

# Individual budgets for families with disabled children

## Final evaluation report: The family journey

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Government policy and may make reference to the Department for Children, Schools and Families (DCSF) which has now been replaced by the Department for Education (DFE).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

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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

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## Purpose of this report

- 1.1 This report is the second of three volumes containing the findings from the first two years of the Individual Budget programme for families with for disabled children. The three volumes cover:
- *The IB process evaluation*, which describes the approaches adopted to implement the pilot and the lessons emerging
  - ***The Family Journey evaluation***, which provides an assessment of the outcomes and distance travelled by participating families - **these issues are contained in this volume**
  - *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<sup>1</sup> 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*

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<sup>1</sup> 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*<sup>2</sup>. 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.

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<sup>2</sup> 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**

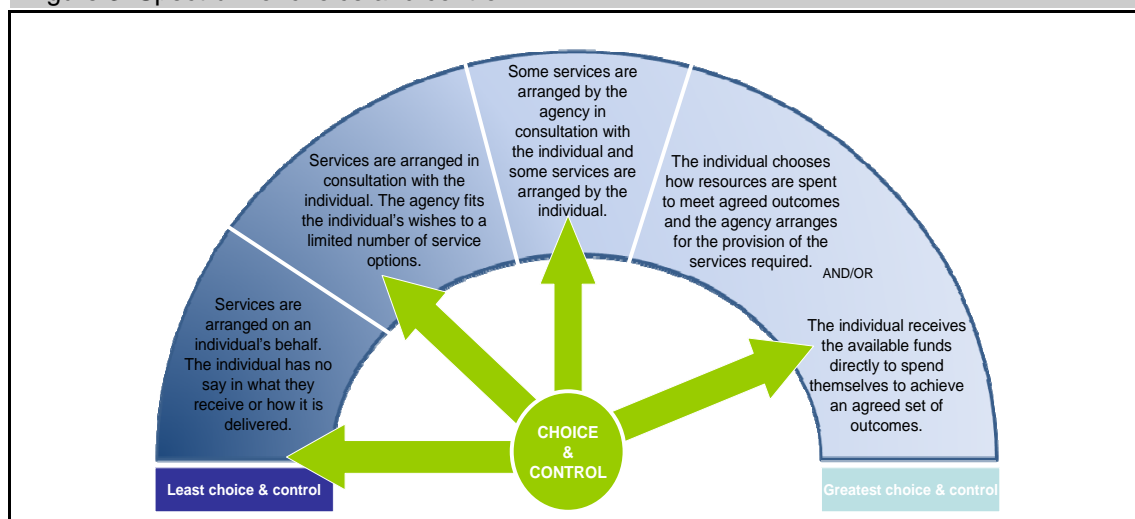
- 1.7 The IB pilots were originally commissioned to run from April 2009 to March 2011, with a possible extension beyond this period, subject to available funding. Sites received between £200,000 and £280,000 in grant funding over the two years to deliver the pilots.
- 1.8 The activities of each site 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 assess both **the journey through which the families progressed** and the **resultant outcomes and impacts** by participating families over the course of the two year pilot programme. As such, the report provides a description of how families were involved in the pilot activities, an overview of the characteristics of the families that participated in the programme and an assessment of the distance travelled as a result of the IB approach.

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: The family journey** – provides a description of the journey through which families proceeded in each of the pilot sites
- Chapters 2 and 3 replicate and summarise the contents of Chapters 2 and 6 from the Volume 1 report. They are included here for to assist readers who have not read Volume 1, as they provide important context for the concepts and findings that follow.
- **Chapter 4: The families and young people taking part in the pilot** – provides a description of the families who signed up to the pilot and were involved in both the baseline and follow up surveys that were undertaken over the course of the programme
- **Chapter 5: Families that left the pilot** – provides a summary of the qualitative, in-depth interviews that were undertaken with families who had enrolled in the pilot and subsequently chosen not to continue with the programme.
- **Chapter 6: Outcomes achieved by participating families** - presents an analysis of the outcomes achieved by families that participated in the pilot

- **Chapter 7: Impacts achieved by participating families** - presents an analysis of the impacts achieved by families that participated in the pilot
- 1.16 Each chapter contains a summary of the main findings that emerge from the evidence. The implications arising from these findings are considered alongside the process lessons in *Volume 3: The Recommendations and Implications report*, which draws together the findings of the evaluation and presents recommendations for the future use of the IB approach.
- 1.17 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

- 1.18 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.

1.19 The methods adopted are described more fully in the accompanying Technical Report.

## 2: An introduction to the IB Approach and the pilot sites

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- 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*<sup>3</sup> originally recommended that IBs should, in principle be extended to families with disabled children and the subsequent *Aiming High for Disabled Children (AHDC)*<sup>4</sup> 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

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<sup>3</sup> Prime Ministers Strategy Unit (2005) *Improving Life Chances for Disabled People*

<sup>4</sup> 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*<sup>5</sup> 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 the 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*<sup>6</sup> 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 of budgets and includes a series of stages. The IB approach therefore sought to

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<sup>5</sup> HM Treasury and Department for Education and Skills (2005) *Support for Parents: The Best Start for Children*

<sup>6</sup> Department of Health (2010) *Vision for adult social care: Capable communities and active citizens*

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, 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<sup>7</sup> 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<sup>8</sup>.
- 2.10 Similarly, through the December 2008 Department for Work and Pensions White Paper<sup>9</sup>, 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

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<sup>7</sup> Department of Health (2008) *High quality care for all: NHS Next Stage Review final report*

<sup>8</sup> Please refer to the Department of Health website for more details

<http://www.dh.gov.uk/en/Healthcare/Personalhealthbudgets/index.htm>

<sup>9</sup> 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<sup>10</sup>.

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 can be incorporated into an Individual Budget for families with disabled children during 2011-12.

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<sup>10</sup> *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. Table 5 details the range of objectives cited by the pilot sites.

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

### Short term objectives

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

### Long term objectives

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

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*Source: SQW case study research*

- 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.

## Summary

- 2.24 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.

- 2.25 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.
- 2.26 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.
- 2.27 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: The family journey

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- 3.1 Participating families engaged in one of three family journeys. Differences in these journeys were dictated by a difference in the sequencing of activities caused by the use of different resource allocation system (RAS) used by each of the pilot sites<sup>11</sup>.
- 3.2 This chapter describes the three family journeys that were facilitated by the pilot sites, thereby providing a context for the subsequent chapters of the report. Please refer to Chapters 5 and 6 of *The IB Process Evaluation Report* for more detail on the separate elements of the family journey.

### The 'family journey'

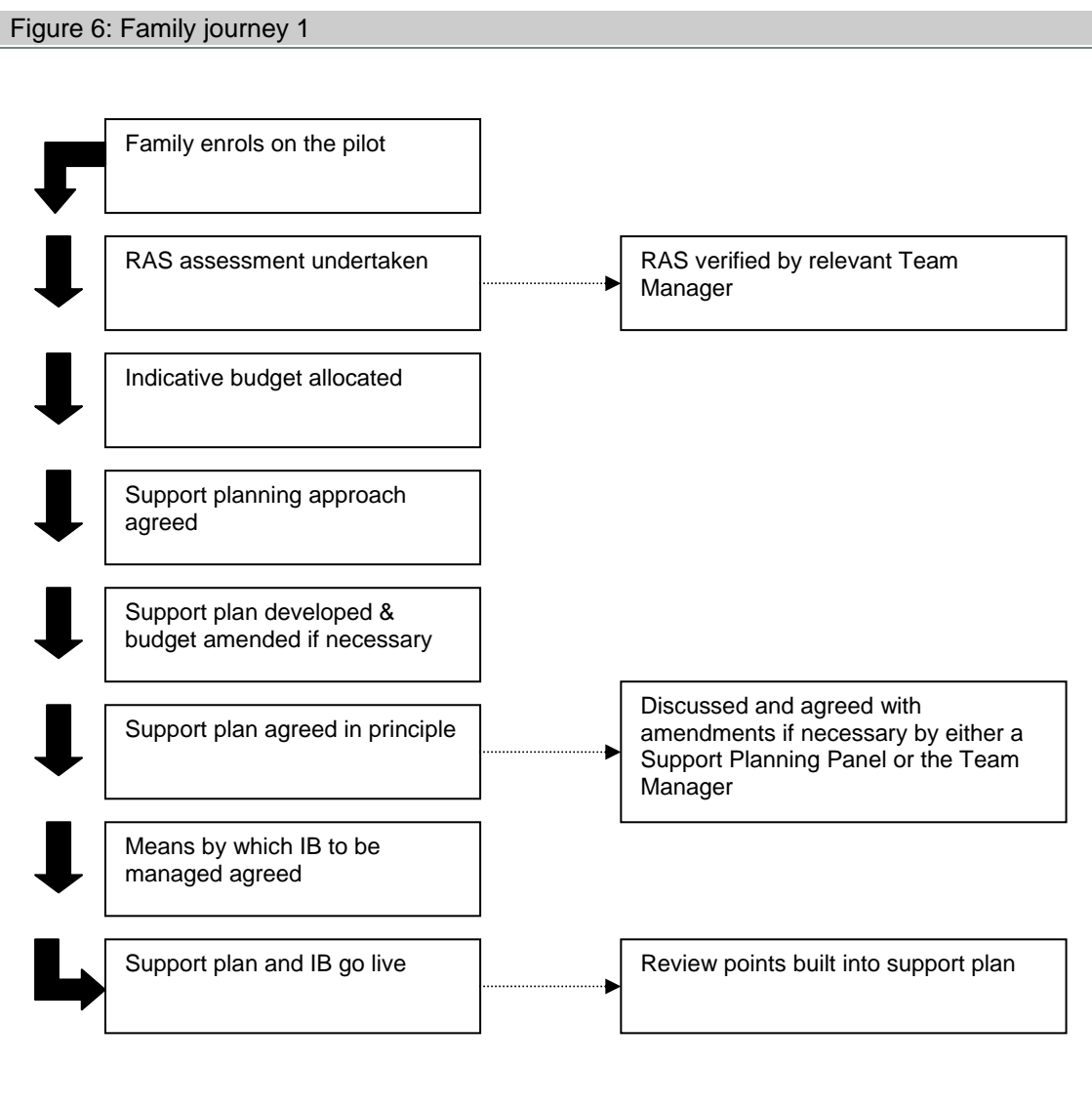
#### ***Family journey one: the In Control RAS***

- 3.3 The three sites that opted to use the in-Control RAS (and one of the sites which opted to use an alternative model of a similar nature) facilitated the process illustrated in Figure 6. This shows that following enrolment on the pilot, the family participated in the RAS assessment and was subsequently provided with an indicative budget. Once they 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.
- 3.4 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.

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<sup>11</sup> Three sites opted to use and adapted version of the in-Control RAS, two sites opted to develop their own alternative system and one site chose to use both the in-Control RAS and to develop an alternative system (where each was used for different age groups).

- 3.5 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.



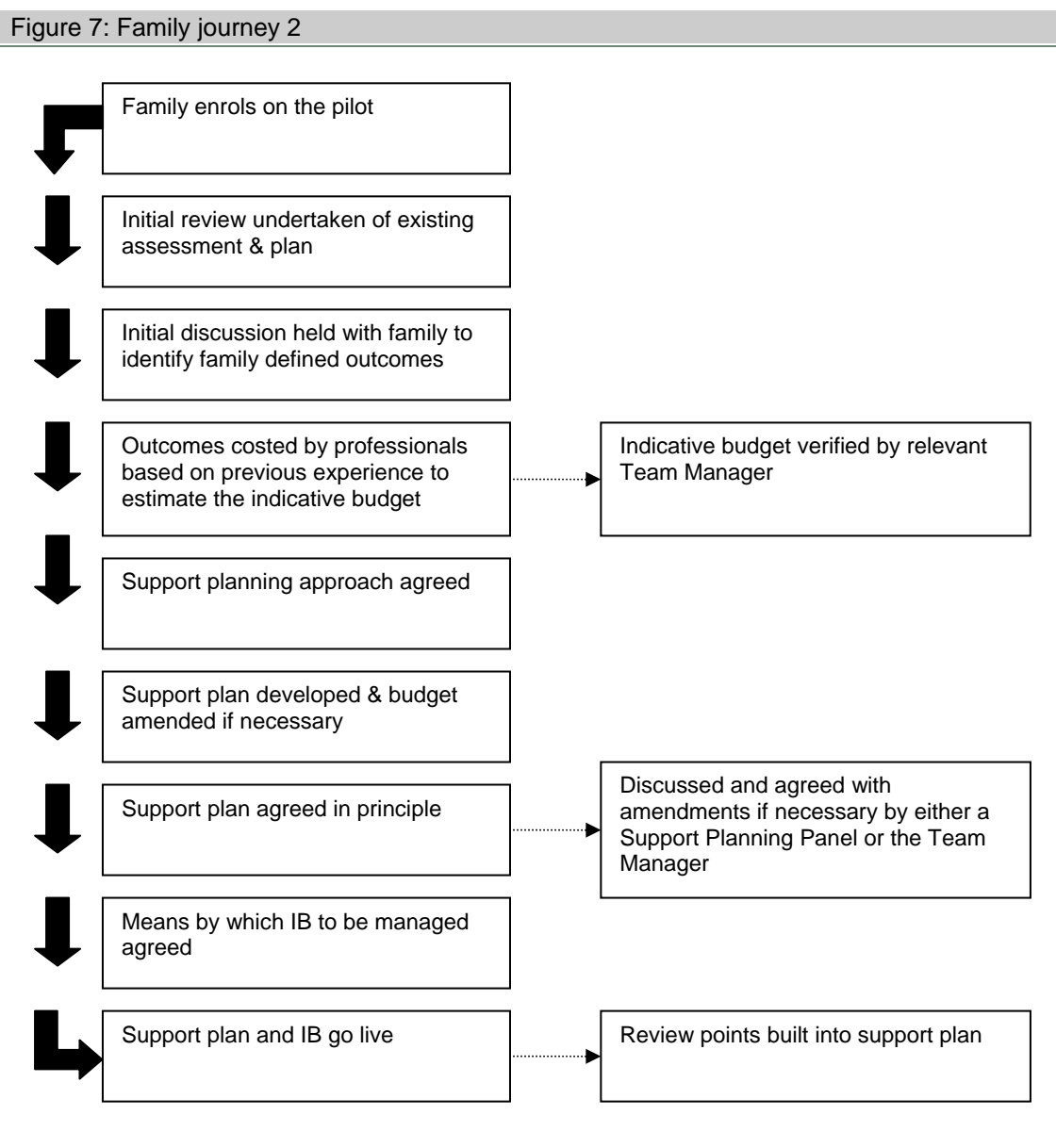
Source: SQW case study research

#### **Family journey two: alternative resource allocation model 1**

- 3.6 The family journey in the first of the remaining two sites is illustrated in Figure 7. 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 involved with the support of that child 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.



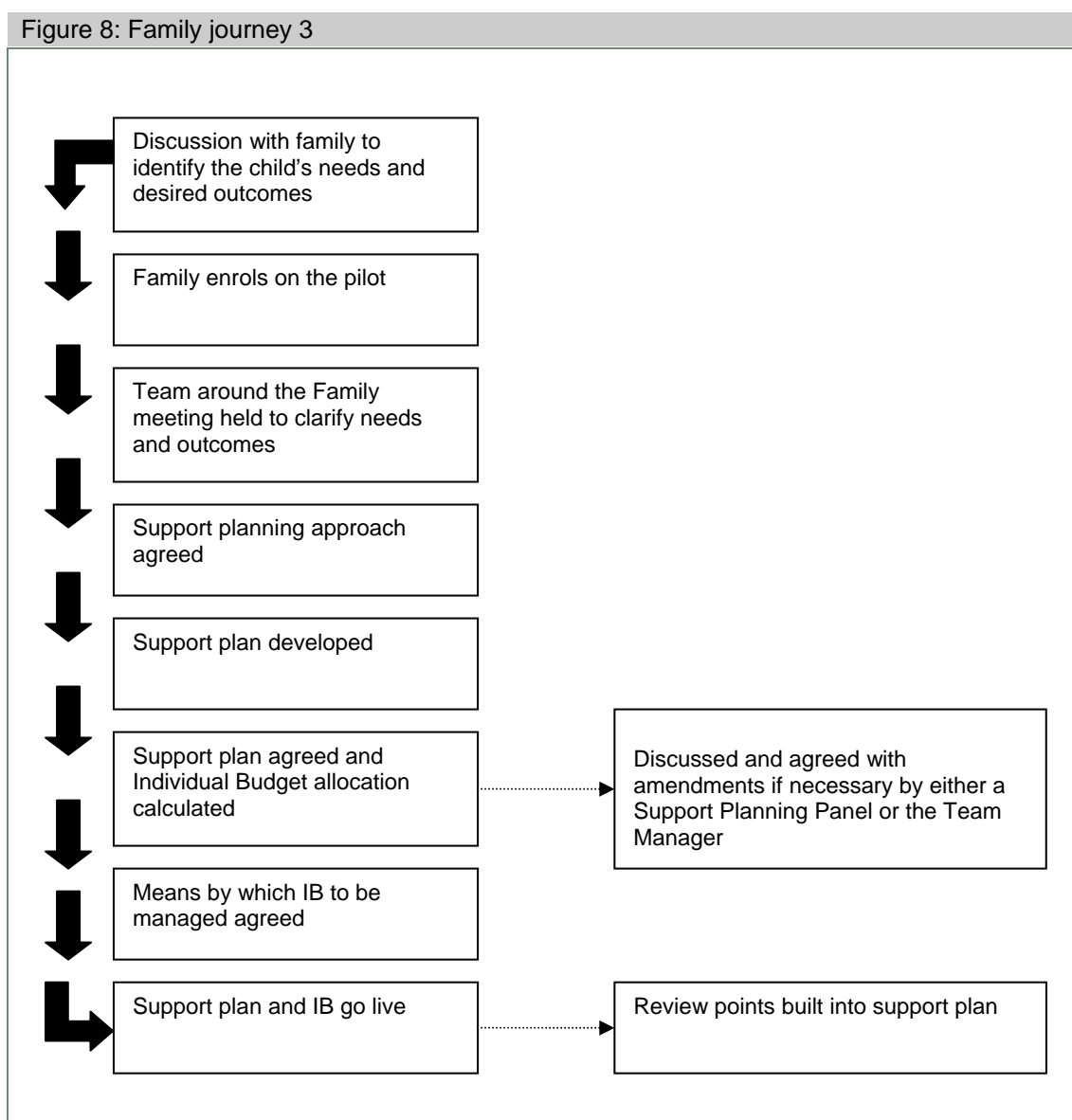
Source: SQW case study research

### **Family journey three: alternative resource allocation model 2**

- 3.7 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.

