



Department  
for Education

Research Report DFE-RR232a

# **Extended evaluation of the individual budget programme for families with disabled children: technical annex**

**SQW**

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

# Contents

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<b>1: Introduction .....</b>	<b>1</b>
<b>2: Scoping strand methodology .....</b>	<b>4</b>
<b>3: Evaluation methodology .....</b>	<b>7</b>
<b>4: Family survey methodology .....</b>	<b>16</b>
<b>5: The activities of the support team.....</b>	<b>24</b>
<b>Annex A: The Common Delivery Model (CDM).....</b>	<b>A-1</b>

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# 1: Introduction

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- 1.1 SQW was commissioned by the Department for Education (DfE) to lead a consortium to undertake the evaluation and support of the extended year of the Individual Budget (IB) Pilot Programme for Families with Disabled Children. The consortium comprised of SQW, Ipsos MORI and iMPOWER, and drew upon expert advice from individual health and education specialists.
- 1.2 This report presents the methodology used to undertake both the evaluation and support of the extended IB Pilot Programme. It acts as a supplementary report to the overarching Evaluation Reports of the Extended Individual Budget Pilot Programme for Families with Disabled Children and quarterly reports that were made available over the course of the extended third year of the programme<sup>1</sup>.

## The extended Individual Budgets programme

- 1.3 The IB pilots were originally commissioned to run from April 2009 to March 2011 by the former Department for Children, Schools and Families (DCSF), 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.
- 1.4 The programme operated in six pilot local authority areas -Coventry, Derbyshire, Essex, Gateshead, Gloucestershire and Newcastle – which were commissioned following a selection process which sought to include sites of varying nature to ensure a comparison of provision in different contexts could be made. Each of the sites generated a wealth of information and learning about the introduction of IBs for families with disabled children<sup>2</sup>. However, much of the evidence was based on the inclusion of only or very largely social care funding in the IB packages, as in most cases it proved difficult for the social care led pilots to gain the active involvement of health and education colleagues. As such the health and education monies were often limited, for example to very specific items or to nominal amounts of money.

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<sup>1</sup> <http://www.sqw.co.uk/services/personalisation>

<sup>2</sup> The suite of reports from the original two year evaluation of the IB Pilot Programme can be found at <https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DFE-RR145>

- 1.5 Similarly, although the pilots demonstrated a clear linkage between the use of the IB approach and an increased sense of choice, control and satisfaction on the part of families, limited time had passed for the change in process to lead to changes in wellbeing. It was therefore unclear how far the initial short-term outcomes would lead to improved sustained impacts on wellbeing across the group of families.
- 1.6 In May 2011, and following the change in Government in 2010 when delivery of the Programme passed to the Department for Education (DfE), the six IB pilots were extended to run for an additional year (i.e. 2011-12). With the extension came an expectation that the pilots would:
- Test how they could broaden their offer to include Education and Health funds/services into their IB packages
  - Continue to support the cohort of families that had participated in the original pilot, to enable the tracking of distance travelled by these families during the extended year, as a means of understanding whether the approach led to improved wellbeing.

### An introduction to our extended evaluation and support approach

- 1.7 Given the intentions set out in the SEND Green Paper, the focus for the third year of the pilots was to gain effective buy-in from education and health agencies, as a means of broadening the scope of the IB packages. Our approach to the evaluation of the extended programme was therefore developed to ensure consistency with the work undertaken during the preceding evaluation along with a broader perspective to reflect changing policy aspirations.
- 1.8 The approach incorporated a mix of on-the-ground research/support and desk based research. The work programme was divided into three strands, each of which was delivered simultaneously by different parts of the research and support consortium and is explained in more detail in subsequent chapters of this report:
- **Scoping strand** – in-depth strategic work with social care, education and health colleagues was undertaken in each of the pilot sites over the course of the first three months of the extension (i.e. late May-August 2011) as a means of identifying the challenges faced in drawing together resources from the three agencies and how these issues might be worked through

- **Evaluation strand** – the evaluation research undertaken during the first two years of the pilot programme was extended, to enable the tracking of both the IB process and distance travelled by the families over an additional year
- **Support strand** – bespoke on-site support was offered to support the development and delivery of local pilot activities and then provided on an ad hoc basis, as requested by sites.

1.9 In light of the change in focus for the programme, the original team was broadened to include additional health and education expertise – Rob Whiteford, Professor Anne West and Phillip Noden. These members of the team acted as expert advisors to the consortium.

## Structure of the report

1.10 The remainder of the report is structured as follows:

- **Chapter 2: Scoping strand methodology** – sets out the approach used to undertake the initial scoping work
- **Chapter 3: Evaluation methodology** – sets out the approach used to undertake the evaluation
- **Chapter 4: Family survey methodology** – details the specific research methodology used to develop and undertake both the Wave 3 survey with participating families with disabled children
- **Chapter 5: The support activities** – presents an overview of the approach used by the support team.

