

Individual Budgets for Families with Disabled Children - Scoping Study

Final Case Study Report

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SQW Consulting



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1: Introduction

Introduction to the case studies

- 1.1 Six case studies were undertaken after the consultation exercise, which sought to provide a more detailed assessment of the workings of each area¹, to test the feasibility and desirability of the final list of potential pilot options and to fill any gaps in the existing evidence. This involved gathering the views of a range of local authority staff from each area, e.g. staff from Children's Services, Disabled Children and Young People's Services, Social Care, Commissioning and Finance, as well as front-line staff and providers from the independent sector. This provided a more detailed assessment of the how things are operationalised at a local level and of the possible pilot options in this context.
- 1.2 Case study local authorities were selected from those who took part in the consultation stage of the research. This ensured that the selection was informed by the type and depth of information available from each area and resulted in six local authorities taking part in the case study exercise. The following five case studies are presented in this report:²
- Coventry City Council
 - Gloucestershire County Council
 - Newcastle City Council
 - Northumberland County Council
 - London Borough of Redbridge.

Report structure

- 1.3 The following report presents five of the six case studies, which were conducted during the latter stages of the research. This report acts as a supporting document to the main scoping study report.

¹ The case study topic guide comprised of appropriate questions from the analytical framework.

² The sixth case study could not be published due to disagreements raised within the area on the topic of Individual Budgets.

2: Coventry City Council

Context

- 2.1 Coventry City Council is one of seven metropolitan authorities in the West Midlands conurbation. Coventry has a population of just over 300,000 thousand and the Council employs nearly 18,000 people.
- 2.2 The most recent estimate for the number of disabled children and young people in Coventry is 8,000 (aged up and including 18). This is based on the DDA definition of disability – i.e. refers to children with significant and long-standing disabilities. Of the 8,000:
- 5,500 are children at School Action Plus or above;
 - 1,500 are children with a Statement of SEN;
 - An estimated 1,000 children with higher level of needs requiring support from a specialist children's disability team or short break services.
- 2.3 This figure of 8,000 is out of a total of around 44,000 school age children. At any one time around 300 children are being supported by the Children's Disability Team, and approximately 100 children are receiving short break services from the Primary Care Trust.
- 2.4 For this case study, the following individuals were interviewed:
- The IB pilot lead and service manager for adults with physical and sensory impairments
 - The Transitions Coordinator
 - The project officer for the Lead Professional Family Support pilot
 - The service manager for the Life Chances Service in the Children, Learning and Young People's Directorate
 - The project administrator for the IB pilot

Existing Approaches

- 2.5 The Council has been at the forefront of several developments relevant to the Individual Budgets approach.
- It has a strong track record since 2004 of actively promoting direct payments for adults as a way of providing users with greater choice and control over how their care support is delivered, and who provides it. Currently 35 families with disabled children receive direct payments. The Council has a service level agreement with Penderels Trust to provide support and advice to users

on managing direct payments and an Independent Living Advisor who coordinates the direct payments

- The Authority was one of the 13 pilot sites for the IB Pilot Programme. It developed an alternative framework for assessment based on an outcomes focus.
- Although it was unsuccessful in its bid to be one of the DCSF Budget Holding Lead Professional (BHLP) sites, Coventry set up and funded its own pilot - the Lead Professional Family Support Budget (LPFSB) – on the BHLP model.
- In the Children, Learning and Young People's Directorate, pioneering costing work on establishing unit costs for provision of the range of short breaks options, has been undertaken. [This information has been used to inform the report chapter on costs.]

The IB pilot

2.6 The Coventry IB pilot was targeted at people going through 'transition'. This included not only young people aged 16-18 but also people going through different kinds of transition including:

- People leaving residential care or long-stay hospitals for sheltered accommodation or tenancies in Coventry
- People moving from out of city learning disability placements back to city placements (mainly supported living).

2.7 A key aspect of the Coventry approach that differentiated it from the other pilots, was its use of a different assessment framework – the Outcomes Focussed Assessment (OFA) – instead of the Resource Allocation System (RAS) developed by In Control. Coventry initially tried out the RAS for some individuals leaving residential or institutional care, but found that there were great variations between the value of people's current care packages and the RAS assessment, and that there was no consistent pattern to these variations. In the case of people with learning disabilities, the variation was between 100% and 200%, and in the case of people with mental health problems, the variation was up to 500%.

2.8 Coventry's preferred assessment model was based on that designed by the Social Policy Research Unit (SPRU) for its work for Derbyshire Social Services. The Coventry version was developed using a pathfinder group of social workers who trialled it and revised it through a process of eight iterations. The starting point was identifying the individual's desired outcomes. Whereas a needs led assessment focuses on a person's *current* needs, the outcomes based approach involves the individuals in looking ahead at what they would like to achieve both now and in the future. The notion of outcome was based on SPRU's definition of 'goals that service users wish to achieve'. The SPRU outcomes framework comprises Autonomy Outcomes, Personal Comfort Outcomes, Economic Participation Outcomes, and Social Participation Outcomes. Examples given of Coventry IB clients' outcomes

included: 'staying out of hospital and off medication', 'a home of my own', 'do things I enjoy and stay safe'.

2.9 Following the initial stage of agreeing outcomes, the process of support planning was then used to identify the level of support the service user required to achieve these outcomes. The final plan involved drawing up a costed package of support which formed the basis for the level of award for the IB. The way in which the costs were calculated was set out in *Guidance for Social Care Staff*, which stated that the support plan should record the following:

- Against each outcome:
 - Who will support the meeting of each outcome; this may be the service user, a carer or family member, or statutory or other agency
 - The level of support to meet each outcome; this will often be in units such as hours or days
 - The cost of that support, where that support is to be funded via the Individual Budget. This should be costed using the schedule of costs.
- Distinguish between one off costs (e.g. equipment) or recurring costs
- Total figures for both 'one off' and 'recurring costs must be completed on the last page as this figure is the cash value of the Individual Budget
- Where possible, the unit costs of in house services should be included, so their value can be added to the total budget.

2.10 Once the IB was awarded, the service user was then supported to make decisions about how they wanted to spend the budget. Of the 44 beneficiaries:

- 16 opted for Direct Payments which could be used for everything except residential services
- 16 opted for a mix of Direct Payments and Council services
- The rest opted for Council services.

2.11 Different options for delivering support depended on the form in which the Budget was taken up. These options included Penderels Trust which already had a contract to support those using Direct Payments; support from carers or family members; and care management by Community Services. The Council is also in the process of developing other options including an independent sector care brokerage service.

Demand for existing approaches

IB pilot

2.12 The IBs were offered to all those eligible for a social care service and who were 'In Transition'. In targeting people in transition, the Council argued that:

We have the opportunity to use the pilot to make a positive impact on people experiencing significant life changes requiring them to make major choices, and learn from this focused approach. This includes transition from adolescence to adulthood, education to employment/independence and hospital or other rehabilitation setting to independent living in the community. These are critical processes and milestones in helping move people to independent living, consistent with the notion of individual budgets, which will also provide an objective towards which young people would work during their transition to Adult services³.

- 2.13 Team managers were responsible for identifying suitable individuals, and it was explained to these individuals that it was thought that the IB approach would work better for them in supporting them to make important decisions during a major life change. Only three of those offered the IB did not take it up. A total of 44 took up the offer, of whom around 10-12 had a physical or sensory impairment, two had mental health problems and the rest had learning disabilities. The age range of participants was from 16 to 50+, and 10 were in the 16-18 age group.

Lead Professional Family Support Budget

- 2.14 The pilot was targeted at 0-19 year olds with additional needs (i.e. level 2/3) as part of the early intervention/prevention agenda. It could not be used to purchase services for children with more complex needs requiring statutory intervention (level 4). Young people aged 19-25 with learning difficulties or a disability were also eligible. A total of 369 families were supported through the pilots, involving over 414 children.

Funding

- 2.15 The main funding streams for the IB pilot were:
- Social care support funded by Community Services Community Care budgets
 - Housing related support funded by Community Services Supporting People budgets
 - Minor equipment funded by the joint Integrated Community Equipment Store (ICES).
- 2.16 Whereas assessment for support from these streams were included in an Integrated Assessment, some other funding streams were not able to be integrated, and involved additional assessments, called Coordinated Assessments. The funding streams requiring additional assessments were:
- Major Equipment and Disabled Facilities Grant (funded by the ICES or Housing Grants)
 - Additional social care support by the Independent Living Fund
 - Access to Work support

³ Coventry City Council (2006), *Projects Initiation Document, Individual Budgets Pilot*

- Continuing Health Care support from the PCT

Effectiveness of existing approaches

IB pilot

- 2.17 According to the IB lead and the transitions coordinator, the OFA was considered one of the most successful aspects of the IB pilot. It was felt that the approach was aligned to the personalisation agenda and the principles of choice and control for service users because it was user led rather than service led. Where it worked well, it led to better communication between service users and professionals.
- 2.18 The OFA was recognised by the Council as marking a significant change from the traditional needs led assessments and as requiring a major cultural shift for professionals involved in the process. A training programme on the new assessment framework was put in place for social workers and detailed guidance produced. Some professionals initially found the process was more difficult and took much longer at the front-end, but the benefit was that the service users were more involved and engaged through the process of agreeing what they wanted to achieve.
- 2.19 To ensure that the lessons from the Coventry pilot could be drawn out, the Council commissioned an independent user-led local evaluation by a research team at Coventry University⁴. This involved working with 30 IB users to explore their experiences, as well as gaining the views of some of the social care staff involved in the IB pilot. The overall findings from that evaluation were generally positive:

The Individual Budgets initiative has generally been perceived by service users and their families as a very positive development, not least in terms of allowing service users to be able to set the agenda, to have choice and autonomy, which in turn enables service users to grow and develop holistically, and to become part of their family and community on the same terms as other citizens.

- 2.20 In addition to the main evaluation report, a booklet detailing the 'stories' of service users in their own words was produced⁵.

Barriers to delivery

- 2.21 A wide range of barriers identified in the process of implementing the IB pilot were highlighted in the local evaluation by Coventry University. These included:
- Different levels of knowledge and understanding of IBs both amongst service users and professionals
 - Delays in the process of getting the IBs paid
 - Difficulties in recruiting support staff in the open market

⁴ Coventry University (2008), *Evaluating Individual Budgets in Coventry, Final report for Coventry City Council*. available from www.coventry.gov.uk

⁵ Coventry City Council (2008), *Our Stories; Individual budgets in Coventry*. available from www.coventry.gov.uk

- Service users' difficulties in coping with the pressures of being an employer and managing budgets
- Professionals' resistance to changes in their role
- Lack of cooperation between departments and effective partnership working.

2.22 Other barriers mentioned by the individuals consulted by SQW included:

- The underdevelopment of the marketplace and the consequent limitation on the choices exercised by IB users. There is no standard package for IBs and therefore there is scope for individuals to opt for different services to the traditional range of options that they have been offered. However, it appeared that some individuals and their families found it difficult to conceive of alternatives or assumed that if something had not already been made available, it would not be possible.
- A major issue is commissioning and the ability of the existing market to meet demand. Associated with this is the difficulty of assessing future demand and identifying the level of demand for different types of services.

2.23 If IBs are to be rolled out to families with disabled children, the development of an adequate supply of appropriate services was considered a challenging one. Until now, home based services for children have been procured through adult services. The Council is in the process of developing a framework agreement for use in commissioning specialist children's services. If the IB approach leads to a demand for a range of alternatives to residential care services for children currently funded by the Council, this will require greater capacity to be built up to meet that demand. There was a general view that this would need to come from a combination of providers including private and voluntary sector, and that it would take some time to build up the required supply.

Lead Professional Family Support Budget

2.24 An independent evaluation of the pilot was conducted by OPM⁶. Among its conclusions, were the following:

- The approach allowed more creative, flexible and personal interventions than were possible through other methods of service provision
- The flexibility and creativity were valued by professionals and their families
- The pilot 'led to a strong sense of empowerment for families, through enabling them to see clearly how their situation will improve in the near future and giving them a sense of control and ownership over the process'.
- Although there was limited evidence on cost-effectiveness, what data there was indicated that the interventions funded by the pilot were good value for

⁶ OPM (2008), *Lead Professional Family Support Budget, Local pilot evaluation*, Final report to Coventry City Council.

money. For examples, there was some evidence that the cases were less likely to escalate to requiring more specialised social care services as a result of the intervention.

- 2.25 The pilot was seen as empowering the lead professional as well as the family. Over 350 lead professionals were trained and they developed a greater knowledge of the range of services available to families and how to access them. This in turn helped them to improve their communication and relationships with the families. The lead professionals worked closely with a Community Resource Officer who supported them in identifying the appropriate services. The pilot is viewed by the Council as having been successful and the process of mainstreaming the approach is now being undertaken.

Barriers to delivery

- 2.26 The LPFSB evaluation also identified some barriers to delivery. These included:
- Constraints on the ability of existing service providers to meet demand. The demand in particular for short-term flexible services was particularly seen as putting pressure on service providers who could not predict the level of demand for their services
 - More training needed for lead professional around integrated working

Key requirements of a successful approach

- 2.27 The consultees identified a number of key requirements for a successful IB/BHLP intervention:
- A pilot requires a senior manager to coordinate the pilot, a dedicated project manager and administrator, and substantial input from in-house staff from other departments, including finance and IT. This investment will be crucial in the first year of setting up the pilot.
 - An IB approach involves a significant shift from the traditional model for delivering services, and requires investment in awareness raising and training for professionals. There will be resistance to change and the authority needs to be proactive in supporting staff to understand the potential benefits of the changes.
 - The adoption of an outcomes based assessment is viewed as one of the most successful aspects of the IB pilot, but it is recognised that a new assessment framework requires considerable investment in training and support to ensure that staff are able to carry out the assessments consistently.
 - It is important to recognise that not all service users will want to take on responsibility for managing a budget – at least not initially – and the majority will need some assistance with this process. Service users should have access to a variety of different support requirements and a menu of support options is needed.

- Involving service users in the evaluation process has proved to be an effective way of ensuring that their views are heard and can influence the ongoing development of the pilot.

Summary of existing approaches

Coventry has recently completed both an IB pilot and a LPFS pilot. The evaluation of both pilots has been positive and identified important lessons for future IB pilots with families with disabled children.

Barriers to effective delivery have included market development constraints, resistance to culture change, delays in implementing IB payments, lack of coordination between departments, and difficulties integrating a variety of funding streams. Despite these barriers, however, the local evaluations have concluded that the pilots have delivered considerable benefits to both service users and professionals and promoted the personalisation agenda of choice and control.

Looking Ahead...

- 2.28 The latter half of the case study research focused on the design and development of the forthcoming IB pilots for families with disabled children. Therefore, consultees were asked to provide their views on the potential shape, format and content of the pilots, where responses were overwhelmingly positive and reflected a strong commitment to deliver user-led services within the local authority.

Pilot options

- 2.29 The interviewees did not generally favour the targeting of any future IB pilot for families with disabled children at specific groups according to type of disability. Most favoured the comprehensive offer. One interviewee argued that the type of disability was not the key factor, as children and families responded to the same type of disability in different ways.
- 2.30 While all agreed that eventually the offer should be available to all families with disabled children, there were some suggestions about a focus for some of the pilots. Following the focus of the IB pilots on adults in transition, there was a view that it would be valuable to target older children in transition. There is currently a different approach between service provision for children and adults within the authority. Whereas adult services have no in-house residential provision, children's services directly provide residential care. When young people move from Children's Services to Community Services (i.e. adult services), parents often view the change as a loss of existing provision. It is now seen as a priority within the Council to smooth that transition and provide a more integrated framework. It was felt that targeting older children for the pilot would help to address some of the challenges involved in the transition and help to equip young disabled people to achieve outcomes that are about independence.

Potential demand

- 2.31 There is no data specifically on the potential demand. The IB pilot evaluation did, however, point to the positive response from service users and their families which suggests that there may be a high take up when IBs are rolled out.
- 2.32 Further evidence comes from the work done for the Short Breaks Review by the Life Chances Service in the Children, Learning and Young People (CLYP) Directorate, which points to considerable interest amongst parents in an approach which gives them greater control over budgets. A consultation process was carried out involving a questionnaire and focus groups. Around 200 parents responded to the questionnaire and 48 parents and 50 children participated in focus groups. The aim of the consultation service was to find out the range of services people wanted, preferred times of day/week and how they might spend the money if they had the choice. Participants were provided with a pack of cards representing different options – overnight residential, day trips/outing and community/home-based activities – equating to the same monetary value. The participants were asked how they would spend the imaginary budget they were given. The monetary value of the options was based on unit costs established in consultation with current service providers.
- 2.33 The parents responded positively to the consultation exercise. Nearly half the respondents wanted a combination of different services – residential, community and home-based. There were differences in preferences according to attributes such as the child's age and the type of impairment. Many parents and carers expressed the need for increased choice and flexibility in provision and for the tailoring of services to the needs of children. Such findings point to the potential demand for an approach which expands choice of provision and enables the children and parents to have greater control over how the budget is spent.
- 2.34 The fact that there are an estimated 8,000 disabled children in Coventry, of whom around 300 receive services from the Children's Disability Team, and 100 receiving short break services from the PCT at any one time, suggests that there is the potential for demand for an IB approach from families of disabled children who are not currently accessing any services.

Potential resource implications

- 2.35 The experience of Coventry in setting up both the IB pilot and the LPFSB pilot has highlighted the importance of putting sufficient resources into the initial set up costs. The following elements were important in the first year of the IB pilot:
- Allocating in-house staff resources including a senior management lead, a project manager, a project administrator and input from the finance team
 - Resources to commission the production of a tailored electronic database to record the outcomes of the pilot

- Training sessions for all those involved in the pilot in key roles, including social workers, managers to cover all aspects of the pilot approach and associated culture change etc
- Advertising campaign to raise awareness and understanding of the pilot
- Resources to fund a range of support options for the service users.

Potential Funding

- 2.36 The main challenge in integrating funding streams for IBs for families with disabled children was thought to lie primarily with the Health funding streams (e.g. Continuing Care, Therapy Services). All the funding streams within the local authority were considered to be relatively easy to incorporate, including education. However, although the health funding streams were seen as relevant, differences in philosophy and demarcation issues - about what is a health needs or an educational need – were likely to create problems in seeking to integrate health within the IB package.

Looking ahead summary

The interviewees at Coventry City Council were generally positive about extending the IB approach to all families with disabled children. While they favoured a comprehensive offer to all families, there was also support for targeting older children in transition for any future IB pilot.