3.8 Figure 8 summarises this process.



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

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### Families on the pilot

- 4.1 Each of the IB pilot sites was tasked to engage 30-50 families with disabled children to take part in the pilot. Across the sites, 189 families were engaged in the pilot by March 2010. The experiences of these families were tracked through surveys of the families and disabled children and young people, surveys of the professionals who worked with them and site monitoring data. The surveys were all conducted on a before and after basis, through which we gathered baseline data on the position of the family prior to its receipt of an IB, and then revisited the same questions after the family had engaged in the IB process to assess distance travelled.
- 4.2 The baseline survey was completed by 173 families. Almost three quarters of these families (126) went on to complete the follow up survey. The main reason for follow up interviews not being conducted was that 33 of the families had left the pilot since the baseline.<sup>12</sup> Families' reasons for leaving the pilot are described in the next chapter.
- 4.3 The *Interim Report* described the characteristics of participating families who signed up to the pilot by March 2010. It highlighted a good level of diversity across participating families in relation to: socio economic status; nature of the child/young person's disability; and previous use of personalised approaches. This chapter considers the 126 families that responded to the follow up survey to see whether this still holds. The outcomes and impacts arising following the IB for these families are then explored in the chapters 6 and 7 of this report.

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<sup>12</sup> The remaining families did not complete the follow up survey, either because they could not be contacted during evaluation timescales or they refused the consultation due to personal circumstances (for instance the illness of a child or other family difficulties). For further details, please see the *Technical Report*

## Nature of the participants

### **Characteristics of families**

- 4.4 The majority of households contained two adults and almost half also contained two children (Table 9). On average the households had 2.1 children under the age of 18, compared to the national average of 1.8 children per family.<sup>13</sup>
- 4.5 A third of children/young people on the pilot were from single parent or legal guardian families, while nationally 22%<sup>14</sup> of households with dependent children were lone parent families.

Table 9: Number of adults and children living in household

Number in household	Number of adults (aged 18 or over) living in household		Number of children (aged under 18) living in household	
	N	%	N	%
None	0	0%	2	2%
1	31	25%	31	25%
2	66	52%	60	48%
3	19	15%	22	18%
4	7	6%	8	6%
5	2	2%	0	0%
6+	1	1%	3	2%

Source: SQW and Ipsos MORI follow up survey

### **Family economic status**

- 4.6 In over half of the families (52%) the responding parent/guardian was not in work. This included 41% of families where the parent was not seeking work. However, where the enrolled child/young person lived in a dual parent household, the second parent tended to work full time (Table 10). Overall, in one third of households no-one was working at the time of the follow up survey.

<sup>13</sup> The national average figure was calculated using 2001 Census data. It calculates the average number of dependent children (aged 0-18) per household with dependent children. This differs slightly from the IB definition, where children are aged under 18. Note that the IB cohort includes two families with no children under 18, as the children/young people turned 18 during the pilot.

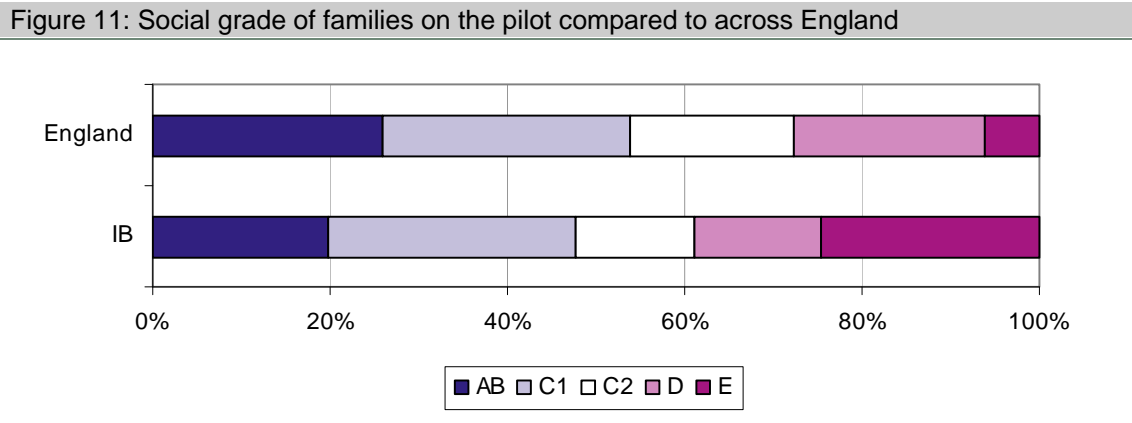
<sup>14</sup> This figure is calculated using 2001 Census data. It calculates the proportion of all households with at least one dependent child that were lone parent families.

Table 10: Occupation of parents in the household

	Occupation of responding parent/guardian		Occupation of second parent/guardian	
	N	%	N	%
Working full-time (30 hours a week or more)	26	21%	48	38%
Working part-time (less than 30 hours a week)	28	22%	10	8%
Long-term sick/disabled	8	6%	7	6%
Registered unemployed	6	5%	3	2%
Not registered unemployed, but seeking work	0	0%	1	1%
At home/not seeking work	52	41%	11	9%
Full-time student	1	1%	0	0%
Fully retired (including retired early)	0	0%	3	2%
Other	5	4%	0	0%
Don't know	0	0%	1	1%
Not applicable	0	0%	42	33%
Total	126	100%	126	100%

Source: SQW and Ipsos MORI follow up survey

- 4.7 Figure 11 illustrates the range of social grade distribution amongst participating families. This shows that 48% of families were from the higher social classes (ABC1 – these grades include: upper middle class, middle class, lower middle class), and 52% were from the working class (grades C3DE – including: skilled working class, working class and those at the lower levels of subsistence). A quarter of families were categorised in social grade E, implying that the chief income earners occupation was in casual or lower grade employment, or dependent on the welfare state. While this contrasts with the national figures where only 6% of families with dependent children fell into social grade E, the breakdown across social groups is broadly in line with the population of families with disabled children. Gordon et al (2000) indicated that around 55% of disabled children lived on or near the margins of poverty.



IB figures sourced from the SQW and Ipsos MORI follow up survey (N=126)  
 Figures for England sourced from Census 2001. They include the social grade of the Household Reference Person who completed the Census families for families with a dependent child aged up to 18 (N=6,023,856)  
 Source: Census 2001 and SQW and Ipsos MORI follow up survey

- 4.8 The rates at which families had dropped out of the pilot were consistent across the social grades. Approximately 15% of families from the higher social and working classes left the pilot prior to receiving an IB.

**Characteristics of children and young people**

- 4.9 The pilot covered children and young people across the age spectrum (Table 12). Approximately half of the participants (52%) were of transition age (14-18), reflecting that four sites targeted this group. In contrast, the site targeting newcomers to the social care system recruited younger children (including seven children aged 0-5).
- 4.10 Approximately two thirds (67%) of the children/young people from the families surveyed were male.

Table 12: Age band of child/young person at the start of support planning

Pilot site	1		2		3		4		5		6		Total	
<b>Target group</b>														
14-18 year olds	✓		✓		✓						✓			
0-16 year olds							✓							
Newcomers to system									✓					
	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>
0-5 years	0	0%	0	0%	1	6%	2	8%	7	35%	1	5%	11	9%
6-13 years	1	5%	4	18%	12	75%	19	73%	10	50%	3	15%	49	39%
14-15 years	10	45%	9	41%	3	19%	3	12%	3	15%	10	50%	38	30%
16+ years	11	50%	9	41%	0	0%	2	8%	0	0%	6	30%	28	22%

Source: SQW pilot monitoring returns

- 4.11 For the most part, the ethnic make-up of participating families was in line with the population of the area. Indeed, several areas recruited a larger than proportionate number from the BME community (Table 13), including two sites in particular which had focused on recruiting hard to reach individuals onto the pilot.

Table 13: Proportion of children/young people from a black and minority (BME) ethnic group

Pilot site	Proportion of participants from a BME group	Proportion of residents from a BME group	Difference between proportion from a BME ethnic group (percentage point)
1	32%	20%	12%
2	0%	3%	-3%
3	0%	6%	-6%
4	4%	4%	0%
5	20%	5%	15%
6	15%	11%	4%

Note: the proportion of residents from a BME group was calculated using ONS mid-2007 resident population estimates by ethnic group.

N=126

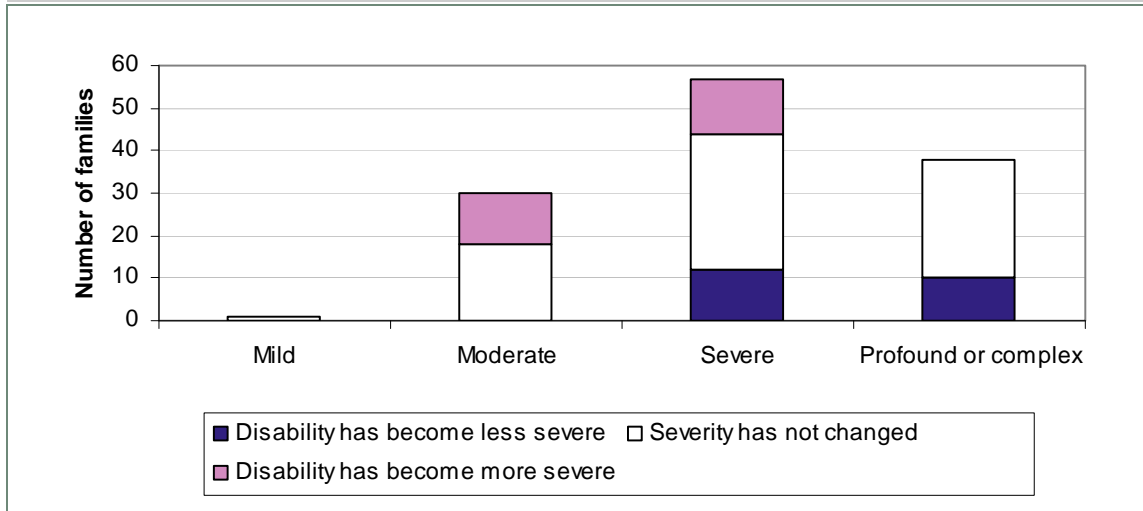
Source: ONS 2007 Mid-Year population estimates, SQW pilot monitoring returns

### **Nature of disability**

- 4.12 The pilot contained children whose lives were impacted upon severely by their condition or disability. Indeed, the majority of children and young people (75%) were

reported to have severe, profound or complex needs (Figure 14). Children aged 6-13 years and newcomers to the system, who came into the pilot at the point of diagnosis, tended to have less profound or complex needs. Therefore, the sites that focused on recruiting younger children and newcomers to the social care system rather than young people in transition had fewer families with severe, profound or complex needs.

Figure 14: Intensity of child/young person's condition or disability, and the change of intensity since enrolling on the pilot



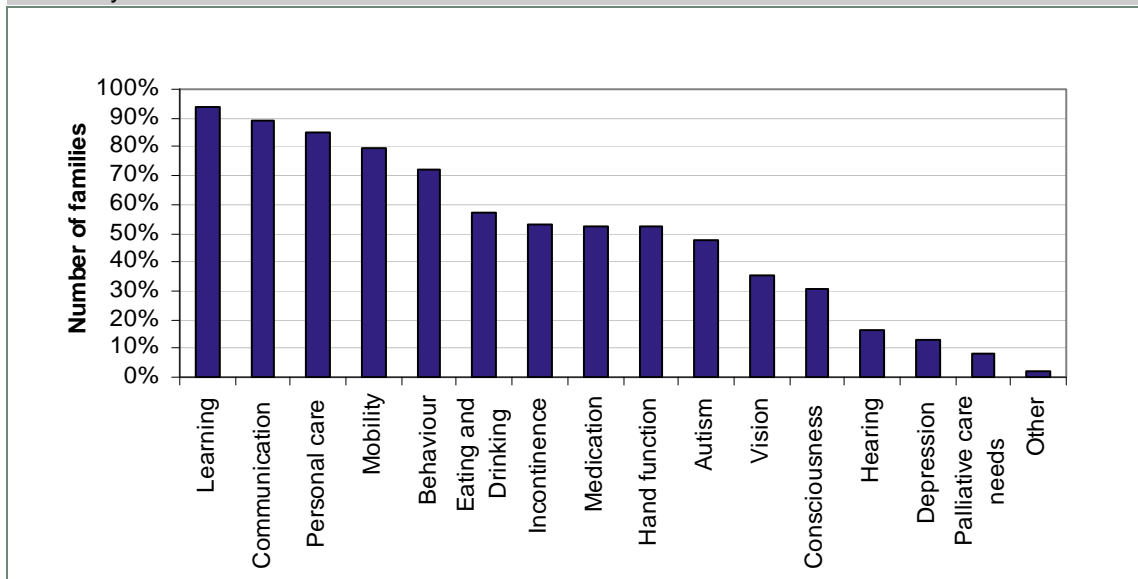
N=126

Source: SQW and Ipsos MORI baseline and follow up surveys

- 4.13 Figure 15 illustrates the nature of the children's disabilities. It shows that the child/young person's condition was most commonly demonstrated through learning difficulties (94% of children/young people were felt by their parent/carer to be affected in this area), communication difficulties (89%) and challenges in managing personal care (85%). A small minority of the children/young people (8%) were reported to have palliative care needs.



Figure 15: Areas in which the child/young person is affected as a result of their illness, disability or condition



Note: The proportion of children/young people affected by Autism includes those diagnosed with Autism, Aspergers Syndrome or an Autistic Spectrum Disorder (ASD).  
N=126

Source: SQW and Ipsos MORI follow up survey

## Previous use of services

- 4.14 The majority of children/young people from the evaluation cohort had accessed social care (72%), health (71%) and education provision (95%) prior to enrolling on an IB (Table 16)<sup>15</sup>. However one site, which targeted newcomers to the social care system, had a much higher proportion of children who had not previously accessed social care provision (55%).

Table 16: Previous experience of services and personalisation approaches

Pilot site	Targeting newcomers to social care	Newcomers to social care provision		Newcomers to health provision		Newcomers to education provision		Past experience of personalisation	
		N	% of families	N	% of families	N	% of families	N	% of families
1		3	14%	4	18%	1	5%	6	27%
2		4	18%	9	41%	0	0%	9	41%
3		5	31%	1	6%	0	0%	10	63%
4		10	39%	5	19%	1	4%	8	31%
5	✓	12	60%	0	0%	0	0%	8	40%
6		1	5%	4	20%	2	10%	11	55%
Total		35	28%	23	18%	4	3%	52	41%

Source: SQW pilot monitoring returns

<sup>15</sup> It was not known whether a further 11% of families had previously accessed health provision or whether the remaining 2% had accessed education provision.

- 4.15 A significant number (41%) of the families had experience of personalisation approaches prior to enrolling on the pilot, most commonly through receipt of a Direct Payment. As a result of this experience some families described feeling more comfortable with the notion of taking on an IB. Where families had already experienced increased choice and control through other personalised approaches, it was possible that they would gain less through the pilot. The evaluation explored the extent to which families had different experiences of IBs given their different starting points.

## Summary

- 4.16 Table 17 presents a summary of the characteristics of the families and young peoples taking part in the pilot.