1.11 The report should be read in conjunction with the Technical Report that was developed to support the preceding evaluation of the IB Pilot Programme. This can be found at the following link:

<https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DFE-RR145>

## 2: Scoping strand methodology

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- 2.1 This chapter sets out the approach used to undertake the scoping strand of the research.

### Scoping research

- 2.2 An initial period of scoping research was undertaken to support the sites to build relationships with the relevant health/education colleagues and to subsequently identify which services/funding streams each intended to explore. Table 1 presents a summary of the support/tasks that were undertaken as part of this strand of the research, each of which is presented in more detail below.

Research tool	Inputs required from	Resultant outputs
<b>Pilot delivery plan</b>	<ul style="list-style-type: none"> <li>Pilot site delivery staff</li> </ul>	Six finalised delivery plans which illustrated how each of the sites intended to broaden their IB offer to include both health and education services
<b>Consultation with nine expert stakeholders</b>	<ul style="list-style-type: none"> <li>Expert stakeholders</li> </ul>	Wider evidence collected from outside of the pilot sites to understand how other programmes and areas were seeking to personalise education/health related services and include these in IB packages
<b>On-site development support</b>	<ul style="list-style-type: none"> <li>Pilot delivery staff and health/education colleagues</li> </ul>	<p>Shared understanding of the IB approach</p> <p>Identification of which services/funding streams intended to explore</p>
<b>Two scoping workshops</b>	<ul style="list-style-type: none"> <li>Pilot delivery staff and health/education colleagues</li> <li>Evaluation expert advisors</li> </ul>	Sharing of intentions and lessons learned to inform on-going developments of the extended packages in the sites

Source: SQW

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

- 2.3 Each of the pilot sites was asked to set out their intentions for the extended IB Pilot Programme. This led to the development of six site-specific Delivery Plans over the course of May-August 2011, which identified each site's objectives and planned activities for the third year of the pilot.

2.4 The Delivery Plans, written to a common template developed by the evaluation team, focused on three key areas of activity:

- The inclusion of health services/funding
- The inclusion of special educational needs services/funding
- Process alignment.

2.5 The finalised plans were used as a reference point against which the evaluation was undertaken. That is, the research team has cross referenced the information in the delivery plans with the information supplied in the monitoring returns to understand whether it has been possible to implement the pilot activity as planned. And similarly, the team have investigated the reasons for any changes that have occurred during the case study research.

#### ***Consultation with expert stakeholders***

2.6 A series of consultations were undertaken with nine expert stakeholders working in the personal budgets field to understand developments that were taking place outside of the pilot sites. This included consultations with In Control, the Council for Disabled Children and non-pilot site local authorities, each of which had either been identified as:

- A leading support organisation in the personal budgets field
- OR an area which had begun to develop their thinking around health/education IB packages.

2.7 Data was collected through a mixture of face-to-face and telephone consultations. Information from these consultations was used to inform the development of health and education scoping papers (see below for more detail).

#### ***On site development support***

2.8 Each site was provided with three days of on-site development support, to firstly help the pilot delivery team to map out an intended direction of travel and secondly to help engage the relevant education/health colleagues to buy-into and take part in the extended pilot.

2.9 This work fed into the development of the delivery plans.



### **Scoping workshops**

- 2.10 Two scoping workshops were held, one at the outset of the extension in May 2011, to introduce the objectives of the programme and discuss what could be done, and the second in August 2011, to discuss intentions and some of the challenges that were likely to arise. Both workshops were facilitated by the SQW leads that led the scoping strand of the research. In addition, the health expert that acted as an advisor to the evaluation team attended the second workshop to help work through health-related challenges with the relevant attendees.
- 2.11 The first introductory workshop was attended by eight representatives, which included the Pilot Lead from all six sites. The second workshop was attended by twenty representatives from the pilot sites, which included the Pilot Leads and representation from social care, health and education across all six of the sites.

### **Reporting**

- 2.12 The above information was synthesised into health and education scoping reports, which provided suggestions to sites about what may be possible in relation to the inclusion of health/education services into IB packages.
- 2.13 The reports can be found using the following link:  
<http://www.sqw.co.uk/services/personalisation>

## 3: Evaluation methodology

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- 3.1 This chapter sets out the evaluation approach used to undertake the research over the course of the extended year of the programme. The approach was developed to ensure consistency with the work undertaken during the preceding evaluation<sup>3</sup>.