The evidence from the IB pilot evaluation and consultations with parents for the Short Breaks Review suggests that there may be a high take up when IBs are rolled out to families with disabled children. Many parents and carers expressed the need for increased choice and flexibility in service provision.

Coventry's experience with the IB and LPFSB pilots has highlighted the initial resources required to set up an IB pilot, including in-house staff, IT resources, training for staff involved in delivering the pilot, and a variety of support options for service users.

3: Gloucestershire County Council

Context

- 3.1 Gloucestershire is a large rural shire County situated in the south west region of England. The County is made up of six district councils - Cheltenham, Cotswold, Forest of Dean, Gloucester, Stroud and Tewkesbury - and had a population of approximately 580,000⁷ in 2006. Approximately 140,000 children and young people live in Gloucestershire, which accounts for around 25% of the total population and national prevalence rates suggest that approximately 4000 children in the county have a disability^{8,9} (3%).
- 3.2 The County has an established and strong commitment to improve the outcomes achieved by its children and young people, including those with disabilities. For example, Gloucestershire set up a Children and Young People's Strategic Partnership (CYPSP) in 2002 in response to an identified need for improved integrated working when planning and providing services for children and young people across Gloucestershire. The CYPSP facilitates the County's local Change for Children programme and includes representatives from the County Council, district councils, Connexions, the Learning and Skills Council, the police and probation service, schools and the voluntary and community sector. The Partnership also draws on the views of children and young people through its affiliated Children and Young People's Participation Group.
- 3.3 The activities of the CYPSP were further developed through the Gloucestershire Children and Young People's Plan 2006-09. This was created to meet the requirements of the Children Act 2004 and the National Service Framework for Children, Young People and Maternity Services. GCC also investigated a significant amount of resources into their Common Assessment Framework (CAF) implementation, where Multi-Agency Groups had been set up and over 1,300 CAFs had been undertaken by the beginning of April 2006 and 1,924 by March 2008.
- 3.4 Looking specifically at the service offer for disabled children and young people, Gloucestershire has developed specific programmes of work to support the needs of this group. For example, the Children and Young People with Disabilities Integrated Working Project was initiated in March 2003, where phase one sought to integrate health, education and social services for children and young people with disabilities and their families. This project was followed by an increase in activities for this group and the concept of improved joint-service provision has since been developed, leading the County to become one of the Budget-Holding Lead Professional (BHLP) pilot sites, a Taking Control pilot and a Short Break Pathfinder Authority.

⁷ Sourced from the ONS Mid Year Population Estimates, 2006.

⁸ The Family Resources Survey 2002-3 estimates there are approximately 700,000 disabled children under 16 in Great Britain – NSF Standard 8 section 2

⁹ Gloucestershire Children and Young People with Disabilities Integrated Working Project: Phase One Report

- 3.5 This case study report sets out the County's approach to the recent pilot activity it has undertaken to support service provision for children and young people with disabilities and the key learning the activity has facilitated. The information presented in the report draws on both the views of five members of Gloucestershire County Council (GCC), each of which took part in a face-to-face interview and on additional literature/reports provided by the consultees.

Existing Approaches

- 3.6 GCC has or is currently piloting the following self-directed support interventions:

- Budget-Holding Lead Professional pilot¹⁰
- Taking Control pilot
- Short Break Pathfinder.

- 3.7 Each of the above pilots is currently based around an assessment process, where the Children and Young People's Directorate currently undertake two forms of needs assessments for children, young people and their families. The first, the core assessment, is undertaken if a child or young person meets the County's threshold for social care provision and is therefore thought to have relatively complex needs. This assessment process results in the assignment of a designated social worker or family support assessor. The second form of assessment, the common assessment framework (CAF), a simpler and more self-directed form of assessment, is undertaken for children and young people who have relatively lower level needs and therefore do not meet the threshold for social care provision. GCC have also used the CAF in situations where a child/young person is eligible for social care, but where the needs of the individual can be met in the absence of a core assessment.

Budget Holding Lead Professional pilot

- 3.8 Gloucestershire took part in the BHLP Early Intervention Pilot from April 2006 to March 2008, which sought to provide targeted support for children and young people with additional needs who required the support of more than one agency. The pilot was granted a total of £532,107 from the DCSF over the two year period, which was used to deliver the following:

- **17 pilot sites across the County** covering a range of children and young people aged 0-19 years in a range of settings including health, district councils, schools, special schools, children's centres and the Children and Young People's Directorate.
- **Two county-wide projects** targeted at specific groups of children and young people with higher level needs but who do not meet the threshold for complex services, each of which was designated £10,000:

¹⁰ The pilot has now finished and is now part of a change for children project funded from a locally pooled budget

- Children and Young People with a disability (CwD) who do not meet the social care threshold
- Children and Young People whose statutory involvement with children and families teams is ending but who still have on-going needs.

3.9 GCC was the only BHLF pilot to target disabled children and young people. The reasons for this included recognition of the high social care thresholds prevalent in the County and therefore a decision was made to also pilot to this county wide group to ensure inclusivity.

3.10 The pilot was delivered by a project team which included dedicated project management time, two project workers, a performance officer (0.5) , a project officer (0.5) and a finance officer for two days a month. As the pilot developed other people were seconded in – a further project worker and an assistant head teacher for 1.5 days a week. Funding was devolved to an organisation within each selected Multi-Agency Group and authority given to individual BHLFs to purchase goods and services up to an agreed amount of a £1,000 per child.

3.11 All children who participated in the pilot had a CAF – this was a requirement of the pilot – and the majority were not eligible for social care support or had been ‘closed to social care’ i.e. were no longer eligible for a service (sometimes due to capacity constraints in the service provision).

3.12 The general BHLF process worked as follows:

Table 3-1: BHLF process	
Stage	Description
Stage one: Assessment and action plan using the CAF	The assessment identified the needs of the child or young person and resources needed to help them achieve the desired outcomes. The person doing the assessment becomes the lead professional/BHLF
Stage two: Co-ordination of services	If support from more than one agency is required, the lead professional/BHLF is confirmed at the multi-agency meeting (the LP/BHLF could change at this point) and resource identified to help the child/young person to achieve the outcomes identified in the CAF. The needs of many children, young people and their families can be met through existing support and services within the community or through Multi-Agency Groups. Where there are unmet needs which cannot be met by existing services or resources, the LP/BHLF can use the BHLF funding to commission individual services.
Stage three: Review of progress against outcomes	A review of the CAF and Strength and Difficulties questionnaire is completed by the LP/BHLF together with the child, young person and family and is focussed on what has changed and an evaluation of outcomes. This process also assists agencies to evaluate the effectiveness of services and identify gaps in provision.
How to access budgets and purchase goods and services	
Step 1	Cost the goods or service(s) the family wishes to purchase or commission
Step 2	Obtain cash or a cheque from the local BHLF budget holder e.g. school, or arrange with the supplier for an invoice to be sent to the BHLF budget holder or administrator.
Step 3	Purchase goods/commission service or make a direct payment to the family
Step 4	Confirm spend and lodge receipts with the BHLF budget holder. Record the outcome on the BHLF monitoring sheet.

Source: Gloucestershire County Council BHLF Toolkit, Second Version, January 2008

- 3.13 The CWD pilot ran for one year and originally targeted those children who did not meet social care thresholds and were therefore deemed as having 'additional needs'. However, during the course of the pilot a decision was made to also include children from the social services waiting list, who were awaiting referral for specialist assessment. This additional group accounted for 15 out of a total of 40 CWD supported by the pilot, where the remaining group were recruited through referrals from schools, housing officers etc. It was also evident that the BHLF team had been proactive in marketing the BHLF offer and had tried to avoid a child being passed through both a core assessment and a CAF.
- 3.14 The pilot work was extended between January and March 2008 to enable a small number of BHLFs to access a larger budget to enable them to commission the whole package of support for children and young people with additional needs. This extension was known as the Enhanced BHLF or EBHLF.
- 3.15 Gloucestershire also became one of the Children in Care BHLF Pilots, which focused on the following three groups of children and linked in with the Making Good Progress pilot to support children and young people (C&YP) who are 'stuck' in their educational progress between KS2 and KS3:
- Young people in short-term residential care with a view to providing a holistic assessment of their needs when admitted and meeting these needs using the BHLF approach
 - Children waiting for permanent placement for longer than 6-12 months using the 'Taking Control' model
 - Children with a substance misuse problem
 - Children in care identified as being 'stuck' through the Making Good Progress pathfinder, using the CAF and Personal Education Plan together to provide holistic support to improve education attainment.
- 3.16 This pilot is using the Taking Control model of service provision in relation to the permanent placement workstream and therefore is being delivered in conjunction with the Children and Young People with Disabilities Team. An adapted Resource Allocation system is being developed for children in care.

Taking Control pilot

- 3.17 Following the BHLF pilot, GCC has chosen to become a Taking Control pilot site, where the progression from BHLF to the additional provision of IBs was felt to be a positive extension of the County's programme of self-directed support. GCC had also conducted a review of their Short Breaks provision during 2007 and had been in discussion with parents, children¹¹ and the commissioning team about service provision for CWD and therefore felt that the concept of IBs aligned with the philosophy and direction the County were moving towards.

¹¹ The pilot was also preceded by some local research conducted with young people, which provided an introduction to IBs and sought to find out their views on the concept.

- 3.18 The pilot is following the 7-step delivery process set out by in Control and therefore has adopted the adapted Resource Allocation System (RAS) developed for disabled children. The GCC pilot aims to offer IBs to two distinct groups of disabled children/young people:
- **Group one: Individuals who are eligible for social care and have already had a core assessment** – the County aim to pilot IBs with up to 12 disabled children and young people, who will be drawn from across the age ranges and the County. These individuals are likely to have already had a core assessment and either require or be in receipt of specialist services. Each of the designated social workers will support the family and child to update their assessment and to complete the RAS, with the expectation that the IB will be used to support the child. The team also aim to expand the remit of their IB provision to support the family of the child, to facilitate the provision more holistic approach.
 - **Group two: New referrals who do not meet the social care threshold** – up to 12 random new cases referred to the Community Lead Professionals (CLPs), will be supported to undertake a CAF and to complete the RAS. This will result in an allocation of funds which will be used to support the child and their family, including their siblings.
- 3.19 The pilot is in its early stages of development, where the project team have recently completed the development of the RAS. This involved the assessment of the packages of 50 social service users and 20 BHLP users (who require continuing care, as opposed to one off payments). This resulted in a price point of £71 for the social service users and £10 for the BHLP users. The significant discrepancy between price points was caused by the difference between BHLP service provision and provision required for children with more complex needs. For example, the BHLP provision has involved sourcing a significant number of existing services from the Voluntary and Community Sector (VCS), which did not require major funding. In addition the BHLP pilot was not able to access specialist services, which have a high cost.
- 3.20 Following this exercise, a decision was made to utilise both price points for the different entry groups initially, using the pilot to move towards a single price point, as there was no clear way of reconciling the two for the start of the pilot. At the time of writing the price point for group 1 will be top-sliced to allow for a contingency budget, and is currently being looked at as £55. At the time of writing the price point for group 2 will remain at £10 (ie not be top-sliced), but with an additional contingency budget to allow for access to small amounts of specialist care where needed.
- 3.21 The project team added that the price points would be subject to annual review, to align with the setting of budgets at the beginning of each financial year. The team would also like this review to involve the re-setting of the budgets of all service users to accommodate and change in the price points – which should include both existing service users and new referrals.

- 3.22 Looking specifically at user involvement, GCC has spent a significant amount of time establishing relationships with potential beneficiaries. This has involved the project team going out to visit some of the families to engage them and to discuss the process, the setting up of a steering group for the pilot which includes parent members and the development of a parent reference group (involving all those who have agreed to take part in the pilot), who will be involved in development and decision making. GCC also feel strongly about the need for transparency and therefore have made it clear that the IB offer is part of a pilot and therefore will form part of a learning process for the families and GCC.

Short Break Pathfinder

- 3.23 GCC became a Short Break Pathfinder in April 2008, which entitles the County to a total of £489,000 revenue funding and £228,000 capital funding to invest in short breaks over the course of 2008/09. The team expressed the desire to develop a short and clear route into short breaks, to ensure that children who require support can access this through the common assessment framework route. This process will be facilitated by the Community Lead Professionals (CLP), who will complete assessments, co-ordinate plans with a multi agency group and act as 'bridging people' to offer short-term coordination between the child, family and a universal or mainstream provider. For example, this could entail the CLP holding an initial meeting with a provider and the family to assess the needs of the child to enable them to attend a community activity over the longer-term.
- 3.24 GCC are also seeking to encourage existing voluntary and community groups who are already providing support to families with disabled children, to extend their services to assist children to take part in short breaks in the community i.e. to expand from the provision of specialist segregated services to the provision of tailored and supported access to community arts, sports and leisure activities. This extension in service provision will be accompanied by additional funding from the Short Breaks money received by GCC. For example training, networking and support will be made available to mainstream creative arts, sports and leisure providers, and it is intended to use some capital funding to improve toileting and changing facilities and equipment for outdoor activities.

Next steps

- 3.25 GCC is currently developing a single system which aims to integrate the three interventions, to provide a single point of access and single assessment process for all service users. To date this process has involved the disability service, a corporate lead from the finance team, a HR lead, and the Community and Adult Care Directorate who are also introducing self-directed support and personal budgets.

Demand for existing approaches

- 3.26 The BHLPI pilot supported 371 families in total over the period April 2006-March 2008, 40 of which were families with disabled children. Parents were very positive

about the CAF/BHLP process as they felt it met the needs of the whole family and was not focused on eligibility criteria and panel assessments.

- 3.27 Goods and services provided through the BHLP included: additional learning support and help with homework, laptops for school work, family mediation and problem solving, play and activities, breakfast club, respite care, youth activities/workshops, shoes, food, washing machine, clothing, transport to activities etc.

Funding

- 3.28 The three self-directed support interventions have been funded as follows:

- The **BHLP pilot** was awarded £532,107 in total from the DCSF over the two year period. An additional £80,000 was committed by a wide range of agencies, which was to be pooled and added to the total budget. Since the ending of the project this is now funded from budgets from PCT, Area Based Grant and DSG, totalling £350k for 08/09.
- At present, the **Taking Control pilot**, whose management and delivery elements are being funded by GCC, has integrated only the social care budget into its IB funding pot. However, it is the intention of the team to include funding from both the LSC and PCT at a later date, where the PCT have expressed an interest in being involved but do not want to participate at this point in the process.
- **Short Breaks** – short break services have been funded by GCC prior to April 2008. This included a £100,000 grant from the Extended Schools budget for children with disabilities over the period 2007-08, where the budget was given to all special schools to enable them to extend their play schemes over the summer holidays or to extend their after school clubs. GCC have been awarded £489,000 revenue funding and £228,000 capital funding by the DCSF as part of the Short Breaks Pathfinder Programme, which is to be spent on short breaks over the course of the current financial year. In addition, the CLP team have asked to pool the additional Extended Schools money with the Short Breaks and BHLP funding to facilitate an ‘inclusion grant’, which can be used as a flexible grant for a range of services e.g. transport.

Effectiveness of existing approaches and added value

Budget-Holding Lead Professional pilot

- 3.29 The pilot’s main achievements have been summarised as¹²:

- Children, young people and their families have engaged with the model and support the use of the CAF and the associated user-led needs assessment process. They reported the process as supportive and empowering

¹² BHLP Final Summary Report

- Families have developed innovative means of addressing their needs, which would not have been available through traditional service provision
- Decision making was devolved down to the Lead Professionals in agreement with the families and with the support of their Multi-Agency Groups
- Both professionals and multi-agency groups have begun to 'bend' their roles and boundaries to meet individual need within existing core services
- BHLP has strengthened the partnership between family and professional
- Has helped to consolidate integrated working at universal/targeted level
- Some early indication that individual, area and strategic commissioning are transforming how services are commissioned and delivered. For example, parenting support, one to one and group work block commissioned by BHLP, will now be incorporated into the key parenting contract going out for tender in July 2008 and be funded by mainstream grants.

3.30 Looking now at the user experience, nine parents were interviewed between November 2007 and January 2008¹³ to gain feedback on their experiences. This exercise indicated an overwhelmingly positive response to the BHLP support and service provision. Similarly, a parental survey conducted with 27 parents, indicated an 81% satisfaction rate with the BHLP services and that 86% of parents would recommend the BHLP service to a friend.

3.31 The BHLP Final Summary Report stated that parents thought that BHLP enabled a wider range of services to be offered which were flexible and met their needs. For example, money to pay for transport proved to be especially helpful in rural areas. Practical help was also highly valued and parents indicated that low cost help could make a big difference to the lives of their children and the family. The report also highlighted the outcomes experienced by children & young people and by families as a result of the BHLP service provision. This feedback included:

- **Improvements for children and young people:** improved behaviour; school attendance; child feeling more confident; child joining in activities outside the home; 'the shouting and bawling has stopped'; child/young person happier (several parents); children happier at school; 'a huge step forward for our children'; daughter more confident and interpreting for other people; child achieving at school.
- **Improvements for the family:** home life more relaxed; improved relationship with child; young person stopped self-harming; constant rows have stopped; parents more confident in dealing with problems; 'made me face up to things'; parents feel supported and more in control. Some families are still receiving help. For others, help was given to cope with a crisis and minimal support is needed now. Two families indicated that although things had improved things were still difficult.

¹³ BHLP Pilot Final Summary Report

- 3.32 The report also includes an assessment of the learning from the children and young people with disabilities BHLP, which reported that:

Families qualifying for a specialist service have found better solutions based on their needs through BHLP (e.g. a home carer and gym membership rather than the 'respite' care originally sought) and have had choices that are not available through the specialist team. BHLP has reduced the waiting list as families have not required specialist services when assessment of need has been done collaboratively.

There is a perception from professionals that disabled children and young people 'need' a specialist service and that their needs cannot be met in mainstream, universal services. Considerable work has been done on shifting this perception with some success.

- 3.33 This impact has been acknowledged at a strategic level, which has resulted in the provision of £150,000 from the Direct Schools Grant to contribute to a budget to continue the pilot for an additional year¹⁴ i.e. over the course of 2008/09¹⁵.
- 3.34 In addition, it was noted that approximately 90% of the County wide disabled children and young people processed initially stated that they required specialist 'respite care'. However, once the needs of the child and their family were unravelled by the BHLP, the family often recognised alternative means of supporting their needs, which resulted in the provision of less expensive and more appropriate type of care in a significant amount of cases. Therefore, the CAF and BHLP approach may result in a more cost effective approach to service provision over the longer term.

