

Evaluation of the Made to Measure Pilot:
Pooling Personal budgets
First Interim Report

Samantha McDermid
Centre for Child and Family Research, Loughborough University

February 2014

Table of Contents

Executive Summary	4
Introduction	4
Aims and methods	4
Key findings	5
Conclusion	8
1. Introduction	9
1.1 Scope and purpose of the report	9
1.2 Background	10
1.3 Aims and objectives	13
1.4 Methods	14
2. The Made to Measure Projects	17
2.1 The system context	17
2.2 Progress to date	21
2.3 The mechanism for change: the Made to Measure logic model	25
2.4 Summary of Section 2	27
3. The short breaks market	28
3.1 Overview of the service provision	28
3.2 The availability of services	33
3.3 Parents' views on the short breaks market	36
3.4 Summary of Section 3	40
4. Pooling personal budgets	41
4.1 Initial interest in the pilot: impact and advantages	41
4.2 Moving forward: issues for consideration	45
4.3 Summary of Section 4	50
5. Conclusion	52
5.1 Summary of key findings and implications	52
5.2 Summary of recommendations	56
References	58
Appendices	61
Appendix A: Mapping Plymouth	61
Appendix A: Mapping Trafford	63

Table of tables

Table 1: Focus Group participants by site and characteristic	15
Table 2: Background information on the two hosting local authorities.....	19
Table 3: Parental engagement by project.....	25
Table 4: Summary of the short breaks offer in both hosting local authorities.	30
Table 5: Summary of the services available by local authority	35

Table of figures

Figure 1: Key Stakeholders in Made to Measure	18
Figure 2: The stages of implementation for each local Made to Measure project ...	22
Figure 3: The Made to Measure logic model	26
Figure 4: The proportion of services by provider in both local authorities.....	34

Executive Summary

Introduction

Made to Measure is a pilot programme to trial a new approach, offering parents of disabled children the opportunity to share information and jointly commission activities by pooling personal budgets. One of the key aims of Made to Measure is to support policy objectives to improve choice and control for families of disabled children (Department for Education, 2011a). It is anticipated that the pooling of direct budgets will stimulate the local short breaks market and achieve value for money for families. Two projects have been established in Trafford and Plymouth. These projects will be working alongside parents of disabled children, to develop relationships between parents with similar interests and needs, and to support these parents to pool their personal budgets in order to directly commission the services they would like to use.

The Centre for Child and Family Research (CCFR), at Loughborough University has been commissioned to undertake an evaluation of Made to Measure. This is the first interim report of the evaluation of the Made to Measure pilot programme. The report will present the emerging findings of data collected between August 2013 and January 2014, approximately nine months into the pilot.

Aims and methods

The aim of the evaluation is to evaluate the effectiveness of the Made to Measure pilot to increase the availability of short break services for disabled children and their families, facilitate family involvement in the commissioning of short break services in their locality, and improve the 'added value'. The evaluation also explores parent's views and experience of the pilot programme and the factors that inhibit or facilitate the successful implementation of the pilot.

A mixed method approach has been taken. The methods included:

- Four focus groups consisting of 25 parents of disabled children.
- A mapping exercise of the nature and availability of short break services in each locality.

- Five baseline interviews conducted with the Made to Measure project managers in each locality, short break service commissioners in both localities, and a short breaks' broker in one locality.

Key findings

Progress to date

- As might be expected, both projects have advanced at different paces. However, it is evident that both projects have made substantive progress in the first nine months of the pilot.
- Both projects have established good links with the hosting local authorities and service providers and have started to develop processes for working together.
- At the time of the data collection, both projects had made good progress toward engaging parents in the pilot.

The wider context

- The evaluation found that the context within which Made to Measure is being implemented is a complex one, with many national and local changes to the delivery of services to families of disabled children being implemented. This complexity has been further compounded by uncertainties relating to budgetary constraints. It is anticipated that implementing a new way of working may be more difficult where the supporting structures to that innovation are in flux.
- Some parents expressed a degree of dissatisfaction with personal budgets themselves. Their views and experiences of personalisation *per se* may influence the extent to which parents wish to engage in Made to Measure.
- There was also some evidence to 'pilot' fatigue among some focus group participants, who were more reluctant to engage with Made to Measure.
- It was evident that both local authorities are committed to the principle of pooling personal budgets. However, all the professionals interviewed acknowledge that the process of pooling and how Made to Measure intersects with wider changes within the sector is still to be clarified.

