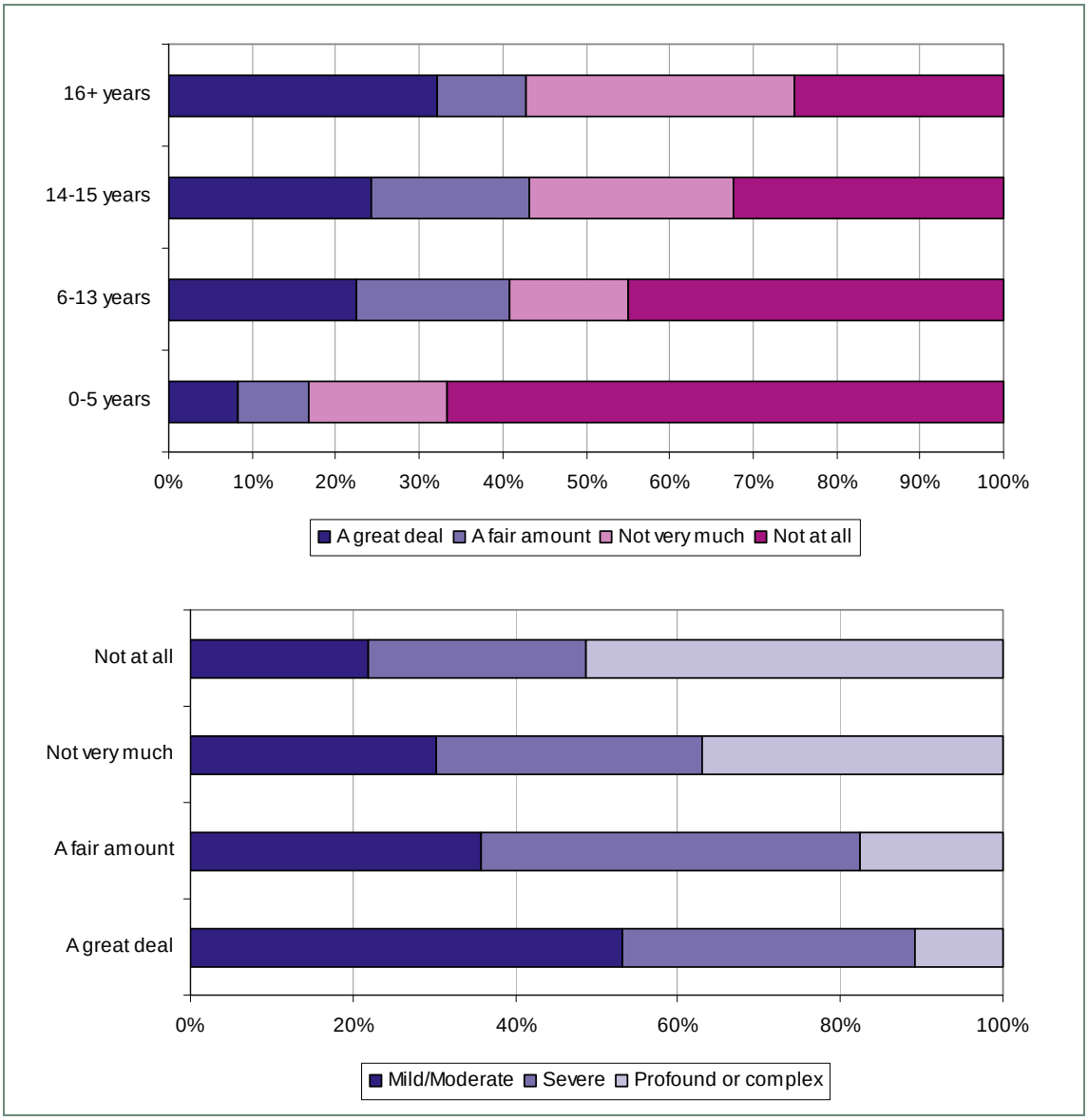
6.40 Problems were also encountered by many families around how best or whether to engage their child/young person in the support planning process. That is, although some families in conjunction with their support planner had effectively engaged their child in the process, other families had felt that the process had not been tailored to effectively engage their child. As such, some parents voiced their frustration that processes were not inclusive and had instead led their child to become confused or isolated from the process.

> *'My child was able to participate in the support planning process despite him being unable to communicate verbally…xxx supported him to develop a video to illustrate what he wanted to achieve and this video was shown at the support planning approvals panel'*
>
> *'They asked us [the parents] what we wanted but didn't really try to engage xxx, who really should have formed the focus of the process'.*
>
> *Quotes from the focus groups*

6.41 Figure 46 illustrates the extent to which the main parent/carer felt that the disabled child or young person was involved in the support planning process. This shows that only 40% of families reported that their disabled child/young person had either been involved to 'a great deal' or 'a fair amount'. The survey data also indicated that involvement was positively correlated with the age of the child, i.e. older children were more likely to be involved in their support planning process, and negatively correlated with severity of impairment, i.e. the more severe the child's impairment, the less likely they were to be involved in the process.

Figure 46: Extent to which the disabled young person was involved in the support planning

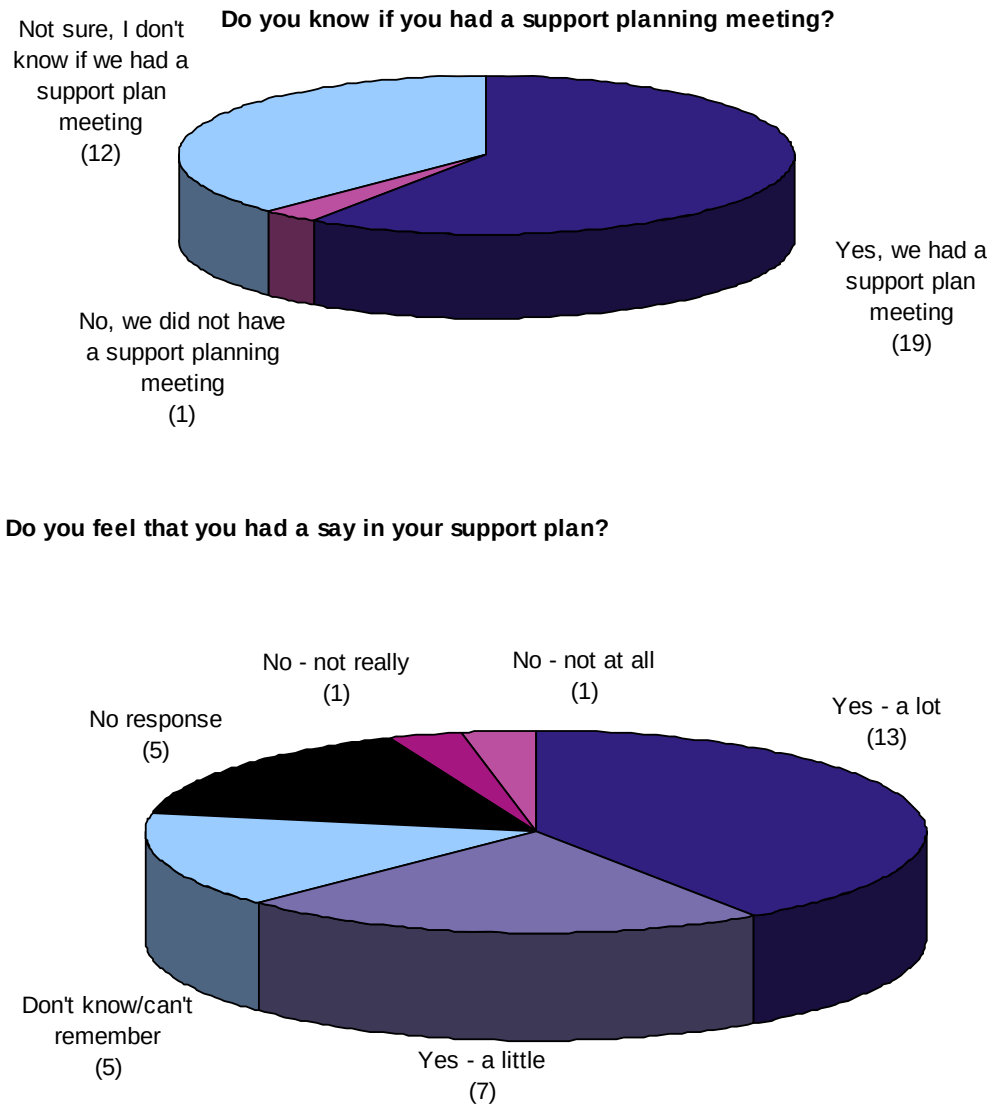




N=126
Source: SQW and Ipsos MORI Follow Up Parent/Carer Survey

6.42 Similarly, although the majority of children (19 out of 32) that took part in the follow-up survey reported that they had taken part in support planning meetings, a large proportion (12 out of 32) had also reported that they were unsure whether they had participated in this process (see Figure 47). It was also clear that although a number of the young people felt that they had had a say in their support plan (13 stated they had had 'a lot' of say and 7 stated they had had 'a little' say), a number of children either did not know or did not think that they had had much of an influence on their support plan.

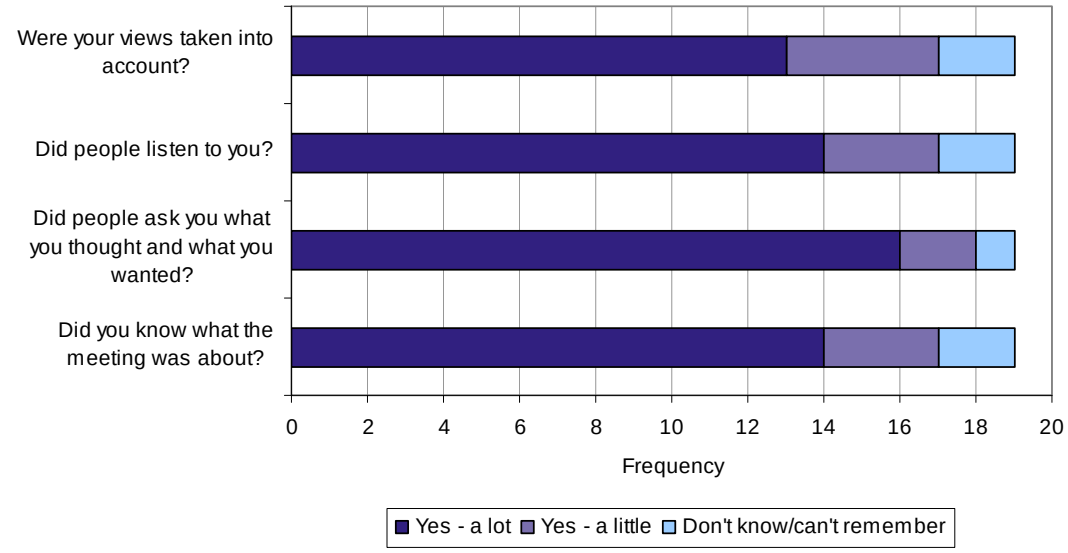
Figure 47: Awareness of involvement and influence held in support planning meetings



N=32
Source: SQW and Ipsos MORI Follow Up Child/Young Person Survey

6.43 Encouragingly, of the 19 children/young people that were aware that they had taken part in support planning meetings, the majority felt that: their views had been taken into account; people had listened to them; people had asked them what they had thought and wanted; and were aware what the meeting was about (see Figure 48). However, it is likely that those young people that took part in the follow up survey were also more likely to have participated in their support planning process and therefore the figures should be viewed as illustrative of the achievements that could be made in the event that more children/young people were engaged in this process.