Taking Control pilot and Short Break Pathfinder

- 3.35 As a result of the developmental stage of both the Taking Control pilot and Short Breaks Pathfinder, it is too early to assess the effectiveness of both approaches.

Barriers to delivery

- 3.36 Each of the five GCC staff who took part in the case study research were asked to comment on the legislative/organisational barriers and risks associated with the delivery of the BHLP, Taking Control and Short Break pilot. Their responses included the following:

Local Authority staff:

- **Staff reluctance to culture change** – culture change within the LA has proven to be a significant challenge, as members of fieldwork teams have found it difficult to understand how their role will align with the new forms of service provision.
- **Lack of people able to complete CAFs** – occurred as a result of confidence issues, as individuals within the Multi-Agency Groups did not feel they knew

¹⁴ BHL P Pilot Final Summary Report

¹⁵ This was not in relation to the children with disability only but across the whole of BHL P with additional needs

enough about disabilities and stated a lack of staffing resources as a barrier to completing CAFs.

- **Logistics of getting payments for people** – as the facilitation of one-off payments was new to the finance department, who were not given additional resources to manage the BHLF work, staff found it difficult to process payments. This also resulted in providers and the finance department referring a large number of finance related queries to the BHLFs, which was extremely time consuming. Only latterly has the learning from Direct Payments for disabled children been recognised.
- **Finance** – one of the main challenges to the delivery of IBs and Short Breaks, was the need to know the unit costs of all services in order to inform the RAS process. This exercise was very resource intensive and required a dedicated finance resource.

Engaging users and parents:

- **Recruitment of parents onto steering group** – GCC highlighted the need to involve users in the development of any pilot activity and stated that they found it a challenge to find parents to sit on the project steering group. A parent carer worker is now being recruited to Carers Gloucestershire, funded by GCC.
- **Changing the views of specialist providers and families** – specialist providers and families often feel that specialist provision is the only effective means of offering support and are therefore reluctant to either enable or receive more innovative forms of support.

Providers:

- **Universal providers do not currently have the capacity to provide tailored service** – although the majority of universal providers would like to support more innovative, inclusive and user-led approaches to service provision, they are unable to self-fund the necessary training to facilitate this culture change. Many were not aware of some existing additional funding that is currently available to them to support children with additional needs.
- **Difficulties associated with discussing changes collectively with external providers** - competition between providers makes them reluctance to discuss innovative ideas in front of one another.
 - GCC have started to meet providers (with Adult Care) again, where concerns have been raised by traditional in-house providers who are anxious about the potential change in provision. Similarly, although mainstream providers were enthusiastic about IBs, external specialist providers were more reticent as they felt threatened by the potential changes.

- GCC facilitated an event for providers to discuss the implications of IBs and Short Breaks, where providers had responded by asking what specific services were required and how they could provide them. The team had been quite frustrated by this response, as this question could only be answered by the service users themselves.
- Some providers were concerned about losing their block contracts, which they felt were required to form a basis from which to grow their services, without which, they may no longer remain financially viable.

Absence of national guidance:

- **Legal framework** – the responsibility of the BHLP was considerable and required additional guidance to ensure that legalities of the process were well understood.
- **Funding restrictions** – it is not clear what funding streams can and should be included within an IB package.
- **Safeguarding** – safeguarding is not an issue at present as the BHLP pilot only used Ofsted providers or existing service provision, both of which have passed through CRB checks. However, this issue will become more important as the market develops and if the pilot is mainstreamed.
- **Need to ensure that IBs are not bound in a tight framework** – families may simply use their IB to buy back the service they already receive if the IB framework does not facilitate innovative means of service delivery.
- **Adverse public perceptions of new form of service provision** – consultees highlighted the potential adversarial reactions of the public in response to the new forms of service provision, which may for example include the purchase of a family holiday or a football season ticket.

Key requirements of a successful approach

3.37 The consultees felt that the key requirements of a successful IB/BHLP/DP intervention were as follows:

Local authority staff:

- **Require a dedicated project manager** – to ensure that pilot is driven forward and conducted effectively.
- **Require dedicated time from a member of the finance team** – to support the development of financial auditing systems and the RAS.
- **Require dedicated time from a member of the commissioning team** – an IB pilot requires dedicate time from a member of the commissioning team who has the capacity to enable and manage the culture change process.

- **Staff training and culture change** (linked to the above point) – need to change the way professionals work to facilitate a change in the way they approach families with disabled children. That is, instead of telling families what they need, professionals should help unravel what the ‘real support needs’ are and explain that not all children require respite/specialist services.
- **Training, support and culture change for Families with disabled children** – to include significant awareness raising at the outset of the pilot and facilitation of some form of peer support. It is also important to work with families to unravel what is actually needed and to not just comply with their initial expectations or demands. By explaining alternative courses of action, families were able to be more innovative and move away from the specialist and traditional service provision e.g. residential care for short breaks.
- **Parents and families must be involved in developing the interventions** – GCC has parents on their project steering groups and ensure that parents talk directly to the providers.
- **Involvement of C&YP in development and review of processes and interventions** right from the start.

Service providers:

- **Market development and working closely with providers** – GCC are supporting their providers to develop their services to accommodate the new forms of demand. For example, they have worked in partnership with Adult Care to recruit a sports inclusion workers and an arts/creative inclusion worker, to support providers to develop innovative approaches to service provision.
 - The BHL P pilot helped individual providers to develop their services and capacity to deliver for individual BHL P users i.e based on individual commissioning.
 - GCC also conducted a baseline assessment of their providers to assess current capacity and capabilities, to enable them to understand the magnitude of development required to accommodate new forms of provision.
 - They are currently engaging with providers to develop a bank of Personal Assistants (PAs) which will accommodate the varying needs of the families who receive an IB/Short Break/BHL P.
- **Need to ensure that providers and parents/young people are brought together to promote understanding of need** - GCC also facilitated sessions between parents/young people and providers and GCC to discuss their needs.

National guidance:

- **Need a national lead to offer guidance on how to develop the commissioning process** – for example, guidance on the legalities of tendering, IB and its implications and perhaps a forum/network to facilitate a debate around the subject.
- **Flexible pot of money in addition to the IB** – GCC has an inclusion grant, which is a flexible pot of money, used to pay for additional needs. This is currently used for children identified with additional needs, who are provided with support to attend a youth club, where the grant pays £5.50 per hour for an additional member of staff to attend and support the child.
- **Need to think about eligibility of what IB money can and cannot be spent on** – e.g. on families and siblings of a disabled child, as well as the disabled child.

Summary of existing approaches

GCC delivered a successful BHLF pilot, which uniquely included the targeting of disabled children and young people who did not meet the social care threshold. The learning and development from this pilot is now being used to deliver an extension of the BHLF pilot and both a Taking Control pilot and the Short Break Pathfinder project. This set of interventions forms the basis of a comprehensive approach to self-directed support for families with disabled children.

The barriers to delivery and key requirements of a successful approach highlight some of the issues that should be taken into account when designing and delivering the forthcoming IB pilots for families with disabled children. The majority of the issues raised reflect difficulties encountered during the preliminary stages of the interventions, indicating the significant level of resources required to effectively set-up a pilot of this nature. It will be important to provide general guidance to and ensure adequate resources are provided to the DCSF pilots to address these issues where possible.

Looking ahead...

- 3.38 The latter half of the case study research focused on the design and development of the forthcoming IB pilots for families with disabled children. Therefore, consultees were asked to provide their views on the potential shape, format and content of the pilots, where responses were overwhelmingly positive and reflected a strong commitment to deliver user-led services within the County.

Pilot options

- 3.39 Initial stages of the IB scoping study research sought to compile a long list of potential pilot options, whose feasibility and desirability was considered during the case study. These options were mainly identified through either the literature review or via consultations, and in a small number of cases, options were developed to potentially fill gaps identified in service provision.

3.40 Table 3-2 presents the pilot options and the responses provided by the consultees on the desirability of each option.

Table 3-2: Pilot options			
Pilot Option	Yes	No	Response
Children in continuing care		✓	Targeting by diagnosis is inequitable
Children needing 24 hour continuity		✓	Targeting by diagnosis is inequitable
Specific age groups with high support needs		✓	Targeting by diagnosis is inequitable
Autism Spectrum Disorder		✓	Targeting by diagnosis is inequitable, however, this set of individuals currently often fall through the gaps of service provision, therefore should be targeted in a more general pilot
Aged 11+ with moving and handling needs that will require equipment and adaptations		✓	Targeting by diagnosis is inequitable
Children coming out of the Early Support Programme	✓		There is currently limited support for children aged 5-6 yrs passing out of the Early Support Programme. Continuity in support would be useful.
Disabled children who are moving from primary to secondary		✓	A large proportion of children with disabilities attend special school and therefore do not face significant transition when moving from primary to secondary school. This pilot will target only children in mainstream schooling and is therefore relatively limited in its nature.
Disabled children aged 5-14 yrs	✓		Good idea, as this pilot could target children who attend both mainstream and special school.
Children aged 14+ yrs i.e. those in transition	✓		Transition from children's to adult services requires specialist support and therefore would benefit from an IB approach. However, this will be dependent on close working relationship between children's and adult services.
Newcomers to the social care system or disabled children at the point of intervention	✓		Early intervention will be effective, is an obvious area to start and should prevent the development of complex needs. However, there may be difficulties recruiting sufficient nos of beneficiaries as a cohort for a pilot as new referrals to the system come in 'dribs and drabs'.
Disabled children from BAME groups	✓		The BAME community in GCC are less likely to access social services than their counterparts and are under-represented within the service. Therefore, there is likely to be significant unmet need from this group, who may find IBs more culturally sensitive. However, a pilot of this nature may require more resources to engage the relevant communities.
Disabled children from families who are 'on the edge of care'		✓	Controversial in its nature and would be too difficult to define the group and hence recruit beneficiaries. May also be inequitable to target the intervention at this group.
Mixture of both rural and urban areas	✓		Service provision is likely to vary between urban and rural areas and therefore it will be important to pilot IBs in both types of area.
Offer IBs to target number of families with disabled children regardless of type of disability	✓		This option was the most popular, as it was equitable, offered flexibility and could later be analysed by type of disability.
Extend the current adult IB pilots to cover families with disabled children		✓	Inequitable as only a limited no of LA can take part and provision of adult IBs is likely to significantly differ from provision to children.

Pilot Option	Yes	No	Response
Extend only those adult IB pilots that have a disproportionately high demand for IB and number of disabled children		✓	Inequitable as only a limited no of LA can take part and provision of adult IBs is likely to significantly differ from provision to children.
Extend the service provision offered by the existing BHLPP pilots to families with disabled children	✓		As GCC were a BHLPP pilot, they favoured this option and added that less resources would be required to fund pilots of this nature. As they had already begun to develop interventions of a self-directed nature.

Source: SQW Consulting

Potential demand

- 3.41 Consultees were asked to comment on the types of services that are likely to be requested by beneficiaries as part of an IB package. Responses included the provision of short breaks, practical parenting support, support with lifting and handling, transport support and provision of appropriate specialist equipment. There was also a general consensus on the need to provide appropriate personal assistants, who could enable a child to access community based activities and hence increase their interaction with other children.
- 3.42 Case study research also highlighted the need to engage and work with the families to understand their needs and to support them in developing innovative ideas for support plans. For example one consultee stated:

“The pilot and its staff need to work with the families to help them understand what is available, as they will not be used to thinking about what would make a difference. This form of engagement is key, as it will lead to a more innovative approach to service provision which will be formulated by the child and their family.”

- 3.43 Additional comments indicated that although parents and young people were interested in the concept of an IB, the responsibility of managing a budget and general lack of awareness of what an IB could be used for, may discourage them in taking up the support. Therefore, it will be important to engage and appropriately promote the pilot to potential beneficiaries to ensure sufficient take-up during the pilot period.

Potential resource implications

- 3.44 Through the experience gained in setting up (and delivering) a BHLPP and Taking Control pilot, GCC emphasised the need to recognise the significant staff and resource commitment required to effectively pilot an IB type approach. This commitment was felt to be especially important during the set-up phase, which was estimated to take at least a year to complete, following which a two year period would be required to embed the activity. Consultees also felt it would be important to assess the starting point of each pilot Local Authority, where those that had already piloted an IB type approach e.g. Taking Control or BHLPP, would potentially require less time and resources to set up and deliver a pilot of this nature.

3.45 Looking specifically at the set-up stage of an IB pilot, consultees felt that the following set of resources would be required:

- **Staff resources and workforce development** - each pilot will require a dedicated, full-time project manager, a part time performance officer, a part time finance officer and dedicated time from a member of the commissioning team, senior-level buy-in to drive forward the idea and proactive engagement from the social work fieldwork team. It was also noted that all staff would require sufficient training at the beginning of the process to facilitate the necessary change in culture and to enable them to act as the ambassadors of the project.
- **User engagement** – need to develop facilitate user engagement, to ensure potential beneficiaries are informed about the process and to engage them in the development process. Training is likely to be required for this group also.
 - Ideally, each site should recruit 1-2 champions from their user group to help promote the activity to their counterparts and form a reference group, which includes both users and non-users of IBs.
- **Provider engagement** – it will be vital to engage providers from the out-set of the pilot, to ensure that they are aware of the implications of the new form of service provision and to enable them to enhance their current service offer/increase flexibility where required. This again is likely to involve provider training and capacity building exercises.
 - Ideally, each pilot site should conduct a mapping exercise to understand what services are currently available in the area and any gaps in the market. This should be used as the basis for market development and disseminated to providers.
- **IT system development** – each pilot will need to develop a specific IT system to monitor and audit the activities of the programme. This process needs to accommodate the spectrum of funding deployment options made available to beneficiaries
- **RAS development** – the project team in conjunction with a member of the finance team, will need to develop some form of RAS upon which to base the division of monies. Consultees stated that this process was complex and the time taken to develop this system, which can take up to a year, should not be underestimated.

Looking ahead to the completion of the RAS, the team have discussed how to complete the self-assessment questionnaire with families. They also indicated that there was an intention for both the family and their associated support worker to complete a self-assessment questionnaire, therefore producing two indicative budgets. This will enable them to assess any differences between the results of the family and those of their support worker and to review consistency between support workers. The opportunity to discuss the process

will be available at all times, as the team feel the ethos of the pilot is centred on problem solving with the family and child/young person.

- **Development of funding deployment options** – each pilot site will need to consider which funding deployment options they intend to offer to their beneficiaries and how each option will be resourced and facilitated. For example, if the site offers the choice of either a Direct Payment to the family or an Individual Service Fund (ISF), the resource implications are likely to impact on the existing direct payments provider and on developing capacity in an external provider organisation to enable the provision of ISFs.
- **Potential of double funding** - each pilot site must be willing to run the IB forms of service provision alongside its traditional service provision, which may result in double-funding in some cases, and requires up-front pump-priming.
- **External support** – all pilot sites require some form of continuous and consistent external support. This could include the facilitation of residential workshops, where pilot sites can come together and share issues/best practice with one another, as well as having a specialist organisation/points of contact to use as a sounding board for the various components of the pilot e.g. distinct finance and legal contacts at the DCSF.
- **National guidance** - the research also indicated a need for national guidance on funding integration, legal issues surrounding IBs e.g. safeguarding and public liability insurance, and on a 'loose' form of guidance on what IBs have been used for to date.

3.46 Consultees noted that the above list was not necessarily comprehensive, but that it encompassed a number of the significant resources which would be required to deliver an IB pilot to families with disabled children.

Potential Funding

3.47 Integration of funding streams was seen as the main challenge to delivering a meaningful IB pilot. Consultees specifically cited health funds as being problematic and added that the current legal framework prohibited the inclusion of funding streams such as Continuing Care.

3.48 Consultees were asked to comment on the funding streams they felt were currently feasible to include in an IB package, those which they would ideally like to include in addition and those that were infeasible. Responses highlighted the following:

- **Feasible funding streams** – Social care budget, Short Breaks funding.
- **Funding streams LA would like to include** – health related therapy services funding, community health funding, pooled health and social services funding, Integrated Community Equipment Service Fund, area based grants, SEN, education based transport funding, Sure Start and Extended Schools funding, LSC funding

- **Infeasible funding streams** – Independent Living Fund, Disability Living Allowance.

3.49 One consultee highlighted the importance of separating funding streams into two groups, one which provided funding for services and one which provided some form of income for the family. They added that it should only be the former that should constitute part of an IB funding package.

Looking Ahead Summary

Staff at GCC were very positive about the forthcoming IB pilots for families with disabled children. When asked about how they were likely to add value, responses included: the empowering nature of the approach, which would give families a new sense of confidence and control over their lives and therefore result in positive outcomes; a whole systems change for local authorities, who would take a more holistic approach to service provision; and lastly, the pilots would facilitate a form of service provision which responds at the point of need.

4: Newcastle City Council

Context

- 4.1 This case study report presents the findings of consultations with key staff, stakeholders and families working within or with experiences of services for children and families with disabled children. The report examines current and planned activities and service developments supporting these families and outlines the lessons, good practice and views on the development of a pilot programme.
- 4.2 During the course of the case study 7 people were consulted and particular thanks should be given to Pat Thompson, the manager of the Children with Disabilities Services Team and Paul Connolly the transitional worker for the same team who were interviewed twice and supported the undertaking of the case study.
- 4.3 Newcastle City Council has been developing their Direct Payments (DP) and Individual Budgets (IB) offer for adults and children for a number of years and as such, have been able to provide valuable insights into the barriers faced and critical success factors in establishing and implementing such activities.
- 4.4 Newcastle City Council serves 266,000 people directly, with approximately 64,000 young people in the 0-19 age range (2004 mid year estimate).
- 4.5 The Newcastle Plan for Children and Young People reports that the Northern Region has the highest proportion of children with disabilities in the country (3.9% cf 3.1% nationally). The Royal Victoria Infirmary Neonatal Unit (part of Newcastle upon Tyne Hospitals Trust, providing tertiary services across the region) has the lowest mortality rate in the country, which increases the number of children requiring support from Health, Education and Social Services. The needs of children with complex health issues and those of disabled children are often very similar. Children become disabled if their complex health issues remain over time¹⁶.