The short breaks market

- Both hosting local authorities provide a range of services for disabled children and their families. In total 68 services were identified in Trafford, and 42 services were identified in Plymouth.
- The short breaks market is complex, with considerable variations in the types of services available, the children and young people they seek to support and the range of providers active in the market.
- Research carried out by CCFR suggests that local authorities are delivering fewer services. The findings of this evaluation support this view: in total, seven services were provided by the local authority and one was provided by health. The remainder were provided by voluntary and independent providers. This finding suggests that providers are central to improving the short breaks market as a whole and are therefore key stakeholders in Made to Measure.
- A number of gaps in the type of provision were highlighted, including afterschool and school holiday activities, services for children with physical disabilities and occasional one off care for, for example, dentist appointments.
- In addition to the type of services available, it was evident that other factors, such as transport, the number of staff available at the service, and the skills and knowledge of those staff, are very important factors for parents choosing to access short breaks.
- Addressing the 'wrap around' factors identified by parents will be central in ensuring that the Made to Measure pilot is able to improve existing services (as rated by families) through the timeframe of the pilot. Both projects have begun to work towards this aim.

Pooling personal budgets

- Overall the focus group participants were interested in the idea of pooling personal budgets and perceived it to be a useful route to access a better range of services and to exercise more choice and control than presently exercised.

- The projects have already begun to achieve positive outcomes for families, through bringing together parents of disabled children who have been able to share information and provide informal support.
- While pooling personal budgets may be suitable for some families and some services, the evaluation participants noted that careful consideration should be given to when and for whom pooling is appropriate. It will be important to bear in mind that pooling will not be appropriate for all families. Parents engaging in the pilot, but not moving on to pool should not be considered 'failures' in all cases. However, it will be important to ensure that families who might benefit from a pooled budget are given all the information and support they need to do so.
- There was some evidence in the focus groups, that those parents who felt better informed, who had previous experience with providers and who felt more confident, were more interested in the engaging with the pilot. It will be important to ensure that the pilot does not produce a 'virtuous circle' whereby those parents who already have access to the social and personal resources available to them are those who are primarily engaged in the pilot, at the exclusion of others.
- The focus group participants were also of the view that the pilot would help to improve the quality of services overall, through families 'voting with their feet' on the recommendations and experiences of other families.
- Concerns were raised regarding the practical implications of pooling budgets, including how the process would work in reality, how to manage insurance and make the payments.
- Some participants questioned whether pooling those budgets would add an additional layer of process onto an already complex procedure. The need to clarify the additional work required and whether this would be carried out by the parents, the Made to measure facilitators or another party such as a personal assistant was identified.
- It is important to recognise, however, that the pilot is in the early stages. As such, there are still ample opportunities to resolve these practical difficulties and to develop systems and processes that are not prohibitively time consuming for parents or professionals.

Conclusion

While not without its difficulties, the Made to Measure pilot presents parents with a unique opportunity to ensure that the short breaks' market is sufficient to meet their needs. The ability to shape that market may ensure that parents can spend their budget in the way that will best meet their needs, and therefore, lead to the best outcomes. If the Made to Measure projects are able to respond to the questions about how the pooling process might work in practical terms, Made to Measure has the potential to lead to positive outcomes for disabled children and their families. The extent to which this is achieved will be explored in the next evaluation report.

1. Introduction

1.1 Scope and purpose of the report

This is the first interim report of the evaluation of the Made to Measure pilot programme. The report will present the emerging findings of data collected between August 2013 and January 2014, approximately nine months into the pilot.