Table 17: Summary of findings and actions moving forward

### Summary findings and lessons

- There was a good range of diversity between participating families in relation to: socio economic groups; nature of the child/young persons disability; and previous use of personalised approaches
- On average, families on the pilot had 2.1 children under the age of 18. A third of children/young people were from single parent families.
- The pilot sites engaged families from across the social classes. Forty eight percent of families were from the higher social classes (ABC1), while 52% were working class. A larger proportion of pilot families were from working class social grades (C2DE) than the national average. This is encouraging given that a concern at the time of the *Scoping Report* was that the personalised approach would appeal most to more articulate, wealthier families
- A number of sites also engaged a larger proportion of families from BME groups relative to the local population
- The majority of children/young people (75%) were reported to have severe, profound or complex needs. However, children aged 6-13 and newcomers to the system, who came into the pilot at the point of diagnosis, tended to have less profound or complex needs
- The majority of children/young people had accessed education, health and social care provision prior to enrolling on the pilot. However, over a quarter of children/young people (28%) were newcomers to the social care system. A third of these children were from one site, which specifically targeted newcomers to the system
- Overall the diversity of families engaged has enabled the evaluation to examine how different types families responded to the pilot – an important consideration for further roll out beyond the pilot

## 5: Families that left the pilot

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- 5.1 As part of the evaluation, Ipsos MORI were commissioned to undertake a set of qualitative, in-depth interviews with families who had enrolled in the pilot and subsequently chosen not to continue with the programme. The interviews sought to explore their experience of the pilot in more detail and to understand the reasons why these families left the pilot.
- 5.2 The sample of families selected to take part in the research were chosen by the pilot site managers to ensure that they were appropriate for inclusion<sup>16</sup>. This led to the issuing of eleven invitations to take part in the research, out of a total of 33 families who had left the pilot before October 2010. Of these, ten families took part in an interview between 13<sup>th</sup> October and 10<sup>th</sup> November 2010. Given the variance in the number of families that had left the pilot across the sites, the ten participating families were not evenly distributed across the sites; and seven of the interviews were conducted with families in one pilot site. It should also be noted that the needs and ages of the children in the families involved in the research varied significantly. As such, each family had varying support needs and thereby had differing expectations of the pilot.
- 5.3 The following Chapter presents a summary of the findings from this research.

### Previous experience of service provision

- 5.4 Most families reported that they were happy with the support they were receiving prior to joining the pilot and felt in the main that the services they had access to supported both the needs of the child and the wider family. The families stated that they placed a great deal of value on one-to-one care and/or short breaks where they formed part of their support package. That is, they felt that these services in particular provided both a break from their caring responsibilities and the opportunity for their child to experience a sense of independence.
- 5.5 However, whilst the families were generally positive about the services that they received prior to joining the pilot, they also identified weaker aspects of, and some dissatisfaction with, their previous support packages. These mainly related to the way the services were delivered as opposed to a feeling that the services they were being

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<sup>16</sup> Reasons for excluding other families that had left the programme from the sample included family illness or bereavement and other difficult personal circumstances.

offered were inadequate. This included issues relating to: the assessment procedure; the reliability of service provision; limits on the flexibility of the services; and constraints on the amount of choice and control families could exercise. For example, three of the families commented:

*'I think we had, out of the possible 26 [short breaks] that she should have had in the year, I think she got 16. The rest of the time the staff was off sick or the day of the pantomime they lost the tickets so she couldn't go. We were so sick of the carer saying, oh my dog's had an operation, I can't come for you. But she never gave me the opportunity to get somebody else in, so [our daughter] was constantly getting let down'*

*'It's hard to find a job when you know that every half term it's hard to get someone to look after [my son]. Sometimes they do have schemes like in the summer holidays and that's good. But when it's Christmas or they're not on it's a bit difficult and unless you go private you can't do very much'*

*'If they weren't going to offer it via Social Services, that was it. If that service changed then they say "no, he no longer qualifies for that one.". You have no control because they've said no and that's it. You've got no way personally of accessing [the service yourself] because you need them to arrange everything for you'*

## Experience of the IB programme

### **Expectations of the pilot**

- 5.6 The majority of the families that took part in the research hoped that their situation would improve as a result of the IB programme and related this to an expectation that an IB would offer them more control and flexibility over the services they receive. As such, their enrolment onto the pilot was not necessarily driven by a desire to access *different* services, but to maintain, extend or improve the types of services they already used. The families also reported a general expectation that they would experience an increase in the level of funding they were entitled to as a result of joining the pilot, with none expecting their allocation to decrease as a result of joining the pilot. For example, families provided the following comments:

*'That's how they sold it, that as long as it met certain criteria you could basically do what you liked with it and that he may actually get a much bigger budget. It sounded as if it would give him more independence; that you could use it really in any way, just even if he was supported to go and do some gardening somewhere or whatever'*

*'We just thought that perhaps the pilot would just give us a little bit more control and that we could work out exactly what we wanted'*

*'I didn't expect to get more services from it, I just expected to be able to use that allocated budget more creatively really... predominantly people with a disability, choices are made for them and they're told what to do'*

*and I really was keen to make sure that [my son] was given as much choice as possible’.*

- 5.7 The families reported that they had experienced some initial concerns at the point at which they signed up to participate in the pilot. These included: the possibility of losing services; a concern around the level of responsibility that they would have to take on to manage budgets and become employers; and whether the programme would actually meet the expectations it was raising. That said, many families were fairly relaxed about their concerns as a result of the safety net of being able to go back to their previous provision if they decided to leave the programme. For example, one family stated:

*‘The only concern I had was if it didn’t work. They made it quite clear you wouldn’t lose your existing services but I suppose at the back of my mind there was a little niggle, what if they say you’re entitled to less service than you get [now], in the future are they going to try and reduce those services? Is it like a cost cutting exercise? I suppose I was a little bit suspicious, that they were trying to give you less than you had’.*

### **Experience of the pilot**

- 5.8 Overall the families’ initial experiences of participating in the pilot were fairly positive, with few major concerns about the actual process up until their decision to leave. This was especially true of those families who already had experience of direct payments. The decision to join was usually talked through with social workers and other support staff, and all families appreciated the effort made at this stage, although a few felt the support staff did not have all the information they needed to make an informed decision about joining the programme.
- 5.9 All families that participated in the research had been through some form of resource allocation process before they had left the programme. The families in the main reported that they were content with how this process had been carried out, especially in the cases which had been facilitated in a more informal manner. However, a small number of the families expressed some dissatisfaction, where the main issues mentioned related to the length of time it took to complete the allocation process, its complexity, and concerns around the fairness and transparency of the resource allocation process. For example, two of the families commented:

*‘I couldn’t believe all the things she had to ask us. It was so much stuff to go through and some of the [RAS] questions were hard to answer. You had to think very hard and you couldn’t see how to answer it, you know it was all to do with health and things like that and if you have got a child like*

*ours that's got so many different types of difficulties some of it was quite hard to answer'*

*'I knew a couple of people who were on it and they all had bigger budgets and yet had more capable children, a bit more independent and that, so I just didn't think it was very fair if I'm being honest. I don't really call it unfairness, but what's the word? There's a lot of discrepancies, I've got friends who are on massive, massive budgets and allowances plus respite. One night of respite a month is extremely expensive, I've never had anything like that, I've wanted it but I haven't had it'.*

- 5.10 A small number of the families also stated that they had found it difficult to define either their desired outcomes or the support they would require to meet a stated outcome during the resource allocation process. This difficulty arose as the families were unaware of what services were available, how much each of these was likely to cost and therefore how far they could afford to access the relevant services. As such, they questioned the sequencing of the IB approach and felt that they would have been more comfortable discussing outcomes during the support planning stage, alongside discussions about the likely value of their IB, as opposed to at the outset of the resource allocation process when they were unable to set these desired outcomes within the context of the finances and services on offer.
- 5.11 Looking specifically at the sub-set of families that had participated in support planning before leaving the pilot, the majority reported that they had found this an extremely worthwhile and beneficial part of the process, which had led them to learn new things about their child. That said, a few families highlighted areas that they were concerned about or felt could be improved. These concerns related to a lack of information on what they could do with their IB, a lack of contact with other families on the programme, the workload and burden involved in the planning process, the stage at which they were provided with an indicative budget, and concerns about the need to better manage the expectations of their child to avoid disappointment further down the line. For example, one family commented:

*'Basically, all she was saying was you will be allocated x amount of pounds per year, and it's left with you how you choose, to make sure [your son] benefits from that. We can't tell you what to do, we can just put ideas to you', and that was it. Every time they came, [I asked], have you got any information of what you can offer, [and the response was] no, we're sorting that out for you. Well, unless you tell me, I can't decide. It just weren't getting anywhere'.*

## Leaving the pilot

### **Reasons for leaving the pilot**

- 5.12 All the families bar one received their indicative budget before they decided to leave the pilot. In most cases the amount they were awarded, which they described as being substantially less than they had been receiving prior to the pilot, was the main reason why families decided not to continue with the programme. Most families interviewed were unclear as to why there was such a difference between their current package and the proposed IB.

*'I was told how much I would be getting. Yeah well I worked [the comparison to my previous package] out myself as well and I thought you know okay that's a lovely sum of money but it would not last very long to get what [my son] is getting now. It wouldn't have been enough. I expected it to be higher as it was a year budget, I thought it would have been higher [in monetary terms] and I would have got the same [services]'*

*'I have spoken to some other families. I've found it quite interesting how some families had even half of the [RAS] score that my son had but they didn't have half the money. .... it makes you feel cheated ... I mean if you were in a competition and you scored 70 points and somebody else next to you scored 151, would you expect to win the same prize as the person who had scored 151? You wouldn't. So why was my son's budget several thousand pound less than somebody who got half the RAS score?'*

- 5.13 Whilst this was not specifically mentioned by families themselves during the interviews, subsequent discussions with the pilot sites indicated that the decision to leave or remain on the pilot when an indicative budget was lower than the current service package, could be strongly influenced by the way in which the indicative budgets were communicated to the relevant families. That is, in one site, families received notification of their indicative and comparative, existing budget by letter and as such, were not given sufficient opportunity to think through how they could use the reduced fund to better meet the needs of the child and family. This learning was shared across the pilot sites, who subsequently sought to ensure the indicative budget was communicated either in person or by phone, to provide an opportunity to discuss the indicative budget and potential implications, especially highlighting the benefits of having an IB even though the budget may be of a lower monetary value than their previous support package. This change appears to have subsequently led to a lower proportion of families leaving the programme in other sites.
- 5.14 Before leaving the pilot programme some families tried to challenge their indicative budget. However, families did not feel that there was any room for them to negotiate

their allocation. Others families chose not to challenge the allocation because they were daunted by the process they thought they would have to go through to resolve the issue.

### ***Feelings after leaving the pilot***

- 5.15 The families generally did not have many regrets about signing up to the pilot or their decision to leave. That is, whilst a number of the families stated they were upset that they had invested a significant amount of time in this process, they also reported that they had experienced positive gains from their participation, which included learning more about their child's needs and wishes. For example, two families commented:

*'We learnt things about [our son] ... We never knew that he loved basketball, I had no idea. And that came out of the process ... And even though we hadn't done the individual budget it's been beneficial for [our son] because we learnt a lot about him and he's done a lot of the things that he actually wanted to do so I feel he's had a lot more control and say over his life'*

*'Well at first I was annoyed and then I just thought, well thank God that's over really. I suppose for me it was like, well we've got this good plan out of it, we've learned a lot about [our son] so it wasn't a waste of time and it's not going to happen with the support of Social Care so we'll just make it happen for him ourselves as much as we can'.*

- 5.16 A couple of families were however left a little frustrated by the pilot as they felt their child's expectations had been raised as a result of the support planning process, which had sought to understand the types of services and support they would like to receive. However, on leaving the pilot, these expectations could not subsequently be met, which at times placed a burden on families who did not want to disappoint their child and decided to fund the activities their child expected out of their own pocket.

### **Summary**

- 5.17 The majority of families that took part in the research stated that the main reason they had left the pilot was because the amount of money they were awarded through their indicative budget was substantially less than they had been receiving prior to the pilot. These families, primarily from the same pilot site, preferred to return to their original service allocation.
- 5.18 Subsequent discussions with the pilot sites, and changes to the way in which indicative budgets were communicated suggest that the number of families leaving the programme for this reason could be substantially reduced by changing from a



letter based, to a personal method of communicating the indicative budget, as evidenced by lower 'drop out' rates in other pilot sites. This is thought to be because a personal approach provides greater opportunity to discuss how a reduced budget facilitated through an IB approach might outweigh the loss of monetary resource.

- 5.19 Whilst this research primarily focused on exploring the reasons for leaving the pilot, it highlighted other important learning for the programme as a whole. In particular, it showed the importance of reassuring families and managing their expectations, with regard to the level of funding they could expect, the flexibility an IB provides, what will be expected of them during the support planning, and the potential burden involved in managing suppliers and invoices. These issues replicate those raised by the families that remained part of the pilot, as reported in the subsequent two Chapters.
- 5.20 Good information provision is key to managing expectations. The interviews also suggested that communications between support staff and families needed to be managed effectively from the outset, to ensure that families feel the resource allocation process ran smoothly, was fair and transparent, and that they understood the range of services and options available to them through the IB.

## 6: Outcomes achieved by participating families

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- 6.1 This section examines outcomes relating to the disabled child/young person and their family. It is based largely on findings from the family survey, augmented by feedback at the focus groups. The family survey was augmented by the survey of professionals, and this is used where appropriate as a cross-check and external view on the feedback from families.
- 6.2 The family survey findings have been cross-tabulated by a number of characteristics to investigate whether the results differed across families and identify any themes. The analysis included cross-tabulations based on differences in pilot site, family characteristics (including parental marital status, social grade of chief income earner and whether child has siblings), the child/young person's age and the severity of their disability, past experience of personalisation and previous access to social care provision. Where families had accessed social care services previously, analysis also examined responses by whether their budget had increased or decreased compared to traditional provision.
- 6.3 This chapter and the next report on the main survey findings and draws attention to the cross tabulations described above only where substantial differences emerged.
- 6.4 Aside from where explicitly stated, it reports on the outcomes for families who had completed support planning (111 families). In the vast majority of cases these 111 families were in receipt of an IB at the time of the survey. The 15 families who were still at the support planning stage were considered to be too early in the process to be in a position to comment on the possible benefits of an IB in terms of control and quality and appropriateness of care. Even so, in reading these results it must be remembered that for many families the IB had gone live only in the last few months.

### Expectations

- 6.5 The evaluation tested the hypotheses that IBs would lead to increased choice and control and improved quality and appropriateness of care, which would in turn lead to improved outcomes (Table 18). This chapter focuses on the initial outcomes and the next chapter discusses to what extent impacts have been identified.

Table 18: Family related outcomes and impacts framework

	Disabled Child/Young Person outcomes/impacts		Theme		Family-based outcomes/impacts
<b>OUTCOMES</b>	Increased user satisfaction with service provision Increased control over daily life Increased personal costs e.g. increased responsibility	←	<b>INCREASED CHOICE AND CONTROL</b>	→	Increased user satisfaction with service provision Increased control over daily life Increased responsibility of coordination/personal costs
	Improved access to more appropriate services Greater continuity of care Improved quality of care Fewer unmet needs	←	<b>QUALITY AND APPROPRIATENESS OF CARE</b>	→	Improved access to more appropriate services Greater continuity of care Improved quality of care Fewer unmet needs
↓					
<b>IMPACTS</b>	Improved health (self perceived) Increased user satisfaction with service provision	←	<b>BE HEALTHY</b>	→	Improved health (self perceived) Reduction in family stress levels Increased user satisfaction with service provision
	Increased sense of safety when undertaking activities both inside and outside of the home	←	<b>STAY SAFE</b>	→	Reduced anxiety associated with child undertaking activities inside and outside of the home
	Increased enjoyment of learning/school Improved educational attainment	←	<b>ENJOY AND ACHIEVE</b>	→	Increased labour market participation Improved educational attainment of siblings
	Increased self confidence Increased independence Increased social engagement and participation in the community	←	<b>MAKING A POSITIVE CONTRIBUTION</b>	→	Increased parental confidence
	Increased range of social and economic opportunities available Improved quality of life Increased labour market participation or engagement in non-compulsory education (for children in transition)	←	<b>ACHIEVE ECONOMIC WELL BEING</b>	→	Wider range of social and economic opportunities available Improved quality of life Strengthened family units Increased labour market participation or engagement in non-compulsory education (for children in transition)

*Note: Content that relates to impacts is greyed out and is discussed in the next chapter.*

*Source: SQW IBs Evaluation Briefing Note*

### **Family expectations when they joined the pilot**

6.6 Families had a variety of expectations and hopes at the beginning of the pilot, concerning both changes in the way services would be delivered and in terms of the types of support that they would access. The focus groups provide a good insight into the expectations and experiences of some parents. In these groups, parents tended

to describe their expectations in terms of 'outcomes' around changes in service planning and provision, rather than the subsequent 'impacts' on the lives of the children/young people and their families. The most common expectations voiced were for:

- **Increased flexibility of service/support provision** – services and support would be built around the young person and more responsive to the changing circumstances that they faced
- **A move from professional led to family led provision** – the forms and frequency of provision would be directed by the family with support from the relevant professionals
- **Greater choice and control over service provision** – the IB approach would enable families to do more things that they knew worked for their child/family, whilst reducing or stopping the things that currently weren't working.

