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## The family journey one year on Research Brief

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1. This report is one of two volumes containing the findings from the extended year of the Individual Budget (IB) Pilot Programme for families with disabled children. The two volumes cover:
  - *The Extended Packages*, which provides an assessment of how the pilot sites sought to broaden their IB offer to include both education and health funding, and the challenges associated with this
  - *The Family Journey One Year On*, which provides an update on the position and views of the original cohort of families that participated in the IB pilot 12-18 months after they began to receive their IB payments - **these issues are contained in this volume.**
2. 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.
3. The programme operated in six pilot local authority areas.

### Our extended evaluation and support approach

4. 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.

5. 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:
- **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 and then provided on an ad hoc basis, as requested by sites.

### Methodology

6. Table 1 provides a description of the research and support that was undertaken, where elements highlighted in pink illustrate the methods that were used to gather information to inform the Family Journey One Year On Report.

Table 1: Research and support undertaken during the extended year of the IB Pilot Programme	
Research Method	Description
<b>Scoping</b>	
<b>On site development support and wider consultation</b>	<ul style="list-style-type: none"> <li>• Liaison with the six IB pilot sites, other areas which are taking forward IB related work and subject experts to more fully understand what could be possible and achievable in terms of bringing wider funding streams into an IB</li> </ul>
<b>Two workshops</b>	<ul style="list-style-type: none"> <li>• Pilot site workshops held in May and August 2011</li> </ul>
<b>Development of health and education ‘scoping’ papers</b>	<ul style="list-style-type: none"> <li>• Development of health and education scoping papers which set out some of the options and possible paths for local areas to explore – see <i>separate reports which can be found at <a href="http://www.sqw.co.uk/services/personalisation">http://www.sqw.co.uk/services/personalisation</a></i></li> </ul>
<b>Review and finalisation of delivery plans</b>	<ul style="list-style-type: none"> <li>• Support to complete year three delivery plans</li> </ul>
<b>Evaluation</b>	
<b>Area case study fieldwork</b>	<ul style="list-style-type: none"> <li>• 3 rounds of case study fieldwork were undertaken with each of the sites</li> </ul>

Research Method	Description
<b>Monitoring</b>	<ul style="list-style-type: none"> <li>Four monitoring submissions for 2011/12 were received and analysed</li> </ul>
<b>Workshop</b>	<ul style="list-style-type: none"> <li>Pilot site workshop held in Jan 2012 to share lessons learned</li> </ul>
<b>Wave 3 family survey</b>	<ul style="list-style-type: none"> <li>Wave 3 family survey undertaken over the course of Jan-Feb 2012 with families who took up the original IB offer and were surveyed in 2010 and 2011</li> </ul>
<b>Support and challenge</b>	
<b>Development of bespoke support</b>	<ul style="list-style-type: none"> <li>Tailored packages of support delivered to two sites to support development of: <ul style="list-style-type: none"> <li>➤ Health-related extension activities</li> <li>➤ Shared objectives and processes between strategic partners</li> <li>➤ Development of education transport budgets</li> </ul> </li> <li>On-going support and feedback was provided to sites when requested</li> </ul>

7. A more detailed account of the evaluation approach is provided in the accompanying *Extended Evaluation of the Individual Budget Pilot Programme Technical Annex*.

### **The original cohort of families**

8. The original cohort consisted of 189 families engaged in the pilot by March 2010. Of these, 173 (92%) completed the 2010 baseline survey, 126 (67%) also completed the 2011 Wave 2 survey and 78 (41%) also completed the 2012 Wave 3 survey. The characteristics of families still engaged at Wave 3 were broadly in line (proportionately) with the original cohort.
9. Certain groups (existing social care users, families from lower social grades, young people aged 16+ at baseline and those with lower level needs) were more likely to leave the pilot; either through choice or transition into adult services. Families most commonly left the pilot before finishing support planning. A small number of families did drop out once in receipt of their IB – but this tended to be because they no longer required support, rather than that they were dissatisfied with their IB.

### **The IB review process**

10. The review process has tended to check that the agreed support plan was working as intended to achieve the agreed outcomes, rather than to revisit the assessment or resource allocation. Just over two fifths of families did not experience a change in

package through their review. However, a number of budgets changed at review, with an average increase of £1,473.

11. Most changes were relatively small, yet in some cases package costs were revised dramatically at review. The largest changes in budget have been increases rather than decreases; five families had increases in their budget of more than £11,000. **Such large changes tended to reflect a significant change in the needs of the young person, rather than indicating an issue with the original allocation process.**
12. The majority of families felt that the views of themselves and their family were taken into account during the last review process. Social workers also perceived the IB review process to be more inclusive, supportive and person centred than before and 'much more positive' than other types of review.
13. The most common changes in service provision were increases and decreases to provision of personal assistants and short breaks. On balance, **the use of personal assistants appears to have increased and the use of short breaks decreased.** However, the changes were often small and reflected changing needs of the family, or in some cases families were reported to be becoming more creative in the use of their IB as they became more experienced.