The evaluation is taking a measurement of change approach to explore the impact that the Made to Measure pilot has had in each locality. In addition to testing the evaluation against the pilot objectives, the evaluation will measure the change that occurs in each locality from the onset to the end of the programme. This report explores the early stages of implementation of the pilot, which might be described by implementation analysts, as 'exploration', 'installation' and 'initial implementation' (Fixsen *et al.* 2005). This report is intended to explore these early stages, and where possible, highlight issues that may be helpful for consideration as the pilot progresses. As such the findings presented in this report should be considered to be 'emerging'. Findings will be followed up and verified as the pilot enters year two.

The report is intended to fulfil two primary purposes:

- i. *Describe the baseline* context within which the two Made to Measure projects are being delivered. This includes an exploration of the short breaks market to date and how personal budgets are currently delivered by the 'hosting' local authorities.
- ii. *Outline emerging findings* regarding achievements to date, any early impact that the projects are having on commissioners, providers and families, and any issues arising from the early implementation of the pilot. The views and experiences of parents of disabled children regarding access to support and services, personal budgets and their initial views on the pilot will also be explored.

1.2 Background

Research and policy context

Existing evidence shows that a break from caring is one of the most frequently requested services by families caring for disabled children (Robinson, Jackson and Townsley, 2001; Holmes, McDermid and Sempik, 2010; Brawn and Rogers, 2012), and many studies point to the positive outcomes achieved through the provision of short break care (Hatton *et al.* 2011; McDermid *et al.* 2011; Johnson, Thom, and Prabhakar, 2011; Welch *et al.* 2011). Short break provision may offer families increased independence, improved quality of life and reduced social isolation, along with providing opportunities for children to experience social interaction with their peers at different types of activities (McDermid *et al.* 2011; Johnson, Thom, and Prabhakar, 2011; Welch *et al.* 2010; 2011)

However, accessing appropriate short break services for disabled children can be a difficult task for families (Mencap, 2006; Carlin and Cramer, 2007; Hamlyn *et al.* 2010; Johnson, Thom, and Prabhakar, 2011; Welch *et al.* 2011; Brawn and Rogers, 2012). Research has found that the lack of appropriate short break provision is the most frequently cited cause of unhappiness and the greatest unmet need among parents of disabled children (Carlin and Cramer, 2007; Welch *et al.* 2010; McDermid *et al.* 2011). A number of studies have found that parents feel excluded from short break provision whereby, information regarding which services are available, and how they might access them is insufficient (Johnson, Thom, and Prabhakar, 2011; Welch *et al.* 2011). Meeting the varied needs of a diverse group of children and families requires flexible and diverse service provision (Welch *et al.* 2011).

Steps have been taken in recent years to improve both the variety of short break services and the routes through which families might access them¹. One way to address the difficulties in accessing suitable provision faced by families has been to 'personalise' services (Johnson, Thom, and Prabhakar, 2011; Welch *et al.* 2011). The 'personalisation agenda', as it has come to be known, was initiated for disabled children by a previous government. *Aiming High for Disabled Children* (HM Treasury

¹ For a useful summary of origins and policy context relating to personal budgets, see Johnson, Thom, and Prabhakar, 2011, pp 9 – 12.

and DfES, 2007) sought to increase the number and range of short break services available by redefining the types of services that might be considered to be a 'short break'. *Aiming High* states that 'short breaks' should not be constrained to overnight stays, but include any service that offers disabled children enjoyable experiences away from their primary carers and parents and families a necessary and valuable break from their caring responsibilities (HM Treasury and DfES, 2007; Holmes, McDermid and Sempik, 2010). The underlying principle of this definition is that families should be able to access services that meet their individual needs, rather than taking a 'one size fits all' approach.

The agenda has become further cemented through the present Coalition Government through the Green Paper *Support and Aspiration: a new approach to special educational needs and disability* (Department for Education, 2011a). The green paper, along with the Children and Families' Bill 2013/14, includes an expectation that parents and young people should be given greater control and choice over the support and services that they receive (Johnson, Thom, and Prabhakar, 2011). The provision of personal budgets for disabled children and their families, is one of a range of measures currently being implemented through which this might be achieved.