Existing Approaches

Direct Payments

- 4.6 Newcastle have been delivering Direct Payments for adults since the late 1990's and have established an independent advice service to support this.
- 4.7 Direct Payments for families with disabled children were introduced five years ago. There are currently 67 children benefitting from the DP scheme all of whom have significant support needs and span an age range of 3-17 years. The Children's Services Team have used the support services developed for the adult DP scheme

¹⁶ The Newcastle Plan for Children and Young People April 2006 – April 2009.
<http://www.newcastle.gov.uk/wwwfileroot/socialservices/children/TheNewcastlePlanforChildrenandYoungPeople.pdf>

to provide support to families in the recruitment of staff and services, employment regulations and training¹⁷.

- 4.8 The DP scheme for families with a disabled child is generally viewed to have been a success by both staff and the family consulted. The scheme is identified as having grown largely as a result of word of mouth amongst satisfied families. There is an expectation that all social workers offer DPs when designing a child's plan but that it is only emphasised in cases where it is likely to be most helpful in accordance with the national guidelines. However, whilst the local authority is confident that the social work team have fully bought into the ethos of DP, some concern was raised by consultees regarding the extent to which social workers inform parents about the scheme, although it is acknowledged that confidence has grown in the support that is available through the Direct Payments Support Team.

The Dynamite Pilot

- 4.9 The Dynamite pilot has targeted young people aged 15-17 years old and their families. This group is generally referred to as the *transition* group because they are in the process of moving from children's to adult services. The pilot has targeted young people with learning difficulties as a primary disability although they may have additional disabilities. The pilot originally sought to target families from a wide range of socio-economic backgrounds but this has generally been achieved within the small group.
- 4.10 The Dynamite pilot began in began in October 2006 and was introduced to families in January 2007. Plans were developed with the families who were interested over the course of the last year and budgets were agreed in March 2008. In order to give families an understanding of how the IBs would be planed and used, a taster budget of £200 was given to families to plan and use in the summer of 2007. A full pilot schedule is provided in Table 4-1.

Figure 4-1: Key milestones in the pilot

Date	Action
October 2006	Newcastle City Council Signed up to the pilot
January 2007	Overall pilot project plan submitted
May – August 2007	RAS Allocation
Summer 2007	£200 given to participating families to test out how budgets could be used
October 2007	Feedback from families on use of funding over the summer
November 2007	Agreed allocations
March 2008	3 plans signed off
July 2008	1 plan signed off.

Source: SQW Consulting from consultations

¹⁷ The service is funded by Newcastle Social Services and is managed by Disability North a registered charity which aims to support disabled and older people, their families, friends and carers. Services are also provided for students or professionals working in the statutory, voluntary and the public sector.

- 4.11 The pilot has supported seven young people and their families (4 male and 3 female). Recruitment of families to participate in the pilot was undertaken in two stages. Firstly, an open invite was sent out to all families with a disabled child to attend an introductory event. Following the open invitation, the social work team identified those families who were most likely to be interested and followed up with them to encourage them to attend the event. Following the event 7 families signed up to the Dynamite pilot, some of these were previously DP users. Of these 7 families, 3 have had their support plans signed off and another plan is due to be signed off by July 2008. The remaining 3 families are undecided about taking up IBs but remain involved in the work of the project attending the regular sessions that are organised with parents.
- 4.12 Whilst some families may not take up the IB offer, take-up and the experience of the pilot is viewed as positive by all consultees and those involved have had positive experiences.
- 4.13 Each family within the pilot was provided with a facilitator to support them through the development of their support plan. Each of the seven participating families was allocated a different facilitator. The facilitators were recruited from a range of backgrounds including social work, the voluntary sector, adult services, a provider organisation and the Newcastle Special Educational Needs Network (a parent led group). Each of the 7 facilitators participated in a two day Support Provision training course (provided by Paradigm).
- 4.14 The time taken to develop the plans has varied depending upon the skills and experience of the facilitator. Experienced facilitators worked with families on the plans for 8-10 hours whilst those with less experience took up to 25-30 hours.
- 4.15 The assessment process used within Dynamite in Newcastle requires each individual and their family to complete a self assessment with their facilitator. Newcastle originally used Version 1 of the in Control questionnaire but after holding a staff feedback session on the self assessment process they changed to Version 2.
- 4.16 In order to allocate budgets the pilot used the adapted Children's RAS. The pilot believes this produces a more equitable distribution of funding compared to the traditional system. Between May and August 2007, the needs of 76 young people and their families were assessed to develop the RAS and associated price point. This process produced a price point of £92 per point (consultees noted that this was perhaps a little lower than what was actually spent). This estimation was based on nearly £1million worth of spending on 60 of the 76 individuals (spending total was £2 million for all 76 but was reduced to £1 million when anomalies were removed from the sample i.e. those with very high and very low levels of need).
- 4.17 Newcastle is also a key worker pilot for the **Early Support Programme (ESP)** which has proved to be 'quite successful' (has received positive feedback from carers) and hence is considering rolling the pilot out across the Local Authority.

Demand for existing approaches

- 4.18 The Direct Payments support team in Newcastle currently supports over 400 users (using a mix of adult and child DPs and IBs). The Dynamite programme has worked with 7 families and will agree support plans for 4 families by July 2008.
- 4.19 The Direct Payments Support Team, who also provide support to those accessing adult and family IBs report that the services in greatest demand are transport (which is currently very restricted within DPs) and respite care/overnight care. The pilot co-ordinator reported that in general the young people and their families in Dynamite have requested similar services as were provided under the traditional budget, but have simply tailored the services to meet their needs more effectively. The services in greatest demand have been respite care and home and night care often to allow the young person to stay at home whilst the family go away or care support to enable young people to go away with the family. The funding has also been used to provide access to venues for example, one young person used their budget to purchase health club membership thus providing access to community facilities.
- 4.20 One of the consultees believed that the use of CAF (Common Assessment Framework) should alleviate a significant proportion of unmet need. The CAF is seen as a real opportunity to promote problem solving and supportive networking at the heart of interventions with children young people and their families. The Self Assessment Questionnaire (SAQ) could identify need earlier and quantify that in a way that allows you to support a more preventative strategy of intervention with children and their families. A small level of resources may be good in relieving stress earlier which helps to support a child's place within the family.
- 4.21 The threshold for social care was set independently in each local authority and for Newcastle it has been set relatively high and focused on complex disabilities. The local authority would require more resources if the threshold was lower.
- 4.22 Of the 7 families who have participated in the Dynamite pilot only 4 have so far progressed to completing and implementing plans. The family interviewed had taken up the offer but noted that one of the families that hadn't progressed with implementing the IB plan had a lower budget, which may have contributed to their decision to stall the process, given the effort required for what seemed to be limited gain.

Funding

- 4.23 The Dynamite pilot has mainly drawn on social care budgets, as these were less complicated to access and draw into an IB. However, the pilot is currently trying to draw in some education funding for one of the individuals, who had asked to be reimbursed for petrol costs incurred on the way to and from school/college.
- 4.24 The Integrated Community Equipment Service Fund is identified as having potential to be drawn into an IB because it is 50:50 funded by health and social care. However, to date this funding hasn't been targeted as the team have focused on social services funds rather than health. The Independent Living Fund (ILF) (for

aged 16+) is identified as being difficult to integrate into an IB because it has to be spent on social care and has different eligibility criteria to IBs.

- 4.25 The Continuity Care Budget would be significant if it could be integrated but it has a restrictive eligibility criteria and process for allocation. Newcastle has been monitoring developments within the Eastern region regarding LSC funding through the Individual Learning Funds and is seeking to learn from the emerging demand-led lessons.
- 4.26 The Disabled Facilities Grant was highlighted as a funding stream which the LA would not even consider trying to integrate into an IB, as it would be too complicated to include, given the stringent rules on the use of the fund.

Effectiveness of existing approaches and key requirements of a successful approach

- 4.27 Consultees identified the following aspects of the pilot to have been most important in ensuring its success:
- **Supported Planning** – this has been one of the most important elements of the programmes and has taken a number of forms:
 - **Regular meetings families** – since the initial introductory meeting with families the team delivering Dynamite has met with the families as a group 8 times to discuss progress, issues and concerns.
 - **Peer support** – as well as providing an opportunity for the delivery team to meet with families, the regular meetings have offered an opportunity for the participating families to provide peer support to each other. The families have gone on to set up an email group which has been invaluable, providing mutual advice and support e.g. one family had trouble setting up a bank account for their son (which is a requirement of an IB to facilitate transferral of funds) and another family was able to assist as they worked in a bank.
 - The role of the **facilitator/broker** was identified as essential and the success of the Dynamite pilot's facilitation was linked to the quality and enthusiasm of the brokers used.
 - **Project Co-ordinator** – the role of a project coordinator was identified as one of the key success factors and the local authority felt that without the coordinator the pilot would have failed.
 - The project has benefitted from **IT and resource allocation support** from Paradigm (helped develop the in Control RAS for their own purposes) and the Newcastle Direct Payments Team whose support has been invaluable.

Barriers to delivery

4.28 The following legislative/organisational barriers to the Dynamite project were identified by the consultees:

- **Engaging other funding agencies** – it was noted that the Social Care Department is currently leading this work with limited involvement of other services. There would be much more scope to be flexible if health, education and the LSC were committed to and engaged in IBs. Newcastle has made some progress in engaging partners, the LSC were on the project steering group and have contributed funding to the cost of administering the pilot, health contributed by facilitating the support plans with young people for the initial £200 given to families but had to withdraw their engagement subsequent to this due to capacity. Education colleges have also shown some interest. The manager noted that whilst it has been difficult to engage partners it is likely that if the social care team were to proceed in isolation, without the support of other partners, tensions would arise.
- **Challenging the culture** – the concept of IBs is a huge shift from traditional delivery of support and has challenged social workers, the delivery team, families and young people. Staff involved can be fearful of the impact on their role and the responsibility to get the plan right and ensure the funds are used effectively to best meet the needs of the children and young people involved. The Newcastle team note that it has been useful to discuss these risks and challenges with families and staff together to share their fears around the safety of children, budgets and the reputation of the local authority.
- **Safeguarding** has proved to be one of the major risks as even within DPs there are no national standards. Challenges have included a situation where one of the IB clients had purchased support from a residential respite provider which the local authority had actively chosen not to contract with. This raised potential safeguarding difficulties. In this instance the local authority enlisted the Looked after Children Team to conduct an individual evaluation of the provider.

Added value

- 4.29 Although it was difficult to quantify the outcomes at this stage in the process, consultees from the local authority felt that the families and young people had felt more in control and choice in the type of support provision they were able to access through their IB support plan. The indicative £200 ‘taster’ budget had led to a feeling of ‘freedom’, which all thought was very positive.
- 4.30 One of the consultees believed that there may be scope for savings on the assessment process as the IB assessment process was far less timely than the traditional assessment process. He added that the traditional process involved ‘far too many people, was too time consuming and that families were not always clear of the outcomes at the end of the process’. Therefore the IB assessment would lead to the re-deployment of resources to situations which warranted their use.

- 4.31 Furthermore the costs of the Dynamite pilot IB provision has been 12% less than the comparative traditional service provision costs¹⁸ and has built in a contingency for increased need and planning for emergencies when family crisis occurred. This saving is based on a small number of participating individuals but in light of their high support needs it is possible that if adopted across a wider number of families with lower levels of needs the savings could be maintained if not increased.
- 4.32 Anecdotal evidence from consultations with families suggests that families within the Dynamite pilot have reduced need for contact with their social worker as the system is easier for the family to manage. The pilot coordinator believes that families generally make good decisions about spending money, they look for best value, they make savings and they can think creatively. This is a challenge for children's services as it requires a shift in culture to accept that 'we [professionals] don't always know best'.
- 4.33 The pilot coordinator believes that IBs can and should be the central plank of the AHDC strategy. Individual Budgets should provide greater transparency, understanding and quicker assessment information. The approach represents a move away from state paternalism to children young people and families making these decisions for themselves.
- 4.34 Looking to the future, added value from adopting an IB approach was identified from both the perspective of responsible agencies and individuals and their families.
- 4.35 The local authority view IBs as:
- providing a method of joining up budgets and commissioning strategy
 - providing fit with workforce reform agendas
 - contributing to the participation agenda
 - providing scope to create more efficient services
 - contributing to the inclusion agenda.
- 4.36 Whilst it is too early to make a judgement on the cost effectiveness of IBs overall, in Newcastle individual packages of care are costing less so at the micro-scale there is evidence to suggest that IBs are cost-effective.
- 4.37 From a personal perspective, the family interviewed reported that the overriding added value of the IB approach is that it allows their son, Tom¹⁹, who has high level needs, to be cared for within the family home by staff that the family and Tom are comfortable with. The family had felt that prior to engagement with DPs and subsequently IBs, the favoured approach of social services was to promote respite care which would have broken up the family. Other benefits identified by the family were:

¹⁸ This was mainly a result of one of the individuals reducing the amount of residential respite they required from 28 to 2 days

¹⁹ Please note names have been changed to preserve anonymity.

- through IBs and direct employment of support staff they are able to only pay for the hours used and as such maximise the care they receive for their allocation
 - within DPs the family were unable to use surplus funds which arose if Tom was too unwell to attend activities with his carer, within IBs these hours can be used when Tom is better
- the IB scheme is more flexible to Tom's needs and has helped to keep the family together and work as a family
- the IB scheme has benefitted Tom's sister as they have been able to take a carer on holiday with them meaning that holiday options are much wider for the family that previously
- the family are able to pay staff more than they were paid through the agency whilst still making an overall saving on the agency rates previously charged.

Summary of existing approaches

- Direct Payments for adults and children have been in place in Newcastle for a number of years. The Direct Payments scheme has proved to be successful in supporting individuals and families to tailor the services they access. The scheme has highlighted the need for good quality information, advice and guidance and this has been provided by a dedicated team.
- The Dynamite pilot in Newcastle has targeted the transition group (15-17 year olds) and has supported 7 families through the planning process with 4 families deciding to take their plans forward into a full IB budget.
- The Dynamite pilot engaged facilitators from a range of backgrounds to support families to develop their plans and has also engaged the services of the Direct Payments Support Team to provide employment, training and regulations advice to families.
- The Dynamite pilot has taken 18 months to progress from initial sign-up to the pilot to signing off family budgets.

Looking ahead...

- 4.38 This section of the case study examines consultees views on the shape and focus of the forthcoming pilots. Consultees were asked to consider potential target groups, the set-up requirements (timescale and resources) and any additional anticipated barriers.
- 4.39 Overall consultees were enthusiastic about the possibility of extending the IB pilot in Newcastle. They made particular reference to the potential opportunity to continue to focus on the transition group and provided insights into the approach that should be taken when setting up and implementing pilots.

Pilot options

- 4.40 During case study consultations opinions were gathered on the list of potential pilot options developed in the Interim Report. The responses are summarised below.

- **Targeting by type of disability** – targeting those with high support needs or continuing care was highlighted as being sensible as these individuals are always going to receive support. Given the recent shift towards higher eligibility criteria resulting in only those with higher support needs being supported, targeting in this way would mean that those targeted would be able to access support. The Direct Payments Team noted that adults in continuing care are not eligible for DPs due to disagreements between health and social services regarding who pays for these services, so it is likely that incorporating this group into IBs would be challenging. The high support needs groups were identified as offering a real opportunity to engage other partners, namely health, but as also being very challenging and posing risks around safety and accountability for the local authority and as such are probably not an ideal group to start furthering understanding of delivering IBs.
- **Targeting by age group** – targeting the transition group (15-17years) was viewed as a priority by all consultees reflecting the opportunity to build on existing provision in Newcastle and also highlighting the importance of bridging the gap between children's and adult services. Targeting children moving from primary to secondary school was viewed as much less important, partly because those with high level needs are generally in segregated provision and those who are in mainstream provision may find this a stressful enough time without additional change. From a general perspective, the Manager of Children's Services for Disabled Children felt that targeting those aged 0-5 would provide a good fit with the existing Early Support Programme (ESP) and also provide an opportunity to engage health and education from the outset. But if given a choice, this group would not be a priority for Newcastle as adding IBs for this group to existing activity may be more than the team has the capacity to manage at present. It was noted that any introduction of IBs targeted at specific age ranges would have to commit to ongoing access to the offer after the child leaves that age group.
- **Targeting by socio-economic characteristics** – the Direct Payments Team noted that DPs have proved popular amongst families from BAME backgrounds in Newcastle as it enables them to recruit and commission culturally responsive services. This may mean there is an opportunity to test this further through IBs. However, some consultees felt that socio-economic characteristics shouldn't matter if a quality service is being provided to support all to access IBs.
- **Targeting by geographical location** – Newcastle is an urban area so has limited experience of rural issues but all consultees acknowledged the significant challenges encountered accessing services in rural areas and that there is huge variation in what you can get for your money in rural areas compared to urban areas.
- **Comprehensive offer** – offering IBs comprehensively was identified as a good opportunity to fully engage partners and to see which groups embrace the offer but this is likely to be a very challenging approach.

- **Extension(s) of existing service provision** – introducing IBs as a follow-on from the Early Support Programme (ESP) was received positively as consultees felt that families would be open to alternative approaches and would be able to adapt easily. It was noted that families and individuals value continuity and as such, following on from ESP could be a valuable opportunity to provide continuity. Extending the delivery of the current Transitions focused work in Newcastle was the preferred option for the local authority. It was noted that there are other local authorities who have delivered adult IBs and are very interested in extending this offer to include children’s IBs.

Potential demand

- 4.41 In their experience, the Direct Payments Team has found that those families and individuals most likely to be reluctant to participate in DPs are those who have had to ‘fight’ to secure a service. This is largely because they are concerned that there is scope to lose the service and therefore encouraging this group is very difficult despite the fact that they may benefit from having control given back to them.
- 4.42 The Dynamite coordinator noted that it is important to seek to engage those families who are at first reluctant but who have been identified by social services staff as having potential to benefit from IBs, as otherwise the offer is only being tested with those families who are most confident and pro-active. Therefore, appropriate support would have to be incorporated for all participating families.
- 4.43 As noted earlier the greatest demand through Direct Payments has been for transport and respite and overnight care.

Potential resource implications

- 4.44 Consultees generally agreed that planning, setting up and implementing such a pilot requires a significant time input which should not be underestimated or under-scoped. Consultees from the delivery and strategic perspectives identified the importance of the planning and engagement stage highlighting the need to secure agreement and commitment from the local authority and other budget holding stakeholders before widening engagement to include other stakeholders including providers and brokerage organisations at an early stage. It was suggested that this top-down strategic approach would help to ensure trust arrangements are in place and all partners are committed thus facilitating the culture shift.
- 4.45 Figure 4-2 summarises the anticipated time required for different elements of the set-up and planning process. The manager of Children’s Services for Disabled Children noted that some of the most valuable learning for the pilots may well arise during the initial 6 month set-up and engagement period and as such this element should not be underestimated.