6.7 An additional view expressed by some families was that the motivation for their enrolment on the pilot was more exploratory – in part to see whether they could get more from an IB (including whether they could access more money). One parent commented:

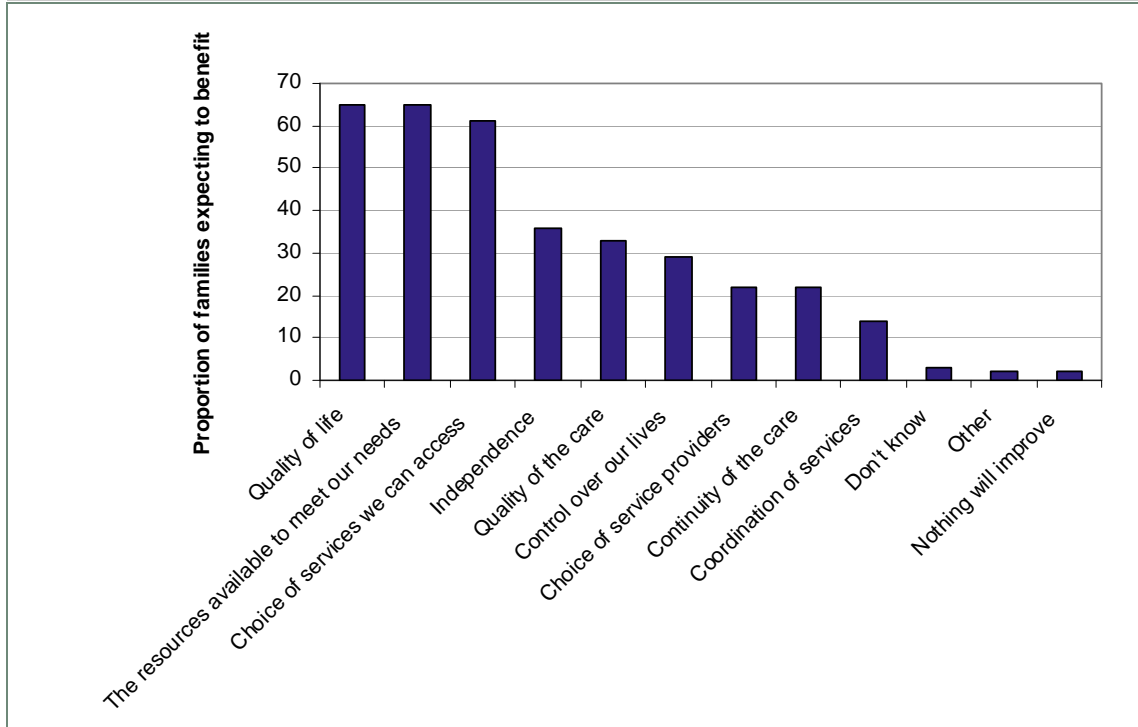
*“We had enough in place for us so we couldn't see any great advantages [joining the pilot]. But from my point of view it was curiosity as much as anything. Just to see what it could open up. Ask me if I would go into it next year and initially I would have said 'no' but now I would say 'yes'.”*

6.8 A newcomer to the system also reported trying the pilot out:

*“We've never had anything so why not try and see if we can get something and that's when it came about.”*

6.9 Figure 19 illustrates the breadth of changes that families expected at the time of the baseline survey. They highlight both a desire to improve service provision, and across a majority of families a hope that their quality of life would also improve.

Figure 19: Areas families expected to improve as a result of the IB



Note: Survey respondents were asked to select up to three of the areas (above) in which they expected their lives to change as a result of the IB.

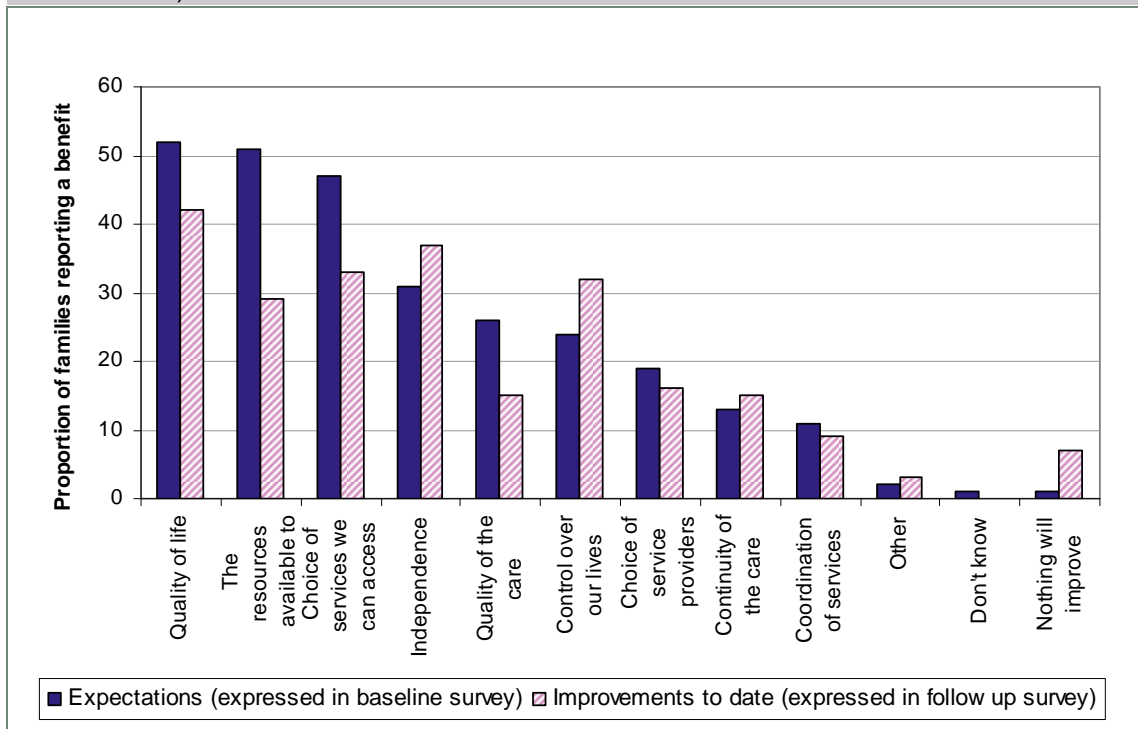
N=126

Source: SQW and Ipsos MORI baseline survey of families

## Achievement against expectations

- 6.10 Figure 20 illustrates the most commonly expected and achieved self reported outcomes and impacts to date for families in receipt of an IB, according to data from the baseline and follow up surveys. Families were able to select at most three of the outcomes and impacts, so the chart provides an indication of the main perceived outcomes and impacts, but not necessarily of all those experienced by families.
- 6.11 Early benefits were reported in terms of outcomes including choice of the services we access (34% of families) and the control over lives (33%), as well as impacts such as quality of life (43%) and independence (38%). Choice and independence come out more strongly from the follow up survey, while an improvement in the resources available received fewer mentions. This may reflect unmet expectations around an increased budget, which had been a motivation for some families to take part.

Figure 20: Expected and experienced outcomes and impacts (families only able to select three at most)



Notes: Survey respondents were asked to select up to three of the areas (above) in which they expected their lives to change as a result of the IB.

This chart only includes responses from families who were in receipt of an IB at the time of the follow up survey. N=97

Source: SQW and Ipsos MORI Baseline and Follow Up Parent/Carer Surveys

## Increased choice and control

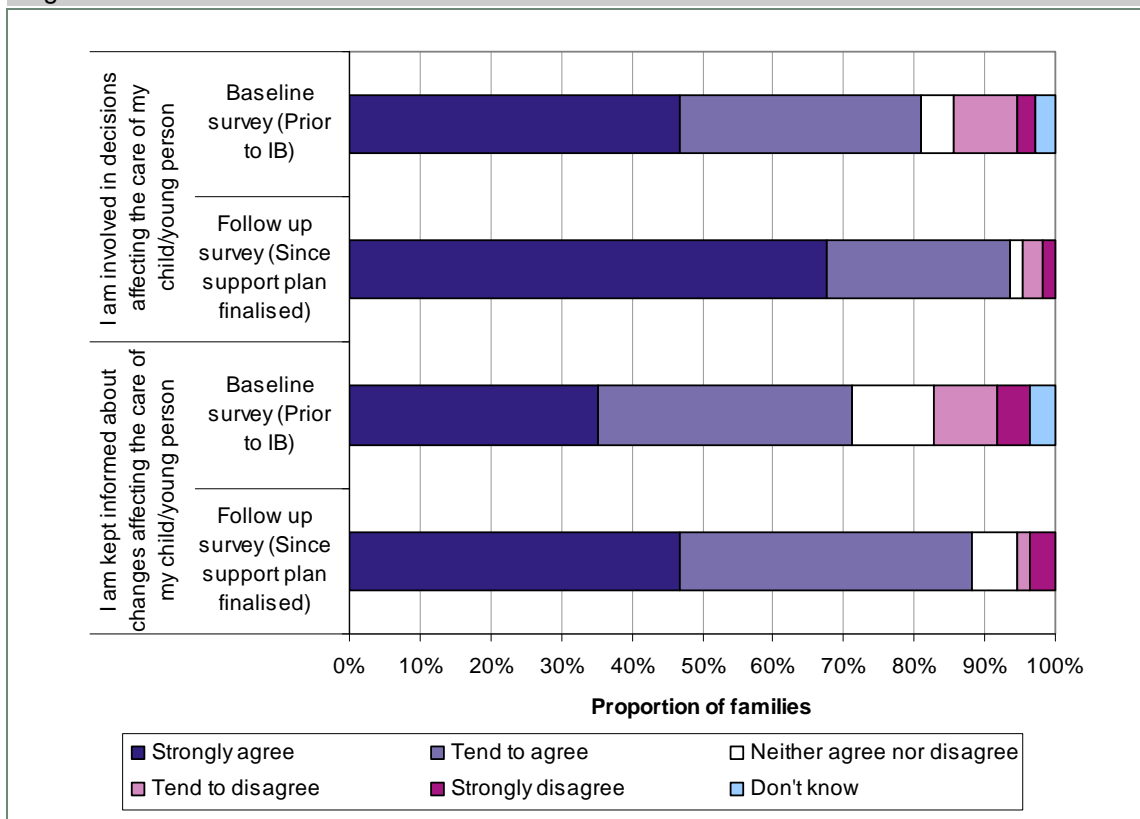
### Control over services

- 6.12 Prior to enrolling on an IB, the majority of parents and legal guardians who had been through the support planning stage felt that they were already kept informed (71%) and involved in (81%) the decisions that affect their children/young people (Figure 21). By comparing parental responses to the baseline and follow up surveys, it is possible to calculate changes in perceptions since enrolling on an IB. Thirty eight percent of responding parents and legal guardians felt that they were now kept more informed about decisions affecting the care of their child/young person by the time of the follow up survey. By contrast, 15% reported feeling less informed and 47% reported no change as of the follow up survey. Therefore, overall there was a net change of +23%, indicating a considerable level of improvement even from a high base.
- 6.13 Perceptions of involvement in decision making also saw a net improvement of +24% between the two surveys. Indeed, by the second wave of the survey 94% agreed

(68% strongly) that 'I am involved in the decisions affecting the care of my child/young person'.

6.14 Across families without past experience of personalisation, there was a net improvement of +33%, compared to +13% for those with past experience of personalisation. This appears to indicate the benefits that can be attained through other forms of personalisation, although an IB approach can further enhance these benefits.

Figure 21: Parental involvement



Note: This chart only includes responses from families who have completed support planning.

N=111

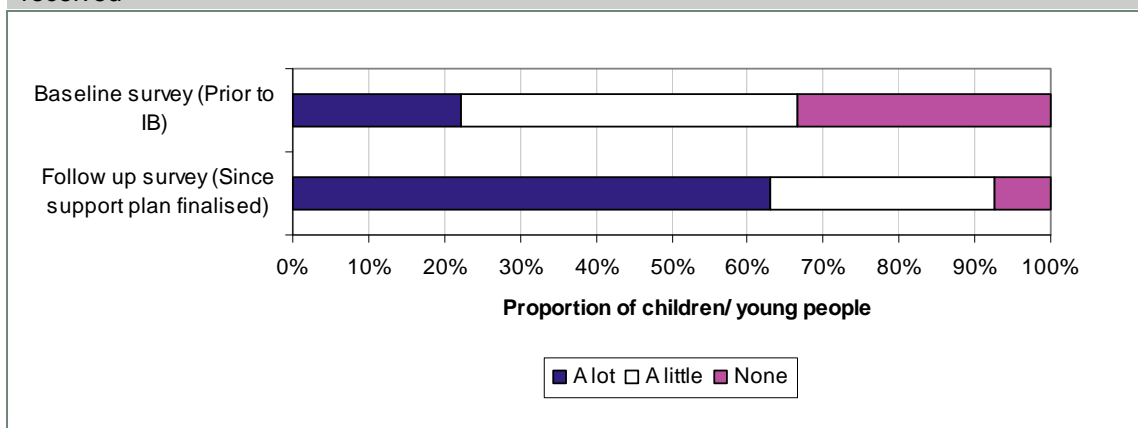
Source: SQW and Ipsos MORI Follow Up Parent/Carer Survey

6.15 Families reported that they had gained more choice and control since beginning their participation in the pilot. Since enrolling on an IB, 60% of responding parents reported having more control over the help they received, 9% reported that they had less control during the follow up survey than at the baseline and 31% reported no change – a net improvement of +51%. One parent commented:

*“This was a way of managing things where we had more control over it and could actually make things better for her.”*

- 6.16 Families from higher social grades (ABC1) were considerably more likely than those from lower social grades (C2DE) to rate their control over the help received as higher during the follow up than baseline survey. Nine of the ten families to report a negative change in their control since enrolling on the pilot were from the groups C2DE. Between the baseline and follow up surveys, there was a net increase in control of +69% amongst families from social grades ABC1, while for families in social grades C2DE there was a net increase of +33%.
- 6.17 Newcomers to the social care system were slightly more likely than existing service users to rate their control over the help received as higher during the follow up than baseline survey. Amongst families new to the social care system there was a net +61% increase in control over help received, while amongst existing users there was a net +48% increase.
- 6.18 The survey of professionals was broadly in line with the views of families, with a significant increase in family control reported in a majority of cases.
- 6.19 The children interviewed also reported having more control over the services they received. Sixteen of the 27 interviewed young people who had finished support planning felt that they now had more say in deciding what services they received, while only two children now felt they had less say. Indeed, almost two thirds of the children now felt that they had 'a lot' of say personally over what services they receive (Figure 22). None of the children felt that there remained a 'big' problem with staff in services ignoring their views (whereas four of the children had reported staff ignoring their views to be a 'fairly' big or 'very' big problem prior to enrolling on the pilot).

Figure 22: How much say do you think you personally had in deciding what services you received



Note: This chart only includes responses from children and young people who have completed support planning. N=27

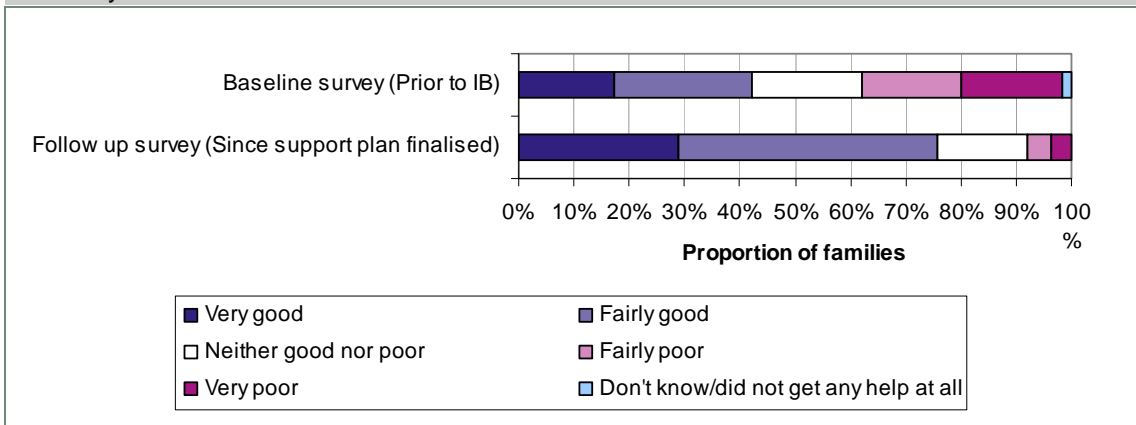
Source: SQW and Ipsos MORI Follow-Up Children and Young People Survey



**Satisfaction with services**

- 6.20 Since enrolling on the pilot and completing the baseline survey, parent and legal guardian perceptions of the services received in relation to their child/young person have undergone a marked change (Figure 23). Over half of responding families (57%) rated the support received higher during the follow up survey than at the baseline, and three quarters rated the support as 'very' or 'fairly' good. By contrast, 17% rated the help received as lower during the follow up survey, and 26% reported no change, a net improvement of +40%.
- 6.21 Newcomers to the social care system were particularly likely to report an improvement in the help received in relation to their child's disability (a net improvement of +75%). This most likely reflects that previously they were not receiving significant support. Eighty six percent of families rated the help received as higher in the follow up survey, although 11% rated the help received as worse.
- 6.22 For families who had past experience of social care services, perceptions of the help received did not vary substantially according to whether the family's IB was higher or lower than their previous, traditional budget. Broadly, families who reported an increase in control were slightly more likely to report feeling more satisfaction. Of the 65 families who had experienced an increase in control since the baseline, over two thirds felt that the support received had improved. By contrast, eight of the 10 families who had experienced a decrease in control were now less satisfied with their support.
- 6.23 The increase in responsibility that accompanies an increase in control may not be suited to all families. A number of parents at focus groups described increased stress associated with managing the budget, particularly when becoming an employer where a PA was recruited. They had drawn heavily on the support of their peers and the pilot team. The survey findings highlight positive benefits that can occur where this transition is made successfully.