#### **Outcomes achieved by families**

14. **The survey findings indicate that 12 months after the last survey the net improvements in outcomes have generally been sustained at Wave 3**, but in most cases have not become more widespread. Despite already having relatively high levels of involvement in decision making prior to receiving an IB, the IB has led to a net improvement in around one quarter of families.
15. The majority of families experienced an increase in control over the help they receive in relation to their child/young person's disability (net improvement of +54% by Wave 3), while satisfaction with the help received in relation to their child/young person's disability also improved (a net improvement of +45% by Wave 3). A Wilcoxon Signed Ranks Test on the responses from all families showed statistically significant improvements between the baseline and Wave 3 responses across both indicators.
16. Access to the social care services required has increased considerably since the baseline (a net improvement of +47% by Wave 3). While still a strongly positive and

statistically significant improvement from the baseline, the net improvement has fallen back from the +63% improvement reported by Wave 2.

17. The improved outcomes were fairly widely distributed, with almost two-thirds of families reporting improvements in four or more of the outcome indicators.

### **Impacts achieved by families**

18. One year on from Wave 2 the net improvements in impacts have, for the most part been sustained, although they have not been experienced more widely as families acclimatised to their new packages of support. This repeats the findings around outcomes.
19. Changes over the course of the pilot (baseline to Wave 3) are set out below against elements of the Every Child Matters framework, which was selected in 2009 as the basis against which the original set of pilot impacts were developed:
  - Be healthy – The health of a quarter (24%) of children/young people was perceived to have improved since the baseline, while the health of 21% had deteriorated. The overarching change in health over the course of the pilot was not statistically significant, meaning we were unable to rule out the possibility that the change occurred by chance rather than reflecting a pattern of improvement and so we cannot be confident that such changes would occur across a wider population. Also, given the limited direct engagement of health, factors outside the pilot are also likely to have been key to any changes.
  - Stay safe – Since enrolling on the pilot, there have been net decreases in levels of parental concern over the children/young people's safety when undertaking activities inside (+19%) and outside (+24%) the home. Both changes were statistically significant. The pilot has provided children/young people with increased opportunities to socialise through the use of personal assistants.
  - Enjoy and achieve – There has been some net improvement in perceptions of the children/young people's attainment (+15%) and enjoyment (+9%) of school since the baseline, although these changes were not statistically significant.
  - Making a positive contribution – Since the baseline, there have been statistically significant net improvements in both parents (+27%) and their

children's (+35%) social lives. Increased use of personal assistants is likely to have been a factor in these improvements.

- Achieve economic wellbeing – There had been net improvements in quality of life for around one quarter of parents and young people, which was statistically significant. Six parents also entered employment from the baseline, in some cases as a direct result of the pilot.

### **Conclusions and implications**

20. Most families in the pilot that engaged in the IB process have remained in receipt of their IB package. High retention and positive feedback about the review process would suggest that **many families in the pilot have accepted and welcomed the IB approach.**
21. The reasons behind families' satisfaction with the process are indicated by **most frequently reported outcomes**, around:
  - **Access to social care services**
  - **Control over services received**
  - **Satisfaction with the support received.**
22. It is likely that these bullet points reinforce each other, i.e. that improved access and control will lead to increased satisfaction. That said, it is interesting that satisfaction has actually gone up least of the three indicators, perhaps suggesting how challenging some circumstances or indeed family demands are (or perhaps that levels of expectation have risen over the life of the pilot).
23. Although most families gained something, it also appears that **those most likely to report improved outcomes are those who were initially less satisfied.** So, while some families who were satisfied to begin with became more satisfied; it was more common for families who were not previously satisfied to become satisfied across a number of the indicators.
24. This is potentially important in terms of a wider roll out as the extent of any gains in outcomes achieved will depend on the initial level of satisfaction. It would suggest that in targeting or phasing any rollout it may be best to begin with those families that are expressing dissatisfaction as this is where most benefit will be gained. Indeed, this type of 'problem solving' approach is one that we have observed in the IB pilots

whereby the IB approach has been used to provide a more tailored and flexible approach to difficult cases.

25. The **most commonly reported impacts are the improved social life of both the child/young person and the family, and improved family togetherness**. These impacts are similar to those reported in the previous wave of the survey, again indicating that **where benefits arise they tend to be maintained**.
26. However, the **reported impacts are considerably less widespread than the achieved outcomes**. The net change in impacts ranges from 3-35%, compared to 24-54% for outcomes (and the changes were statistically significant for just over half of the impact indicators compared to almost all of the outcome indicators). We had anticipated that the level of impacts would grow over time as a result of families improved access to services that better suited their needs. This chain of impact appears not to have developed as hoped, and given the time that has passed it seems unlikely that they will.
27. While the level of impacts has not increased as hoped, it should be remembered that **most families did report improvements on some indicators and that most families are happier with the support that they receive**. And, as with outcomes, there are relatively limited negative effects in terms of impacts. So, if going forward the key policy objective is to increase choice and control, then that has broadly been achieved. If however, the expectation is that choice and control will in turn improve impacts, then the results are less conclusive.
28. This leaves a dilemma around both the IB approach as piloted and the wider SEND Pathfinders. One option would be to focus on families that are unhappy with their current offer. Perhaps where families are broadly happy with their current support then in moving to an IB approach the level of investment around these families should be fairly limited. For example, the amount of time and effort invested in support planning could be limited on the grounds that relatively little needs to change.

The second, more positive, option is to take the initially more expensive, holistic approach across education, health and social care in the expectation that this will lead to greater benefits. The evidence generated by the on-going SEND Pathfinders will be crucial in demonstrating if these greater benefits can be evidenced.

### **Additional Information**

The full report can be accessed at <http://www.education.gov.uk/publications/>  
Further information about this research can be obtained from  
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