Figure 4-2: Suggested timescales for set-up and implementation of a pilot

Action	Time-period required	
Securing sign-up and partner commitment	Engaging commissioners and securing commitment	3months
	Engaging providers and other stakeholders	2 months
Developing and establishing plans	1 year	
Total time required	1 Year 6 Months	

Source: SQW Consulting from consultation

- 4.46 Consultees agreed that subject to specific targeting of the pilots, all eligible families (e.g. within a transition targeted pilot all aged 15-17 years or within a comprehensive offer all families with support needs) should be offered an open invitation to introduction sessions but that care should be taken to ensure families are aware of the way in which IBs work and the expectations upon them within the scheme. It was agreed that it is worth putting effort in at this early stage to ensure that there are no false expectations and the families signing up are informed.
- 4.47 Consultees felt that engagement of service providers at an early stage would prompt the market to consider ways in which they can provide a more flexible service and develop responses to the demand likely to emerge. The development of a dialogue can be supported by engagement of providers in discussion groups in the planning stages with families and users. There is some evidence from the existing Dynamite pilot in Newcastle that providers are seeking to be more flexible and are willing to train staff to meet families needs.
- 4.48 The role of appropriate brokers was highlighted repeatedly in consultations. As noted earlier the Dynamite pilot in Newcastle provided 2 days training for the facilitators. The Direct Payments Team made reference to previous experience of introduction of IBs for adults with learning difficulties in which many of the brokers were from provider organisations. This arrangement was deemed to be inappropriate and alternative arrangements were subsequently made.
- 4.49 A wider concern was raised regarding the ideological clash which may arise if the personalisation agenda combined with eligibility criteria leads to a situation where all access to care is focused on those with substantial and critical need. This would leave a huge vulnerable group who may have lower support needs but as a result may in fact be more vulnerable, raising a question of how those with lower support needs are supported and where prevention fits in the discussion.

Potential Funding

Please refer to earlier section on funding.

Looking ahead summary

- The preferred targeting option for the pilots from consultations in Newcastle was an extension of existing activities (i.e. targeting the Transition Group) or focusing on families with children aged 0-5 years.
- When considering targeting the importance of ensuring outreach and support is available to attract families from a range of socio-economic backgrounds was highlighted to ensure that the pilots are really 'testing' IBs for a wide range of beneficiaries.
- Ensuring that sufficient time is given for the engagement and commitment of services, providers and families was identified as essential in the planning of the pilots. Consultees felt that this stage is the most important as solid foundations and commitments to 'make this work' need to be secured before families are involved.
- The IB approach is identified as being the basis of the AHDC strategy and provides fit with and opportunities to contribute to a range of agendas including workforce reform, participation, inclusion and the development of efficient services.

5: Northumberland County Council

Context

- 5.1 Northumberland is geographically one of the largest shire counties in England with a large proportion of the population residing in rural areas. From April 2009 structural changes will result in the creation of a single unitary authority for Northumberland which was previously made up of six district councils and Northumberland County Council.
- 5.2 We have been unable to accurately source the numbers of disabled children in the County; however, national prevalence rates suggest that approximately 2000 children in the County have a disability²⁰.
- 5.3 There is a clear distinction in the delivery of Adult and Child social care in Northumberland. Adult Services are delivered by Northumberland Care Trust. Children's Services are delivered by Northumberland Families and Children's Trust (FACT).
- 5.4 During the course of this case study, three members of staff were able to contribute:
- Social Worker from the Disabled Children's Team within Families and Children's Trust (FACT). With responsibility for being the Transition Champion for Dynamite and is involved in the Taking Control pilot
 - Children and Families Support Worker for Direct Payments
 - Direct Payments Senior Support Worker.

Existing Approaches

Dynamite Pilot

- 5.5 The Local Authority was involved in a two year pilot for the Dynamite project for young people in transition from 2005 – 2007. The Dynamite project targeted young people with a learning disability and was relatively small scale in its nature, where it aimed to target eight families with young people aged 14-18 years. The young people recruited were aged 16-18 and all were aged eighteen by the end of the pilot. Six families progressed through to the IB stage; however, only 2/3 of the families went on to continue accessing their services beyond the end of the pilot.

²⁰ The Family Resources Survey 2002-03 estimates that there are approximately 700,000 disabled children under 16 in Great Britain, indicating a national prevalence rate of 3% of all children aged 0-16 years. Please note that the estimate used in this paper is based on 3% of the 0-19 yrs population.

Taking Control Pilot

- 5.6 Following the delivery of the Dynamite pilot, the Local Authority chose to become a 'Taking Control' pilot site in Sept/Oct 2007. The pilot is currently in its initial phases, with staff in discussions to identify a number of families to take part in this pilot.
- 5.7 NCC's Taking Control pilot will target children and young people who are aged between 5 -14 years and who fall within the remit of the Disabled Children's Team, i.e. children who have a 'substantial and enduring disability'.

Direct Payments

- 5.8 NCC began to develop its DP mechanisms over the period 2000-2002 and formally implemented its Direct Payments Team in 2002/03. In July 2003, there were ten recipients of Direct Payments within Northumberland, all of whom were adults. As at March 2008, over 90 children and 324 adults were in receipt of a direct payment.
- 5.9 The County now operates a successful Direct Payments (DP) Team, who provide a service for both children and adults. The team comprises five full time staff, one senior support worker, two adult support workers, one children's support worker and a finance and monitoring officer (adult finance only). The team also has a part time administrative assistant. It is important to note that the Children's Finance team is responsible for the financial aspects of children's DP.
- 5.10 The DP Team provides in house support to all beneficiaries, where client referrals are made by social workers, following the assessment of a child and their family. Once a referral has been made, a member of the DP team visits the family to introduce the scheme and later on down the line, the team supports clients who receive money in lieu of services, to commission their own care. Support workers from the DP team provide intensive assistance to support clients through all aspects of the DP process. This includes:
- Information and guidance on receiving DP
 - Assistance in completing any application forms
 - Identifying services and assisting in examining commissioning options
 - HR, employment and payroll advice
 - Assistance with advertising for staff
 - Recruitment and selection guidance
 - Training sessions for carers and care workers
 - On going support to clients.

Demand for existing approaches

- 5.11 There has been a positive and continual increase in the take-up of DP across Northumberland, which has been accompanied by fewer people declining DP

provision. In the cases where the DP offer is declined, it is often because individuals do not want the monetary responsibility associated with managing and holding their own budget. In addition, some individuals do not want the additional responsibility of becoming an employer.

- 5.12 Consultation undertaken by NCC with families for the Taking Control Pilot highlighted that potential beneficiaries appear to be quite excited at the prospect of receiving an individual budget. The consultation exercise also indicated that many families would not choose to send their child to an external 'respite unit' and would instead prefer to employ an extra pair of hands who could provide general support. For example, families would like to employ an appropriate individual to go on day trips with them. NCC also provides clients with information on independent payroll services for those families who employ care workers or personal assistants. This service has been well received by the majority of families, who have reported that they are happy with the support provided.

Demand for services

- 5.13 Consultees felt that there was a great demand for respite care in Northumberland, where for example the current respite unit which caters for 7 – 16 years olds is currently oversubscribed. Recent consultations with potential participants in the Taking Control pilot indicated a demand for the provision of more home-based respite care, as opposed to provision through an external residential unit. However, it is important to note that some families prefer their child to receive respite at an external venue, signalling a need for both the external and more traditional form of provision and home-based support. The consultation exercise also highlighted a demand for short-breaks, specialist equipment, information and guidance.
- 5.14 The case study research also indicated that parents are currently accessing services which they find helpful as part of a DP. These include: sitting services; holiday care; out of school activities; and help with domestic chores.
- 5.15 NCC reports that DP has been successful in meeting the needs of those individuals who do not want to access traditional services. They also stated that there can often be a great deal of stigma attached to accessing local authority provided services, which may lead individuals to opt out of accessing services entirely. Therefore, NCC/ NCT view the provision of DP as an important means of providing choice and thereby reducing the barriers to service provision. For example, the Council identified that some older people did not want to go to the elderly day centres and subsequently they supported this group to use their DP to pay for a care worker to help them access social activities.
- 5.16 For some families, the "stigma" of having a social worker leads to anxiety and concern, as they fear the involvement of social services and the negative implications this involvement may have on them i.e. implying they are 'bad parents' or that their children will be 'taken away'. However, the Council have found that support work has helped to alleviate these fears.

Funding

- 5.17 Direct payments are funded from the same budgets as traditional social care – there are no separate budgets. In adult care supplementary funds may be available from the Independent Living Fund, but this funding is separate from the direct payments. DP team salaries are funded from a combination of monies from Northumberland Families and Children’s Trust and Northumberland Care Trust.

Effectiveness of existing approaches

- 5.18 The implementation and take-up of DP has been successful in Northumberland as a result of their strategic vision and a strong and proactive team driving the agenda forward. There is a clear lead within the team, who ensures that all staff are appropriately informed and possess a good level of understanding about DP. The team also has positive relationships with other teams across the local authority, which includes social services and finance. Consultees stated that developing positive relationships with social workers had been crucial, as they are commonly the first point of referral for clients to DP.
- 5.19 The success of DP is also reflected in a recent report which was compiled by the team to assess the views of DP clients. Over 80%²¹ of adult clients stated they were extremely or very satisfied with the service they commissioned themselves; this compares with 67% of clients receiving their service via traditional methods provided by the local authority.
- 5.20 Looking specifically at children, 77% of clients receiving DP stated they were extremely satisfied or very satisfied with the service which they commissioned themselves.
- 5.21 Figure 6-1 illustrates how the DP team worked in partnership with other agencies to not only increase the take-up of direct payments, but to stimulate demand and ensure this could be met. The project’s success was recognised nationally when it was honoured at the Community Care Magazine award in 2008.

Figure 5-1: The Bell View Brokerage Project

Due to the geographical landscape and rural areas of the district it can be difficult to find sufficient staff to facilitate personalised services. In an attempt to combat this, an innovative joint venture between the Bell View Resource Centre, Northumberland Care Trust and the local Sure Start team was set-up to solve the problems of providing more carers for an increasingly elderly population and improving scarce employment opportunities for parents and carers in need of local flexible work.

The organisations came together to produce a directory of care workers in rural areas, accessible to both direct payments recipients and private funders. This directory put service users in direct contact with trained care workers, allowing all negotiations over work, hours and so on to take place without the need for statutory intervention.

The project demonstrates the advantages of taking an intergenerational and multiagency approach to tackling community problems. Sure Start was able to use its contacts with local children to access parents and childminders who were in need of work whilst children were in school. The Bell View Resource Centre provided specialist knowledge about the local elderly

²¹ DP Service User Evaluation, Northumberland 2008

population and their needs. The project worked across statutory and voluntary organisations to map existing clients in the area. The DP team provided information about employer responsibilities and helped establish Criminal Records Bureau checks.

The project has increased the choice and control of both care workers and service users. It has:

- stimulated the market for new provision;
- provided much needed sustainable employment;
- improved community cohesion;
- increased the take-up of direct payments.

Unexpected benefits have also emerged, as pre-existing care workers have also joined the scheme have gained access to extra work and support.

Source: Community Care, 24 April 2008

Barriers to delivery

- 5.22 A number of barriers were identified by those who participated in this case study. Barriers highlighted present a combination of organisational uncertainties/ issues and practical issues which have arisen during the delivery process:

Organisational Issues

- **Raising awareness and creating new systems is complex.** To ensure effective delivery of new initiatives, it is important to provide both service users and delivery staff with the necessary information, skills and resources to enable effective delivery. The DP team provide mandatory training for care managers, occupational therapists, District Nurses and some physiotherapists. The training consists of a half day session to introduce individuals to direct payments and the independent living fund. Training includes familiarisation with the processes, advantages/disadvantages and care plans.
- **The transition from Children's Services to Adult Services is a difficult move.** Parents cannot see why a service stops simply because the child turns 18 and similarly, issues arise as a result of the change in emphasis from the requirement of consent from the family whilst their child is pre-18 years of age, to the young person once they have reached 18 years of age²² There also appears to be a misalignment between children and adult services nationally- the Every Child Matters agenda works to keep children and families together, but once a young person reaches 18, independence is strongly advocated.

²² Where this is not appropriate parents can give consent under the Mental Capacity Act.

Practical Issues

- **The criteria for accessing Continuing Health Care** – an individual who may have previously received a direct payment for social care needs, and then, usually due to a deterioration in health becomes eligible for continuing health care funding, will no longer be able to access a direct payment. This is because a direct payment can not be used to purchase services which are funded by health they can only be used to purchase services funded by social care. This can sometimes be upsetting for a client who has been happy with the care he/she has been receiving. It is hoped that change of legislation around using health funding for direct payments may happen in the future.
- **Safeguarding and CRB checks** - The issue around safeguarding and the associated need for Criminal Record checks can raise questions. At present there is no ruling on whether care workers, personal assistants or any other staff employed via a DP need to have a CRB check. The DP team advise and strongly recommend that all families undertake CRB checks prior to employment of staff, but there is no statutory requirement to undertake checks. The cost of CRB disclosures will be met by the Local Authority.

The new Independent Safeguarding Authority (ISA) will come into force in October 2009. The ISA been established to help prevent unsuitable people from working with children and vulnerable adults. Working in partnership with the Criminal Records Bureau, the Safeguarding Authority will gather relevant information on every person who wants to work or volunteer with children and vulnerable people. This means any individual who wants to work with children and young people must be registered, and it will be illegal for a person who is not registered to work in this field. Employers will be able to check the register to check their employees, however, at present this is not mandatory for those individuals employing people to work from their home.

- **Criteria for staff selection.** When a family or a Local Authority contract with a carer, the agency will ensure that the individual possesses the necessary qualifications to do that job. As part of an IB or DP, an individual appointed to a post does not necessarily have to hold any specific qualifications.
- **Clear guidance on public spending.** There is very clear guidance on what Direct Payments can be spent on, as the spend must be on the items detailed in the care plan. There is national guidance relating to expenditure on Direct Payments. With individual budgets there is no national guidance and so the issue is much less clear.
- **Managing public perceptions of DPs and other forms of personalised support** - the consultees indicated that there was also a need to educate the public on the rationale for DPs and Individual Budgets. For instance, sometimes the image currently projected to the public only shows how public money is being spent to fund someone's holiday or purchase a season ticket, and fails to convey the positive impact, effects and benefits of this form of

service provision. This has led to negative attitudes and additional public scrutiny of DPs and IB's, which requires careful management.

- **Understanding and developing the market place** – market provision is crucial to success. During the Dynamite pilot service providers were invited to an event with children, young people and families so that both groups could gain an understanding of each other. This helped families to find a service which they thought was appropriate. Consultees stated that market providers need to understand that families will be unwilling to pay for a service which they do not feel is appropriate or provides a good level of care and that providers need to recognise and understand this to ensure they deliver good quality provision. Similar events are planned for the Taking Control project.
- **Information systems** associated with a new form of provision need to be integrated with original systems to ensure some form of continuity.
- **Integrated working** - other departments need an understanding of the concepts associated with the new form of service provision and how their work could impact on this provision.
- **Prohibitive legal structure** – integrating health funding is problematic. There appears to be unclear/complicating guidance.

Added value

- 5.23 Individuals in NCC/NCT have reported that direct payments have produced higher level of satisfaction compared to traditional, centrally provided services. For one particular family an experience paid for via a direct payment helped to improve the quality of the child's life. Direct Payments funded the wages of a carer who accompanied the family on holiday to help provide care for the disabled child. The child was able to experience swimming with dolphins, which had a significant positive impact on both the child, who grew in confidence, and the family. It should be noted that the Direct Payment would only fund the carer's wage and not the cost of the holiday or any activities undertaken.
- 5.24 Consultees stated that self directed support can identify and fill gaps which could previously not be met by traditional services. For example, a social worker may identify a need for six hours of support for a family; sometimes there may be no available traditional services to meet the need. This may be for example, because of a rural location, and agency may not have the staff available to provide the service. With a Direct Payment, the family could employ someone locally, although only six hours of provision may seem insignificant, this support could have a considerable impact on a family in terms of what they can/can not do.

Key requirements of a successful approach

- 5.25 Consultees felt that the following requirements were important and necessary in order to successfully develop an IB intervention:

- **Correct use and implementation of the Resource Allocation System (RAS).** The RAS is fundamental to pilot work. Northumberland have re-drafted their RAS after initial tests produced inconsistent results, where the modified RAS is based around the Every Child Matters agenda and incorporated more user-friendly questions. There is still some testing to be done on the new version of the RAS before it is implemented.
- **Work should be done on a large enough scale to enable sufficient learning to take place.** The contributors suggested a pilot which works across a cross section of disability.
- **Must be a good solid understanding by senior level staff and a clear strategic vision to drive forward the agenda.** Messages must be relayed across entire services on new interventions in order to ensure that departments are working collaboratively and reducing the duplication of services.
- **Timescales and resources must be realistic and appropriate.**
- **Market development is key.** The market place must be developed to cater for the demand of personal assistants and care workers.
- **Managing staff and cultural change.** The personalisation of services is associated with a significant cultural change for social workers. Training and awareness raising are the key methods used to of manage this change. It is also important to ensure that staff are involved in testing options/systems as opposed to simply imposing new systems on them.
- **Safeguarding and ensuring all staff are criminal record checked.** To ensure this takes place all staff employed by families could be checked centrally before appointment. There is no legal obligation to do this and the introduction of a register of all individuals who wish to work with children, by the ISA, is flawed as it is not essential to check against this register for those employing individuals to work in their homes. There needs to be clear and consistent guidance on this. In addition the implementation of the ISA has been delayed until October 2009.
- **Integrated work across health, social and education** – intensive training is required for staff across the health, education and social care arena to ensure effective delivery, when and if health and education come on board with IB's.

Summary of existing approaches

Northumberland County Council and Northumberland Care Trust have successfully developed a Direct Payments Service. At present 90 children and young people are in receipt of a direct payment.

Senior level commitment and a vision to drive change have been integral to the success of implementing direct payments. A team was established to assist in delivery and all support services to clients, are delivered by the in-house team. This has been highly successful.