Figure 48: Children/young people's views on the support planning process



N=19
Source: SQW and Ipsos MORI Follow Up Child/Young Person Survey

6.44 Similarly, family-based case studies provided by the pilot sites showed evidence of a desire to be involved on the part of the disabled young person, therefore implying a need to understand how best to facilitate this engagement.

> *'I don't usually make decisions, I usually get told what to do. I'm slow at making decisions and processing things and my Mum normally makes decisions for me. I would like to make more decisions for the reason of the independence and make my Mum and Dad realise I can take steps in life and I'm trying to climb up the ladder of success and not sitting back and letting them do things for me all of my life. I'm not one of those people. I want them to realise that what's happened has happened and I don't want them to have to do everything for me all my life I want to try to do things. It's not about cancelling my parents out but giving them a break and letting them know they don't have to do everything'.*
>
> *Quotes from a 16 year old young person participating in the pilot*

6.45 In addition, although most parents viewed the support planning process as valuable, some felt that there should have been more clarity around what the IB could and could not be spent on. That is, although they recognised that IBs provided a more personalised response to social care needs and as such could not be accompanied with a defined list of 'can's and cant's', some parameters around what was acceptable and what was not would have been helpful.

Looking to the future

6.46 Given the resource intensive nature of the support planning process, it is likely that sites will need to consider how best to scale up this process in the event that the IB approach is rolled out across the local authority. This should involve consideration of which groups of operational staff are best placed and have the appropriate skills to deliver the process and how continuity between the initial planning and subsequent review process can be maintained.

Summary

6.47 Table 49 presents a summary of the progress made against element four of the CDM.

Table 49: Progress made on the provision of advocacy and support brokerage for IB users

Summary findings and lessons
• The majority of sites commissioned an external advocacy service to offer support to families. • Three main models of support planning have emerged: ➢ Independent support planning provision sourced from the third sector ➢ In-house support planning (i.e. within the local authority) ➢ Mixed forms of provision that combine both internal and external provision These methods were in some cases enhanced by the use of the Planning Live approach and 'self support planning', where the latter was facilitated by the family in the main. • The support planning process was felt to form an integral part of the resource allocation process, which meant that the development of these strands was undertaken simultaneously and resulted in the creation of a single process in each site, through which families progressed – the family journey • The family journey differed by site. That is: ➢ The sites that used the In Control RAS used the RAS questionnaire, which sought to assess the needs of the family against a pre-specified set of outcomes, at the outset of the family journey, subsequently apportioned an indicative budget to meet the identified needs, following which support planning took place. ➢ Conversely, the sites that used an alternative approach undertook intensive planning work with the family prior to the support planning process, as a means of determining the outcomes the family would like to achieve, following which an indicative budget was developed, based on unit costings/the funding required to deliver the agreed outcomes, following which support planning was undertaken • During the second year of the pilot programme, two of the sites were granted provisional status to participate in the Department of Health's Personal budget Programme. This provided an initial catalyst to bring together the IB pilot teams and relevant health colleagues • All sites found the support planning process both rewarding and challenging. That is, in the majority of cases, support planners felt that the process had helped families to access more tailored support and to improve their day-to-day situations. However, the process had in some cases proved to be time consuming as the majority of families had not in the past been aware of the costs of different services and therefore found it initially difficult to imagine exactly what the budget they were allocated could purchase • Support planners stressed the importance of the exploration and subsequent identification of activities to meet the child/young person's goals through discussion and added that families needed to be given sufficient time and encouragement to consider support/service provision outside of the 'norm' that they were used to • The IB support plans were felt to reflect a change in focus from provision of specialist services to

more community-based and/or mainstream services when compared to non-IB care packages

- Well informed parents that were already using the traditional system tended to be more innovative and proactive in identifying activities and making contact with relevant service providers, and were generally more vocal about their needs. Conversely, those new to the system took longer to understand their plans and effectively engage in the process
- Families feedback highlighted the following in terms of what worked well:
  - The flexibility, quality and engagement on the part of the IB project officers and family involved in the support planning process were identified as critical success factors
  - Families found the support planning process 'empowering' and added that they felt they had been 'listened to' for the first time. And similarly, results from the follow-up parent/carer survey showed that 87% of families felt that their views had been taken into account either to a 'great extent' or a 'fair amount' when developing their support plans
  - 55% of families found the design of their support plan either 'very easy' or 'fairly easy', which may reflect the experience and confidence of both the relevant families and support planners
- Similarly, families stated that the following worked less well:
  - Concerns were raised about the timeliness of the family journey, which was felt to have taken longer than expected in some cases
  - The process was often viewed as separate from the families involvement with the social care team
  - Problems were encountered by many families around how best or whether to engage their child/young person in the process
  - Some parents wanted more information on what the IB could and could not be spent on.

Actions moving forward beyond the two year pilot

- Given the resource intensive nature of the support planning process, it is likely that sites will need to consider how best to scale up this process in the event that the IB approach is rolled out across the local authority. This should involve consideration of which groups of operational staff are best placed and have the appropriate skills to deliver the process and how continuity between the initial planning and subsequent review process can be maintained.

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

6.48 Families in the main were offered the following options for managing their IB funds:

- Direct payments – family or disabled young person is paid the budget directly
- Local authority managed budgets – budgets are managed by the social worker, care worker or lead professional
- Provider or third party managed budget – the IB is paid directly to the service provide who managed the money
- Any combination of the above.

6.49 Each option had been discussed with the family during the support planning process or in some cases during the resource allocation assessment. These discussions led the majority of families to opt to use a direct payment and as such, most were holding the funds and facilitating payments themselves. Families accessing a direct payment had also been given access to the free money management support and advice on

how to become an employer, which had been provided through a third party commissioned by the local authority.

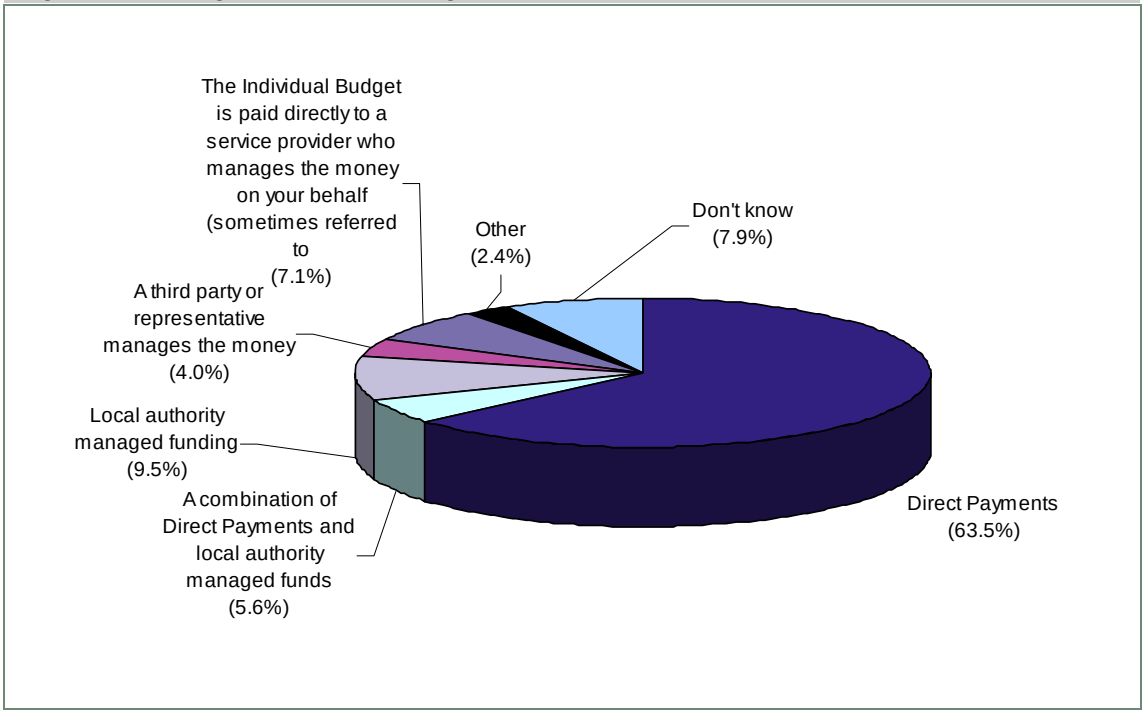
6.50 A small sub-set of families had opted to set up individualised contracts with service providers or third party agencies, as they did not want to take on the responsibility of managing the budget themselves. For example, three families in one site had set up contracts with individual service providers as the majority of the outcomes set out on in the relevant support plans were to be fulfilled through the provision of services from the single supplier.

6.51 Similarly, a small number of families had opted to access their funds through a mixture of direct payments and a local authority managed budget. This option appeared to have been chosen in cases where the family was accessing both PA/support related services and mainstream or short break activities, where the former was facilitated through the direct payment and the latter was facilitated through the local authority, which pays the relevant organisation(s) directly.

6.52 In addition, one site has offered a pre-payment card, which could be used to purchase local authority approved service provision. This option was introduced specifically to support those families that may not have an appropriate bank account to facilitate a direct payment. As such, the IB allocation can be broken up into separate elements which can be loaded onto separate cards and provided to the young person and parent/carer.

6.53 Figure 50 illustrates findings from the parent/carer follow-up survey, which shows the means by which families had chosen to receive their IB funding. This confirms that the majority (63.5%) had opted for a direct payment and smaller proportions of families had opted to manage their funding through alternative methods.

Figure 50: Management of IB funding

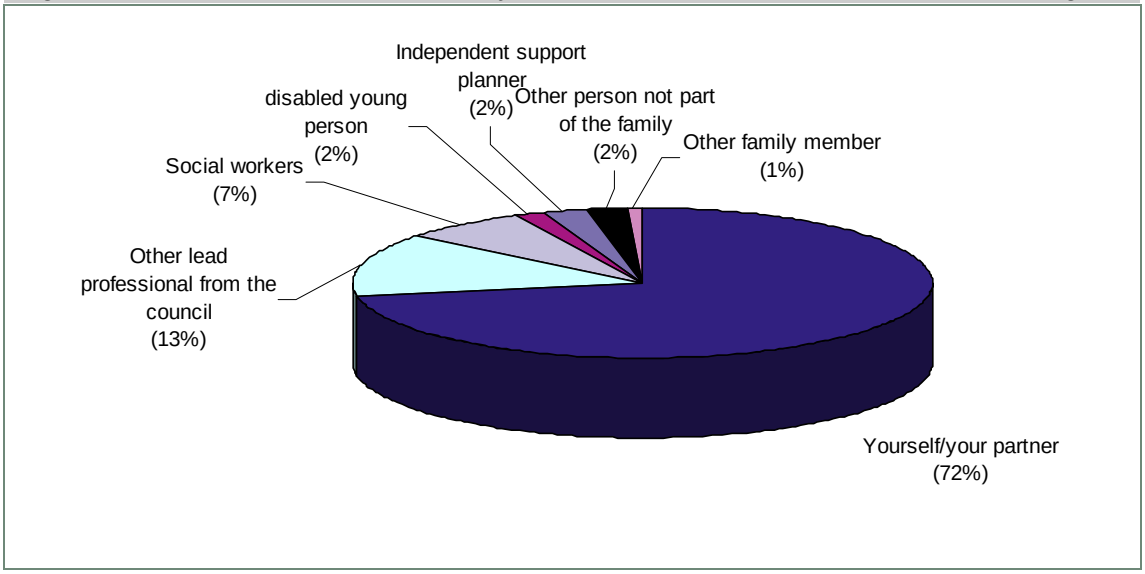


N=126
Source: SQW and Ipsos MORI parent/carer follow-up survey

6.54 The popularity of direct payments appeared to reflect the fact that a number of participating families were accessing direct payments prior to joining the pilot and therefore were more likely to opt for this form of payment. In addition, it was evident that particular sites and specific support workers had promoted this as the preferred option. The rationale behind this preference appeared to be a strong sense that a direct payment could offer more control, as a family would have a clearer sense of what they were accessing if they managed the payments themselves. In addition direct payments were viewed as more flexible, as they gave the family the ability to for example spot purchase a service, such as a taxi, as opposed to having to organise and seek approval from a third party. However, this view was not shared by all the sites, some of which felt that all the options should be equally considered and that each offered the same level of choice and control.