Personal budgets

A personal budget is the provision of funding, given directly to a service user. The funding may be sourced from a number of income streams (such as health, education or social care). A budget is allocated based on an assessment of need, and the user may be offered the support of a broker to help manage and spend the allocation. *Support and Aspiration* (Department for Education, 2011a) states that all parents of disabled children should be given the option of a personal budget by 2014. That budget should be linked to the new 'Education, Health and Social Care Plan' (Johnson, Thom, and Prabhakar, 2011).

A number of studies have been undertaken to explore the impact of personal budgets on disabled children and their families (Prabhakar *et al.* 2008; Welch *et al.* 2011; Johnson, Thom and Prabhakar, 2011). The Governments' SEND (special

educational needs and disability) Pathfinder programme has included a pilot of personal budgets (Johnson, Thom, and Prabhakar, 2011). There is a small, but growing, body of evidence which suggests that personal budgets can improve the choice of services available to families (Johnson, Thom, and Prabhakar, 2011; Welch *et al.* 2011), satisfaction in the services they receive (Thom and Prabhakar, 2011), increased control that families feel that they have over their lives (Johnson, Thom, and Prabhakar, 2011; Welch *et al.* 2011) and improved independence (Johnson, Thom, and Prabhakar, 2011). However, some concerns have been raised regarding the extent to which personal budgets, alone, will improve the availability of services for disabled children and their families (Welch *et al.* 2011).

The policy surrounding personal budgets is underpinned by family centred approaches to services delivery, in which the individual and families are placed at the centre of decision making and are therefore able to influence the types of social care they received (Johnson, Thom, and Prabhakar, 2011). It is this approach that underpins the Made to Measure pilot, which seeks to place families in the driving seat of service provision in a very real and practical way.

The Made to Measure Pilot

Scope received funding from the Department for Education, through the National Prospectus Grant programme, to pilot Made to Measure. Made to Measure will trial a new approach, offering parents of disabled children the opportunity to share information and jointly commission activities by pooling personal budgets. One of the key aims of Made to Measure is to support policy objectives to improve choice and control for families of disabled children (Department for Education, 2011a). Two projects have been established in Trafford and Plymouth. These projects will be working alongside parents of disabled children, to develop relationships between parents with similar interests and needs, and to support these parents to pool their personal budgets in order to directly commission the services they would like to use.

It is anticipated that the pooling of direct budgets will stimulate the local short breaks market and achieve value for money for families.

Objectives:

- Engage with 180 parents across Plymouth and Trafford, months 4 to 24;
- Build one website with two local forums, months 4 to 6;
- Families commission and quality assure 50 new/improved activities (across both local authorities) resulting from budget pooling, months 7 to 24;
- Create calculator tool in year two.

Intended outcomes:

- Parents collaborate to identify new activities and experience added value by pooling budgets;
- Disabled children experience better life outcomes by accessing a greater number and variety of flexibly delivered activities;
- Local markets are stimulated to offer new services in turn informing national delivery.

1.3 Aims and objectives

The Centre for Child and Family Research (CCFR), at Loughborough University has been commissioned to undertake an evaluation of Made to Measure. The aim of the evaluation is to evaluate the effectiveness of the Made to Measure pilot at meeting the programme objectives.

The evaluation will seek to explore the extent to which Made to Measure:

- a. increases the availability of short break services for disabled children and their families
- b. facilitates family involvement in the commissioning of short break services in their locality
- c. improves the 'added value'

The evaluation will also explore:

- d. parent's views and experience of the pilot programme, with a specific focus on the effectiveness of parental engagement
- e. the factors that inhibit or facilitate the successful implementation of the pilot, including recommendations for the future roll out of the programme.

1.4 Methods

A mixed method approach has been taken. The methods have been designed to examine the impact of the pilot on disabled children and their families and the short breaks market within the pilot sites. The following methods have been used.

Focus Groups with parents of disabled children

Four focus groups consisting of 25 parents were conducted across the two projects.

The focus groups explored:

- The range of services accessed by the participants;
- Parents' satisfaction with those services;
- The impact of those services on children and families;
- The extent to which families feel able to access the services they feel their child needs;
- Parents' level of interest in pooling budgets;
- Initial views regarding how the pooling of budgets might be achieved.