Training and increasing awareness on new developments to all organisational staff has been an important part of the role by the direct payments team. This has helped to alleviate fears, reduce duplication of services and keep all staff informed.

The Dynamite and Taking Control pilots have both been conducted on a relatively small scale.

Looking ahead...

- 5.26 Building on the success of the Direct Payments, NCC is keen to move forward in developing self directed support initiatives. Current work to raise awareness of the Taking Control pilot has created a great deal of interest from families with disabled children who are keen to learn more and awareness of individual budgets is growing in the area.

Pilot options

- 5.27 Consultees were asked to give their thoughts on which would be the most successful pilot option for individual budgets for families with disabled children. It was thought that a pilot which targeted either type of disability or age group would not be inclusive to all children and families. Consultees felt that in order for a pilot to be successful, work needed to be done on a larger scale to help produce more conclusive results. For this reason the consultees favoured the comprehensive offer as they felt that this would provide a 'big picture' approach to the pilot and provide a wider scope and therefore more comprehensive findings.
- 5.28 Due to the geographical nature of the region, Northumberland also saw the benefits in piloting IB's with both rural and urban areas. However, they were not in favour of extending either current IB provision of the BHLP pilots, as this would exclude the County from any form of pilot activity and similarly, they did not support the specific targeting of ethnic minority communities as a result of the very small number of this group residing in the area.

Potential resource implications

- 5.29 Consultees were asked to consider the potential resource implications associated with creating a new pilot for individual budgets. In order for an IB pilot to be successful, it was felt the following set of resources would be required:
- Sharing best practice and learning from existing self directed support interventions

- Understanding the needs of beneficiaries
- Understanding the climate in which the pilot is to take place
- Organisational awareness raising of the pilot and its implications on others
- A commitment from the whole organisation
- Staff awareness and training
- Developing and stimulating the market to ensure that service provision exists for clients and that it is of a good standard
- Developing an appropriate resource allocation system.

Potential Funding

5.30 The integration of funding streams was discussed with consultees in order to identify what might form part of an IB package. This illustrated that social care funding is a must, but it was felt that in order to be truly successful it was crucial to also involve health care monies, which should specifically include Continuing Care and Therapy Service budgets, which is not possible at present. Consultees voiced their concern around the legal complexities associated with integrating health funding into an IB, however they added that pooled budgets between the local authority and PCT may make this easier, should government legislation allow this in the future.

5.31 Education funding, including budgets sourced from Special Education Needs, the Learning and Skills Council and Connexions could all be included as part of an IB in the future, but were not used at present. It was also thought the following funding streams could be comprised into an IB package:

- Disability Living Allowance
- Disabled Facilities Grant
- Community Resource Budget
- Independent Living Fund
- Transport.

Looking ahead summary

Northumberland County Council have successfully developed and implemented Direct Payments. More recently they have been a Dynamite Pilot and at present are building their Taking Control pilot. This demonstrates the commitment by the County to the self directed support agenda. The County would be particularly keen to pilot an individual budget for families with disabled children that offered a comprehensive entitlement to families, regardless of age or type of disability.

6: London Borough of Redbridge

Context

- 6.1 This case study comprises findings from consultations and feedback received from seven stakeholders, including key Local Authority personnel in the Children with Disabilities team (CWDT), a social worker, a transition worker and one provider.
- 6.2 According to data supplied by the Children with Disabilities team, there are 437 children with disabilities in Redbridge, with ages ranging from 0 – 19. A majority have Autism and Learning Disabilities. While a majority are from White backgrounds, more than a third belong to Asian backgrounds.
- 6.3 The current service provision is illustrated in the table below. The social care budget offers domiciliary care, residential respite care, family based respite care, holiday schemes and after school clubs.

Table 6-1: Redbridge Children's Services: Current Service Provision

<p>Holiday Play Schemes (4) which receive funding from the CwD team After school clubs (1) and Weekend Clubs (1) Transition Support Clubs – clubs preparing and supporting young people in transition Respite care services Play provision</p>
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- 6.4 With regard to out of authority placements, Redbridge purchases services (but has the opportunity to enter into a block contract) from a private provider that offers residential and short breaks to families. It also has a couple of block contracts for 2/2.5 years with voluntary sector providers on providing day care (adventure playgrounds) and has a spot purchase arrangement with a registered domiciliary care agency that provides support to carers and families with regard to respite care. This includes any type of respite care of 2 hours or more, including home based care and accompanying users to different settings. However, note that respite care and foster care is very limited and Redbridge has to go to neighbouring boroughs.
- 6.5 The Redbridge Children with Disabilities Team has two team managers operating from two separate sites. Redbridge also has a Children's Trust that has initiated an integrated team working approach.

Existing Approaches

- 6.6 Redbridge has delivered or is in the process of delivering the following initiatives:
- The Dynamite Pilot
 - Direct Payments for adults and older people and DP for children and young people as well
 - Taking Control Pilot (recently commenced)

- Adult IB (recently commenced).

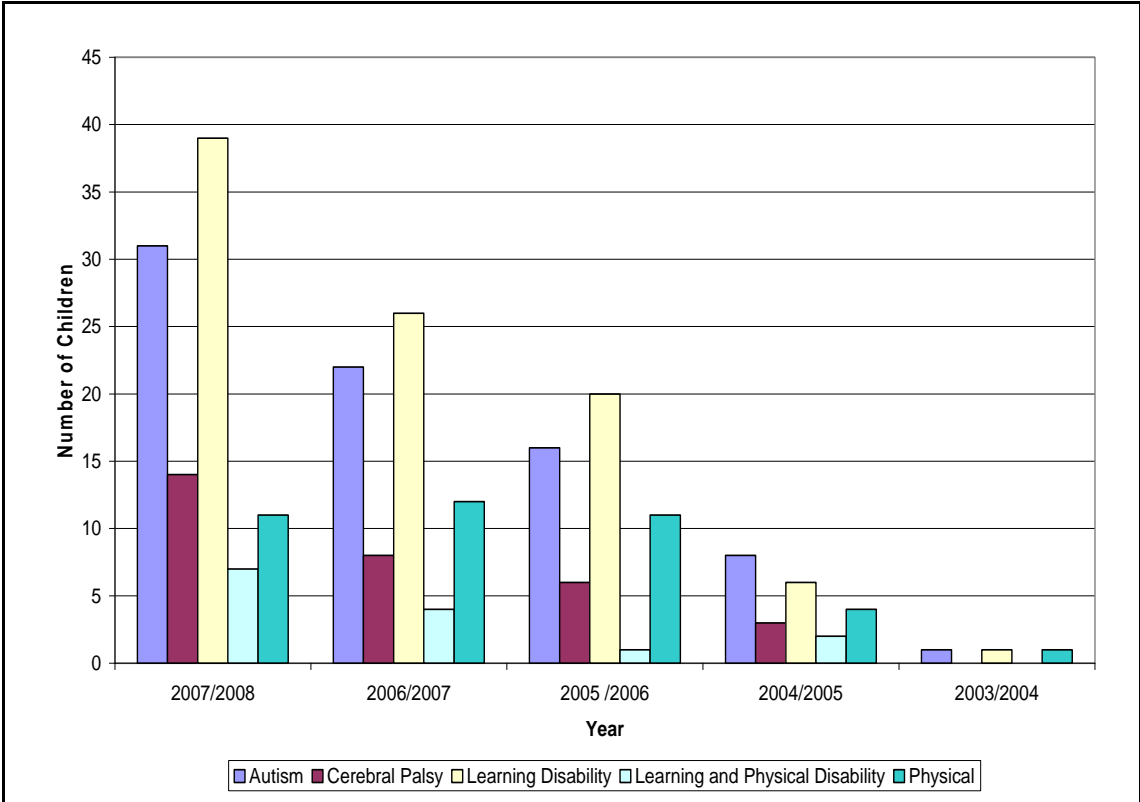
The Dynamite Pilot and Adult IB

- 6.7 Dynamite was agreed and funded by both the Learning Disabilities Partnership, (a partnership between Redbridge and Waltham Forest) and the children with disabilities team (CWDT). The Partnership includes 2 PCTs under the section 75 agreement. Redbridge Children's Services piloted the Dynamite project on 8 young people who were given a small budget of £200 over last summer to spend on services, and a disposable camera to track what they did with the money. The London Borough of Redbridge (LBR) subsequently held a meeting with them and their families to share aspirations. The young people had also developed their own plans around what their requirements were. The average age was 17 years, and a majority of the young people had learning disabilities.
- 6.8 Two of the eight young people have received the IB money to date through adult services – 2 others have had their plans agreed and are currently finalising arrangements before receiving their budgets. LD Partnership (Redbridge) has had a transition worker for over 3 years, who helped deliver IBs for young people. CWDT have now recruited a Transition Worker, and the LDP post is currently vacant. Assessment was written with Foundation for People with Learning Disabilities, and the Waltham Forest Transition Worker.
- 6.9 In early 2007, the Redbridge Children's Trust and LDP jointly decided to extend the work of the Learning Disabilities Partnerships to incorporate the 'We Can Dream' project in partnership with the Foundation for People with Learning Disabilities. This specifically focused on young people with autism; one young person in Waltham Forest and one in Redbridge – neither have received a budget to date, but both have self-directed support plans, that have enabled change and work on the same principles as the Dynamite Pilot. At present, self-directed support is being re-assessed for those currently accessing agency services and the borough hopes to identify at least 160 adults for IB.

Direct Payments

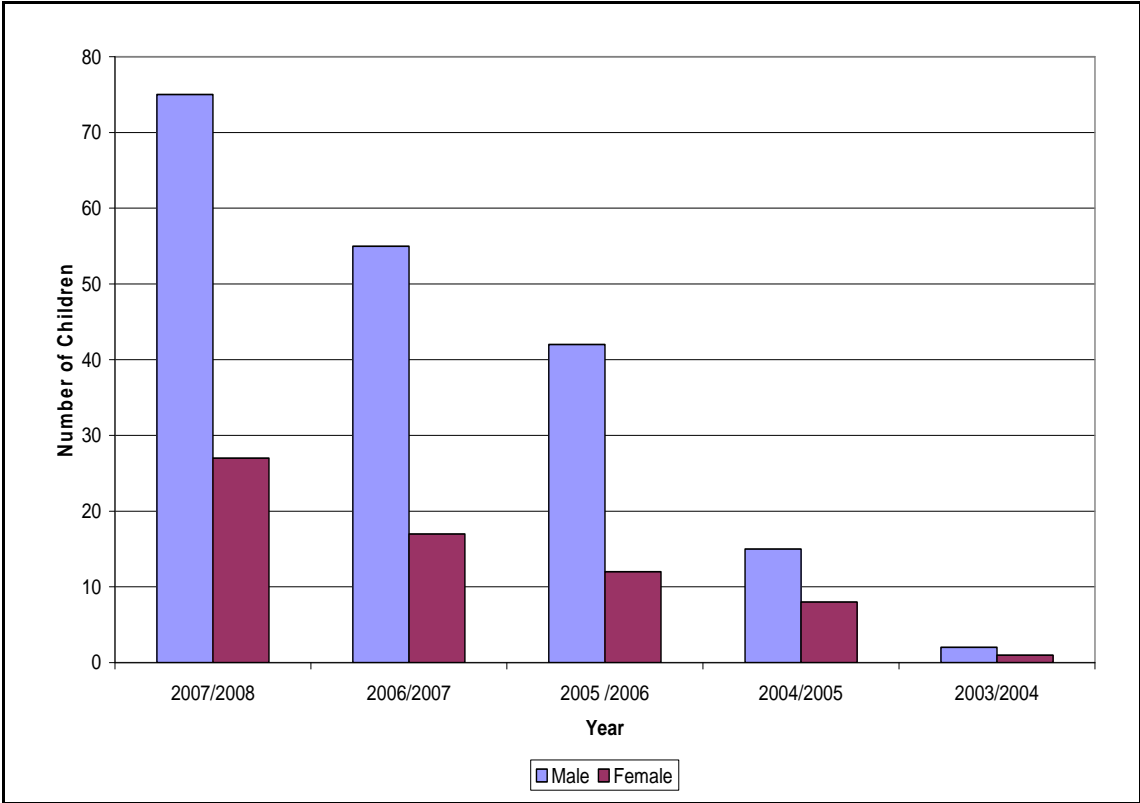
- 6.10 Redbridge has also been promoting Direct Payments over the course of the past 4 years; currently there are 99 families on DP. The charts below illustrate characteristics of the use of Direct Payments by type of disability, gender and ethnicity. Direct Payments use is dominated by male children and those with learning disabilities. Although a majority of children are from White backgrounds, a significant proportion of the total are of Asian origin as well. Stakeholders were of the view that it is likely that the use of Individual Budgets will mirror the characteristics of use of Direct Payments. The take up of Direct Payments was slow to begin with, but subsequently improved. Stakeholders were of the view that most families on Direct Payments may eventually end up taking up IB.

Figure 6-1: Children using Direct Payments by Type of Disability



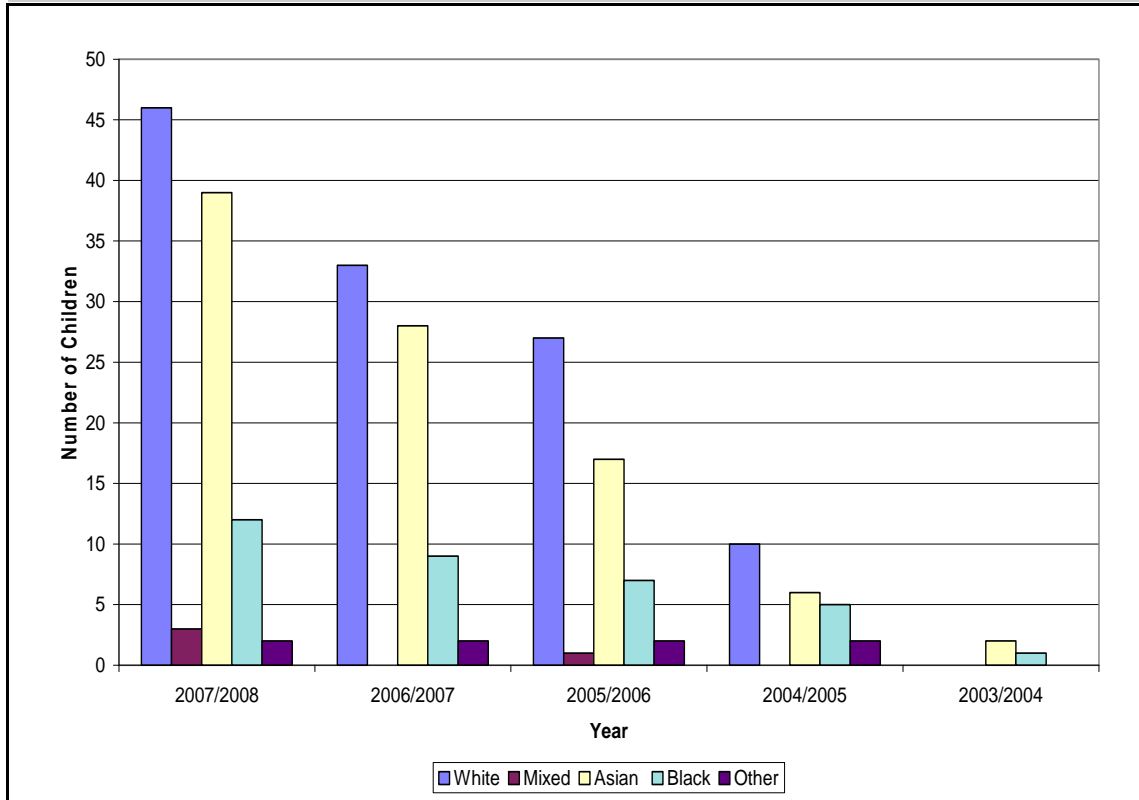
Source: Redbridge Local Authority Statistics, 2008

Figure 6-2: Children using Direct Payments by Gender



Source: Redbridge Local Authority Statistics, 2008

Figure 6-3: Children using Direct Payments by Ethnicity



Source: Redbridge Local Authority Statistics, 2008

- 6.11 The LA holds biannual workshops to promote Direct Payments, and had previously targeted the minority ethnic community. It has just completed an Equality Impact Assessment on Direct Payments and has also been audited for DP. DP is being monitored currently on a quarterly basis.

The Taking Control Pilot

- 6.12 Redbridge is currently in the process of piloting Taking Control. Families are being given the option of whether they want to take up IB, which has resulted in 7 children and families taking up the IB offer. A majority of the families are from minority ethnic backgrounds and children involved in the pilot range from 2 to 12 years of age. The LA will work with these families from July-August 2008 until August 2009 and review the process on a six monthly basis.
- 6.13 The Learning Disabilities Partnership adopted Norfolk's RAS and then adapted to their own needs – for adult services. This was initially completed with CWDT and LDP. The Children's RAS was developed with Nic Crosby in Redbridge, and is being used for the purpose of the pilot. The LA has an online version of the Common Assessment Framework which they are not currently using in their Pilot for assessment purposes. The commissioning team has borrowed the contract from Oldham on IB and sent this to the Legal department to draw up similar contracts for Redbridge providers.

- 6.14 The LA plans to offer the following to families as part of IB²³:
- Support from the allocated social worker to complete the self-assessment questionnaire and the support plan
 - Once the plan is written, the CwD team resource panel will take a look at the outcomes that have been identified in the plan and agree a proposed package that meets the needs
 - Once the plan is agreed, the families will be given a choice over who has control over the budget – the LA or the family
 - The plan will be reviewed every 6 months as part of the CiN review
 - Regular opportunities to meet other families involved in the project.
- 6.15 The LA is also keen to seek parental engagement with regard to the person centred process, and for families to work in partnership with the worker to complete the support plan, be involved in the continuous evaluation of the project and ‘be honest’ with them in terms of providing feedback about what is working and what is not.
- 6.16 IB will be delivered via quarterly payments to families. Families will open up a bank account where the money will be allocated, and the LA will retain some contingency funding. There is not a brokerage system in place as yet, although the LA is in discussion with some providers to find out whether they would be interested in providing brokerage services. The IB at present is in fact very similar to DP in terms of access to funding streams; there are legislative barriers in terms of accessing health care funding under DP, and this situation has not changed with regard to IB. Moreover, like DP, the large bulk of the funds come from social services. The LA plans to conduct assessment of need and derivation of plans jointly between a key worker and the family.
- 6.17 The LA plans to conduct another workshop around November 2008 to promote IB to more families. It believes that there are 550 families across the 2 service areas within Redbridge, and there is a likelihood that families that have taken up DP will take up IB. Currently, 4 sessions are planned annually. The LA also plans to do a mailshot to every family that is known to them to invite them to the workshop. A few weeks prior to the interview, the LA had conducted a workshop on Transition where families discussed their experiences.
- 6.18 The CwD team is gearing up to deliver IB to young people in transition. It has just employed a transition worker who was previously part of the team that delivered the Dynamite project for the Learning Disability Partnerships.
- 6.19 IB is currently being promoted to providers as well. In a recent providers’ forum held by the LA, providers were asked to come forward for participating in IB and 5 agencies volunteered to take part.