6.55 Supporting evidence from the parent/carer follow-up survey (see Figure 51) showed that the majority of parents/carers (72%) felt that they had had the most say in the decision on how to receive the IB funding. Looking specifically at the strength of influence exerted by the relevant professionals, 22% of families reported that either the lead professional (13%), social worker (7%) or independent support planner (2%) had had the most say in the this decision.

Figure 51: Person that had the MOST say in the decision on how to receive the IB funding



N=126
Source: SQW and Ipsos MORI parent/carer follow-up survey

6.56 As such, the IB pilot programme illustrated a clear desire on the part of the majority of participating families to self manage their funding allocations. However, although only a small number of families chose to have their funds managed on their behalf, it is important to note that in the absence of alternative funding methods, the IB offer may have proved inaccessible to this group. Therefore, the provision of a spectrum of choice for the management of IB funds should still be viewed as an important element of this type of approach to service/support provision.

6.57 Having opted to access the IB funding through a direct payment, most families were asked to set up a separate bank account, within which the money was deposited. The frequency and scale of payments varied between families to take account of:

- their differing capacities to manage the funding
- the types of service or support provision being accessed, where for example, in one site, if the family employed a support worker, they were paid monthly amounts to cover the relevant wage bill and if the family accessed mainstream service provision they were given an annual payment (and combinations of this approach in cases where the family was accessing both a PA and mainstream services).

6.58 Decisions about the capacity of individual families to set-up and use a bank account were made during the support planning stage with input from both the support worker and the family. For example, one site used a risk matrix which was completed by the social workers as a means of assessing the appropriateness and means by which a

direct payment should be made. The matrix included risks such as the complexity and cost of the package, and safeguarding concerns amongst others. The risk assessment also determined the frequency of subsequent monitoring carried out by the direct payments team. As such, if the package was deemed to be low risk then the family might not need to set up a separate account from their existing account, and after an initial three month check, follow up monitoring might be annual. However, if the package was deemed to be high risk then more frequent monitoring has been required.

6.59 In the event that the IB approach is rolled out to a wider group of families, sites felt that they would need to increase the administrative resources that had either processed the IB funding invoices or provided employment/direct payment support to families.

Summary

6.60 Table 52 presents a summary of the progress made against element eight of the CDM.

Table 52: Progress made on the provision of a spectrum of choice for the management of IB funds

Summary findings and lessons
• Families were offered a range of options as to how they managed their IB funds. This included: direct payments; local authority managed budgets; provider or third party managed budgets; and any combination of the stated options • The majority of families (63.5%) opted to use a direct payment and smaller proportions of families had opted to manage their funding through alternative methods • The popularity of direct payments appeared to reflect the fact that a number of participating families were accessing direct payments prior to joining the pilot. In addition, it was evident that particular sites and specific support workers had promoted this as the preferred options, as they felt it could offer the most control and flexibility • Having opted to access the IB funding through a direct payment, most families were asked to set up a separate bank account, within which the money was deposited. The frequency and scale of payments varied across families to take into account their differing capacities to manage the funding and the types of services being accessed.
Actions moving forward beyond the two year pilot
• In the event that the IB approach is rolled out to a wider group of families, sites felt that they would need to increase the administrative resources that had either processed the IB funding invoices or provided employment/direct payment support to families.

Element 6: Development of IT resources

6.61 Each site was tasked with developing an appropriate IT resource to enable the effective monitoring and auditing of the pilot. This element of the CDM was approached in one of two ways: the first involved some sites integrating the

requirements of the pilot into existing local systems; and the second involved the development of relatively low-tech and standalone systems.

6.62 Looking at each of the approaches in turn, integration into existing systems was 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[20]. These sites therefore experienced a relatively unproblematic IT development process.

6.63 Development of low-tech, standalone systems was undertaken by sites that were solely dependent on the Integrated Children's System (ICS), where the integration of resource allocation and support planning processes proved 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 had to input their IB data into a standalone specifically developed system and subsequently attached the data as a supplementary case note in the ICS, as opposed to in the relevant ICS record itself. This caused problems, as attachments did not trigger case reviews in the same way as traditional care plans. Therefore, although this solution was sufficient for the lifetime of the programme, it will not be sustainable over the longer term as the IB approach is extended to include more families.

Summary

6.64 Table 53 presents a summary of the progress made against element six of the CDM.

Table 53: Progress made to on the development of IT resources

Summary 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) proved to be too rigid in its nature to facilitate useful IT provision for the IB pilot sites. This was because the system did not allow an individual local authority to make the required additions to the existing fields of information.
Actions moving forward beyond the two year pilot
• Low tech, standalone systems were sufficient for the lifetime of the programme, however, this solution will not be sustainable over the longer term as the IB approach is extended to include more families.

[20] CareFirst is OLM's social care system that has been taken up by several local authorities across England.

7: Funding streams and services

Introduction

7.1 The *IB Pilot Specification and Application Pack* 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.

7.2 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 driven 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 suggested that NHS services with greatest relevance to disabled children and those with complex health needs included 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
- **Non school based education funding –** for example to facilitate transport provision or educational support.

7.3 Table 54 details the inclusion criteria set out in the guidance, which advised that any funding stream should be considered if it met the criteria.

Table 54: 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)

7.4 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 over the course of the two year programme.

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

The intentions

7.5 Each of the pilot sites was asked to set out the funding streams/services that they intended to include within their IB packages at the outset of the programme. This included a wide range of funds, which were made up of contributions from social care, health and non-mainstream education budgets.

7.6 Social care related funds were expected to be the least problematic to draw into the IB packages. This was in part a result of the pilot design, which led all sites to be social care driven. Therefore each area had buy-in from the social care leads from the outset. Moreover, the nature of the core social care budget, which sat in a single pot and was viewed as easier to draw down.

7.7 Conversely, early reflections from the pilot sites highlighted a set of anticipated challenges that were likely to be faced in trying to draw in both health and education funding streams. These included recognition that unlike social care, health and education funding was formed from many different sources and as such would be difficult to disaggregate. Similarly, the pilot sites also acknowledged that the AHDC programme and roll out of Adult Personal Budgets had given social care a 'head-start' in relation to personalisation, which had often not been translated into either the

provision of health or education services. As such, although PCT and education partners had expressed an interest in engaging in the programme, the extent to which they would contribute funding to the IB packages was unclear at the outset.

The reality

7.8 As of March 2011, the spectrum of funding streams/services included in the resultant IB packages across the pilot sites comprised of:

- **Social care services/funding** – including funds from the core Social Care budget, Short Breaks services/funding, Childcare funds and Domiciliary service funding
- **PCT services/funding** – made up from limited and/or restricted funding that could for example only be used for community nursing to meet physical and mental health needs, or for health-related equipment
- **Education services/funding** – including limited amounts of Extended Services funding (involving the allocation of a set amount of funds per family), Early Years funding and School Transport funding which was only applicable for a small number of cases
- **Other funding streams** – one site accessed some Raising Participation Age pilot funding, which was used to provide support to assist a small group of young people to address barriers to employment participation, and another accessed some area based grant funding, which had been allocated into a personalisation fund to support families with disabled children.

7.9 Table 55 provides a site-level map that sets out the progress made by each site. This shows that the majority of sites had successfully broadened the scope of their IB packages beyond social care funds (i.e. contributions from short breaks and the social care core budget) by the end of the two year programme.

Table 55: Funding stream/service inclusion by site

Site	Funding stream/service							
	Short Breaks	Social care core budget	PCT funding	Early Years funding	RPA pilot funds	Extended services	School transport funds	Are based grant
Coventry	✓	✓	✓					
Derbyshire	✓	✓	✓			✓	✓	
Essex		✓						
Gateshead	✓	✓	✓					
Gloucestershire	✓	✓		✓				✓
Newcastle	✓	✓	✓		✓			

Source: SQW case study research

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

- a focus on a limited number of cases where young people 'brought PCT funds with them', where the funding remained directly linked to the relevant young people and was re-shaped (and as such, was not available to all children and young people)
- PCT funds used for health equipment purposes only, as requested by families
- PCT funding used 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 for a small number of young people.

7.11 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. For example, sites with joint health and social care commissioning posts often had greater success in drawing in health related funds. However, this situation was more of an exception to the general pattern, which showed that sites had few levers with which to gain the required buy-in from the required fund holders.

7.12 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. For example, the IB delivery team in one of the sites that was unable to draw in either education or health funding stated that support planning was undertaken in a holistic manner, with an emphasis on meeting social care needs. Any education or health related needs were recorded in the relevant support plan and support/advocacy was offered to enable the family to access suitable other services. This signposting exercise also included ongoing discussion with relevant service heads to ensure that they were informed of the needs identified by the families, which raised awareness of the benefits of the IB approach.

7.13 A number of the pilot sites had also sought to engage with additional programmes that would offer complementary activities and therefore enhance the workings of the IB pilot. This included two sites being granted approval to take part in the Department of Health's Personal Health Budget (PHB) Programme during the second year of the IB programme, based on the premise that the complementary work would seek to join-up the IB and PHB activities[21].

7.14 The link to PHB proved relatively fruitful in both of the sites. For example, the first site had undertaken a piece of scoping work to understand which health services could form the focus of their combined IB-PHB work. Similarly, the second pilot site, which had employed a dedicated PCT IB project officer as part of their IB pilot, had undertaken preparatory work which had resulted in the identification of the continence service and a small group of ten families as a test-bed for their IB-PHB work. However, this work was subsequently put on hold as a result of a delayed Government decision to extend the IB pilot and therefore the funding for the dedicated PCT post (see Chapter 5 for more details). As such, the health related work undertaken was exploratory in its nature and was yet to be taken forward at the end of the two year programme.

7.15 Another site sought to align the activities of their Raising Participation Age (RPA) pilot, which enabled them to draw in £25,000 of time limited RPA funding to support a small number of the disabled young people that were participating in the IB pilot to access employment and training opportunities. This was felt to have provided a valuable opportunity to consider and test the ways in which young people with

[21] PHB pilot status was not associated with the receipt of any grant funding from the Department of Health.

disabilities can be supported in a variety of ways to fulfil the Authority's responsibility to engage young people in education and employment with training until the age of 17 by 2013 and 18 by 2015.

Barriers to accessing funding streams/ services

7.16 The sites experienced multiple barriers during their ongoing attempts to draw in both health and education funding streams/services.

Health

7.17 Focusing first on health, the sites identified the following issues following their approaches to health colleagues:

- The PCT was unable to provide funding as a result of **conflicting health priorities**, which had meant that relevant funding streams had been allocated to meet specific, non-pilot needs. As such, a reallocation of committed funds to the IB packages would have required a disinvestment of funds from other areas, which was not possible
- Issues relating to **block contracting** which could not be broken up during their commissioned period and therefore restricted the creation of flexible funds within the time period of the pilot
- **Cuts to service funding** during 2009/10, which has 'squeezed' any budget that could have been contributed to the IB packages
- The **absence of a 'safety net' for PCT contributions (or double funding mechanism)** had not been available to support the transition from centrally commissioned services to an individually directed service, which prohibited the PCT from contributing funds
- **Health monies could not legally be provided through direct payments** and therefore would not comply with the ethos of providing families with more choice and control. This issue can be addressed in the event that an area is granted approval to be included in the direct payment related legislative cover that forms part of the PHB programme
- Health monies could only be supplied through notional budgets, which would be associated with high administrative costs, which could not be covered by the relevant health agency

- The provision of health funding through an IB could throw up **clinical governance issues**, which would a dedicated resource and take time to work through
- Unclear policy direction from the Department of Health in relation to the personalisation of health services for families with disabled children, which was further compounded by the adult focus of the PHB Programme.