### The evaluation approach

- 3.2 A multiple-method approach was adopted to undertake the evaluation (please see Table 2 for more details). This approach was chosen to ensure/enable:

- Sufficient evidence was gathered to inform progress made against the two aims/expectations for the extended pilot programme
  - Broadening of the IB packages to include Education and Health funding/services
  - Tracking of the original cohort of families for a further year to understand distance travelled
- An appropriate level of flexibility in the delivery of each element, to ensure that the evaluation could be tailored to accommodate any challenges faced and the pace at which each pilot site progressed.

- 3.3 Table 2 presents a summary of the research tools that have been used to undertake the evaluation. The specifics of each tool are presented below.

Table 2: Evaluation research tools

Research tool	Inputs required from	Resultant outputs
<b>Family registration form</b>	<ul style="list-style-type: none"> <li>• Pilot delivery staff in conjunction with the families and children/young people participating in the pilot</li> </ul>	Electronic registration data was collected as and when new families signed up to take part in the pilot to gain consent from families for specific information to be shared with the evaluation team
<b>Revised monitoring tool</b>	<ul style="list-style-type: none"> <li>• Pilot delivery staff</li> </ul>	Quarterly electronic monitoring data to track expenditure, activities and progress made by families that took part in the pilot

<sup>3</sup> More detail about the method used in the original evaluation can be found in the previous Technical Report at <https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DFE-RR145>

Research tool	Inputs required from	Resultant outputs
<b>Area case study research in the six pilot sites</b>	<ul style="list-style-type: none"> <li>• Pilot site delivery staff</li> <li>• Wider stakeholders e.g. Project Board members</li> <li>• Providers</li> </ul>	Consultation evidence from a range of staff and stakeholders to understand the progress that had been made against the intended delivery set out in the Delivery Plans
<b>Focus groups or telephone interviews with nine participating families</b>	<ul style="list-style-type: none"> <li>• Participating families</li> </ul>	Feedback from families on the extended IB process i.e. following the inclusion of health and/or education services
<b>Family survey</b> <ul style="list-style-type: none"> <li>• Wave 3 survey</li> </ul>	<ul style="list-style-type: none"> <li>• Families and disabled children participating in the pilot</li> </ul>	Distance travelled evidence from participating families
<b>Evaluation workshop</b>	<ul style="list-style-type: none"> <li>• Pilot delivery staff</li> </ul>	Sharing of lessons learned to inform on-going developments in the sites

Source: SQW

### **Family registration form**

- 3.4 The family registration form was developed as part of the preceding evaluation to gather the contact details and basic characteristics of each participating family (including family contact details and basic demographic information). This form was used to gain informed consent to take part in the evaluation from families that took up the IB offer over the extended year.
- 3.5 The registration form was completed at the point at which each family signed up to take up the IB offer. The sign up process included a discussion (facilitated by the pilot sites) about participation in the evaluation and what this would entail. As such, the data was then transferred into the relevant section of the revised monitoring tool (see below for more details), which was subsequently shared with the evaluation team via appropriate data sharing mechanisms.

### **Revised monitoring tool**

- 3.6 The SQW team developed a monitoring tool at the outset of the preceding evaluation to provide a framework within which pilot sites were asked to record their progress. The original tool contained a set of eight worksheets, which sought to gather three types of information:
- Reflective data – to gather views on the progress made in terms of process and system change, which were measured against the Common Delivery Model (the CDM). The CDM was developed by SQW as part of a scoping study commissioned by the former Department for Children Schools and Families in 2008 to inform the development of the IB Pilots and included ten

key elements which were to be addressed by the pilot sites. Evaluation of the CDM illustrated its effectiveness as a process development tool and led to a refinement of the model to reflect lessons learnt (please refer to Annex A for a summary of both the original and refined CDM<sup>4</sup>).

- Financial data – to model the costs of set-up and implementation of the IB pilot, which were disaggregated against the categories of the CDM to provide an understanding of the proportion of effort/spend that was required to meet each of the requirements
- Family contact and activity-related data – to gain consent to take part in the evaluation, provide information to support the delivery of the family survey and contextualise the responses, and understand the family journey.

3.7 The original monitoring tool was revised to meet the needs of the extended evaluation. The main changes included:

- Removal of the reflective component of the tool, as the sites had set up much of the infrastructure required to deliver an IB approach during the original Pilot
- Simplification of the means by which the financial data was collected, where sites were asked to disaggregate their spend against the four themes that were included in the refined version of the CDM (see Annex A)
- Extension of the family tracking data for the original cohort of families to understand when families had participated in a review of their IB support plan and the outcomes of the relevant review processes – this information was used to inform the undertaking of the Wave 3 family survey to ensure families were only asked about the relevant review processes
- The addition of family tracking fields for new families that registered to take part in the pilot during the extended year.

3.8 The revised monitoring tool contained a set of six worksheets, where each sheet began with an introduction box to illustrate the rationale for collection, expected frequency of collation, data type and instructions for completion. Table 3 presents a summary of the informational requirements. All data was collected on a quarterly basis, where sites were required to submit their data seven days after the end of the relevant quarter.