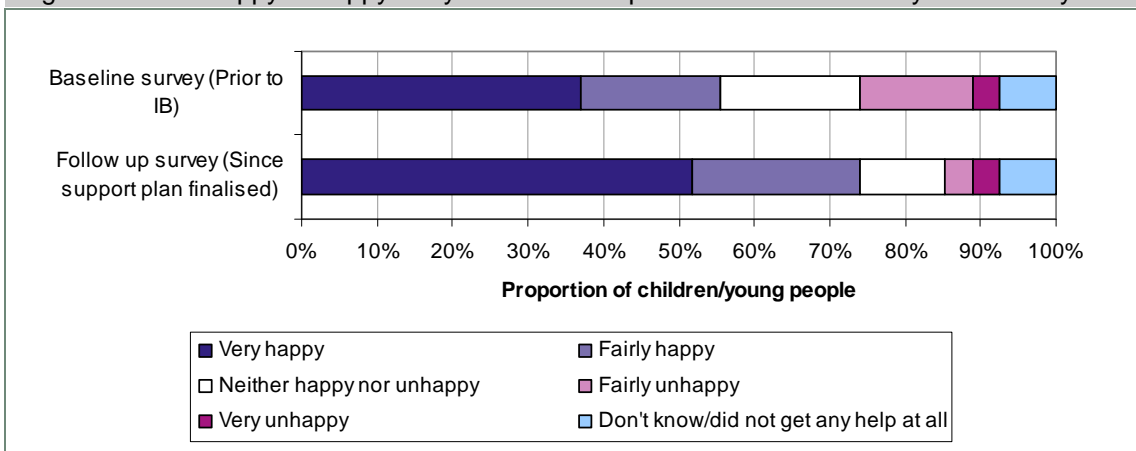
Figure 23: How would you rate the help you receive in relation to your child/young person's disability



Note: This chart only includes responses from families who have completed support planning.  
 N=111  
 Source: SQW and Ipsos MORI Follow Up Parent/Carer Survey

6.24 Children and young people also reported being more content with the help that they received in relation to their disability than prior to their enrolment on the IB pilot (Figure 24).

Figure 24: How happy/unhappy are you with the help received in relation to your disability



Note: This chart only includes responses from children and young people who have completed support planning.  
 N=27  
 Source: SQW and Ipsos MORI Follow-Up Children and Young People Survey

**Increased control over daily life**

6.25 A sizeable minority of families experienced a wider improvement in control since enrolling on an IB with 40% of parents reporting more control over their daily lives in the follow up than baseline survey, while 9% reported less control (51% reported no change). Three quarters (32) of the families who reported increased control over their lives had also reported having an increased control over the help they received since enrolling on the pilot.

- 6.26 Single parents/guardians were particularly likely to report that they had an increased control over their daily life since the pilot. Half of single parents and guardians reported more control over their daily lives in the follow up survey compared to the baseline, compared to 35% of parents from dual parent households. Newcomers to the system and those without past experience of personalisation were also slightly more likely to report improvements in control over their daily lives since enrolling on the pilot.
- 6.27 Responses from the baseline and follow up surveys suggest that the amount of time parents spent accessing, coordinating and overseeing services for their child varied substantially, most likely reflecting the nature of the family and the child's disability. Once the IB became live parents were more likely to report that the time spent managing services decreased (44%) than increased (24%). This moved the average time spent to 7.0 hours from 8.7 hours. This reported change contrasted with the findings expressed at the indicative focus groups, where a number of families reported being among those who spent longer coordinating services once in receipt of an IB.
- 6.28 The support planning process involved families spending time thinking through their child's provision in detail (see *The IB Process*). The apparent lessening of time spent accessing and coordinating services after completing this support planning process may be the result of activities undertaken in the support planning process.
- 6.29 Changes to the length of time spent accessing services were not consistent across pilot sites. At least half of families from two pilot sites spent less time accessing services for their child after signing up for an IB. By contrast, 55% of respondents from another site now spent longer coordinating services.
- 6.30 While the net amount of time spent by families accessing, coordinating and overseeing services fell in many cases, a few young people took on more of the decision making and coordination of their services. This was most likely for older young people, albeit based on a small number of responses. Figure 25 presents an example of a young person who used her IB to take an active role in coordinating her services.

Figure 25: Examples of young people coordinating services

Since enrolling on an IB, the young person took on a much more active role in terms of accessing and coordinating the services that she received. Her mother said she was confident and responded well to the increased independence this afforded her.

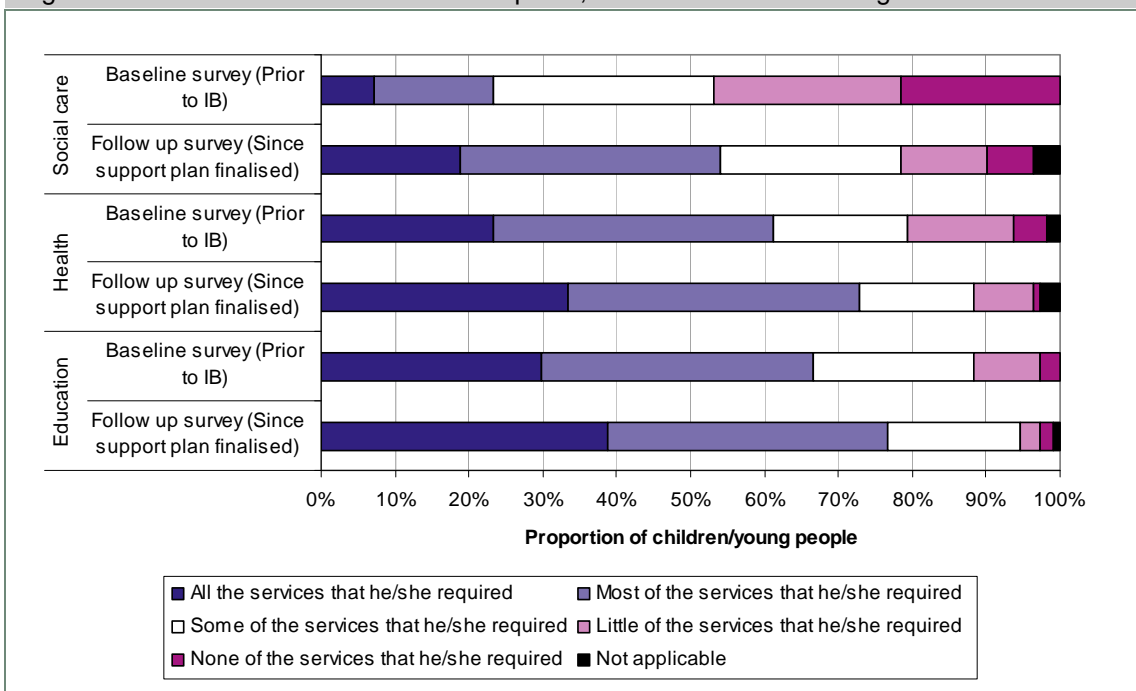
In another group, a similar story was told about a young boy (aged seven) who had led the development of his own support plan.

Source: IB Focus Group

**Quality and appropriateness of care**

6.31 At the time of the follow up survey, two thirds of families who had finished support planning felt that once their support plan was live their child received ‘all’ (26%) or ‘most’ (42%) of the services they required (Figure 26). Almost a third of families (31%) felt that ‘some’ of the services required would be received, but this still highlights more general concerns amongst families as to how much support they would like as opposed to what is being funded. This is a wider issue than IBs, being more heavily dependent on local authority resources and spending priorities.

Figure 26: Access to services the child required, before and after enrolling for an IB



Note: This chart only includes responses from families who have completed support planning.

N=111

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

6.32 However, this varied by pilot site: all families from one site felt that once their support plan was live they would receive ‘all’ or ‘most’ of the services they required; while

almost half of families from two other sites felt that they would only receive 'some' of the services their child required, or for one family 'none' at all. One of the latter sites was also where the average budget declined significantly, although in the second the average budget rose indicating a complex relationship between satisfaction and resources.

- 6.33 The majority of families felt that they had access to all or most the education and health services that they required prior to their enrolment on an IB. Families most frequently reported lacking access to social care services. This is consistent with the 2008-09 National Indicator 54 survey which reported lower levels of parental satisfaction with social care than health and education in terms of four of the five Core Offer standards for services - information, assessment, transparency and feedback.<sup>17</sup>
- 6.34 Sixty four percent of families rated their access to the social care services their child required as higher during the follow up than baseline surveys, while 11% of families rated their access as lower. Twenty four percent reported no change, a net increase of +53%. The survey of professionals revealed a similar net increase (+49%) in access to social care services.
- 6.35 Eight of the 16 existing users who experienced a decrease in budget of more than 10% still felt that their access to the social care services their child had access to had improved (although two felt that their access to the services required had reduced). An example is provided in below Figure 27.

Figure 27: Example of family with lower budget being satisfied

An annual budget using social care funding was worked out through using a resource allocation system that reduced the cost of the previous provision. The family found that they were able to provide better support and more interesting activities with less resources by using links to voluntary organisations, the support of a PA and using outward bound centre and centre parks rather than local authority residential care and an independent care provider.

*Source: IB Pilot Site*

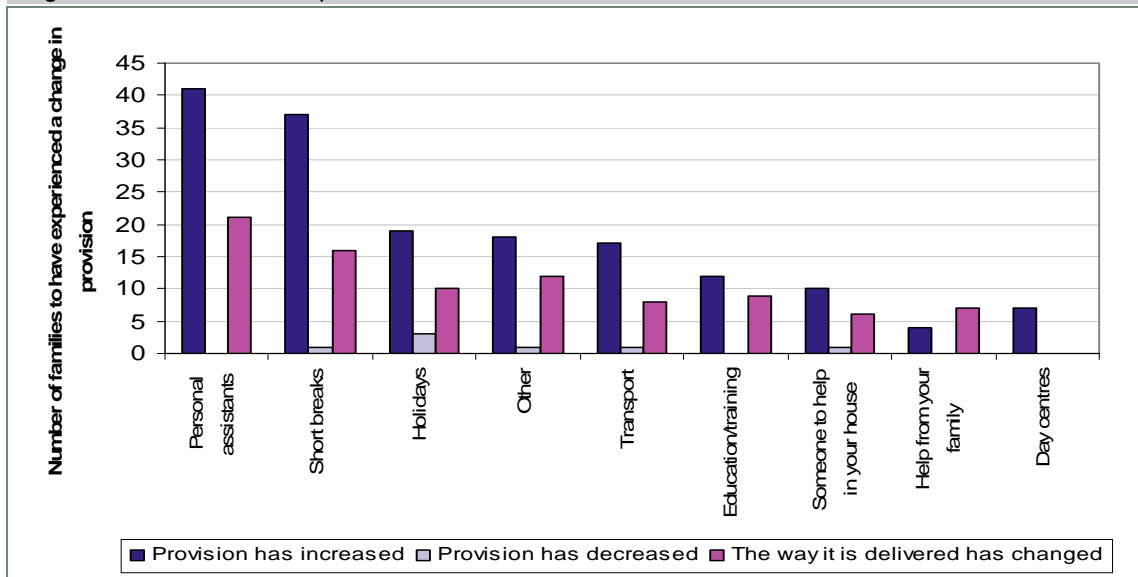
- 6.36 Over a third of families felt that services they had access to as a result of the IB differed 'a great deal' from the services they were getting before and a further 29% of families felt that there was 'a fair amount' of difference. However, a quarter of families

<sup>17</sup> <http://www.education.gov.uk/rsgateway/DB/STR/d000846/index.shtml>

felt that the services they had access to did not change 'very much' as a result of their IB, and 10% felt they would not differ at all.

- 6.37 The changes occurred across a number of services, with increases most apparent in terms of short breaks and the use of PAs (Figure 28). Over one third of families reported that their use of PAs had increased following receipt of an IB, while 19% stated that the way in which PAs were delivered had changed. Changes in the use of PAs were reflected to a similar degree in groups who had/had not experienced DPs previously. The wider changes in PAs appear to reflect families viewing the PA as one means to deliver a range of very specifically tailored benefit. An example is provided in Figure 29.

Figure 28: Differences in provision as a result of IB



Note: This chart only includes responses from families who have completed support planning.

N=111

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

Figure 29: Examples of changing packages of support

The parent was initially difficult to engage as she was asking for things which she thought would not be able to happen. She soon realised that we would all work together try to enable things as long as they were going to be helpful. The key changes that were made included:

- Continuing overnight respite but at a reduced rate
- PA support for holiday/overnight sleep-ins/activities
- Attendance at after school club/summer scheme.

Source: IB Pilot Sites

- 6.38 Families with past experience of direct payments were slightly less likely than other existing users to report a change in short breaks provision as a result of their IB (33% of families relative to 54%).

- 6.39 In a focus group one newcomer to the system described some of the benefits associated with the PA, which the pilot has enabled her to access.

*“[It means that] she can get out and meet other people and be a typical teenager. At that age normal kids would be out with their mates in the town. It gives [her] the opportunity to go out with the play worker who is a couple of years older than her – take her shopping, looking in the shops at clothes and doing make up – things that she probably wouldn’t want to do with me.”*

- 6.40 Some families used their IBs to ensure their child had access to appropriate services, even where these had not been available before. Figure 30 and 31 provides examples of some ways in which families chose to use their IB.

Figure 30: Examples of services provided through IBs

- Purchased membership to local zoo
- Building works to property (e.g. modify patio for wheelchair access)
- Transport to Short Breaks activities
- Trampoline
- Residential breaks
- Centre Parks trip in adapted accommodation
- Specialist carer
- Sessions at after school club (staff need right training and equipment/adaptations)

*Source: IB Support Plans*

Figure 31: Example taken from a family specific case study

Child D (8) and her brother T (7) both have a diagnosis of autistic spectrum disorder. A Residence Order was granted to their grandmother and her husband in 2006 due to poor conditions and an unsafe environment in their parental home. The grandfather died and in September 2009 the grandmother self referred to the Disabled Children Team, reporting that she had reached a crisis point where she felt unable to continue caring for her grandchildren.

A number of temporary interventions were put in place to help the children to remain with their grandmother. This meant the family were dealing with a wide range of providers that had been selected by the local authority. Daisy and Tim joined the Individual Budgets pilot, with a view to giving the family the opportunity to choose how they would like to meet their needs. A joint person centred plan was facilitated as well as considering their grandmother’s needs as a carer.

The family chose to consolidate their support and to manage their own services. The family receive a direct payment, which they use to pay a childminder before/after school, and for a monthly two night break. The residential weekends were negotiated and agreed between the family and the childminder, and provide excellent value for money.

Now, the family is stable, when the alternative would probably have been a placement with a specialist Independent Fostering Agency at a cost of four to five times the value of the combined IB.

*Source: IB Pilot Site Family Case Study*

- 6.41 One mother at a focus group felt that having the money put her in a more powerful position, enabling her to negotiate for appropriate disability-friendly services for her son including a suitable music class in her community. This type of provision is probably more accessible on an individual basis than if sought through a local authority wide framework.
- 6.42 IBs offered many families the opportunity to be more flexible in terms of the provision they could access. Increased flexibility was a common expectation amongst families enrolling on the pilot, with the potential to lead to more appropriate provision to meet their needs. One parent at a focus group commented that:

*“It is about not being tied to set services.”*

- 6.43 In practice, findings from the focus groups showed that parents felt the IB gave them more freedom and flexibility to choose appropriate services and activities. Examples are provided in Figure 32.