7.18 As such, although progress had been made with some of the PCT fund holders they had only contributed limited funds, most of which carried restrictions. The sites added that future progress would be largely dependent on support from the Department of Health to drive the cultural change required to move from traditional to personalised service provision.

Education

7.19 Although small amounts of non-mainstream education funding had been drawn into the IB packages in one of the pilot sites, little or no progress had been made in the remaining sites. This was felt in some cases to be a result of national policy direction, which had led to a slower pace and sometimes lack of cultural change towards more personalised approaches outside of social care.

7.20 It was also evident that the origins of personalisation in an education context differ from those in social care, which had caused confusion between the agencies. A recent paper published by the Council for Disabled Children titled *Personalisation in education*, identified the origins to lie in a '*political discourse about both quality and equity in the outcomes of the educational process'*. Moreover, much of the focus to date has been on the individualisation of education, i.e. focussed on individual learner plans which had been drawn up by professionals and remained largely professional led. This approach is somewhat different to the personalisation approach in social care and therefore of the IB pilots, where leadership is more strongly transferred to the user and the professional plays a facilitation role.

7.21 An increased understanding of the different positions and approaches of each profession would be required to address some of the barriers experienced. This has in part started to occur within the post-16 education setting, through the Young People's Learning Agency (YPLA), which has sought to develop a more personalised approach to the provision of post-16 education services relative to the traditional model. The YPLA's work on this agenda informed the development of the draft Learning for Living and Work Framework (LLWF), which seeks to support young

people with special educational needs and disabilities from Year 9 at school in their transition onto their next step.

7.22 The draft LLWF includes a partially developed resource allocation system (RAS), which is similar in nature to that used by some of the IB pilot sites. Although both the LLWF and IB resource allocation models seek to facilitate a holistic view across social care, health and education, the systems have been developed from different starting points. That is, the LLWF RAS has been developed from an education and employment perspective, whereas the relevant IB RAS has been developed from a social care perspective. As a result the nature of the questions asked have a very particular focus, and in practice it is unlikely one set of questions would seem sufficiently detailed to the other set of professionals.

7.23 As such, broadening the scope of the IB packages beyond social care funds will require consideration of how best to allocate resources derived from different funding streams/agencies. This may involve:

- The enhancement of existing resource allocation models to incorporate the allocation of additional funding streams, which flow into a single support planning process

OR

- The development of separate resource allocation models for distinct funding streams that enable an efficient allocation of resources which can be married up through either an aligned or single support planning process.

Summary

7.24 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. Where additional funding streams had been drawn in, they had often come with some restrictions which differed across areas. One site for example was restricted to using their PCT funding contribution for health equipment purposes only.

7.25 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. For example, sites with joint health and social care commissioning posts often had greater success in drawing in health related funds. However, this

situation was more of an exception to the general pattern, which showed that sites had few levers with which to gain the required buy-in from the required fund holders.

7.26 The sites experienced several barriers during their ongoing attempts to draw in both health and education funding streams. Looking first at health, the sites stated that limited or no contributions had been made largely as a result of the unclear policy intentions of the Department of Health in relation to personalisation of health services for families with disabled children. And focusing now on education, although small amounts of non-mainstream education funding had been drawn into the IB packages in one of the pilot sites, little or no progress had been made in the remaining sites. This was felt in some cases to be a result of national policy direction, which had led to a slower pace and sometimes lack of cultural change towards more personalised approaches outside of social care.

7.27 As such, this strand of the programme remained a ‘work in progress’ at the end of the original two year programme, where sites intended to continue discussions with both health and education leads to further the progress that had been made. Further progress is therefore required to bring together social care and education professionals, as a means of forming accountable and collective responsibility for the personalised provision of services for families with disabled children.

8: Pilot inputs and costs

8.1 The aims of the evaluation included the provision of a comparison of:

- The costs to the local authority and PCT of implementing the IB approach for disabled children
- The costs of providing services through current arrangements
- Recommendations on the likely costs of extending the IB approach to all eligible families with disabled children in the pilot areas and actions that the Government could take to support the extension of the IB approach for disabled children and young people beyond the pilot areas.

8.2 As such, this chapter sets out the pilot inputs and costs involved in setting up and running the two year pilot in each of the sites; both in terms of the use of expenditure from the Department funded IB grant allocation and in-kind time contributions from staff that were not directly funded by the pilot. These costs are derived from the monitoring data, which was provided by the pilot sites on a regular basis and are set out both in aggregate and against the ten elements of the CDM.

8.3 The chapter subsequently uses the above analysis to estimate both the set up and running costs that may be associated with an extension of the IB approach to all eligible families with disabled people in the pilot areas. This estimation process has required a series of assumptions, which are set out below.

Development and implementing the IB approach

Pilot and additional funding

8.4 The IB application process for the pilot programme stated that the Department envisaged issuing grant payments to local authorities ranging between £75,000 to £125,000 per annum and which did not exceed £150,000 per annum. This grant was to be used to fund infrastructure requirements and therefore did not include grant contributions to the IB funding allocations for families, which were to be drawn from existing funding streams/services., Each potential pilot site was asked to provide an estimate and indicative breakdown of the costs that would be required to deliver the pilot as part of the application process. This led to the issuing of just under £1.5

million to deliver the two year pilot programme across the six successful sites (see Table 56).

Table 56: Departmental IB grant allocation for the two year pilot programme

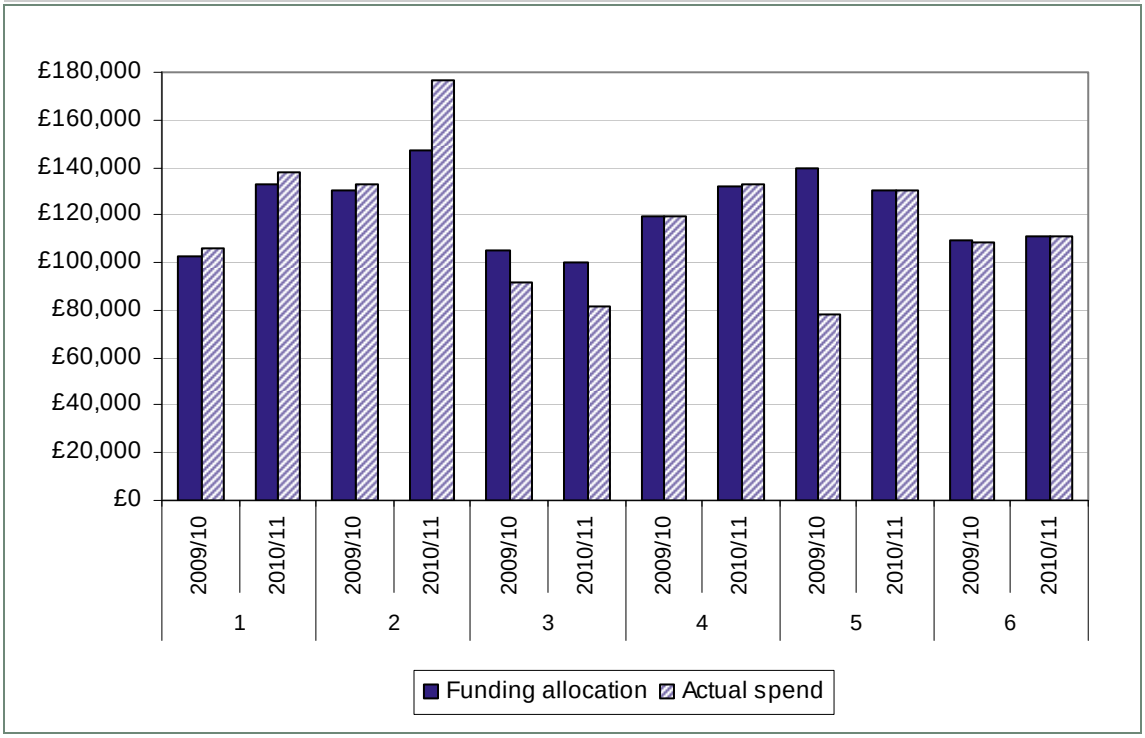
2009/10	2010/11	Total
£715,000	£755,000	£1,470,000

Source: Pilot site grant letters

8.5 Figure 57 sets out the actual spend relative to the grant allocations of each of the sites. This shows that two of the six sites exhibited over-spend, another two delivered on budget and the remaining two sites exhibited under-spend. Under-spend was largely caused by either delays in the recruitment of funded pilot staff or a recognition that a number of the pilot activities could be absorbed into current working practices and therefore be undertaken using 'in-kind' time instead. Conversely, over-spend in one case resulted from a need to provide maternity cover for one of the project officers and in the other was used to ensure pilot staff were appropriately remunerated.

8.6 The costs of any over-spend were met by the relevant local authority and similarly, any under-spend was returned to the Department at the end of the relevant financial year.

Figure 57: Funding allocation and spend by pilot site



Source: SQW pilot monitoring returns

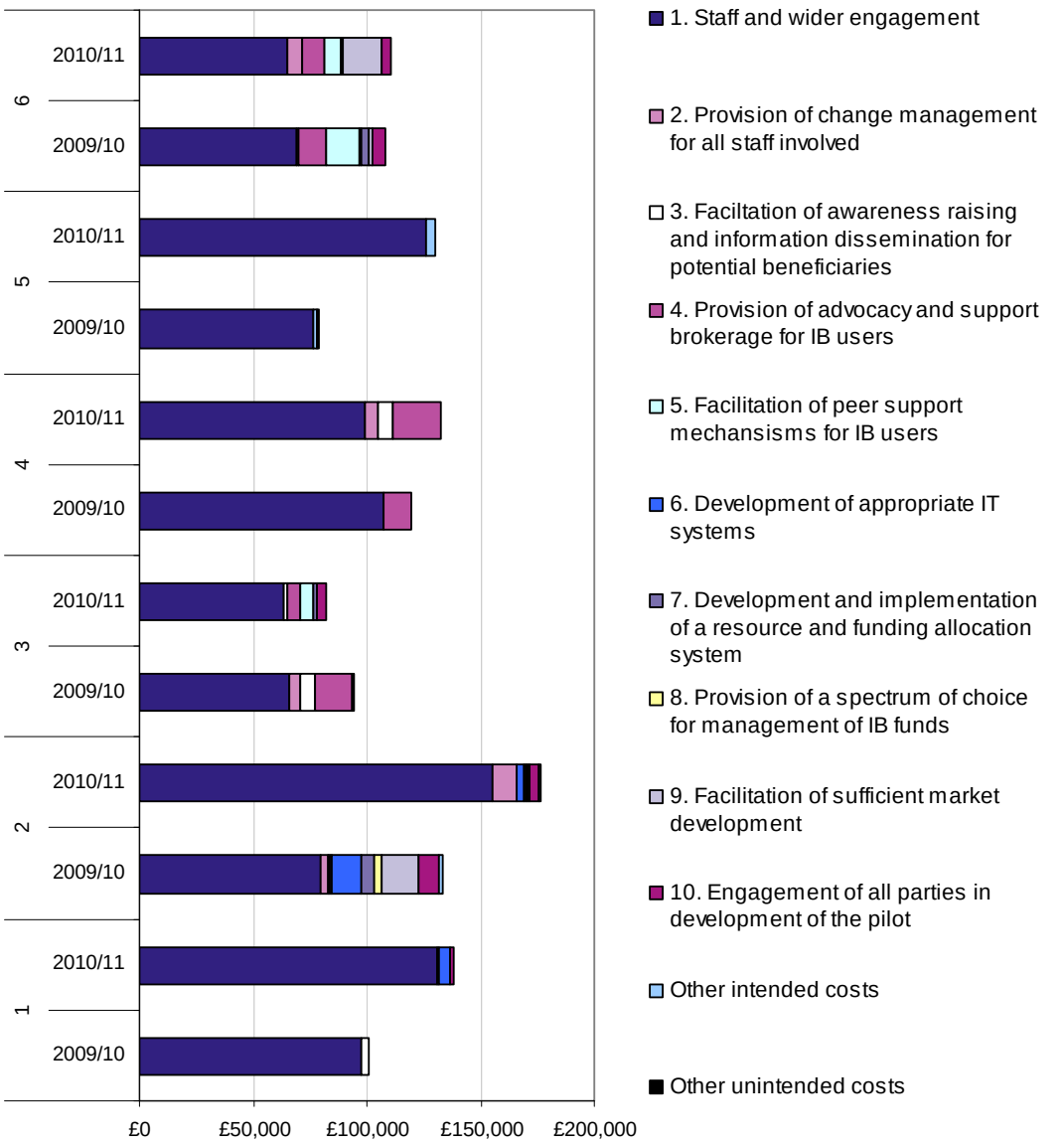
Cash and in-kind spend against the CDM

8.7 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. Figures 58 and 59 illustrate this breakdown by site.