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<sup>4</sup> More detail about the original and refined CDM can be found in the previous suite of evaluation reports at <https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DFE-RR145>

Table 3: Summary of revised monitoring tool requirements

Monitoring category	Brief description	How the data was used
<b>Spend sheet</b>	This tool had two purposes: * to capture details of the total amount of expenditure to deliver the pilot * to capture information on expenditure across the four themes of the refined Common Delivery Model (organisational engagement and culture change, engaging and involving families, setting up and delivering the infrastructure, safeguarding and risk management and other expenditure)	To understand pilot inputs and costs – see Chapter 3 of the Extended Packages Report
<b>Activities (linked to spend)</b>	This sheet captured details on activities undertaken by pilot sites against each of the cost categories from the spend sheet	To understand pilot inputs and costs – see Chapter 3 of the Extended Packages Report
<b>IB packages (new and existing cohorts)</b>	This sheet sought to collect details on the funding streams incorporated into the relevant site's IB packages	To understand which funding streams were incorporated – see Chapters 4 and 5 of the Extended Packages Report
<b>Family tracking (original evaluation cohort families only)</b>	This sheet sought to track the activities undertaken by the children and young people from the <b>original evaluation cohort</b> using family evaluation reference numbers (provided at the beginning of the initial evaluation process)	To understand the review process for the original cohort of families and to track numbers and reasons for those leaving the pilot – see Chapters 2 and 3 of the Family Journey One Year On Report
<b>Family tracking (new cohort families in receipt of health and/or education packages through their IB)</b>	This sheet sought to track the activities undertaken by children and young people who registered to <b>take up an extended IB offer which included health and/or education</b>	To understand the numbers of families recruited and where possible the process each went through - see Chapters 3, 4 and 5 of the Extended Packages Report
<b>Family tracking (new cohort families in receipt of social care funding only through their IB)</b>	This sheet sought to track the activities undertaken by children and young people who registered to <b>take up an IB offer which included only social care funding/services</b>	To understand the extent to which the scale of the original social care focused IB packages was increased – see Chapter 3 of the Extended Packages Report

Source: SQW

### **Case study research**

- 3.9 The original pilot-specific case study work, which was undertaken in all six pilot sites, was extended over the third year of the programme. The case studies sought to explore the activities undertaken by the sites during the extension with a particular focus on understanding how each of the sites engaged and worked with health and education colleagues to draw broaden their IB packages. This included undertaking:
- Consultations with IB delivery teams, key stakeholders (including both strategic and operational staff), providers and support brokers – an average of 5-6 consultations was undertaken during each round of consultations
  - A means of verifying the information provided in the monitoring data that was collated on behalf of the evaluation team.
- 3.10 Pilot areas were asked to participate in two rounds of consultations, which sought to build on the initial scoping visit and subsequent work that was undertaken by both the evaluation and pilot delivery teams. Both visits were undertaken face-to-face, included an average of 5-6 consultations and took place in September/October 2011 and January/February 2012.
- 3.11 The following topics were explored through the case study research: the IB review process for the original cohort of families; understanding the intentions for the extended pilot; progress made against intentions set out in the delivery plan; inclusion of health/education services within an IB package; process alignment; barriers and critical success factors; engagement of families; and achievements and looking forwards.
- 3.12 Written summaries of the consultations responses were provided by each of the SQW case study leads following both rounds of fieldwork. The set of responses were then used to inform the content of the quarterly and final evaluation reports that were developed during the extended evaluation.

### **Family focus groups / telephone interviews**

- 3.13 Where possible, a focus group or set of telephone interviews were undertaken with a small number of families that had taken up an IB offer including health and/or education services/funding over the period January 2011 – February 2012. The purpose of this research task was to gain a first-hand insight into how families felt the

process had worked. They explored the experiences of participating families and so provided feedback on:

- Why they took up the offer
- What they intended to/had used their health/education funding to purchase
- Whether this would/had led to any improvements and if so, what these would be/were.

3.14 Owing to the small numbers of families that were offered an extended IB package, the evaluation team undertook this form of research in two out of the six sites and involved nine families. The families that took part, included all those who were willing to take part in the research, and were recruited in conjunction with the pilot delivery teams, to ensure that any sensitivities and/or particular needs were catered for. They had each completed a support planning process to agree how the relevant services/funding were to be used and in a minority of cases, included families that were also in receipt of the agreed service package.

3.15 Issues explored through this element of the research included: how families were engaged/introduced to the offer of an extended IB package and their associated expectations; the activities they had participated in; and what had been achieved as a result or expectations of what would be achieved.