Figure 32: Discussion of the differences between IBs and Direct Payments in focus groups

**Appropriateness**

One parent described how her Direct Payment had given the family access to respite care. The IB enabled the family to choose who was paid to look after the child, rather than being told their child could stay at a particular place. According to her, “that for us is a much better way for [my child].”

**Flexibility**

Another described how IB funding was less restrictive than Direct Payments. She gave an example where the child went to the cinema with his PA. While the Direct Payment could only be used to pay for the hours of care when the PA was with the child, the IB could be used to pay for the PAs time and her cinema ticket (although not the child’s ticket).

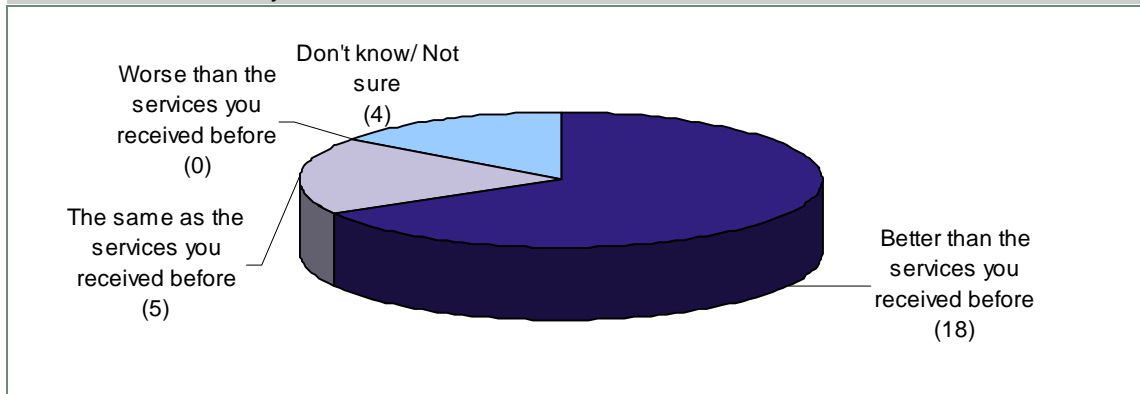
*Source: IB Focus Group*

- 6.44 During the focus groups a number of parents described how they planned to (and in some cases had already) amended their child's IB as they became more knowledgeable about the different services they could use the budget to buy, often as a result of hearing the experiences of other families on the pilot.
- 6.45 However, some parents reported that once they had received their IB funds, they had found it difficult to make any changes to the support/services set out in the approved support plan and as such, hoped that this form of flexibility would become easier in future. The review process should provide an opportunity for such flexibility, but this perhaps needed to be more fully explained to some parents.



- 6.46 Of the 27 child respondents who had gone through support planning, 18 reported in the follow up survey that the services they received through their IB were better than those they had received in the past (Figure 33). None of the children felt that their services had worsened.

Figure 33: Do you think the services that you are receiving/ will receive are better, worse or the same than those you have received before



Note: This chart only includes responses from children and young people who have completed support planning. N=27

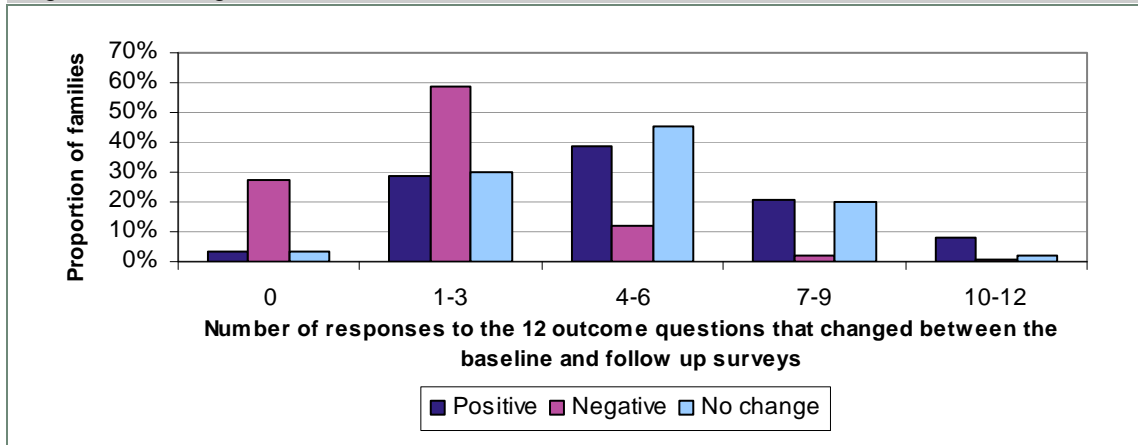
Source: SQW and Ipsos MORI Follow-Up Children and Young People Survey

- 6.47 At the time of the follow up survey two thirds of families agreed that 'the staff providing services for my child are joined up', 24% strongly agreeing this was the case. Almost half (47%) of families thought that staff providing services had become more joined up since the baseline survey, although 21% of respondents felt that staff had become less joined up. Looking forward, the integration of health and education services into IBs may present opportunities for services to become more joined up in the future.

### Distribution of outcomes

- 6.48 The text above has presented a fairly consistent picture of a fair proportion of families reporting positive outcomes. Figure 34 illustrates the number of changes in outcomes experienced by families. The majority of parents (68%) answered more than four of the 12 outcome questions positively, while most families (86%) answered less than four questions negatively. This highlights that benefits are spread widely across the cohort and that the relationship between variables is complex - simply improving some issues will not address all. In particular, while most families reported some changes, most respondents (65%) gave the same answers in the baseline and follow up surveys to between four and nine of the twelve questions.

Figure 34: Change across all outcomes



Note: This chart only includes responses from children and young people who have completed support planning. N=111

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

- 6.49 Nine (8%) parents reported an overwhelmingly positive series of outcomes – answering between ten and twelve (of the 12) outcome questions more positively in the follow up than baseline survey. These families came from a variety of backgrounds as demonstrated the box below, which highlights the variety in these families.

#### Characteristics of the nine families who have reported improved outcomes across 10-12 outcome indicators

- From across four of the six pilot sites
- Included newcomers to the system (3) and existing service users (6)
- Time between sign up and IB going live ranged from 9 to 56 weeks
- Children/young people aged over five years old
- Children had a wide spectrum of impairments, although none had profound or complex needs
- From both dual parent households (6) and single parent/guardians (3)
- Included families from both ABC1 (3) and C2DE (6) social grades
- Most (8) had no past experience of personalisation.

### Satisfaction with the pilot

- 6.50 During focus group sessions, families reported that their expectations of the pilot had been largely met. Overall, three quarters of the 126 surveyed families were satisfied with the pilot (42% of them 'very satisfied'). Twenty one of the 32 young people interviewed reported being satisfied with the pilot along with 23 of their surveyed parents. Parents in one of the focus groups reported that their hopes and expectations had been fulfilled in the main and went on to tell stories of how the lives of the relevant young people had been enhanced as a result of the IB approach.

*“The pilot is ideal for my daughter; I could see how it would benefit her – help her to get out and socialise and meet new people ... It has widened opportunities for my daughter, Through the Individual Budget we have been able to experiment with new things and this has led the discovery of the enormous benefits to her of having regular aromatherapy massages.”*

- 6.51 This apparent high level of satisfaction most likely reflects the considerable input from staff to support families and to make the pilot work. It also means that the results reported are based on a generally good experience, i.e. the pilot families had the opportunity to test IBs in a supportive environment and so the results provide a fair indication of the benefits that can accrue.
- 6.52 However, the pilot did not suit all families. A number of families dropped out and so were not included in the survey. The experiences of some of these families are discussed in Chapter 5. Also, just under a fifth of all families interviewed (23), including eight families who were receiving payments, reported being either ‘fairly’ or ‘very’ dissatisfied with the pilot overall, in addition to 3 of the 32 children who responded to the survey.
- 6.53 Five of the eight ‘very’ dissatisfied families came from one pilot site, which may reflect the site’s comparatively long enrolment process. Two of these dissatisfied families had not begun support planning until more than 30 weeks after signing up to the pilot according to site monitoring data. These two families were still not in receipt of an IB at the end of March 2011. Of the other three families, one had experienced a significant decline in budget, but for the other two there was little change.

## Summary

- 6.54 Table 35 presents a summary of the findings from the chapter.

Table 35: Summary of findings and actions moving forward

### Summary findings and lessons

- Families had a range of hopes and expectations of IBs at the beginning of the pilot. The most common expectations voiced in focus groups focused around: increased flexibility of service/support provision; a move towards family led provision (where professionals play a supporting role); and greater family choice and control over service provision. Some families reported a more exploratory motivation for enrolling on the pilot – in part to see whether they could get more from an IB (including whether they could access more money).
- There was a net improvement of +51% in parental perceptions of their control over the help received between the baseline and follow up surveys. Families from social grades ABC1 were more likely than those from C2DE grades to report experiencing this improvement, along with (to a lesser extent) newcomers to the system
- Sixteen of the 27 interviewed young people who had completed support planning also reported an increase in their own say over the services they received
- Over half of responding families (57%) rated their support higher during the follow up than baseline survey. Newcomers to the social care system were particularly likely to report an improvement in

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the help received in relation to their child's disability

- Existing users, perceptions of the help received did not vary substantially according to whether the family's IB was higher or lower than their previous, traditional provision
- Broadly, families who reported an increase in control were slightly more likely to report feeling more satisfaction with services
- A sizeable minority of families experienced a wider improvement in control of their lives since enrolling on an IB, especially single parents/guardians
- There was a net improvement of +53% in perceived access to social care services, since the baseline survey
- The majority of families felt that there was at least 'a fair amount' of difference between the services they could access through their IB and previous service provision. Common changes include increases in the use of PAs and short breaks. At focus groups, families talked in depth about the difference that PAs had made to the lives of their children
- Eighteen of the 27 children felt their IB services were better than those received before, while none felt the services were worse
- The majority of parents (68%) answered more than four of the 12 outcome questions positively, implying that benefits were widespread rather than concentered in a few families
- Eight of the nine families who reported an improvement across ten or more of the twelve outcome indicators had no past experience of personalisation

#### **Actions moving forward**

- Some families (particularly those from lower social grades) had not experienced an improvement in control as a result of the pilot.
  - A number reported at focus groups that they were daunted by the prospect of managing the money directly and becoming an employer if they hired a PA for their disabled child/young person.
  - A number of families reported through focus groups that they were not aware of all the options (for instance the option for the local authority to retain control of the budget rather than families handling the money directly).
  - Although families felt that, on the whole, they were provided with the information they required, perhaps more could be done to consistently inform families enrolling on the pilot of the options available
-

## 7: Impacts achieved by families participating in the pilots

- 7.1 This chapter focuses on the impacts that have occurred following the outcomes reported in the previous chapter. It therefore considers how far improved choice and control, or access to service can improve family wellbeing. It may be that impacts will take time to occur, and as such the findings in this chapter should more accurately be described as 'early impacts'.
- 7.2 The impacts are considered against the elements of the Every Child Matters framework (Table 36) and covers in turn:
- Be healthy
  - Stay safe
  - Enjoy and achieve
  - Making a positive contribution
  - Achieve economic wellbeing.

Table 36: Beneficiary related outcomes and impacts framework

	Disabled Child/Young Person outcomes/impacts		Theme		Family-based outcomes/impacts
<b>OUTCOMES</b>	Increased user satisfaction with service provision Increased control over daily life Increased personal costs e.g. increased responsibility	←	<b>INCREASED CHOICE AND CONTROL</b>	→	Increased user satisfaction with service provision Increased control over daily life Increased responsibility of coordination/personal costs
	Improved access to more appropriate services Greater continuity of care Improved quality of care Fewer unmet needs	←	<b>QUALITY AND APPROPRIATENESS OF CARE</b>	→	Improved access to more appropriate services Greater continuity of care Improved quality of care Fewer unmet needs
↓					
<b>IMPACTS</b>	Improved health (self perceived) Increased user satisfaction with service provision	←	<b>BE HEALTHY</b>	→	Improved health (self perceived) Reduction in family stress levels Increased user satisfaction with service provision

Disabled Child/Young Person outcomes/impacts		Theme		Family-based outcomes/impacts
Increased sense of safety when undertaking activities both inside and outside of the home	←	<b>STAY SAFE</b>	→	Reduced anxiety associated with child undertaking activities inside and outside of the home
Increased enjoyment of learning/school Improved educational attainment	←	<b>ENJOY AND ACHIEVE</b>	→	Increased labour market participation Improved educational attainment of siblings
Increased self confidence Increased independence Increased social engagement and participation in the community	←	<b>MAKING A POSITIVE CONTRIBUTION</b>	→	Increased parental confidence
Increased range of social and economic opportunities available Improved quality of life Increased labour market participation or engagement in non-compulsory education (for children in transition)	←	<b>ACHIEVE ECONOMIC WELL BEING</b>	→	Wider range of social and economic opportunities available Improved quality of life Strengthened family units Increased labour market participation or engagement in non-compulsory education (for children in transition)

*Note: Content that relates to outcomes is greyed out and was discussed in the previous chapter.*

*Source: SQW IBs Evaluation Briefing Note*

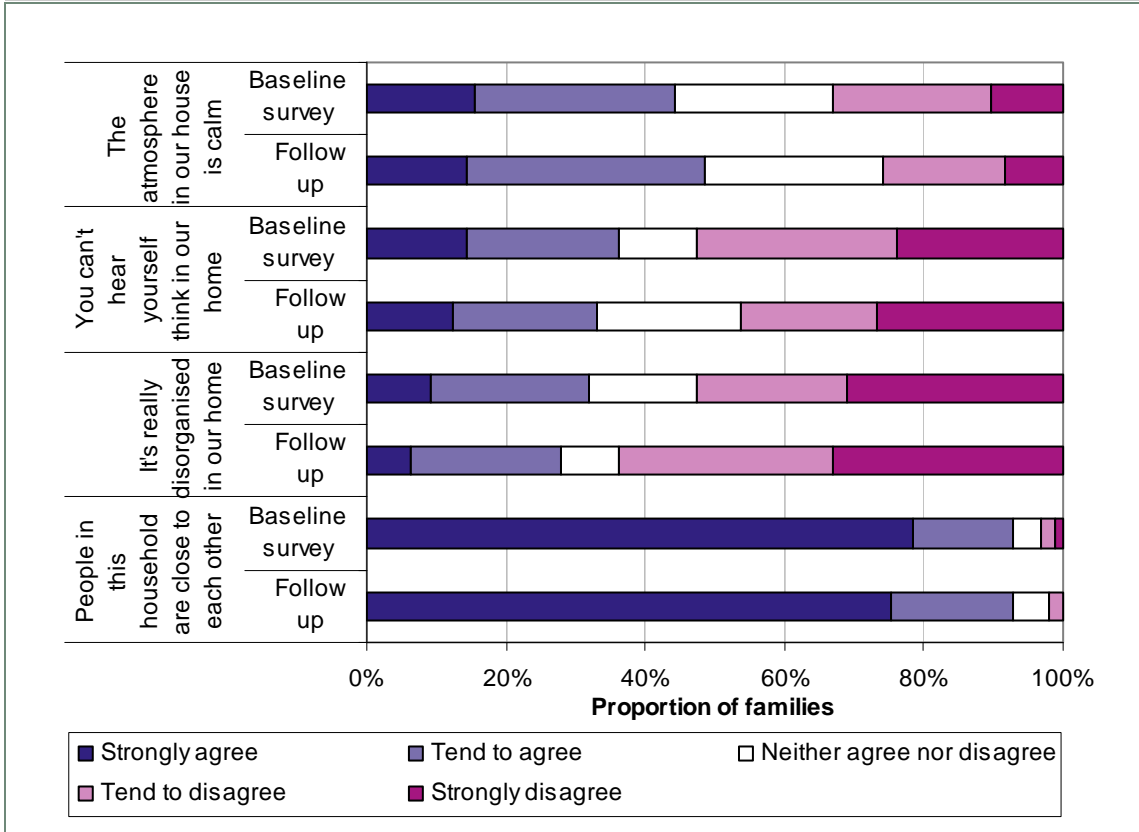
7.3 The chapter reports on the impacts for the 97 families in receipt of an IB at the time of the follow up survey. The 29 families not in receipt of their IB at the time of the follow up survey were considered to be too early in the process to be able to comment on the impacts of the pilot.

### ***Be healthy***

- 7.4 Calmer and less chaotic households are an indication of lower family stress levels. Almost one third (32%) of the families in receipt of an IB became less inclined to agree that ‘it’s really disorganised in our home’, while 20% reported higher levels of disorganisation – a net improvement of +12%. Similarly, 33% reported that ‘the atmosphere in our house is calm’ compared to when they completed the baseline survey, while 22% reported a less calm atmosphere - a net positive change of +11%.
- 7.5 Families where the child/young person was an only child were particularly likely to report an improvement, although overall the picture in terms of family stress had not yet changed substantially (Figure 37).
- 7.6 A higher proportion of newcomers to the social care system also reported their homes were less chaotic since enrolling on the pilot; 42% of newcomers reported that their home was less disorganised than at the time of the baseline survey

compared to 15% who felt their home had become more disorganised - a net improvement of +27%. The difference for newcomers likely reflects their lack of access to support before, rather than anything particular about the IB packages of newcomers.