8.8 Looking first at Figure 58, this shows that staff and wider engagement represented the biggest financial expenditure across all the pilot sites in both year one and two of the programme (accounting for between 61% and 97% of total expenditure). This reflects that the staff recruited under this element of the CDM then used their time to deliver many of the other elements.

8.9 The next largest financial cost was incurred in the development and delivery of CDM element 4 – the provision of advocacy and support brokerage for the participating families, where three sites used between 10%-13% of their total expenditure to fund this element. This relatively high cost was used to commission several independent third sector organisations to facilitate support planning.

Figure 58: Breakdown of financial costs by element of the CDM



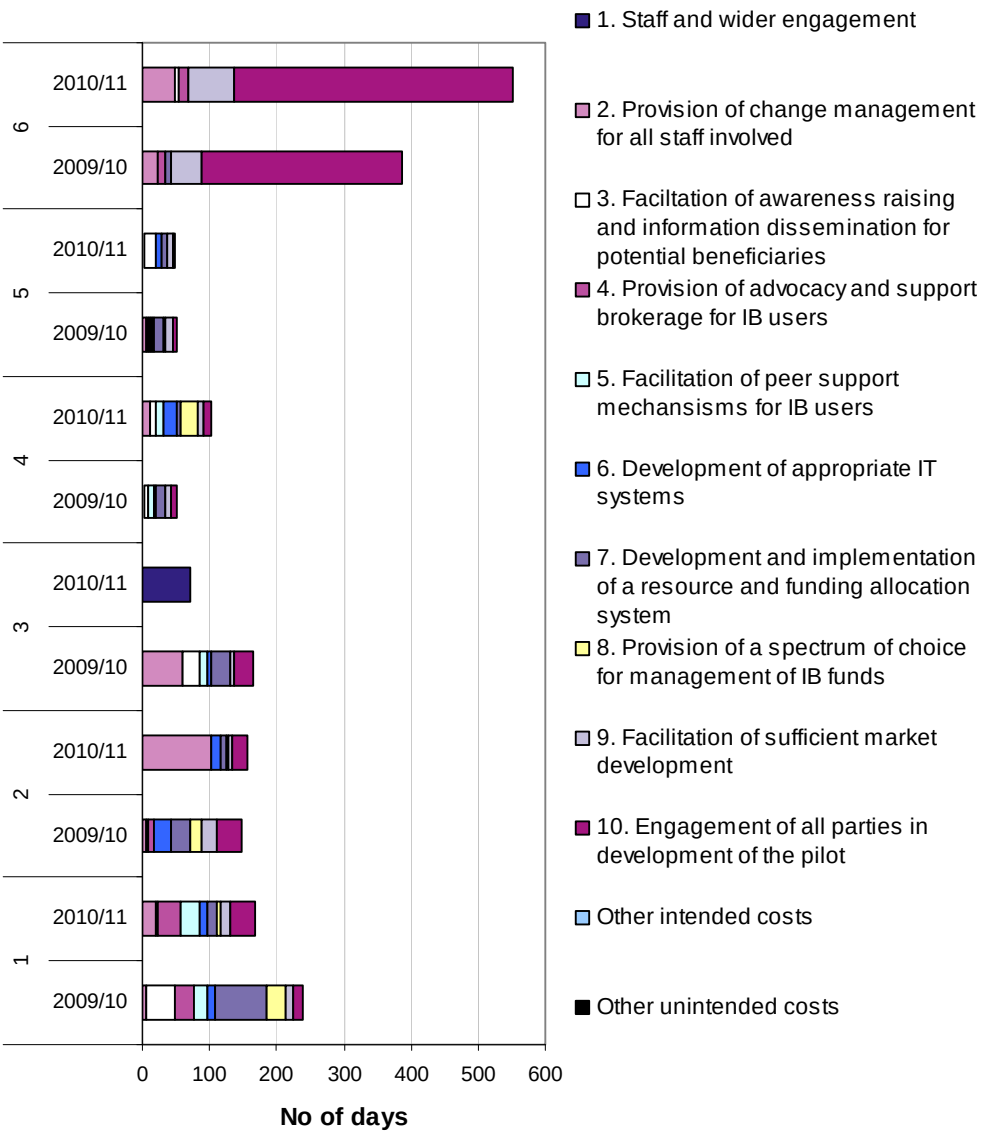
Source: SQW monitoring pilot monitoring returns

8.10 There was substantial variation in the in-kind costs reported by the sites. This in part reflected: the means by which the pilot was delivered; the extent to which each site recruited and funded pilot specific staff to undertake various roles (who as a result would be accounted for in financial as opposed to in-kind costs); and the extent to which sites sought to engage staff from outside the pilot specific team to support the development of the relevant activities. For example, one site (labelled 6 in Figure 59) had particularly high levels of in-kind costs (over 900 days), the majority of which (76%) 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 work groups have been accounted for in the monitoring data.

8.11 The provision of change management for staff also required a considerable amount of in-kind input within some sites. For example, in sites 2 and 6 in Figure 59, change management took around 110 and 70 days respectively. Activities to facilitate change management included staff training, development days, conferences and contributions at various meetings.

Figure 59: Breakdown of in-kind costs by element of the CDM



Source: SQW monitoring pilot monitoring returns

Comparative costs of the IB approach relative to the traditional approach

8.12 Although many of the pilot teams felt that it was too early to say whether the provision of the IB approach was associated with additional costs or savings relative to traditional service provision, they did reflect on what they felt was likely to happen over the longer term. The pilot teams generally felt that the additional costs of implementing an IB approach were seen as occurring mainly in the set up phase, including recruiting staff, developing the resource allocation model, and setting up the support planning and monitoring processes. They added that in delivery terms, support planning in particular was likely to be more resource intensive than the traditional approach. However, this initial increase in resources was likely to decrease over time as the IB approach became embedded as part of the 'norm' and as families became more adept at participating in support planning. As such, the informed opinions across the sites implied that the costs of an IB approach compared to traditional service provision were likely to be broadly cost neutral as the approach was rolled out over the longer term.

Estimating the costs of undertaking an IB pilot and roll out of the IB approach

8.13 This section estimates the costs of undertaking both a small scale IB pilot and of roll out of the IB approach to a wider range of families across a local authority. This estimation is divided into two components – set up and running costs – to show the distinction between the resources required to develop end embed the IB approach and to subsequently sustain this activity.

Assumptions used to estimate set up costs

8.14 The following assumptions were made to estimate pilot and roll out set up costs associated with the IB approach:

- As each of the pilot sites were at **different starting points** when they entered the IB pilot programme, the set-up costs experienced by each of the sites varied considerably. Therefore, data from three of the sites was used – the site perceived as furthest ahead at the beginning of the Programme, the site perceived as having the largest distance to travel at the beginning of the Programme and a site which sat in-between the two in relation to its starting point – to present **three cost-scenarios** and therefore to ensure that a range of costs were presented. The remaining three sites sat within the selected range and therefore were not considered as part of this estimation exercise

- The set-up period of the pilot sites was defined as including all activities up to the point at which all/the majority of IBs have gone live for participating families
- The estimation of the set-up costs associated with undertaking the IB pilot and roll out were **based on both financial and in-kind time data for the four quarters of Year One and for Q1 and Q2 of Year Two of the Programme**. This data was supplied by the three selected pilot sites and was aggregated across the elements of the CDM to reflect the set-up costs of each of the pilot sites
- The estimation process presents a set of costs that are likely to be incurred over a period of years as development and take up by families takes place as has happened in adult social care. It does not represent an annualised set of costs
- The costs associated with individual elements of the CDM have been scaled up in one of two ways:
  - The first set of costs were perceived to be '**fixed costs'** i.e. costs that were not dependent on the scale of activity, and would therefore be **accounted for as single lump sums**
  - The second set of costs were perceived to be '**variable costs'** i.e. costs that were dependent on the scale of activity, and were therefore **analysed to form unit costs**, **which were scaled up** in accordance with the size of the roll out.

8.15 Table 60 illustrates the categorisation of the ten elements of the CDM.

Table 60: Cost categorisation of the ten elements of the CDM

Fixed costs	Variable costs
• Staff engagement • IT development • Development of resource allocation system	• Change management ➢ Assumed an initial fixed cost for change management within the IB delivery team and development of a delivery plan, and variable cost over and above this which would be dependent on the numbers of staff/stakeholders involved in the change management process ➢ Associated with economies of scale as cultural change builds momentum and becomes embedded within the local authority • Peer support ➢ For cost purposes, it was assumed that peer support formed a subset of the change management element, as it was facilitated through the reshaping of existing services • Spectrum of choice for management of IB funds ➢ For cost purposes, it was assumed that peer support forms a subset of the change management element, as it was facilitated through the reshaping of existing services • Market development ➢ The full costs of market development are likely to be incurred iteratively through both the set-up and subsequent running stages of the IB approach, as families become more innovative and the market diversifies to accommodate changing needs • Facilitation of awareness raising and information dissemination • Provision of advocacy and support brokerage • Engagement of all parties in development

Source: SQW

- **In-kind time has been monetised** to reflect the contributions of staff that were not formally funded to support the delivery of the pilot site. Table 61 illustrates the two sets of unit costs that were considered, the first of which relate to nationally derived adult-based social care staff and the second of which relate to data derived from the children's social care departments of three local authorities. Given the similarities between the two data sets and the children's focus of the pilots, the children's based unit costs have been used, which include salary, on-costs and overhead costs.

Table 61: Unit costs of social care provision

	Unit costs 2009/2010
1. PSSRU Unit costs of health and social care 2009	• Social Care Team Leader - £37 per hour • Social Worker (Adult) - £30 per hour • Social Work Assistant - £22 per hour
2. Costs of short break provision, Centre for Child and Family Research, Loughborough University, 2010	• Team Manager - £36 per hour • Social Worker (Children) - £29 per hour • Administrator - £17 per hour

- **In-kind time was monetised on a weighted basis** to ensure the data submitted in the pilot monitoring submissions reflected time inputs across three levels of staff – team managers, social workers and administrators – all of whom were perceived to have contributed non-pilot funded time to support the set-up of the pilot. This **weighting is based on an estimated 20:60:20 split between the three levels of staff respectively, which therefore amounts to a unit cost of £28 per hour and £210 per day[22] (based on a 7.5 hour day)**

- The **data presented for each scenario reflects differing models of delivery** which are not described as part of this process. The rationale for this assumption is based on the premise that the roll out of the IB approach will be based around a flexible framework (such as the CDM) and as a result, its delivery will vary across areas.