3.16 Given the low numbers of families involved in this element of the research, the findings detailed in the Extended Packages report should be treated as indicative in their nature

### ***Family survey***

3.17 The evaluation tested the hypothesis that IBs would lead to increased outcomes (such as choice and control and improved quality and appropriateness of care), which would in turn lead to improved impacts. The key parts of the evaluation framework are set out in Table 4.

Table 4: 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		<b>INCREASED CHOICE AND CONTROL</b>		Increased user satisfaction with service provision
	Increased control over daily life	←		→	Increased control over daily life
	Increased personal costs e.g. increased responsibility				Increased responsibility of coordination/personal costs
	Improved access to more appropriate services		<b>QUALITY AND APPROPRIATENESS OF CARE</b>		Improved access to more appropriate services
Greater continuity of care	←	→		Greater continuity of care	
Improved quality of care				Improved quality of care	
Fewer unmet needs				Fewer unmet needs	
↓					
<b>IMPACTS</b>	Improved health (self-perceived)		<b>BE HEALTHY</b>		Improved health (self-perceived)
	Increased user satisfaction with service provision	←		→	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		<b>ENJOY AND ACHIEVE</b>		Increased labour market participation
	Improved educational attainment	←		→	Improved educational attainment of siblings
	Increased self confidence		<b>MAKING A POSITIVE CONTRIBUTION</b>		Increased parental confidence
Increased independence	←	→			
Increased social engagement and participation in the community					
Increased range of social and economic opportunities available		<b>ACHIEVE ECONOMIC WELL BEING</b>		Wider range of social and economic opportunities available	
Improved quality of life			→	Improved quality of life	
Increased labour market participation or engagement in non-compulsory education (for children in transition)	←			Strengthened family units	
				Increased labour market participation or engagement in non-compulsory education (for children in transition)	

Source: SQW

3.18 Each of the IB pilot sites was tasked as part of the original programme to engage 30-50 families with disabled children to take part in the pilot. Across the six sites, 189 families were engaged in the pilot by March 2010. The experiences of these families were tracked through surveys of the families, disabled children and young people, and site monitoring data. Two surveys were conducted on a before and after basis during the original two year programme. The initial questionnaire gathered baseline data on the position of the family prior to its receipt of an IB. The same families were



then revisited, using the same questions one year later to assess the distance travelled by families after they had engaged in the IB process.

- 3.19 The baseline (Wave 1) survey was completed by 173 families. Almost three quarters of these families (126) went on to complete the Wave 2 survey in early 2011. As part of the extension of the pilot, a further wave of the survey was conducted with families who had participated in the baseline and Wave 2 surveys, to understand whether there had been changes in perceptions two years on from the baseline survey. A total of 78 families completed the Wave 3 survey, 41% of the original cohort and 61% of families still reported to be on the pilot.
- 3.20 The main reason for follow up interviews not being conducted was that 62 of the families had left the pilot since participating in the baseline survey (either because they had chosen to leave the pilot or the young person had reached 18 and transitioned into adult services).<sup>5</sup>
- 3.21 Chapter 4 provides a detailed description of the methodology used to develop, undertake and analyse this third wave of the family survey.

#### ***Evaluation workshop***

- 3.22 An evaluation workshop was held in January 2012 to provide the sites with an opportunity to share their experiences and lessons learnt. This involved a short presentation from the evaluation team to share emerging findings and a series of site-led presentations and discussions. Emerging findings from the workshop were synthesised with the case study summaries and used to inform the extended packages report.

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

- 3.23 The above information was synthesised into a set of quarterly reports and a set of final evaluation reports, all which are available on the SQW's website:

<http://www.sqw.co.uk/services/personalisation>

- 3.24 The evaluation team sought to ensure that each pilot site was kept up to date with the progress of the evaluation and where relevant, created opportunities for the sites

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<sup>5</sup> The remaining families did not complete the Wave 3 survey, either because they had not completed the Wave 2 survey, because they could not be contacted, or were unable to commit to an appointment during the evaluation timescales or they refused the consultation due to personal circumstances (for instance because their child was ill).

to influence the direction of the research. This was facilitated through ongoing phone and email contact with each of the sites.

## 4: Family survey methodology

- 4.1 This Chapter provides a detailed description of the research methodology used to undertake the Wave 3 (follow-up) survey with families with disabled children which formed part of the original Evaluation of Individual Budgets Pilot Programme for Disabled Children.

### Scope of the survey

- 4.2 Ipsos MORI conducted the final wave of a face-to-face Computer Assisted Personal Interviewing (CAPI) survey with families who signed-up to the Individual Budgets Pilot Programme for Disabled Children. Wave 3 followed two previous waves of fieldwork with the same audience, returning to those families who agreed to be re-contacted after Wave 2 and who were still part of the Individual Budgets Pilot Programme. Table 5 sets out the characteristics of the families surveyed at each Wave.