Figure 37: Family stress prior to and once in receipt of an IB



Note: This chart only includes responses from families who are in receipt of an IB.

N=97

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

7.7 A quarter of parents and guardians reported that their child's health had improved since the baseline survey. This is encouraging. However, in the scope of the pilot (as described in *The IB Process*) there has been little attention on health services or funding. That said, some of the changes in activity such as the increased use of leisure facilities could have contributed to more healthy lifestyles. It is therefore possible that the IB process made some contribution to the changes reported, although factors outside of the pilot are also like to have been significant.

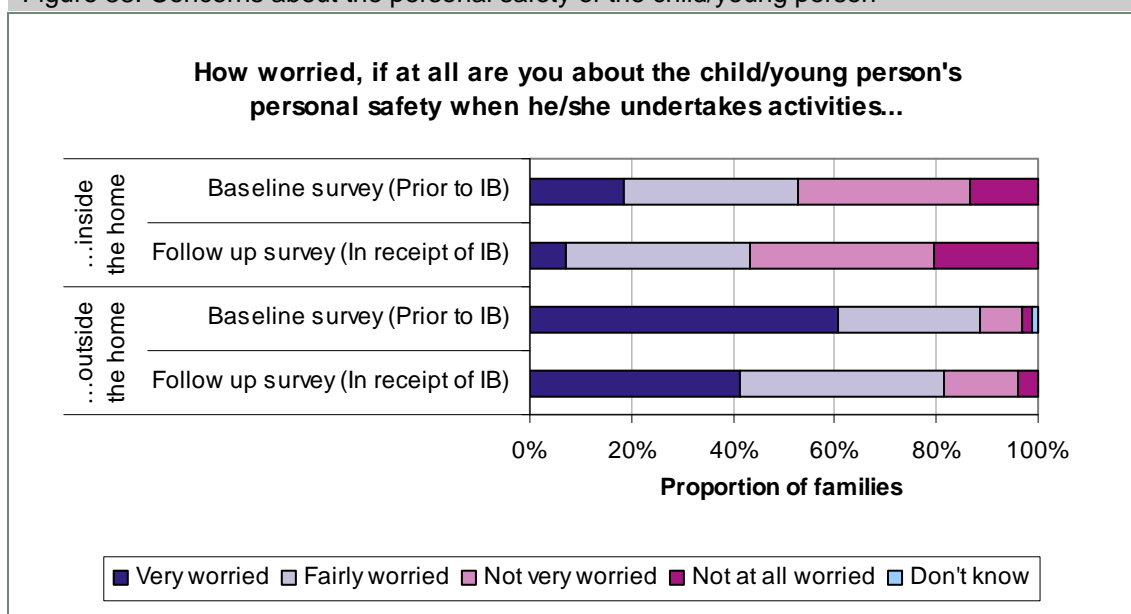
**Stay safe**

7.8 Since enrolling on the pilot, perceptions of what the children were able to do and remain safe have changed. A large minority of responding parents were less anxious with their children undertaking activities inside (45%) and outside (41%) the home at the time of the follow up survey, although a number of parents also reported

becoming more worried about their child's safety when undertaking activities inside (23%) and outside (11%) the pilot. Overall, this suggests a net improvement for 20-30% of families.

- 7.9 Despite this positive finding, most parents (81%) were still 'fairly' or 'very' worried about their child/young person's personal safety when they undertook activities outside the home at the time of the follow up survey (Figure 38). Parents of children with more severe, profound or complex disabilities and existing service users were more likely to have become less anxious about their child's personal safety undertaking activities outside of the home since enrolling on the pilot.

Figure 38: Concerns about the personal safety of the child/young person



Note: This chart only includes responses from families who are in receipt of an IB.

N=97

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

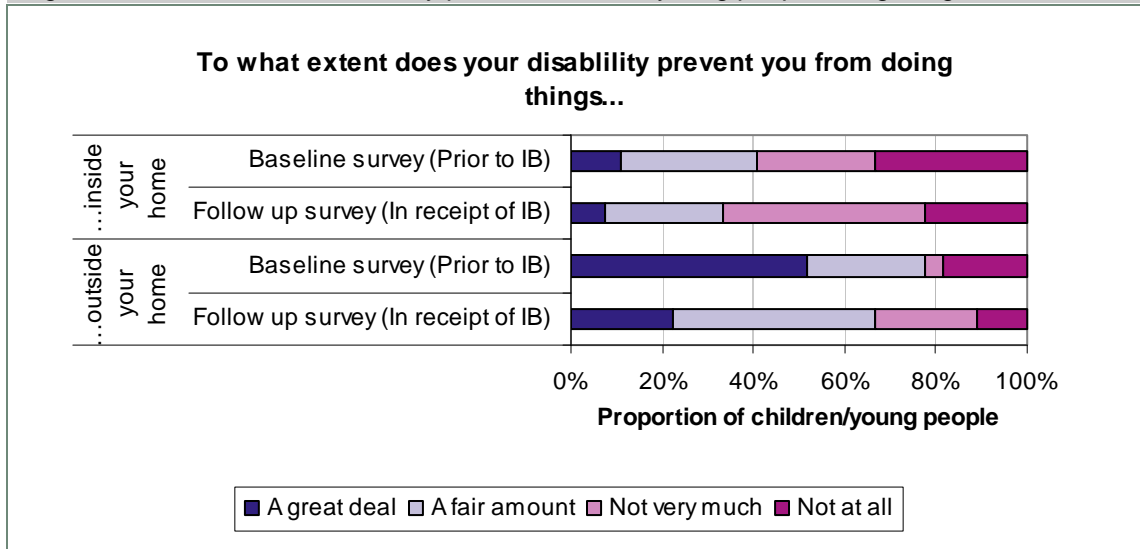
- 7.10 Eleven of the 27 responding children/young people felt less restricted by their disability when doing things outside of their home than prior to their IB, while five felt more restricted (Figure 39).
- 7.11 Families in focus groups discussed increasingly tailored provision resulting from their IBs, including PAs who can undertake activities with the children/young people outside of the home and home improvements to make houses safer. Such changes are likely to have contributed to changes in perceptions of safety and restriction. As shown above this can be positive (for example because the family has more confidence in the PAs they chose) or negative (because the PA takes the young person to new places). It may be that concerns over the latter decline as familiarity returns.



7.12 For example, one parent at a focus group commented:

*“The PA’s 19 ... they [my child and her PA] gel like that. Absolutely fantastic. It’s great and she’s going ‘yes! I’m going out with her today.’ And it’s just that bit of freedom, getting her out and about. It’s great.”*

Figure 39: Extent to which disability prevents children/young people doing things



Note: This chart only includes responses from children and young people who are in receipt of an IB. N=27

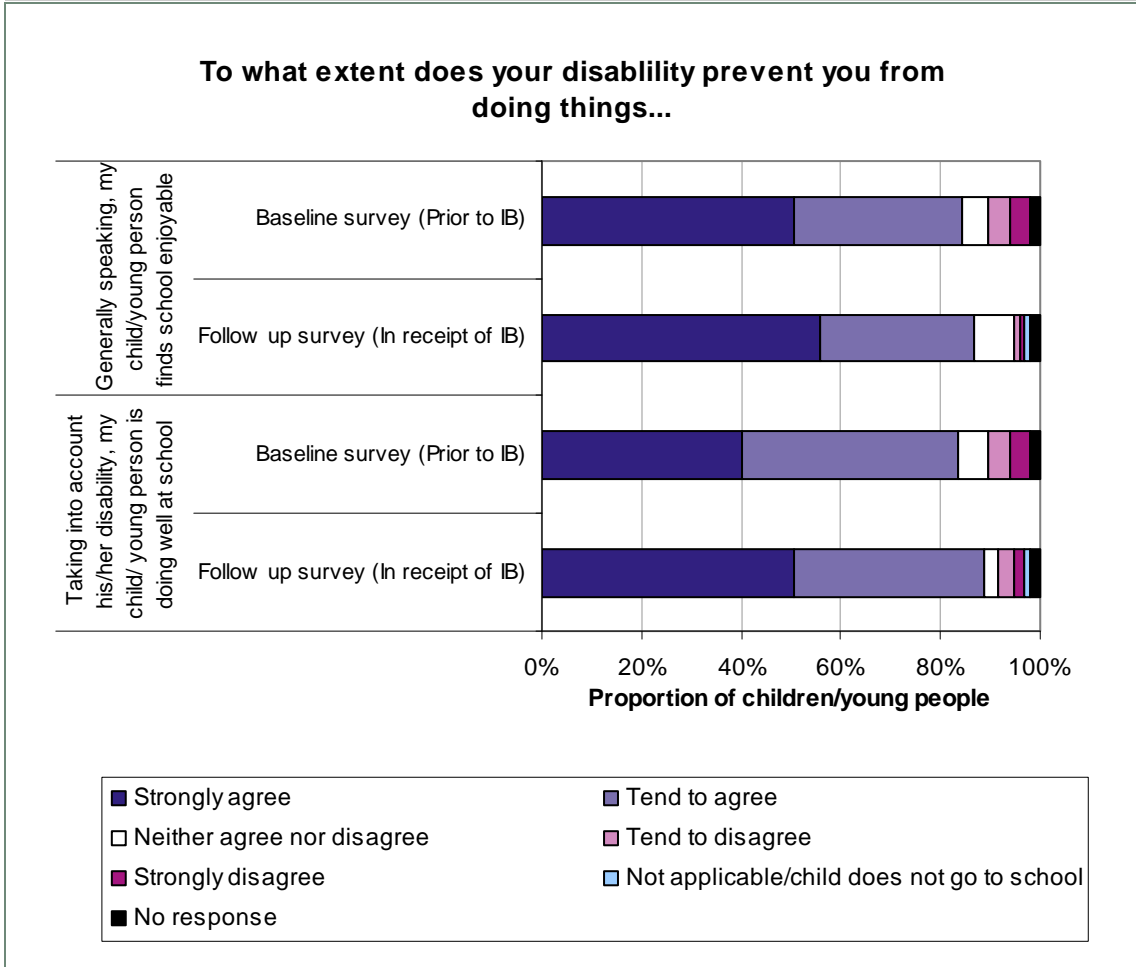
Source: SQW and Ipsos MORI Follow-Up Children and Young People Survey

**Enjoy and achieve**

7.13 There was not a substantial overall change in the proportions of children enjoying and doing well at school, as reported by their parents (Figure 40). However, this masks underlying changes in the perceptions of individual families about attainment. Twenty nine percent of parents rated their child’s attainment at school more highly in the follow up than baseline survey, while 13% rated their child’s school performance as lower; a net improvement of 16%. This change may reflect cases where the school was directly involved in the IB. However, such cases were of themselves limited and so it is also possible, as with health, that the improvements were due to factors outside the pilot.

7.14 Parents reported that over three quarters of any siblings were doing well at school and this had not changed notably since the families had enrolled on an IB.

Figure 40: Experience at school



Note: This chart only includes responses from families who are in receipt of an IB.  
N=97

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

- 7.15 The majority of children/young people surveyed did not experience a change in how much they enjoyed school (16 of 24 respondents to the questions) or how well they thought they were doing at school (16 of 23) between the baseline and follow up surveys.
- 7.16 However, from comparison of their responses to the baseline and follow up surveys, seven of the 24 children/young people felt that when they found things difficult, they could get more of the help they needed. By the time of the follow up survey, all of the children/young people felt they could get the help they needed at least some of the time – including 23 (compared to 16 in the first round) who felt that when they found things difficult they could get ‘all’ the help they needed.

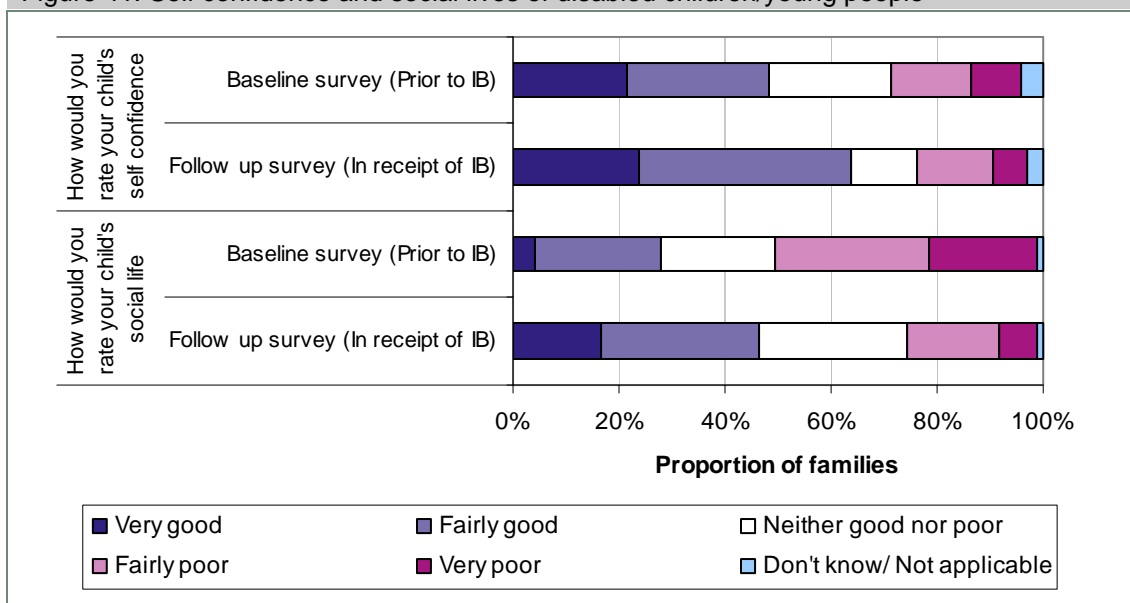
**Making a positive contribution**

- 7.17 Fifty eight percent and 34% of responding parents reported improvements in their child’s social life and self confidence respectively since enrolling on the pilot. By

contrast, around a sixth of the responding families rated their child’s social lives (17%) and self confidence (15%) lower in the follow up survey (Figure 41).

7.18 Over half (55%) of the professionals also rated the child’s social life as better in the follow up than the baseline surveys, compared to 6% who felt the child’s social life had got worse. However, most professionals did not report differing levels of self-confidence between the two waves of the survey. It may be that improved socialisation will lead to improved self confidence, but such additional and behavioural impacts may take time to become as widely apparent.

Figure 41: Self confidence and social lives of disabled children/young people



Note: This chart only includes responses from families who are in receipt of an IB.

N=97

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

7.19 An example of how the IB can be used to enhance a young person’s social life is contained in Figure 42.

Figure 42: Improved social of life through an IB

K and his circle of support were able to identify how he would like to be supported to enable him to access activities and develop his independence. Rather than employing two people to ensure his safety when moving and handling, K’s support plan included a single PA and the purchase of a portable hoist. This specialist piece of equipment, identified by his occupational therapist, could be easily folded and put into a car, allowing his personal assistant to take K out independently. The likely alternative to purchasing this equipment would have been employing two personal assistants for moving and handling.

As well as providing a financial saving, K’s family were happier managing one member of staff, and he has built a strong relationship with his personal assistant over the past year.

Source: IB Pilot Site

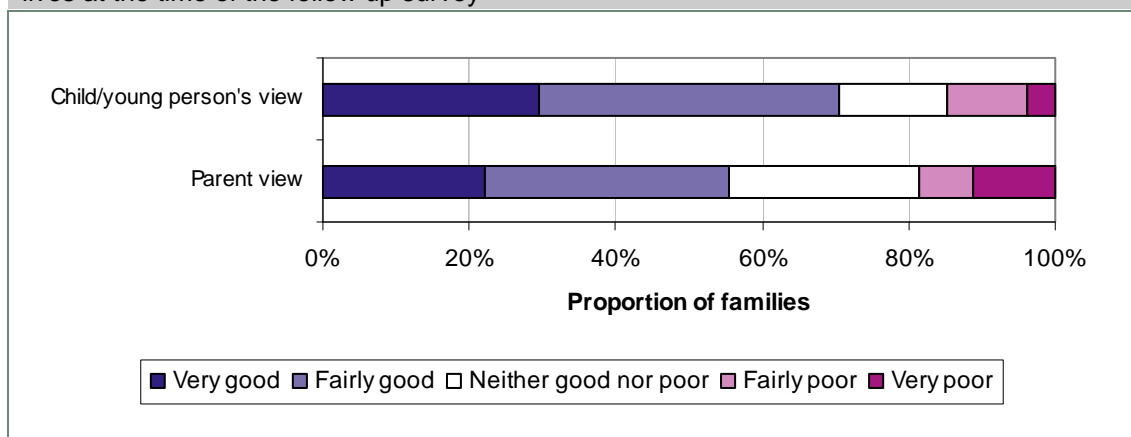
7.20 Figure 43 shows perceptions of the child respondents, and their parents, in relation to their social lives at the time of the follow up survey. Fourteen of the 27 children/young people in receipt of an IB rated their social lives better in the follow up survey than in the baseline, compared to two who rated their social lives worse.