²³ Source: LA presentation at workshop to parents on IB, 2008):

Demand for existing approaches

- 6.20 The extent and nature of demand in terms of numbers of potential users for a majority of the approaches is not entirely known; Direct Payments was slow to take off but now has 99 families. The remaining IB interventions have targeted small numbers of individuals, where the Dynamite Pilot involved 8 people, the Adult IB was taken up by a very small number 4 of young people moving into adulthood and the Taking Control Pilot currently has 7 children and their families signed up to receive an IB.
- 6.21 Families with disabled children were asked by the Local Authority about the types of services that they would like to receive under IB.
- 6.22 **In the Taking Control Pilot**, parents of children that are participating have expressed a need for accessing Health services, especially therapy services. For example, parents are keen that their children receive Speech and Language therapy relatively early on in their lives. Some parents with DP have already been creative and are employing Personal Assistants with such qualifications but it could cost them a lot more than being offered within DP or IB, and potentially reduce the number of hours they could purchase on Personal Assistance. Families have also expressed their need for respite care and short breaks, but in creative ways. One example is having a Personal Assistant to accompany a person to a hotel during a holiday. Users have also shown their own creative thinking; one person used their DP money to purchase a tandem bike which meant that they did not have to go back to being wheelchair dependent.
- 6.23 Stakeholders anticipated that individuals were only likely to decline or drop out of an IB process if they were unable to access health services as part of this package. Under IB would drive them to go back to agency provision. This could be more the case when children's needs are particularly complex and they tend to be heavily reliant on continuing care from the health service.

Funding

- 6.24 In **Taking Control**, currently, the only funding stream to play with is the social services budget. As Redbridge is a Children's Trust, there are some, but limited pooled budgets, however, as Health/PCTs are not on board, families cannot currently access therapy and nursing services required for continuing care needs. Therefore, the funding pot for the LA for the Taking Control Pilot includes:
- the Aiming High for Disabled Children funding pot
 - the Carer's Grant
 - a minimal PCT element.
- 6.25 Although schools are aware of the Taking Control Pilot, SEN money does not feature as part of the IB package, as engagement with schools is minimal at present.

Effectiveness of existing approaches

- 6.26 Stakeholders were unanimous in their view that at a strategic level, approaches to service provision with regard to self-directed support need to focus on user outcomes and not service delivery models. This is a step in the right direction in terms of care provision in the future. However, consultees added that certain key factors drive effectiveness of such approaches on the ground.
- 6.27 This section identifies these drivers and the role that they have played in ensuring effectiveness of existing approaches.

Taking Control

- **Organisational factors:** Clear planning, time and staff training are some of the key success factors in delivering IB to children. A majority of the CwD staff have good knowledge of Person Centred Planning (PCP). Several meetings were held with Commissioning, Finance, Legal, Learning Disability Partnerships and Adult and Children's Services to get different parts of the organisation on board to take things forward.
- **Capacity building for families:** Training for parents/families and information sharing to get them on board is crucial; the LA is undertaking this task via a set of workshops. A recent presentation indicated that clear messages were being communicated to families, and an emphasis was placed on outcomes being achieved as opposed to spend against the total budget during the development of the support plans. There is currently a clear focus on monitoring of the process of delivery as well.
- **Market Development:** The LA has also organised and held a providers forum to invite providers to participate in the Pilot. Within the forum providers were advised about individualised budgets and the need for them to consider brokerage and looking at the current way they provide services in the future. Some stakeholders were of the view that the voluntary sector in the borough is already 'ahead' of the game in many ways and is offering innovative solutions to its users, albeit serving relatively small numbers. For example, one provider offers respite care in the form of taking children to swimming lessons. The provider is also due to start a Saturday club that will provide respite care.
- **Information, advice and guidance:** Some voluntary organisations are set up to support carers. This might be an area where the LA can encourage providers to develop services. There is currently a Children's Participation Officer that plans to co-ordinate all activities for children's services and identify areas of development. Voluntary sector activities for adult services are relatively more innovative in Redbridge as a result of them having had a longer time frame to develop the market compared to Children's services. The borough has a Children's Information Services (CIS) but this may not be adequate as disabled children and their families will require specialised information, advice and guidance, especially around transition.

Barriers to delivery: current

6.28 There are particular barriers to delivering existing pilot approaches, which cut across all of the initiatives that Redbridge has been delivering:

- **Legal barriers;** families cannot access services under continuing care as this falls within the remit of health which cannot currently be accessed from the Pilot or Direct Payments; this issue becomes exacerbated when a young person becomes an adult who could be refused DP/IB and forced to go back to the traditional system of agency provision. Hence individuals could go on and off IB and will not have any consistency in care. Differences in eligibility criteria with regard to assessments for children and adults also pose significant barriers to those in transition.
- **Lack of integration of funding streams:** Another key barrier is the inability to integrate or align particular funding streams within an IB package. For example, in the absence of support from the PCT, health funding and therefore services cannot be accessed under DP or IB. This issue is also reflected in the SEN education funding streams..

Looking specifically at schools, it was felt that they do not necessarily have the staff required to cater for specific needs of children, especially those with complex needs. Therefore, schools need to be sufficiently engaged to appreciate how best to work in partnership with parents while ensuring that they do not take undue pressure in terms of providing individualised services which they may not be capable of delivering.

- **Safeguarding issues:** checks for individuals delivering care services are essential. However, there are currently inconsistencies between adult and children's service provision. Moreover, there is little central government guidance on the subject. The absence of a formal CRB check system may encourage unqualified Personal Assistants to enter the market. The LA therefore needs to strike a balance between independence and choice, and safeguarding. CRB, by effectively regulating and monitoring service provision to children. The local authority currently insists that all their preferred providers have regular CRB checks and advise families accordingly about the service providers.
- **Perceptions with regard to audit:** There is generally a risk aversion to handing over public money to families, and a clear recognition that some form of monitoring system is required for families, providers and young people. Some monitoring systems are already in place but are deemed inadequate. Although audit is clearly recognised as an essential function that will need to be carried out when IB is in operation, currently there appears to be too much emphasis on safeguarding and monitoring and not enough trust. In theory, IB should incorporate lighter touch monitoring compared to DP but this is not the case. This conflicts with the principles of IB of choice, control and independence.

- **Organisational barriers:**
 - **IT and monitoring systems:** The anticipation is that there will be 2 separate contracts for Adults and Children from the Commissioning perspective. However, it will be important to ensure that services are seamlessly delivered during transition. A key issue is that the Adult and Health services do not operate under the same IT systems and information sharing is difficult. The other issue is – who holds the contract? There are several practical issues for consideration – how the money should be paid, how the money should be monitored.
 - **Lead project manager:** A lead person that is wholly focused on managing the pilot is extremely important. This did not happen for the Dynamite pilot where the case worker had her own case load as well as those under the Pilot to take care of. The model had suggested voluntary support workers which did not work. The team underestimated the time that needed to be spent on the pilot and there was too much pressure on one single individual case worker with regard to writing support plans and offering brokerage etc.
- **Lack of sufficient and suitable regulation:** Although market development is key, it raises particular issues with regard to regulation of services and service providers. For example, the early 90s saw a huge growth in domiciliary care with little regulation on the quality of service provision. Individuals hiring Personal Assistants will need to ensure their quality and there is no guarantee that PAs will be sufficiently supervised and receive ongoing training. This could give rise to litigation and put vulnerable people at risk. Under the traditional system, this is unlikely to happen as providers are heavily regulated and insured. Currently, providers are not given any specific guidance with regard to offering PAs that they would have appointed to families and individuals.
- **Quality assurance:** A related issue, individuals setting up brokerage services need to be quality assured. Furthermore, if existing providers are planning to set up brokerage arms, the extent to which they can offer independent brokerage could be questionable. Perhaps the role of the LA would be to help providers develop the market alongside some form of voluntary registration of providers. In addition, LA role could be to develop a 'code of conduct' for brokers especially those that do not get regulated under CSCI or OfSTED. Furthermore, there needs to be some mechanism by which PAs could receive ongoing supervision and training.
- **Current lack of forward thinking:** While cultural change among providers and LA staff is viewed as a key success factor, the lack of it is perceived to be a key barrier. There has been some resistance to IB from LA professionals and voluntary sector providers. At a recent providers' forum for IB, there was a lack of participation from the large children's service providers. Some providers may feel a lack of incentive to provide more tailored services as a

result of their current block contracts. However, the reality of the current market and the skills sets of staff providing services do not necessarily allow a provider to offer total flexibility in service delivery. Providers work within specific parameters and if users demand a particular service as part of self directed support that falls outside these parameters, they are likely to struggle to deliver such services. Moreover, a cultural change is required as the provide is also likely to be used to dealing with a social worker and not the user or parent directly.

- **Lack of an appropriate assessment framework:** One size fits all does not work as far as the assessment framework is concerned. Stakeholders felt that the Resource Allocation System did not work for Dynamite; the adult services RAS was adapted to reflect the Fair Access to Care Services, so that eligibility for support could be clearly identified. The in Control RAS is not being used in Redbridge as it was deemed inappropriate.

The Children's RAS could provide to be easier to use for those children who are not in transition, where the ECM outcomes could ensure that there is some clarity about where the money is spent in terms of outcomes but could be harder for children as their needs are transient.

Barriers to delivery: future

6.29 The likely barriers to be carried forward in the short term are mainly to do with:

- Lack of integration of funding streams, mainly health: This is likely to be a significant barrier in the future
- Lack of shift in cultural change among providers and professionals: This is mainly a time issue; cultural shifts take time and investment, and IB type approaches are being delivered at a relatively short space in time. There is some confusion on the ground about how different an IB is from DP, and whether accountability and responsibilities lie with parents and families or with LAs.
- Lack of a suitably qualified and regulated workforce of brokers, advocates and carers: The development of, and access to, a suitable workforce pool is crucial and is a worry for most stakeholders. A potential surge in demand for certain types of services will need to be matched with additional qualified care staff. However, the care profession is poorly paid and relatively less attractive. There is also the issue of sourcing advocates and brokers.
- Cost of packages: The test RAS indicated that care packages under IB costed much less than those under the traditional system. A possible explanation could be that social services have tended to fund parental need to some extent, which gets reduced to some extent under RAS. To get around this potential issue, the LA could offer the minimum threshold that families used to get under agency provision. However, there is clearly a need

for separate assessment for carers and parents but currently IB does not exist for carers.

- Lack of provider buy-in and market development: The current market is already short of respite care and other services that IB may enable access to. The LA may revisit their existing block contracts with providers in the near future to tailor these for IB. This means that providers could be forced to offer creative solutions. There is some concern that in the longer term, some providers may lose business as the markets get driven by demand expressed under IB. But it is too early to say that this would definitely be the case, as the demand for some traditional services is unlikely to go away, namely, residential respite care.

Added value

6.30 The principles of IB incorporate Person Centred Planning (PCP). Stakeholders were of the view that PCP needs to be embedded in assessment of outcomes and delivery of services, in order for an IB to make a real difference because:

- It will enable a focus on outcomes for the user
- It will engage effectively with the user and their family in planning and delivering what they require
- The decision making will be done by the user and their families.

6.31 IB will also make service delivery relatively transparent; as the market develops, stakeholders were of the view that it will be easier to assess who is delivering what and of what quality, provided an effective audit is maintained.

Key requirements of a successful approach

6.32 Consultees were asked to comment on what they thought were the key requirements of a successful IB type approach. Responses included:

- **A lead project manager:** IB needs an individual case worker/dedicated project manager that works closely with families through the planning stage and in deciding the most appropriate package. This person may need to take this role as part of their existing day job but this is not ideal as it has time and resource constraints. Currently, assessment for children is done in partnership with the parent or the family. However, it is expected that this role is eventually taken up by an independent advocate or broker.

An ideal scenario would be for the project manager to oversee all IBs, including adults and children. This will ensure continuity of care, support and assessment. The borough is in the process of recruiting a Direct Payments Development Manager who could potentially take on this role.

- **Continuity in care and assessment:** IB needs to provide continuity with regard to assessment; children's services may offer IB and set care plans

which may not be followed through when children transition to adults, as new assessments take place. Packages could even get reduced and may not follow a consistent assessment framework.

- **Robust IT systems:** Related to this is the need for an integrated and streamlined IT system for assessment of disabled children's needs. The Integrated Children's System (ICS) initiated a few years ago across LAs was aimed at creating such a system but this is not linked to the care management system.
- **Cultural change:** Cultural change among strategic and front line staff is a big challenge as well as a key success factor.
 - Getting the **legal and finance team** on board is crucial.
 - The LA was very clear that **providers** need to be not just on board but think outside the box and provide services creatively, especially with regard to home care and respite care support. The LA had recently organised a providers' forum to discuss the Pilot and seek engagement from the providers. The LA is encouraging providers to be innovative with the transition group in particular, and as mentioned earlier, a respite care provider is currently running a pilot project with young people in transition.
 - Cultural change is also needed among **professional staff and social workers**. This is because individuals are often dependent on their social workers and social services for their need and over time this will need to be addressed, both by individuals as well as social services. The process needs to start early such that when children reach transition age they can function independently.
- **User engagement:** The process of developing and agreeing support plans is crucial; it needs to be done jointly in partnership with parents and young people and ideally should be done before the budget is determined. The process can also be daunting for families but mainly because they were not exposed to the process very early on in their children's lives. For a young person, there could be conflict between what they want and what their parents want. An important factor would be to ascertain at what stage the key worker engages with young people more than their families.

Summary of existing approaches

Redbridge has initiated several approaches – Direct Payments, Dynamite, Adult IB and Taking Control. The latter two have only just commenced.

Redbridge has undertaken several key activities to ensure success in its approaches:

- Strategic and operational buy in within the Local Authority – commissioning, finance, legal, audit and front line staff
- Buy in with providers and capacity building exercises
- Information sharing with potential beneficiaries and their families, support and guidance with the planning process

It has adopted the Resource Allocation System for the time being as a tool for assessment of outcomes and derivation of budgets.

The borough has also experienced some significant barriers, namely a lack of integration of funding streams on the ground, including health funding. There are internal organisational barriers too; IT systems for adults and children's services are not integrated, and there is no monitoring system as such. There has been some internal resistance towards IB within the LA and concerns expressed externally by providers.

Looking ahead...

- 6.33 The latter half of the case study research focused on the design and development of the forthcoming IB pilots for families with disabled children. Therefore, consultees were asked to provide their views on the potential shape, format and content of the pilots, where responses were overwhelmingly positive and reflected a strong commitment to deliver user-led services within the Local Authority.

Pilot options

Table 2: Pilot options

Pilot Option	Yes	No	Response
Children in continuing care		✓	Targeting by diagnosis is inequitable and unfeasible as Health services cannot be accessed
Children needing 24 hour continuity		✓	Targeting by diagnosis is inequitable and unfeasible as Health services cannot be accessed
Specific age groups with high support needs		✓	Targeting by diagnosis is inequitable
Autism Spectrum Disorder		✓	Targeting by diagnosis is inequitable, however, this set of individuals currently do not receive a specific service and often fall through the gaps of service provision, therefore should be targeted in a more general pilot
Aged 11+ with moving and handling needs that will require equipment and adaptations		✓	Targeting by diagnosis is inequitable although from a provider's perspective this is something they can offer from current provision
Children coming out of the Early Support Programme	✓		There is currently limited support for children aged 5-6 yrs passing out of the Early Support Programme. Continuity in support would be useful. Children that are initially assessed by health visitors when they are under 5 have to wait for statements under SEN once they reach the age of 5 and lose some continuity of care.
Disabled children who are moving from primary to			No opinion expressed

Pilot Option	Yes	No	Response
secondary			
Disabled children aged 5-14 yrs	✓		Thought this was a good idea as no programme was targeted at this age group specifically
Children aged 14+ yrs i.e. those in transition	✓		Transition from children's to adult services requires specialist support and therefore would benefit from an IB approach. However, this will be dependent on close working relationship between children's and adult services and multi-agency partnerships
Newcomers to the social care system or disabled children at the point of intervention	✓		No opinion expressed
Disabled children from BAME groups	✓		Redbridge has a large population of children from minority ethnic communities and a majority of those taking up IB under Taking Control are also from BAME groups. However, the authority does not wish to specifically target these groups as it will be inequitable.
Disabled children from families who are 'on the edge of care'		✓	No opinion expressed
Mixture of both rural and urban areas	✓		Not relevant to Redbridge as it has no rural areas.
Offer IBs to target number of families with disabled children regardless of type of disability	✓		This option was the most popular, as it was equitable, offered flexibility and could later be analysed by type of disability. Until IBs are more widely tested and open to children with more complex needs, it will be hard to know what the key challenges and issues for implementation are.
Extend the current adult IB pilots to cover families with disabled children		✓	No opinion expressed
Extend only those adult IB pilots that have a disproportionately high demand for IB and number of disabled children		✓	Demand is an unknown quantity at present
Extend the service provision offered by the existing BHLPP pilots to families with disabled children	✓		Good idea although the client group is slightly different

Source: SQW Consulting

Potential demand

- 6.34 Stakeholders were of the view that there could be particular vulnerable groups such as those with Aspergers and Autism that are currently not being targeted explicitly. The 'We can Dream' project specifically targeted young people with ASD in transition. CWDT are keen to ensure that they encourage and support families participating in the pilot to feedback effectively their experience of the pilots.
- 6.35 On the other hand, there are families who do not like asking for help and do not wish to associate themselves with social services. These families should also be offered IB as they can access services with minimal intervention from social services.