Table 5: Characteristics of the families surveyed in each wave

		Wave 1		Wave 2		Wave 4	
		N	%	N	%	N	%
IB site	1	30	17%	22	17%	9	12%
	2	28	16%	22	17%	14	18%
	3	27	16%	16	13%	10	13%
	4	30	17%	26	21%	19	24%
	5	25	14%	20	16%	15	19%
	6	33	19%	20	16%	11	14%
Gender	Male	116	67%	82	65%	50	64%
	Female	57	33%	44	35%	28	36%
Ethnicity	White	139	80%	101	80%	68	87%
	BME	18	10%	15	12%	10	13%
	Undisclosed at time of reporting	16	9%	10	8%	0	0%
Previous use of social care	Newcomer to the system	41	24%	45	36%	33	42%
	Existing user	130	75%	81	64%	45	58%

		Wave 1		Wave 2		Wave 4	
		N	%	N	%	N	%
Social grade	ABC1	73	42%	60	48%	39	50%
	C2DE	99	57%	66	52%	39	50%
	Undisclosed at time of reporting	1	1%	0	0%	0	0%
Age when engaged in pilot	0-5 years	12	7%	11	9%	5	6%
	6-13 years	60	35%	49	39%	30	38%
	14-15 years	46	27%	38	30%	10	13%
	16+ years	46	27%	28	22%	33	42%
	Undisclosed at time of reporting	9	5%	0	0%	0	0%
Severity of disability	Mild/moderate	44	25%	31	25%	19	24%
	Severe	74	43%	57	45%	32	41%
	Profound or complex	55	32%	38	30%	27	35%
<b>Total families surveyed</b>		<b>173</b>	<b>100%</b>	<b>126</b>	<b>100%</b>	<b>78</b>	<b>100%</b>

Source: SQW

- 4.3 A total of 78 of the parents and 18 of the children were interviewed at Wave 3 to track their experience of the pilot over time, with a particular focus on the review process. Fieldwork took place between 9th January and 27th February 2012.
- 4.4 In each household, interviews were undertaken with the main parent of the child or young person on the Individual pilot programme, and the disabled child or young person (CYP) where they were eligible and able to take part. The eligibility criteria for Wave 3 is outlined below:
- Only families who took part in Waves 1 and 2 were included in the sample for Wave 3. In addition, families who had left the pilot and those that did not want to take part due to personal reasons or who refused permission to be recontacted after Wave 2<sup>6</sup> were removed from the sample prior to Wave 3 fieldwork.
  - Main parent – the parent of the disabled child on the pilot programme who had the main responsibility for undertaking the day-to-day care of the child at the time of the interview at Wave 3.

<sup>6</sup> One family did not want to be recontacted after taking part in Wave 2.

- CYP – children and young people who completed an interview at Wave 2. Interviewers asked the parent if they could approach the CYP to invite them to take part in an interview.

4.5 All interviews were conducted face-to-face, in-home, using Computer Assisted Personal Interviewing (CAPI).

## Sample and panel management

4.6 The sample database contained the contact details for families participating in the Individual Budgets Pilot Programme collected by the six participating pilot local authorities. It was provided to Ipsos MORI by SQW for use for this research only. For Wave 3 the sample file was updated with current address and telephone details, based on information provided by the six pilot sites in December 2011.

4.7 In addition to the contact information, SQW provided Ipsos MORI with monitoring data from families, with their agreement. This included information on their service use and demographic data on the CYP including their age, gender, and ethnicity. This additional information was linked to responses to the survey with respondents' permission and used to inform the routing of the survey to ensure it was appropriate for each family. Each adult was given a unique address number, which was mapped to the evaluation reference number used by SQW in a separate file. All sample information was stored on Ipsos MORI's secure server, in encrypted WinZip file formats. Passwords to access this file were only given to core research team members.

## Questionnaire

4.8 SQW and Ipsos MORI worked in partnership to develop the questionnaires used for the parent and CYP interviews. The content of both questionnaires was linked to the evaluation criteria for the pilot programme, where the CYP questionnaire contained a tailored sub-set of the questions contained in the parent questionnaire.

4.9 Prior to Wave 1 fieldwork SQW gathered feedback on the CYP questionnaire from two disabled young people who were part of the Individual Budget Evaluation Advisory Group. The aim was to test comprehension and understanding of the questionnaire with people who could have been potential respondents. A number of amendments were made to the CYP questionnaire as a result of their feedback, prior to the commencement of Wave 1. The changes largely centred on simplifying the language used.

- 4.10 For Wave 3, the questionnaire was amended to include questions on the review process.
- 4.11 The questionnaire was scripted for use in CAPI – this meant that routing between questions was automated to ensure all respondents answered the appropriate questions. The average interview length for parents was around 40 minutes, while for the CYP it was around 20 minutes.