7.21 A number of parents in focus groups referred to the benefits of employing a PA who the young person could identify with and wanted to spend time with. Where children were happy with their PA, they looked forward to trips out with their PA. PAs had the potential to positively impact on the social lives of the children and to often bring about wider impacts aside. One mother talked about how her daughter's PA was encouraging her to become more independent:

*“She [his PA] is taking him to the gym, taking him swimming, taking him to places where if I was to tell him I’m taking him to he would have said ‘no’. He’d refuse to do it with me but he’ll do it with other people. It’s given him a helping hand – an extra push into doing things himself.”*

7.22 However, some parents commented that they were spending more money as a result – to fund activities like cinema trips which the child and PA could undertake together. This had not been anticipated by parents, and while most were pleased to see their child going out more it was commented that their expectations could have been better managed.

Figure 43: Comparison of children and parents views of the children/young people's social lives at the time of the follow up survey



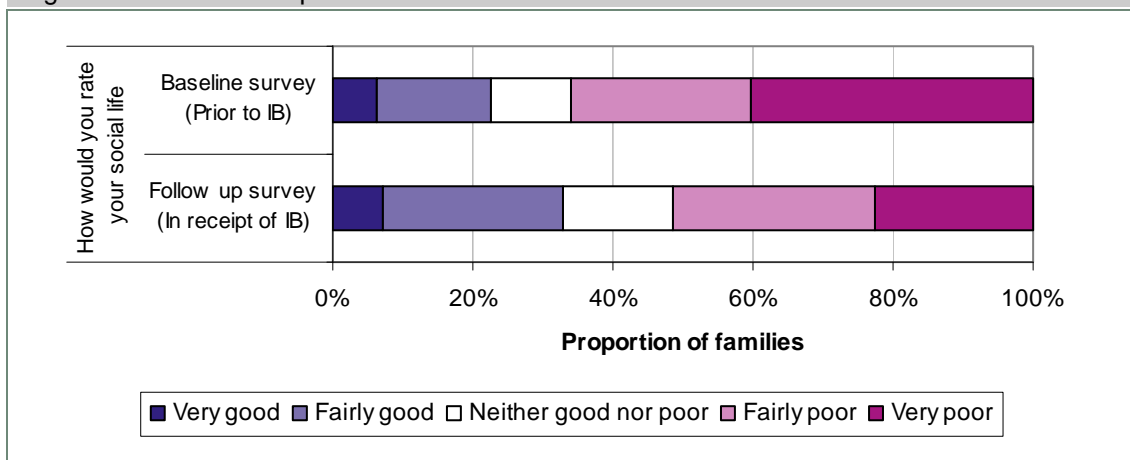
Note: This chart only includes responses from children and young people who are in receipt of an IB. N=27

Source: SQW and Ipsos MORI Follow-Up Children and Young People and Parent/Carer Surveys

7.23 Parents social lives also appear to be improving: 43% of parents reported that their own social lives had improved compared with the baseline survey, while 19% had experienced deterioration in their own social life since the start of the pilot. The baseline and follow up responses are illustrated in Figure 44. Parents of children with more profound or complex impairments were particularly likely to have reported an

improved social life. However, over half of parents still rated their social lives as ‘very’ or ‘fairly’ poor at the time of the follow up survey.

Figure 44: Social life of parents



Note: This chart only includes responses from families who are in receipt of an IB.

N=97

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

### **Achieve economic wellbeing**

- 7.24 Four parents who were not in employment at the time of the baseline survey had returned to work by the time of the follow up survey. While small in number this is a potentially significant change for these individual families. During the focus groups some of these parents spoke animatedly about the difference the pilot had made to their families by enabling them to get back into work. One example is provided in Figure 45.

Figure 45: Example of parent who got back into work

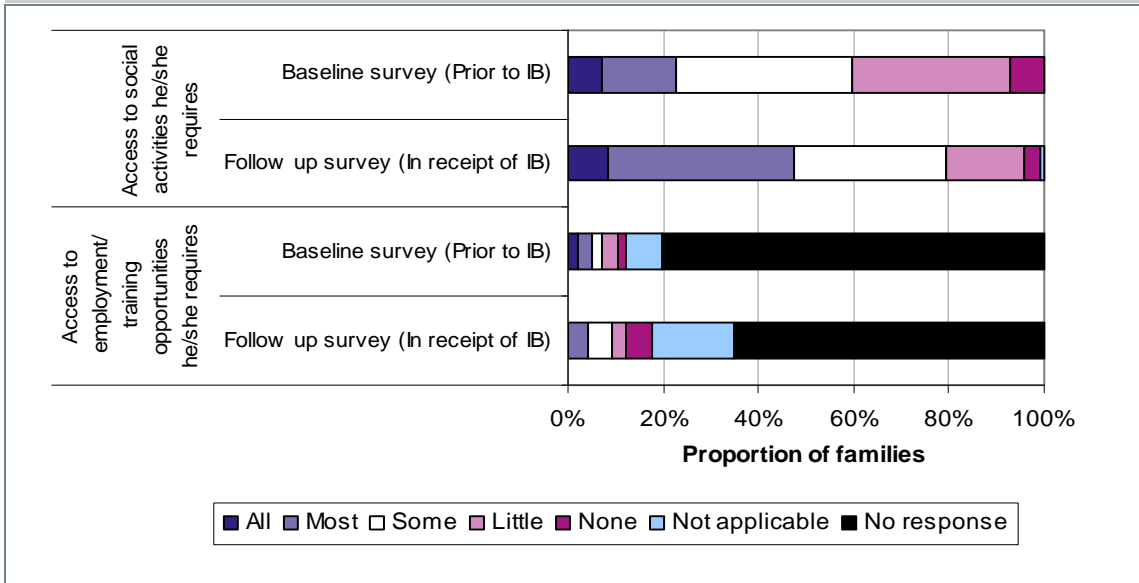
One mother described how the IB had meant that “things have changed for my family”. The IB funded driving lessons for the mother as a means of creating a more appropriate mode of transport for her son. Passing her test has enabled the family to become more independently mobile. The mother described how she was now able to take her son out – something that had previously proved difficult – and how she had been able to get back into part-time work in HR as a result of the increased flexibility offered by her driving.

Source: IB Focus Group

- 7.25 Figure 46 illustrates a sizeable overall improvement in the social activities that the children/young people were able to access after enrolling on an IB. The number of parents who perceived their child had access to all or most of the social activities he/she required more than doubled (from 22 to 46) between the baseline and follow up surveys. Fifty two percent of parents reported that their child had access to more social activities during the follow up than baseline survey, although 18% reported that their child had access to less – a net change of +34%.

7.26 Sixty two percent of newcomers to the system reported having access to more of the social activities their child needed at the follow up compared to the baseline survey (while 15% felt they had access to less of the required activities). Of the existing users, 51% reported a positive change while 19% reported a negative change. This did not vary substantially between families who had experienced an increase or decrease in budget size since enrolling on an IB.

Figure 46: Access to social and employment activities required

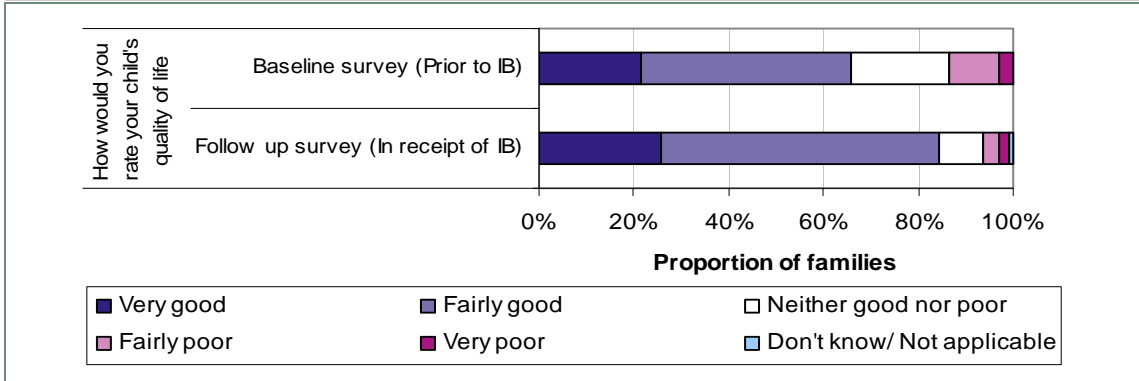


Note: This chart only includes responses from families who are in receipt of an IB. Only families of children aged 16 or over were asked the question on access to employment/training opportunities. For other families 'no response' has been listed in the chart above.  
N=97

7.27 However, the majority of young people (aged 16+) whose parents responded to the survey were not felt to have access to 'all' and 'most' of the all the employment/training support they required at the time of the follow up survey. However, the number of respondents to this question was very small so responses should be treated with caution. Introduction of education funds into IBs may help ensure that young people have access to more training activities they require – opening young people up to the employment opportunities in the future.

7.28 While just over half (52%) of responding families rated their child's quality of life the same during the follow up survey as at the baseline, 35% rated their child's quality of life as higher and 13% rated it lower in the follow up survey, a net change of +22%. Eighty five percent of families felt that their child had a 'fairly' or 'very' good quality of life at the time of the follow up survey, while 5% reported that their child's quality of life was either 'fairly' or 'very' poor (Figure 47). As an overall indicator of wellbeing this improvement is encouraging.

Figure 47: Parent perceptions of child/young person’s quality of life

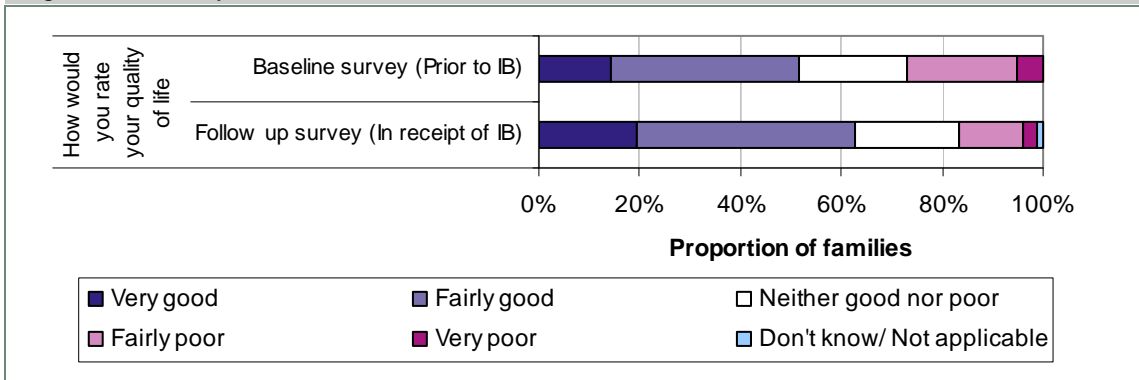


Note: This chart only includes responses from families who are in receipt of an IB.  
N=97

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

7.29 A similar proportion (37%) of parents reported an improvement in their own quality of life, while 19% felt their quality of life had deteriorated since enrolling on the pilot, a net positive change of +18%. Overall, 63% of parents rated their own quality of life as ‘fairly’ or ‘very’ good at the time of the follow up survey, compared to 16% who felt their quality of life was poor (Figure 48).

Figure 48: Quality of life



Note: This chart only includes responses from families who are in receipt of an IB.  
N=97

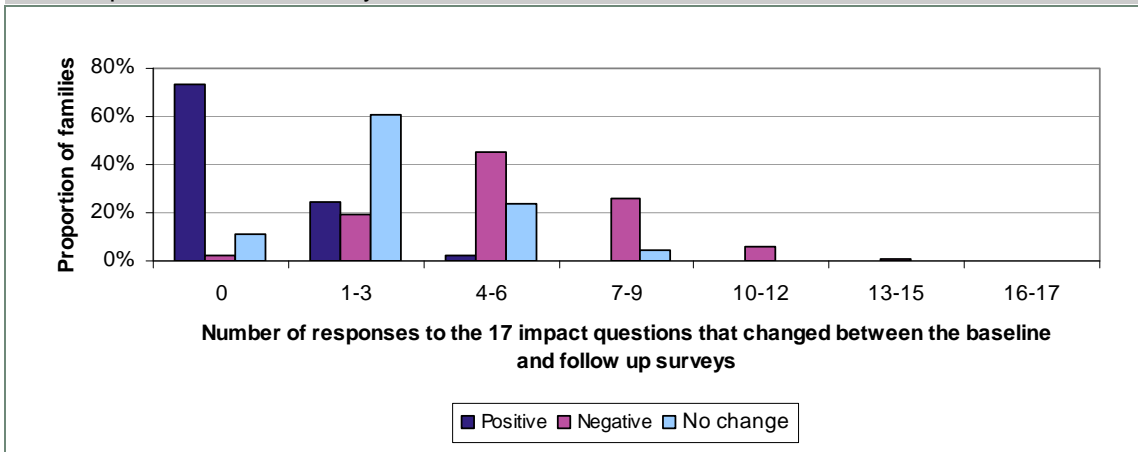
Source: SQW and Ipsos MORI Follow Up Parent/Carer Survey

7.30 There was no change in how parents perceived the closeness of people in their household between the baseline and follow up surveys. Families were perceived to be close to each other at the start of the pilot (in 93% of cases), and this continued to be the case. At the time of the follow up survey, 92% of parents reported that people in the household were close to each other, with 75% strongly agreeing this was the case. Two percent of families ‘tended to disagree’ that their family was close and 5% ‘neither agreed nor disagreed’. That said, 44% of parents reported that they found it less difficult to provide others in the household with the support they needed than when they completed the baseline survey (22% found it harder to provide support).

## Distribution of impacts

- 7.31 Impacts to date have been mixed. Clear improvements have been seen in the social lives of children/young people, and their parents appear to be less worried about their safety while outside the home. However, a large proportion of families were yet to experience changes in impacts against each of the five Every Child Matters themes at the time of the follow up survey. Over two thirds (70%) of parents from families in receipt of an IB did not report a change against seven or more of the 17 impact questions between the baseline and follow up surveys (Figure 49).
- 7.32 This limited change may reflect the lack of time since the IB went live for the improved sense of involvement reported in the previous chapter to lead to impacts. It may also reflect the limited nature of the IB, which in many cases was heavily focussed on social care. As the package grows and additional funds are drawn in wider changes may be more likely.

Figure 49: Extent to which families responded more positively to impact questions in the follow up than baseline survey



Note: This chart only includes responses from families who are in receipt of an IB.

N=97

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

## Future impacts

- 7.33 At the time of the follow up survey there were positive signs that IBs were leading to the desired impacts set out in the Outcomes and Impacts Framework for some children/young people, parents and families. Families that had not reported noticeable impacts may yet see improved impacts over time.
- 7.34 Longer-term impacts are not quantifiable at this stage, but IBs may have the potential to have a lasting impact on the lives of the children/young people and their families. Assessment of longer term impacts will become possible once families have been in receipt of IBs for longer and could be examined in the future.



## Summary

7.35 Table 50 provides a summary of findings from the chapter.

Table 50: Summary of findings and actions moving forward

### Summary findings and lessons

- Overall the picture in terms of family stress has not yet changed substantially, although newcomers to the social care system and single parent families had seen more of an improvement than others
- The main changes were reported around improvements in the child's social life and a lessening of concern over the child's safety when undertaking activities inside and outside the home.
  - A substantial minority of families reported being less anxious about their child undertaking activities inside and outside the house at the time of the follow up survey (compared to the baseline). However, most parents (81%) still reported being 'fairly' or 'very' worried about their child/young person's personal safety when they undertook activities outside the home
  - The quality of the child/young person's social life was rated better in a net +41% of cases. This was often linked to increased or more flexible use of PAs and/or community and mainstream provision. This fed in to a reported improvement in the child's quality of life of +22%
  - Similar but less widespread types of impact were also reported around the parents' own social life (net +24% improvement) and quality of life (+22%)
- By comparison, there were limited improvements apparent in terms of education. This may reflect timing and the emphasis of much of the IB activity on social care activity, given the difficulties engaging and drawing on non-mainstreamed funds

### Actions moving forward

- Through improved choice over services and so access to appropriate services it was hypothesised that IBs would lead to improved family wellbeing. The data reported here was gathered fairly soon after the IB went live. It remains to be seen if the benefits reported are sustained over time, or indeed if they grow as people increasingly experience the new package of support
- Much of the IB activity has been around social care and this is reflected in the balance of the positive impacts. As IB packages increasingly cover health and education it will be important to test if positive impacts become more apparent in these areas

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