8.16 As the data has been supplied as part of a pilot initiative, it reflects the provision of an IB approach as an 'add-on' to existing systems and service provision. As such, the cost data presented is likely to over-estimate the set-up costs associated with a Departmental roll-out of the IB approach. That is, some of the development costs associated with any form of roll-out are likely to be partially absorbed by the existing system, as it evolves to accommodate the new approach

8.17 It has been assumed that the roll-out of the IB approach will take place at the local authority level, where the offer of an IB will be offered to all families with disabled children that are eligible for statutory social care provision and taken-up on a voluntary basis. This implies that take-up will vary across local authorities. However, for the purposes of this exercise, we have developed an average cost per local authority based on the premise that take-up of the IB offer for families with disabled

[22] This includes salary, on-costs and overhead costs

children will be similar/equal to that of the take up of either a personal budget or direct payment by adult care service users[23]. Table 62 sets out the subsequent assumptions that have been made to facilitate the estimation process.

Table 62: Assumptions made to derive range of take-up of the IB offer

Question	Description of statistic	Source	Data
What is the likely proportion of families who might take up an IB?	Average number of clients and carers in England receiving social care through self directed support as a percentage of the total number of clients receiving community based services and carers receiving carers' specific services in the year to 31st March 2009/10	*National Indicator 130 – The National Indicator Set 2009-10* *http://www.ic.nhs.uk/webfiles/publications/Social%20Care/socialcareindicators/Provisional_Social_Care_and_Mental_Health_Indicators_2009-10_v1.6.xls*	13%
What is the number of disabled young people in England?	Lower and upper bound on the number of disabled children in each local authority, based on the number of children with a statement of Special Educational Needs and in receipt of Disability Living Allowance (DLA).	*Disabled Children: Numbers, Characteristics and Local Service Provision, Thomas Coram Research Unit Institute of Education, University of London*	Lower Bound: 288,000 Upper Bound: 513,000
So, how many families might take up an IB across England?	Lower and upper bound of the number of families with disabled children likely to take up the offer of an IB across England	SQW calculation	Lower Bound: 37,440 Upper Bound: 66,690
How many families would take up an IB in an average local authority?	Lower and upper bound of the number of families with disabled children likely to take up the offer of an IB per local authority *Assumption: There are 152 Local Authorities in England*	SQW calculation	Lower Bound: 250 Upper Bound: 440

Source: Various

8.18 As such, the estimated costs have been presented to illustrate both the lower and upper bounds of take-up per local authority, i.e. 250 and 440 families with disabled children, for each of the 3 scenarios.

8.19 In order to **facilitate the 'scaling up' of the variable pilot costs**, which relate to approximately 30 families with disabled children per pilot area, the following assumptions were made:

[23] Owing to an absence of nationally based data relating to the take up of either personal budgets or direct payments by families with disabled children, we have used the comparative figures for adult social care users as the basis for the estimation.

- The roll out of the IB approach will not be undertaken as an 'add-on' to existing systems and will instead form part of a programme of cultural change across a local authority, implying that some costs will be absorbed by the existing system
- Local authorities will achieve economies of scale in relation to the set-up and delivery of the IB approach, for example, change management, market development or fund management should not require twice the input even if the number of families doubles.
- We have therefore scaled up the variable costs to reflect the lower and upper bounds of take up and then discounted this figure by 50% to account for economies of scale. This is an important assumption which could be refined through evidence from the DfE on similar initiatives or via the use of sensitivity analysis

8.20 These assumptions lead to the discounting shown in Table 63:

Table 63: Scaling factors used to estimate costs associated with lower and upper bound roll out

Lower bound	(Lower bound no of families / Average no of families participating in each pilot site) = A	250 / 30 = 8.3 = A
	50% of A – to factor in economies of scale = B	8.3 / 2 = 4 = B
	Scale up variable costs by factor of 4 for lower bound take-up	
Upper bound	(Upper bound no of families / Average no of families participating in each pilot site) = C	440 / 30 = 14.6 = C
	50% of A – to factor in economies of scale = D	14.6 / 2 = 7.3 = D
	Scale up variable costs by factor of 7.3 for upper bound take-up	

Source: SQW cost estimation

8.21 Table 64 sets out the method used to develop the estimated set-up costs associated with both undertaken an IB pilot and the roll out of the IB approach for Scenario 2.

Table 64: Estimated costs of set-up

	Financial	In-Kind		Total
	Cost (£)	No of days	Cost (£)	
Scenario 2: Mid-point site				
• Pilot	E = Sum of the financial costs used to develop the individual elements of the CDM	F= Sum of the no fo days of in kind time used to develop the individual elements of the CDM	G = Sum of in kind days used (F) x cost per day (£210)	E + G
• Lower Bound Roll out: 250 families	H = Sum of the costs associated with the scaled up individual elements of the CDM using method shown in Table 63	I = Sum of the no of days associated with the scaled up individual elements of the CDM using method shown in Table 63	J = Sum of scaled up days used (I) x cost per day (£210)	H + J
• Upper Bound Roll out: 440 families	K = Sum of the costs associated with the scaled up individual elements of the CDM using method shown in Table 63	L = Sum of the no of days associated with the scaled up individual elements of the CDM using method shown in Table 63	M = Sum of scaled up days used (L) x cost per day (£210)	K + M

Source: SQW cost estimation

Estimation of costs of set-up

8.22 Table 65 sets out the cost estimates that have been developed to illustrate the potential set-up costs associated with both undertaken an IB pilot and the roll out of the IB approach. It details the costs associated with each scenario, those associated with the pilot itself and both the lower and upper bounds of take-up of the IB offer (please refer to the Technical Report for methodological detail).

Table 65: Estimated costs of set-up

	Financial	In-Kind		Total
	Cost (£)	No of days	Cost (£)	
Scenario 1: Site furthest ahead at the start of the pilot				
• Pilot	£136,000	83	£17,500	£153,500
• Lower Bound Roll out: 250 families	£136,500	248	£52,000	£189,500
• Upper Bound Roll out: 440 families	£137,000	430	£90,000	£227,000

NOTES: The financial costs associated within scenario one are very similar across the categories as a result of all relevant costs being fixed, which by their nature do not require scaling up.

	Financial	In-Kind		Total
	Cost (£)	No of days	Cost (£)	
Scenario 2: Mid-point site				
• Pilot	£176,000	91	£19,000	£195,000
• Lower Bound Roll out: 250 families	£248,500	277	£58,000	£306,500
• Upper Bound Roll out: 440 families	£328,500	482	£90,000	£429,500
Scenario 3: Site with farthest distance to travel				
• Pilot	£214,500	197	£41,500	£256,000
• Lower Bound Roll out: 250 families	£332,500	572	£120,000	£452,500
• Upper Bound Roll out: 440 families	£462,000	984	£206,500	£668,500

Source: SQW cost estimation, please note that totals may marginally differ from additions of the financial and in-kind costs as a result of rounding

8.23 **This shows that potential set-up costs of an IB pilot** which seeks to recruit approximately 30 families with disabled children **is likely to fall in the range of: £153,500 - £256,000,** where exact figures will be dependent on the existing infrastructure and extent to which appropriate cultural change has already taken place in the area. And similarly, **the potential set-up costs of roll out of the IB approach could fall in the range of: £189,500 - £668,500 per local authority**. [24]

Assumptions used to estimate running costs (costs of sustaining the IB approach)

8.24 The assumptions used to estimate the running costs associated with the IB approach were largely similar in nature to those used to estimate set up costs. Additions/modifications to these assumptions included:

- The estimation of running costs associated with sustaining the IB pilot activities and roll out of the IB approach was **based on both financial and in-kind time data provided for Q3 and Q4 of Year Two of the Programme as supplied by the three selected pilot sites**
- Given the absence of four quarters of running cost data, the **aggregate data from Q3 and Q4 was scaled up by a factor of two to present a set of**

[24] The evaluation team was not aware of any analysis of local authorities which would enable an assessment of how many or which authorities may fall in to which scenario – but this could be readily accommodated if information were made available.

annualised costs and therefore assumes that the running costs reported by the selected sites would remain largely constant over the course of a year.

8.25 It is important to note that this set of estimations present the gross costs of sustaining the IB approach as they do not take into account factors such as ongoing quality improvement, staff development etc, that would be expected to occur within the system.

Estimation of costs sustaining the IB approach

8.26 Table 66 sets out the estimated gross costs of sustaining the IB pilot activities and a roll out of the IB approach. This again details the costs associated with each scenario, those associated with the pilot itself and both the lower and upper bounds of take-up of the IB offer.

8.27 **This shows that potential annual running costs associated with an IB pilot** which seeks to recruit approximately 30 families with disabled children **is likely to fall in the range of: £152,500 - £235,500,** where exact figures will be dependent on means by which the site has chosen to deliver their activities. And similarly, **the potential annual costs associated with sustaining a roll out of the IB approach could fall in the range of: £167,000 - £633,500 per local authority**.

Table 66: Estimated costs of sustaining the IB approach

	Financial	In-Kind		Total
	Cost (£)	No of days	Cost (£)	
Scenario 1: Site furthest ahead at the start of the pilot				
• Pilot	£145,500	35	£7,500	£152,500
• Lower Bound Roll out: 250 families	£145,500	104	£22,000	£167,000
• Upper Bound Roll out: 440 families	£145,500	180	£38,000	£183,000
NOTE: The financial costs associated within scenario one are very similar across the categories as a result of all relevant costs being fixed, which by their nature do not require scaling up.				
Scenario 2: Mid-point site				
• Pilot	£153,000	128	£27,000	£179,500
• Lower Bound Roll out: 250 families	£280,500	428	£90,000	£370,000
• Upper Bound Roll out: 440 families	£420,500	758	£159,000	£578,000

	Financial	In-Kind		Total
	Cost (£)	No of days	Cost (£)	
Scenario 3: Site with farthest distance to travel				
• Pilot	£190,000	215	£45,000	£235,500
• Lower Bound Roll out: 250 families	£250,500	830	£174,500	£425,000
• Upper Bound Roll out: 440 families	£317,000	1507	£316,500	£633,500

Source: SQW cost estimation, please note that totals may marginally differ from additions of the financial and in-kind costs as a result of rounding

Summary

8.28 Pilot sites collected and submitted data to the evaluation team on the inputs and costs used to deliver the two year pilot programme; both in terms of the use of funding from the Departmental IB grant allocation and in-kind contributions from staff that were not directly funded by the pilot. This showed that most sites had incurred costs broadly in line with their expectations and that the largest financial costs had been spent on recruitment of the IB pilot specific teams and commissioning support from wider agencies.

8.29 The data also showed substantial variation in the in-kind costs reported by the sites. This in part reflected: the means by which the pilot was delivered; the extent to which each site recruited and funded pilot specific staff to undertake various roles (who as a result would be accounted for in financial as opposed to in-kind costs); and the extent to which sites sought to engage staff from outside the pilot specific team to support the development of the relevant activities.

8.30 Although no firm comment can be made in relation to the overall cost-effectiveness of the IB pilot relative to the traditional service approach, educated opinions from the sites implied that the relevant costs were likely to be broadly cost neutral as the approach was rolled out over the longer term[25].

8.31 Potential set-up and running costs of an IB pilot which seeks to recruit approximately 30 families with disabled children is likely to fall in the range of: £153,500 - £256,000 (over a 2-3 period) and £152,500 - £235,500 (per year) per local authority respectively, where exact figures will be dependent on the existing infrastructure and extent to which appropriate cultural change has already taken place in the area. And

[25] *The Family Journey Evaluation Report* provides details of the benefits associated with the IB approach and similarly, the *Recommendations and Implications Evaluation Report* provides a synthesis of both the costs and benefits of the IB approach.

similarly, the potential set-up and running costs associated with roll out of the IB approach could fall in the range of: £189,500 - £668,500 (over a 2-3 year period) and £167,000 - £633,500 (per year) per local authority respectively.