## Fieldwork

### ***Interviewers' briefing***

- 4.12 For Wave 3, all but one of the interviewers had previously worked on the project in Waves 1 and 2. Refresher telephone briefings were conducted with all interviewers working on the Wave 3 survey. A more detailed briefing was provided to the one new interviewer, who was also accompanied by a supervisor for their first interview on the project.
- 4.13 All interviewers for these surveys had prior experience of working on pre-selected projects and conducting interviews with children and young people.

### ***Recruitment process***

- 4.14 This survey adopted a census approach: all 189 families taking part in the Individual Budgets for Disabled Children Pilot Programme were originally invited to take part in Wave 1. Wave 2 and 3 followed up with those who were interviewed in the previous wave, as long as they gave their permission to be re-contacted and were still on the pilot at the start of fieldwork.
- 4.15 Prior to Wave 3 all families were sent an advance letter to inform them about the survey, and that an Ipsos MORI interviewer would call them to arrange a date and time for an interview if they agreed to take part. The letter also included details of a free phone helpline and email address of a member of staff at Ipsos MORI for respondents to contact with queries about the survey.
- 4.16 Interviewers were issued with a contact sheet for each address which provided the name, address, and phone number of the parent, the name of the CYP who is taking part in the Individual Budget Pilot Programme and whether the disabled child had been interviewed the previous year (and therefore was eligible to be interviewed at Wave 3). Interviewers were instructed to keep contact sheets in a safe place at all times.

- 4.17 The contact sheets also contained boxes in which interviewers were asked to record details of each attempt at contacting the family. Interviewers were asked to try at least six attempts to make contact with families over the telephone. In practice some families received more calls than this.
- 4.18 The work of at least 10% of all interviewers on the survey was back-checked with a telephone call to the respondent from Ipsos MORI's quality control team. This was to ensure that the interview was carried out correctly. In addition, interviewers were supervised while interviewing as part of Ipsos MORI standard quality control procedures.

### ***Gaining consent to take part***

- 4.19 Where families agreed to take part in the survey, informed consent from the parent-carer was recorded on the contact sheet. Permission to approach the disabled child/young person for an interview was only asked where the CYP had been interviewed in Wave 2. Consent from CYPs themselves was sought after parental permission to approach the child about the survey had been given, and both were recorded on the contact sheet.
- 4.20 Interviewers were instructed to check that the parents-carers understood that by agreeing to take part in the research they were also giving Ipsos MORI consent to link their responses with administrative data and the responses they provided during Waves 1 and 2. The administrative data that was linked to the survey data only included information that the respondents provided to the local authority in the registration form they completed when they enrolled on the Pilot Programme. This included demographic information about the disabled CYP, and the services or support that they have previously made use of.

### **Number of responses**

- 4.21 The following table shows the number of responses for all waves of the survey with the main parents-carers, broken down by the six local authority pilot sites.

Table 6: Number of responses, survey with parents-carers

	Wave 1 (Baseline survey)	Wave 2	Wave 3
<b>Pilot site</b>			
<b>Pilot site 1</b>	30	22	9
<b>Pilot site 2</b>	28	22	14
<b>Pilot site 3</b>	27	16	10
<b>Pilot site 4</b>	30	26	19
<b>Pilot site 5</b>	25	20	15
<b>Pilot site 6</b>	33	20	11
<b>TOTAL</b>	<b>173</b>	<b>126</b>	<b>78</b>

Source: Ipsos MORI

- 4.22 For the survey with parents-carers, the overall unadjusted response rate<sup>7</sup> at Wave 3 was 80% while the overall adjusted response rate<sup>8</sup> at Wave 3 was 82%. Please see the following tables for a more detailed breakdown of the response rates.

Table 7: Wave 3 – parent-carer response<sup>9</sup>

	Total number n	% of addresses issued	% of parent carer eligible addresses
<b>Issued Sample</b>	97	100	
<b>Invalid Addresses</b>	5	5	
<b>No longer on the IB Pilot Programme</b>	5	5	
<b>Valid Addresses</b>	92	95	100
<b>Non Contact</b>	3	3	3
<b>Refusals</b>	6	6	7
<b>Parent-carer refused both interviews</b>	6	6	7
<b>Other</b>	5	5	5
<b>Broken appointments</b>	2	2	2
<b>No up-to-date contact information available</b>	1	1	1
<b>Other reason why could not commit to an appointment</b>	2	2	2
<b>Successful Interviews</b>	<b>78</b>	<b>80</b>	<b>82</b>

Source: Ipsos MORI

<sup>7</sup> This is calculated by taking the number of achieved interviews and dividing this by the total sample of addresses, then multiplying this figure by 100.