Potential resource implications

- 6.36 Stakeholders identified the following resource implications for particular aspects of service delivery under IB:
- **Setting up appropriate brokerage and advocacy** is likely to have resource implications for a pilot site. Person centred services may come at a higher cost; primarily because of risk assessments that each element of the service may require. Previously, an employee of the Local Authority had volunteered to offer brokerage services and found that they were having to spend relatively large amounts of their own personal time devoted to the service.
 - There could be particular issues with **charging**. From the providers' perspective, the issue is the extent to which the price points in RAS are made consistent with the rates that providers charge. For example, how can social services ensure that the cost of respite care matches with the charges made by providers? With Direct Payments, hourly rates based on home care were used but it is unclear what will be feasible under IB. Families can choose a more expensive provider at the expense of receiving fewer hours, according to the principles of IB.
 - **Staff resources and workforce development:** In terms of setting up the IB, the main resource implications are associated with staff costs and time, IT development and getting stakeholder and provider buy in.

Potential Funding

- 6.37 Integration of funding streams was seen as the main challenge to delivering a meaningful IB pilot. Consultees specifically cited health funds as being problematic and added that the current legal framework prohibited the inclusion of funding streams such as Continuing Care.
- 6.38 Consultees suggested the following potential streams of funding that could be used under IB:
- Education based transport funding
 - LSC funding, especially for transition; stakeholders felt that ILF with a young person element would have been very helpful but this is not the case. A significant amount of funding appears to have been going into the Eastern regions on the Individual Learning Fund but not elsewhere.
- 6.39 The funding streams on stakeholders' wish lists included health related therapy services funding and pooled health and social services funding.

Looking ahead summary

- A clear shift away from service delivery to outcomes and effective partnership with children, young people and families
- Potential resource implications will need to be balanced with radical and innovative solutions – employing a dedicated project manager could free up existing resources including current staff time and cost
- Effective capacity building exercises with providers and professionals

Annex A: Glossary of acronyms

AHDC – Aiming High for Disabled Children

BAME – Black and Minority Ethnic

BHLP – Budget Holding Lead Professionals

CAF – Common Assessment Framework

CCNUK – Care Coordination Network UK

CDC – Council for Disabled Children

CiN – Children in Need

CSIP – Care Services Improvement Partnership

CWD – Children with Disabilities

C&YP – Children and young people

DCSF – Department for Children, Schools and Families

DDA – Disability Discrimination Act

DFG – Disabled Facilities Grant

DP – Direct Payment

EBHLP – Established Budget Holding Lead Professionals

ECM – Every Child Matters

EHRC – Equalities and human Rights Commission

ESP – Early Support Programme

IB – Individual Budgets

IBSEN – Individual Budgets Evaluation Network

ICES – Integrated Community Equipment Service

ILF – Independent Living Fund

LA – Local Authority

ODI – Office for Disability Issues

OPM – The Office of Public Management

PB- Personal Budgets

PCT – Primary Care Trust

PSSRU – Personal Social Services Research Unit

RAS – Resource Allocation System

RNID – Royal National Institute for Deaf People

SDS – Self-Directed Support

SEN – Special Educational Needs

SQWC – SQW Consulting

TAC – Team Around the Child

ToR – Terms of Reference

YOT – Youth Offending Team

Annex B: Local Authority Topic Guide

Introduction

SQW Consulting (SQWC), supported by Gerry Zarb from the Equalities and Human Rights Commission (EHRC), has been commissioned by the Department for Children, Schools and Families (DCSF) to undertake a scoping study on Individual Budgets (IB) for Families with Disabled Children. The research will inform the development of future IB pilot work in this area, which is planned to commence in October 2008 and run until April 2011.

The over-arching aims of the scoping study, as set out in the Terms of Reference (ToR), are as follows:

Draw together the existing national and international evidence on the effectiveness of Direct Payments and Individuals Budgets for families with disabled children;

Set out what further evidence is likely to emerge from existing pilot work currently being taken forward; and

Develop costs option for the forthcoming pilots to be taken forward as part of the AHDC programme.

The consultation exercise is seeking to take advantage of the range of pilot work already underway in related areas in order to set out in more detail what kind of IB pilots should be taken forward and how they can be designed to build on and add value to existing knowledge and innovation in this area.

The discussion held during the interview will remain confidential, where no comment will be attributed to an individual or Local Authority prior to gaining their consent.

Context

1. What is your position at the LA? How long have you been in this role and what are your primary responsibilities?

Approaches

2. What approaches have been used (or are you considering implementing) to deliver IB and similar interventions within your LA? And why have you chosen to adopt this approach?

Please consider the following approaches:

IB targeted at adults

Taking Control pilot

in Control adult IB pilot

Budget-Holding Lead Professional

Direct Payments –*please clarify the target group*

Early Support Programme

Dynamite pilot

Other – *please state.*

3. Has the intervention(s) been targeted at specific beneficiaries?

Please consider the following:

age group(s)

type of disability

Socio-economic background e.g. single parent families

BAME communities

4. How have the above approaches been delivered, why and how effective has this been? Please explain the steps through which a beneficiary is supported, what has worked well and what has worked less well.

Please consider the following:

Beneficiary recruitment process

Assessment process – e.g. self assessment, professional assessment, use of the Common Assessment Framework

Allocation of budgets – e.g. use of RAS or alternative method of resource allocation, notional or financial budgets

Support planning – e.g. provision of LA based support, independent support provided by the third sector etc.

Implementation – e.g. commissioning of support?

Review – e.g. how often are the individual's outcomes assessed?

5. What is the evidence on key success factors?

Please collate any hard copies or e-copies of evidence relating to the project(s).

Have any local evaluations or reviews been conducted?

Do you collate data on the numbers of beneficiaries and types of support requested?

6. What do you consider to be the key requirements of a successful IB/BHLP/DP intervention (please consider the key lessons learnt during the process)?

For example (please consider the following from both an LA and National perspective):

Systems development e.g. IT and resource allocation

Independent support brokerage

Staff training – culture change

Market development – review of commissioning procedures

Beneficiary training

Financial and legal support

Buy-in/leadership from senior management

Peer support

Other – please state.

Barriers to delivery

7. What are the legislative/organisational barriers and risks to the effective delivery of the current pilots and which of these may be relevant to the target audience?

For example:

Shortage of Personal Assistants

Under-developed market place

Slow development of IT resources

Staff reluctance

Prohibitive legal structure

Safeguarding – i.e. monitoring the adequacy and quality of support provision

Unmet need

Demand

8. Does the LA collate statistics on the numbers of disabled children within the area and if so, what are the main sources of information?

Is yes – can these be disaggregated by age, type of disability etc?

Would it be possible to pass on a copy to the research team?

9. Can you provide any data on take-up and the reasons why individuals declined the service offer?
10. What types of services were requested by beneficiaries? OR What types of services would families with disabled children like to access as part of the potential IB package?
11. Did you identify any evidence of unmet need during the course of the intervention? i.e. individuals who are eligible for support, were previously not accessing services, but would like to access the new form of service provision. *Please provide details where applicable.*
- OR - Are you aware of any unmet need which may emerge if an IB approach is piloted in your area?
12. Is the IB approach more appropriate for specific sub-groups within the target population? E.g. age groups, type of disability, stage of development of disability etc.

SQWC researcher to run through the potential pilot options developed during the initial stage of the scoping study and discuss their feasibility.

Added value

13. What added value can IB bring to current practice? E.g. increased satisfaction with service provision, increased quality of life for beneficiaries *Please provide copies of any evidence where appropriate.*
14. Can you provide evidence on the cost savings and/or cost effectiveness of the intervention?

15. How could the provision of IB complement the delivery of other strands of the AHDC Strategy? E.g. Short breaks, Early Support Programme, Transition Programme

Funding

16. Which income streams did the existing pilot(s) draw upon in their delivery? What are the associated eligibility requirements?

Specifically with regard to health, how and which budgets have been pooled to facilitate an IB type approach?

17. What set of income streams are applicable to families with disabled children, which could form a component of the IB package? – looking specifically at health, education and social services budgets

Costing

18. Can you provide any data on the costs associated with the intervention? *Please provide copies of any appropriate data.*

For example:

Set up costs – e.g. systems development, workforce development, marketing and promotion, financial planning costs

Running costs – e.g. systems maintenance, support planning and brokerage, resources

Cost of specific service provision – e.g. Personal assistants etc.

Spend per head

Funding associated with a 'price-point'

19. What were the economic and opportunity costs of the intervention? E.g. personal investment in developing won skills to self direct support, costs associated with increase in efficiency of assessment process etc.

We may contact you to seek your permission should we wish to include a quote made during the interview in the scoping study report. Quotes will not be included in the event that permission is not granted. All quotes will be attributable to the LA and not to a particular individual.

SQW Consulting would like to thank you for participating in the scoping study.

Annex C: Case study topic guide

Introduction

SQW Consulting (SQWC), supported by Gerry Zarb from the Equalities and Human Rights Commission (EHRC), has been commissioned by the Department for Children, Schools and Families (DCSF) to undertake a scoping study on Individual Budgets (IB) for Families with Disabled Children. The research will inform the development of future IB pilot work in this area, which is planned to commence in October 2008 and run until April 2011.

The over-arching aims of the scoping study, as set out in the Terms of Reference (ToR), are as follows:

Draw together the existing national and international evidence on the effectiveness of Direct Payments and Individuals Budgets for families with disabled children;

Set out what further evidence is likely to emerge from existing pilot work currently being taken forward; and

Develop costs option for the forthcoming pilots to be taken forward as part of the AHDC programme.

The case study exercise is seeking to build on the information collated during the initial consultation, to test the feasibility of our list of pilot options with potential delivery teams and to gather cost information to support the development of costed pilot options.

We intend to draft distinct reports for each of the case studies, which will form part of the scoping report which will ultimately go to the DCSF. This report will not contain any confidential information and the material developed will be sent to each LA prior to its inclusion in the report to verify its contents. Therefore, each case study will be attributable to an LA but not to the individuals who contributed to the exercise.

We would like to conduct this interview in a forward facing manner to test the feasibility of the potential pilot options (please see supplementary document for details of the options). Therefore, we would like you to consider the pilot options whilst answering the following set of questions.

Context

[Relevant to all consultees]

1. What is your position at the LA (or within your organisation, if speaking to a provider)? How long have you been in this role and what are your primary responsibilities?

Pilot options

[Relevant to all consultees]

2. What are your thoughts on our list of potential pilot options? Do you feel each option is feasible? *In the cases where options are felt to be infeasible, please provide an explanation of why.*
3. How long do you think it would realistically take to set up such a pilot? And what do you think the set up would involve? E.g. Staff training, beneficiary training, IT development, recruitment of staff, market development etc.
4. If you were a pilot site, how would you like to go about recruiting beneficiaries?

Barriers to delivery

[Relevant to all consultees]

5. What are the legislative/organisational barriers and risks to the effective delivery of the pilot options and how could these be alleviated?

For example:

- Shortage of Personal Assistants
- Under-developed market place
- Slow development of IT resources
- Staff reluctance
- Prohibitive legal structure
- Safeguarding – i.e. monitoring the adequacy and quality of support provision
- Unmet need
- Lack of integrated working across health, social work and education teams
- Eligibility thresholds and associated funding allocation
- Double funding – would an LA be able to divert resources from provision of traditional services to IB model or would they be subject to double funding

6. Would the IB offer contradict or clash with existing initiatives such as Direct Payments and the Independent Living Fund (for transition)?

Demand

[Relevant to front-line staff in particular]

7. Can you provide any reasons why individuals may decline the service offer associated with the pilot options?
8. What types of services are likely to be requested by beneficiaries as part of an IB package?
9. Are you aware of any unmet need which may emerge if an IB approach is piloted in your area? i.e. individuals who are eligible for support, were previously not accessing services, but would like to access the new form of service provision.
Please provide details of which groups are likely to form any unmet need.

Added value

[Relevant to Service Provision managers in particular]

10. What added value could the IB pilot options bring to current practice? E.g. increased satisfaction with service provision, increased quality of life for beneficiaries *Please provide specific examples for distinct pilot options where applicable.*

11. Do you think that an IB approach will result in cost savings and/or cost effectiveness in comparison to the use of traditional services? *Please provide details if possible.*
12. How could the provision of IB complement the delivery of other strands of the AHDC Strategy? E.g. Short breaks, Early Support Programme, Transition Programme

Commissioning

[Relevant to Commissioning staff in particular]

13. Do you have a view on how the provider market can be sufficiently developed to accommodate an IB approach? Is this likely to include the provision of provider training/raising awareness of implications of IBs?
14. What are the associated resource implications of the above culture change?

Funding

[Relevant to Finance staff and Service Provision managers in particular]

15. What set of income streams are applicable to families with disabled children, which could form a component of the IB package? – looking specifically at health, education and social services budgets.

Costing

[Relevant to Finance staff in particular]

16. Can you provide any data on the service-level costs associated with delivering the intervention? *Please provide copies of any appropriate data.*
17. What are the potential economic and opportunity costs of the IB pilot options? E.g. personal investment in developing own skills to self direct support, costs associated with increase in efficiency of assessment process etc.
18. Are there any significant costs from existing service delivery/traditional service model that will continue to operate alongside delivery of IB? For example, residential care units, out of area placements

We may contact you to seek your permission should we wish to include a quote made during the interview in the scoping study report. Quotes will not be included in the event that permission is not granted. All quotes will be attributable to the LA and not to a particular individual.

SQW Consulting would like to thank you for participating in the scoping study.

Annex D: Potential pilot options

D.1 The list below details the final set of potential pilot options identified during the research, which were discussed during the consultation and case study exercises.

Targeting by type of disability

- Target **children in continuing care** with complex health needs (CDC, 2006) – the CDC stated that resources should be targeted at this group as a result of the increasing prevalence of children with complex health needs, who in general require very expensive service provision which can be intrusive to family lives. They also state that this group of children are easily identifiable and usually known to a multi agency team, which could be used as the basis of support and who could review the way in which resources are allocated.
- Target **children needing 24 hour continuity** to accommodate severely challenging behaviour – the CDC provides the following justification for targeting provision at this group: “there are a small number of identifiable children in each authority with severely challenging behaviour. The evidence suggests these children need a high level of continuity in relation to the management of behaviour. An Individual Budget pilot would look at whether there were better ways, within current resources, at providing continuity and preventing placement out of authority”.
- Target **specific age groups with high support needs** (ODI reference in the CDC, 2006) – children with high support needs are generally associated with expensive service provision that is not always appropriate or tailored to the family and their child’s needs. Therefore provision of IB to this group may lead increased outcomes as the individual and their families are able to tailor their support provision to meet their specific needs, which may avoid the use of unnecessary and costly traditional provision.
- Target children and young people with an **Autism Spectrum Disorder (ASD)** – the Short Breaks Full Service Offer states that provision must ensure that children and young people with ASD are not disadvantaged in accessing short breaks. Therefore a focus on this group will complement the Short Breaks Programme of AHDC.
- Target children and young people **aged 11+ with moving and handling needs that will require equipment and adaptations** - the Short Breaks Full Service Offer states that provision must ensure that this group are not disadvantaged in accessing short breaks. Therefore a focus on children and young people aged 11+ with moving and handling needs will complement the Short Breaks Programme of AHDC.

Targeting by age group

- Target **children coming out of the Early Support Programme** i.e. those aged 5/6 yrs (CDC, 2006) – the Early Support Programme (ESP) provides support for disabled children aged 0-5 yrs to manage the services they receive, however this provision ceases after the age of 5 and is not available in any form until the child reaches transition stage i.e. 14 yrs old. Therefore, the provision of an IB at the end of the ESP will provide continuity in service provision and is likely to lead to a number of cost effective solutions.
- Target **disabled children who are moving from primary to secondary schooling** i.e. those aged 11/12 yrs – this group of children were identified as requiring additional support during the transition from primary to secondary schooling, which can lead to a significant change in the support required for both the child and their family e.g. new equipment and transportations requirements.
- Target **disabled children aged 5-14 yrs**, to ensure a continuous spectrum of service provision from the Early Support Programme (0-5 yrs) through to the Transition Programme (14-25 yrs) – this option is essentially an amalgamation of the two previous options and has been suggested as a means of providing a continuous spectrum of choice/control service provision for a disabled child and their family as they progress through life.
- Target disabled children **aged 14+ yrs i.e. those in transition** - the Short Breaks Full Service Offer states that provision must ensure that this group are not disadvantaged in accessing short breaks. A focus on young people aged 14 and in transition will complement the Short Breaks and Transition Programmes of AHDC.

Targeting by point of entry to the system

- Target **newcomers to the social care system or disabled children at the point of intervention** – emerging findings from the consultation exercise suggested that families with disabled children may be content with their current package of service provision and therefore that any new form or provision i.e. Individual Budgets, can justifiably be targeted at those who are new to the service/at the point of intervention.

Targeting by socio-economic characteristics

- Target **disabled children from Black and Minority Ethnic (BAME) groups** as a means of understanding the cultural needs of different groups of families with disabled children – the literature has identified the BAME community as a potential group of unmet need, who have in general not accessed traditional services but are more likely to access IB type services as they are perceived to be more culturally sensitive.

- Target **disabled children from families from different socio-economic backgrounds**. This is likely to include families from deprived communities who are unaware that they are eligible to receive services and those who feel unable to access traditional services – this option has been suggested as a means of ensuring the provision of care is provided to all those who are eligible for support and is likely to require a significant amount of out-reach work.

Target by geographical location

- Target a **mixture of both rural and urban areas** to gain an understanding of the differences in service provision required to accommodate geographical characteristics – it is likely that the provision of IBs will vary between locations and may exhibit significantly different characteristics when piloted in urban and rural areas. Therefore, it may be important to pilot the intervention in both settings to understand more about these differences.

Comprehensive offer

- **Offer IBs to a target number of families with disabled children regardless of type of disability, age, socio economic characteristics** etc – it may be more equitable to offer the IB services to all families with disabled children. This will also facilitate a means of testing which groups are more likely to take-up the service and the reasons for this choice.

Extension(s) of existing service provision

- Extend the **current adult IB pilots** to cover families with disabled children – the current adult IB pilots have developed their infrastructure and resource bases and have begun to develop their provider markets and therefore may be in a good position to adapt their provision and pilot the initiative for families with disabled children.
- Extend only **those adult IB pilots that have a disproportionately high demand for IB and number of disabled children** – this option has been proposed for similar reasons to the option above, with the addition that it may be more effective to only pilot the initiative in those areas which experienced a very high demand for IB and who house a large number of potential beneficiaries.
- Extend the **service provision offered by the existing BHLP pilots** to families with disabled children – again as the BHLP pilots have begun to develop the required infrastructure and have begun their transformation towards the delivery of self-directed support, they may be in a good position to extend their current model of service provision to cover families with disabled children and pilot the initiative.

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