9: Refining the CDM

9.1 The CDM was developed to provide a flexible framework against which the pilot sites could structure their thinking and activities. The evaluation sought to assess the effectiveness of the framework, the relative importance of the 10 factors in relation and how these had contributed to the successful implementation of the IB approach.

9.2 This final chapter of the report therefore provides an assessment of the effectiveness of the CDM and presents a refined version of the framework, which takes into account the experiences of the pilot sites and lessons learnt over the course of the two year IB pilot programme.

Effectiveness of the CDM

9.3 The pilot sites reflected that the CDM had provided an appropriate and useful guide/framework upon which to base the development of the IB approach. In addition, the more advanced sites that had already begun to trial personalised services for families with disabled children prior to the IB pilot, cited that the framework had provided a useful benchmark against which they could compare their existing process. Similarly, those sites that had a larger distance to travel found that it provided a valuable starting point against which to structure their activities.

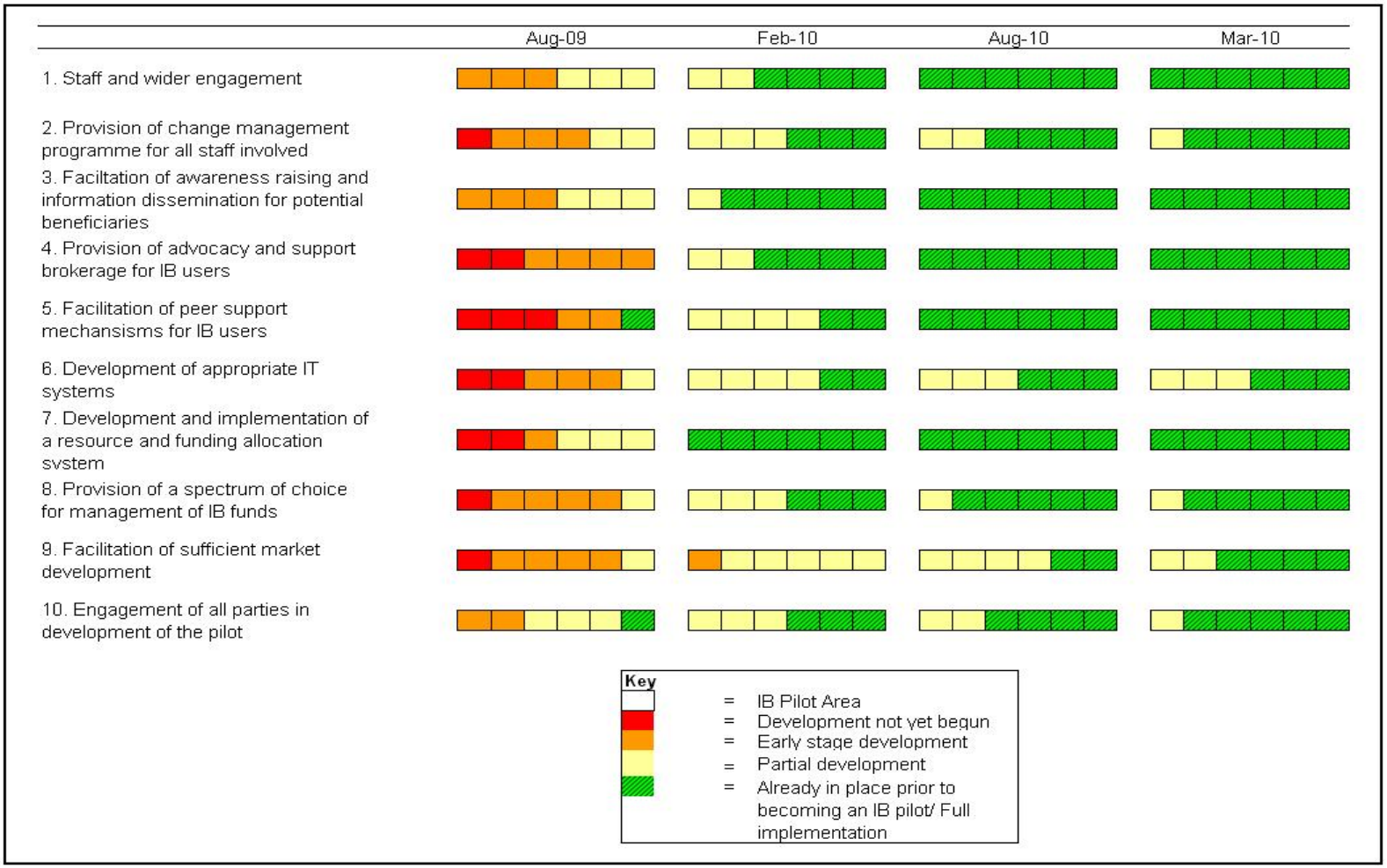
9.4 It was also apparent that the flexible nature of the framework had enabled a range of different approaches to develop within each of the sites. This diversity of approach created a spectrum of learning across the sites, and indeed led some of the sites to adapt their behaviour based on the experienced of other sites.

9.5 In terms of delivery of the 10 elements, it was generally acknowledged by the pilot leads that the set of elements were largely valid and that some elements had been more challenging in terms of implementation than others. These challenges were reflected in the variation between the original intentions and subsequent actual activity of each of the sites (see the individual area case study reports for more details). For example, element 7 – development of a resource allocation and funding mechanism – proved to be particularly challenging across the sites (see Chapter 5 above).

9.6 Figure 67 illustrates the perceived position of the sites, as reported in the sites own monitoring submissions, in relation to the elements of the CDM over the course of the

two year pilot programme (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 highlights that the development of distinct elements was started at different stages of the pilot and the variation in the elapsed time taken to develop of each of the elements. These variations suggest a need to incorporate an element of sequencing into the framework.

Figure 67: Level of implementation against each element of the CDM over the course of the two year pilot programme



Source: SQW pilot monitoring returns

9.7 Looking specifically at the appropriateness of the elements themselves and the ways in which they were illustrated in the CDM, sites provided the following reflections:

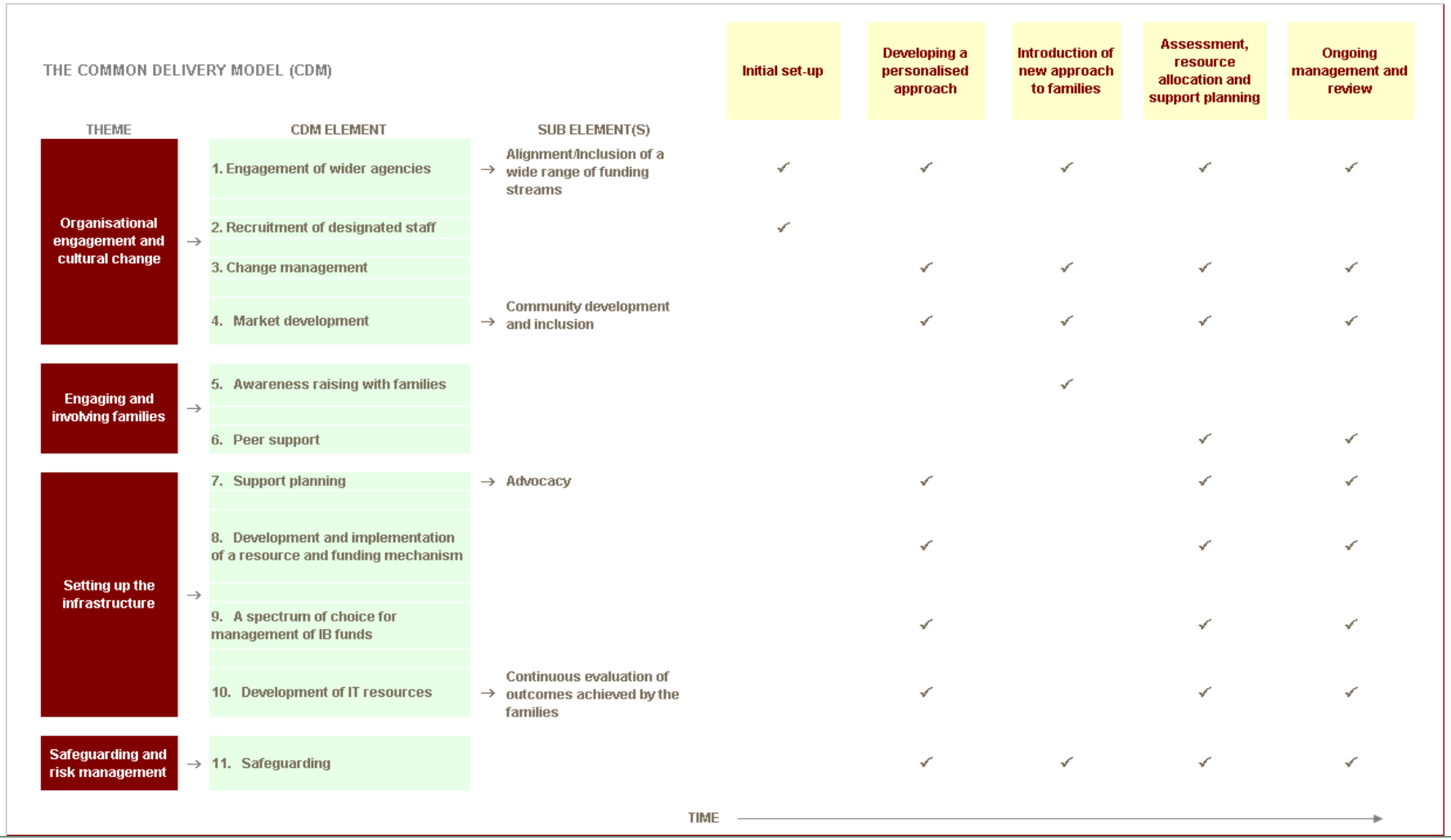
- **Sequencing of the elements -** sites stated that the framework appeared to give equal weight to each element, when in practice it was necessary to give more priority to some components than others at difference stages of the pilot. As such, a number of sites recommended that the CDM should include a sequencing of the elements
- **Distinguish different types of activity –** some of the sites suggested that it would be helpful to distinguish between infrastructural developments (e.g. resource allocation, support planning etc) and overarching development themes (market development, change management), to enable a clustered approach to development
- **Duplication between elements one (staff and organisational engagement) and ten (engagement of all parties in the development of the pilot) –** elements one and ten were felt to both cover partnership working and operational resource activities and as such sites recommended that the elements should either be merged or re-defined to reduce this repetition
- **Safeguarding of disabled children –** the majority of sites felt that the extent of the challenge posed by safeguarding issues warranted focus as an explicit element within the CDM especially in preparation for a roll out of the IB approach which would include families where there were concerns about child protection
- **Community development and inclusion –** as provider related cultural change in the IB context involved a focus on the development of community capacity to enable families to access local and universal services, sites felt that this distinct activity should be recognised in the CDM.