<sup>8</sup> This is calculated by taking the number of achieved interviews and dividing this by the total eligible sample (total sample – invalid addresses), then multiplying this figure by 100.

<sup>9</sup> Excluding those removed from the sample between Waves 2 and 3 – i.e. families who left the pilot, did not want to be recontacted or did not take part in Wave 2.



Table 8: CYP response

	Total number n	% of adds issued	% of CYP eligible adds
<b>Issued Sample</b>	97	100	
<b>Invalid Addresses</b>	77	79	
<b>No longer on the IB Pilot Programme</b>	2	2	
<b>CYP not interviewed at Wave 2</b>	75	77	
<b>Valid Addresses</b>	20	21	100
<b>Non Contact</b>	1	1	5
<b>Refusals</b>	1	1	5
<b>CYP refused</b>	1	1	5
<b>Other</b>	0	0	0
<b>Successful Interviews</b>	18	19	90

Source: Ipsos MORI

## Weighting

- 4.23 Figures and percentages that are reported for all waves are based on unweighted data. Due to the census approach and the high response rate in each of the waves, weighting of the data was not required. The demographic profile of the achieved interviews closely matched that of the valid sample (see Table 5 above).

## Analysis of the data

- 4.24 Analysis of the survey data was undertaken in various stages:
- Analysis of the frequency of survey responses across Waves 1-3
  - Analysis of change and 'net changes' in perceptions expressed in the before (Wave 1) and after (Wave 3) surveys – Net improvement figures are provided to enable understanding of the number of families whose position improved (i.e. who answered the questions more positively in Wave 3 than Wave 1) relative to those whose positions had deteriorated against each indicator. Differences in responses between Wave 1 and Wave 3 were also tested for statistical significance.
  - Analysis of cross tabulations - The family survey findings were cross-tabulated against a number of characteristics to investigate whether the

results differed across families and to identify themes. The analysis included cross-tabulations based on characteristics collated through the monitoring and survey data: pilot site; family characteristics (including 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 (and any change in the severity of their disability between the baseline and Wave 3); past experience of personalisation and social care provision; and changes as a result of their IB (such as the change in the size of their package compared to their traditional service provision).

### ***Testing for significance***

- 4.25 The Wilcoxon Signed Rank non parametric test was run on dependent samples, with significance tested at the 95% confidence level (5% risk level). The use of a dependent (rather than independent) non parametric tests allow for overlaps between comparison groups such as when comparing one group against the total group (in which the first group is contained), or when comparing responses from the same group over different time periods. Where the base size of a group was small (less than 30), no significance testing was run.

## 5: The activities of the support team

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- 5.1 The sites taking part in the pilot were able to access bespoke support commissioned by the DfE from iMPower. Two of the sites took up this offer, which included support to develop:
- Health-related extension activities
  - Shared objectives and processes between strategic partners
  - Education transport budgets, including financial modelling and workforce development.
- 5.2 Support was provided through a series of face-to-face meetings and also included the development and facilitation of a series of workshops in both of the sites.

## Annex A: The Common Delivery Model

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A.1 [\*Individual budgets \(IBs\) for families with disabled children: A scoping study\*](#) published in October 2008 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 A-1 below for a summary of the elements)

A.2 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.

Table A-1: Summary of the Common Delivery Model

### Element of the CDM

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

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

A.3 The evaluation sought to assess the effectiveness of the CDM, the relative importance of the 10 factors in relation and how these had contributed to the successful implementation of the IB approach.

### The refined CDM

A.4 The refined CDM, which reflects the lessons learnt during the original two year IB Pilot Programme, is illustrated in Figure A-2. This included:

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

Figure A-2: Redefined Common Delivery Model

THE COMMON DELIVERY MODEL (CDM)				Initial set-up	Developing a personalised approach	Introduction of new approach to families	Assessment, resource allocation and support planning	Ongoing management and review
THEME	CDM ELEMENT	SUB ELEMENT(S)						
Organisational engagement and cultural change	1. Engagement of wider agencies	→ Alignment/Inclusion of a wide range of funding streams	✓	✓	✓	✓	✓	✓
	2. Recruitment of designated staff		✓					
	3. Change management			✓	✓	✓	✓	✓
	4. Market development	→ Community development and inclusion		✓	✓	✓	✓	✓
Engaging and involving families	5. Awareness raising with families				✓			
	6. Peer support					✓	✓	✓
Setting up the infrastructure	7. Support planning	→ Advocacy		✓			✓	✓
	8. Development and implementation of a resource and funding mechanism			✓			✓	✓
	9. A spectrum of choice for management of IB funds			✓			✓	✓
	10. Development of IT resources	→ Continuous evaluation of outcomes achieved by the families		✓			✓	✓
Safeguarding and risk management	11. Safeguarding			✓	✓	✓	✓	✓

TIME →

Source: SQW

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