The refined CDM

9.8 The refined CDM, which reflects the lessons learnt, is illustrated in Figure 68. This includes:

- **Categorisation of the elements into themes** - organisational engagement and cultural change, engaging and involving families, setting up the infrastructure and safeguarding and risk management (as reflected earlier in the report)
- **Redefinition of some of the elements** – for example, element one now refers to the recruitment of designated staff to run the activities and element three (element ten in the original CDM) involves the engagement of wider agencies outside of this team
- **Sequencing to reflect the stages at which each element is likely to require consideration** – split into five stages leading to IBs going live
- **Addition of safeguarding and risk management as a new standalone element**
- **Addition of sub-elements** to ensure that development of the relevant elements includes critical success factors identified by the pilot sites
- **Ongoing refinement and development of the elements.**

Figure 68: Redefined Common Delivery Model



Source: SQW

Annex A: The Common Delivery Model (CDM) – as specified at the start of the pilot process

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 form 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 process evaluation framework

		Core objectives (from the ITT - shown in capital letters) and associated research questions	Method/tools
Evaluation framework component	Context	**Key contextual conditions** • What are the key contextual conditions in the pilot sites?	• Secondary and administrative data collation
		Pre-IB pilot position – what was the situation prior to the IB pilot? • What existing activity is/was previously undertaken by each pilot site to promote greater user control? • How were local authority/PCT officers involved in the prioritisation and selection of services/support for families with disabled children prior to the pilot? • How were families with disabled children involved in prioritising their needs and selecting their own service/support provision prior to the pilot? • 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? • To what extent did local authority/PCT staff promote or resist greater user control? • What prior knowledge did local authority/PCT staff have of IB provision and what were their attitudes towards this form of provision? • How willing were providers to respond to user-led provision?	• Case study research
	↓		
	Objectives	**Local objectives:** • What was the rationale for becoming an IB pilot? • What are the main objectives of each pilot site? • How many beneficiaries and which target group (or theme) does each pilot site intend to recruit?	• Pilot site delivery plan • Case study research

Core objectives (from the ITT - shown in capital letters) and associated research questions	Method/tools
Assessment of each pilot site against the CDM • To what extent does each of the pilot areas already comply with the CDM, i.e. what is the starting point of each area? • What was the rationale for implementing the relevant components of the CDM model prior to the inception of the IB pilot? • How does each pilot intend to implement each component of the CDM and why have they chosen the relevant methods of implementation? • Which of the components of the CDM are likely to be the most challenging to achieve and why? • Which of the components of the CDM are likely to require significant resources to achieve and why?	• Pilot site delivery plan • Case study research
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	Core objectives (from the ITT - shown in capital letters) and associated research questions	Method/tools
Inputs	**What were the main financial inputs to the process? (see chapter 4 for more details)** *Pilot and additional funding:* • How much funding was awarded by the former DCSF to deliver the pilot? • How much additional funding was required to deliver the pilot and what was the source(s) of this funding? *Implementing the CDM:* • 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. • What other costs were incurred during the set-up of the pilot? *Existing services:* • 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? *Ongoing costs:* • How much per year does/will the IB pilot cost to run e.g. salaries, training, ongoing provision of advocacy and brokerage services etc.? • How will the ongoing costs be used? • How does this compare to existing arrangements? *Funding streams pooled/aligned/integrated:* • 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? • How does this compare to existing arrangements?	• Process monitoring tool • Case study research
	What were the main non-financial inputs to the process? • 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? • 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?	• Process monitoring tool • Case study research
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	Core objectives (from the ITT - shown in capital letters) and associated research questions	Method/tools
Process and activities	**Implementation of the CDM** • Did the IB pilot work build on existing user control mechanisms/interventions? If so, how? • 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? • 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? • What additional activities/mechanisms have been set-up to deliver the pilot and why?	• Case study research
	Partnerships and networks • What partnerships and networks have been set up as a result of the pilot?	• Case study research
	Requirement for existing services • 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?	• Case study research
	Auditing and accountability • What auditing/reviewing processes was the family/manager of the IB funds required to undertake? And how frequently were these undertaken? • How did the pilot sites verify the auditing process? And how were disputes/appeals dealt with?	• Case study research
	IDENTIFY ANY CRITICAL BARRIERS EXPERIENCED BY THE PILOT AUTHORITIES AND PCTS TO THE SUCCESSFUL IMPLEMENTION OF IBS, AND RECORD SUCCESSFUL APPROACHES TO ADDRESSING THOSE BARRIERS **Barriers and critical success factors** • 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? • What critical success factors are necessary to ensure the effective delivery of IBs? What evidence do you have to illustrate your view?	• Case study research
	↓	

	Core objectives (from the ITT - shown in capital letters) and associated research questions	Method/tools
Results/outputs	**Implementation of the CDM** • How has the pilot site implemented the 10 components of the CDM: ➢ Set up appropriate governance and management structures, including local authority, health, education and adults services staff? ➢ Implemented an effective change management programme? ➢ Undertaken sufficient and effective awareness raising/information dissemination exercise(s) for potential beneficiaries? ➢ Set up effective advocacy and/or support brokerage mechanisms for their IB users? ➢ Facilitated peer support for their IB users? ➢ Developed appropriate IT systems to monitor and review the activities of the pilot? ➢ Developed an effective resource and funding allocation system? ➢ Provided a range of deployment options for the management of IB funds? ➢ Stimulated the provider market to respond to the needs of the IB users? ➢ Engaged providers and parents/disabled young people in the development of the pilot? • If all 10 components have not been implemented, which components are absent, what are the reasons for this and what has been done instead?	• Case study research
	Effectiveness of the recruitment process • 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? • How many families are actively engaged in the process? • How many support plans have been developed and finalised and in what timescales were they completed (measure of intermediate retention)? • 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)? • How many families have dropped out of the Programme, at what point did they drop out and why?	• Family monitoring tool • Family survey
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	Core objectives (from the ITT - shown in capital letters) and associated research questions	Method/tools
Outcomes	**ASSESS THE RELATIVE IMPORTANCE OF THE 10 FACTORS OF THE COMMON DELIVERY MODEL TO THE SUCCESSFUL IMPLEMENTATION OF IBs** **Effectiveness of the CDM** • 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? – *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* • How satisfied were beneficiaries with the individual elements of the CDM? – *this question also features in the family journey framework* • How has the process changed the behaviour of those directly and indirectly involved? *This may include:* ➢ Staff more willing to promote IBs to potential beneficiaries ➢ Improved understanding of IBs has increased staff confidence to support the facilitation of IBs ➢ Increased partnership working • How has the process changed the way in which services are provided to families? *This may include:* ➢ Providers have changed their perceptions/attitudes towards user-led provision • Has the process helped to improve safeguarding, e.g. by helping to identify families that could be at risk at an earlier stage?	• Case study research • Family focus groups • Family monitoring tool
Impact	• How has the process changed the way in which services are provided to families over the longer term? *This may include:* ➢ Providers have increased their flexibility and capacity to respond to user-led service provision ➢ Formation of new providers and services ➢ Assessment processes are now integrated ➢ Improved and increased pooling of funding ➢ Quality of provision has improved ➢ Local authority/PCT has undergone a system transformation/significant cultural change ➢ Local authority/PCT have developed plans to continue/develop their IB provision	• Case study research

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

Table B-2 IB family journey evaluation framework

Evaluation framework component		Core objectives (from the ITT - shown in capital letters) and associated research questions	Method/tools
	Context	• What are the characteristics of the families?	• Family registration form
		Pre-IB pilot position – what was the situation prior to the IB pilot? • How were families with disabled children involved in prioritising their needs and selecting their own service/support provision prior to the pilot? *For example:* ➢ In receipt of a Direct Payment ➢ Had support from a Lead Professional ➢ Local authority/PCT staff involved family and disabled child in the service-planning process • 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.?	• Family registration form • Family survey • Survey of professionals
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	Objectives	**Participation objectives:** • What do the family/disabled child hope to achieve by taking up the IB offer? *For example:* ➢ Increased access to appropriate services ➢ Increased control over daily life ➢ Increased choice of service providers ➢ Improved quality of life ➢ Greater continuity of care ➢ Improved quality of care	• Family survey

	Core objectives (from the ITT - shown in capital letters) and associated research questions	Method/tools
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Inputs	**Time/effort contributed towards setting up and managing the IB** • How much time/effort did the family/disabled child contribute towards the set-up process which resulted in receipt of IB funds? • 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?	• Family survey • Case study research
	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 **How much funding was allocated to the family/disabled child?** • 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? • How does this compare to existing arrangements?	• Family monitoring tool
	↓	
Process and activities	**What activities did the family/disabled child undertake to receive an IB?** *For example:* • Meetings with local authority/PCT staff • Attended training to further understanding of IBs and what they could potentially offer • Support planning • Capacity building to understand the potential funding deployment mechanisms that could be used	• Family survey • Case study research

Core objectives (from the ITT - shown in capital letters) and associated research questions	Method/tools
How were the IBs funds managed and by whom? *For example:* • Family or disabled young person is paid the budget and manages the money themselves • A third party 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 • 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	• Family survey • Case study research
How did the family/disabled child access the appropriate services and implement the IB support plan? *For example:* • Worked through a support broker who supported the family/disabled child to access the appropriate services • Worked through a peer support network who provided information on where to access the appropriate services • Worked through the local authority/PCT to access a preferred provider list who were able to provide the appropriate services	• Family survey • Case study research
Auditing and accountability • What auditing/reviewing processes was the family/manager of the IB funds required to undertake? And how frequently were these undertaken?	• Case study research
IDENTIFY ANY CRITICAL BARRIERS EXPERIENCED BY THE PILOT AUTHORITIES AND PCTS TO THE SUCCESSFUL IMPLEMENTION OF IBS, AND RECORD SUCCESSFUL APPROACHES TO ADDRESSING THOSE BARRIERS **Barriers and critical success factors** • 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? • 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? • How satisfied were families with the individual elements of the CDM and which elements proved to be critical success factors? – *this question also features in the IB process framework*	• Family survey • Family focus groups • Case study research • Depth interviews with beneficiaries who drop out

	Core objectives (from the ITT - shown in capital letters) and associated research questions	Method/tools
	↓	
Results/outputs	**What were the immediate and measurable results of the pilot?** • How many support plans have been developed and finalised (measure of intermediate retention)? • How many families are in receipt of IB funds relative to the target number (measure of sustained retention)? • How many families dropped out of the pilot and at what point did they drop out? Why did beneficiaries drop out of the pilot? • Which services did families access using their IB funds? Did the families encounter any difficulties in accessing appropriate services? • How has IB provision differed from traditional service provision?	• Family monitoring tool • Family survey • Depth interviews with families who drop out
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Outcomes	**EVALUATE WHETHER PROVISION SECURED THROUGH AN IB IMPROVED OUTCOMES FOR SOME, OR ALL, DISABLED CHILDREN AND FAMILIES THAN PROVISION THROUGH EXISTING ROUTES** **TEST WHETHER THE IB PILOTS RESULT IN SOME, OR ALL, DISABLED CHILREN AND THEIR FAMILIES REPORTING INCREASED LEVELS OF SATISFACTION WITH THE EXPERIENCE OF GAINING SERVICE PROVISION THORUGH AN IB** **How has the provision of an IB changed beneficiary perceptions of service performance?** • Increased user satisfaction with service provision (NI 54) • Increase control over daily life • Increased personal costs • Increased access to more appropriate services • Greater continuity of care • Improved quality of care • Fewer unmet needs	• Family survey • Case study research • Survey of professionals

		Core objectives (from the ITT - shown in capital letters) and associated research questions	Method/tools
	Impacts	**How has the provision of an IB changed the behaviour and well-being of beneficiaries and their perceptions of service performance?** *Consideration will be given to the effects on both the disabled child/young person and their family.* *Outcomes to be explored:* • Increased self-confidence of the disabled child and increased parental confidence • Improved health (self perception measure, which is closely associated with general well being) of both family and disabled child • Improved quality of life • Increased range of social and economic opportunities available to both the family and disabled child • Increased social engagement and participation in the community • Increased opportunities for independent living • 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 • Reduction in family stress levels • Strengthened family units • Increased labour market participation or engagement in non-compulsory education • Increased educational attainment of disabled child/siblings	• Family survey • Survey of professionals

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