The focus group participants varied in the extent to which they had already engaged in the pilot. Some had already expressed an interest in pooling budgets and some had heard about the pilot the same day as the focus group. These variations, reflect the various stages at which each project was in implementing the pilot (discussed further below). Table 1 gives details of the focus group participants.

The focus groups were hosted by the Made to Measure projects. Three of the focus groups were held with parents who were newly interested in the pilot. For them this meeting was their initial engagement in the pilot. One group was held with parents who had already expressed an interest in pooling their budgets to organise a joint activity for their children. These parents were already engaged in the pilot.

Table 1: Focus Group participants by site and characteristic

Focus Group	Number of Participants	Involvement in Measure	Number of participants in receipt of a personal budget or direct payment
Focus Group 1	12	Initial engagement	9
Focus Group 2	4	Initial engagement	2
Focus Group 3	6	Initial engagement	5
Focus Group 4	3	Interested in pooling	3
Total	25		19

Short break service mapping exercise

A mapping exercise was undertaken to examine the nature and availability of short break services in each locality. A template was adapted from previous studies undertaken by the author (Ward *et al.* 2008; Holmes, McDermid and Sempik, 2010; McDermid, 2010) for this purpose. The template is designed to capture comprehensive information in relation to short break services. Details regarding the type of service, the target group, funding and delivery arrangements (such as staffing), and referral routes were gathered for each identified service.

The template was initially populated using publicly available information including the local authorities' short break statements, commissioning plans, websites and family information services. The pre-populated template was verified by the local authority commissioning managers.

The findings of the mapping exercise have been used to ascertain a baseline understanding of the availability of short break services in both local authority areas. The data gathered included some information, including the costs of some commissioned services, which were considered to be commercially sensitive and have therefore remained confidential to the evaluation team. This report presents the digested data, designed to inform the evaluation and its commissioners, while ensuring commercial sensitivities are protected.

Baseline interviews with professional stakeholders

Five baseline interviews were conducted with the Made to Measure project managers in each locality, short break service commissioners in both localities, and a short breaks broker in one locality. These interviews gathered qualitative data regarding:

- The availability of services within the local authority;
- How personal budgets (and other short break services) are delivered;
- The extent to which families with disabled children are involved in the commissioning process, and in what ways;
- The way in which the two projects are being implemented in each locality;
- How their work aligned with existing services.

Anonymity of research participants

When undertaking evaluations, such as this one, the standard practice of the evaluation team is to maintain confidentiality and anonymity of all research participants, including the research sites. However, in the case of Made to Measure the identities of the two hosting localities (Plymouth City Council and Trafford Council) are in the public domain. These localities have been selected specifically because of their differences, to explore how the pilot might operate in different contexts.

Consequently, throughout the report it has been necessary to describe the sites in some detail, and given that the sites have been named publicly, it is the view of the author that little would be gained from anonymising the sites when describing information that is in the public domain. However, to protect the anonymity of the *individuals* who have participated in the evaluation, this report will not identify which site they are from or their professional role (where relevant).

2. The Made to Measure Projects

Pilots and programmes aimed at improving outcomes for vulnerable children and young people are implemented in a wider context of children's services local and national policy, procedures and practice. In measuring the impact of such programmes, it is therefore, necessary to consider that context. In recognition, this evaluation is taking a *Realistic Evaluation* approach (Pawson and Tilly, 1997). This method acknowledges that the way in which a single programme is implemented varies across localities, and indeed, the localities themselves may vary. It is therefore necessary to measure the effectiveness of programmes in light of these variations. Furthermore, evaluations must seek to identify the *mechanisms* by which interventions work. Thus, this evaluation will seek to identify '*what works, under what circumstances and why*' (Pawson and Tilly, 1997).

This section will firstly describe the context within which the Made to Measure projects are being implemented, and secondly to explore the progress of these two projects to date. This section will also outline the logic model for Made to Measure, which demonstrates the mechanisms through which the two Made to Measure projects may achieve the pilot outcomes.

2.1 The system context

Partnership and collaboration is a key theme through all social care practice. The Made to Measure Pilot is being delivered in a wider system seeking to support disabled children and their families. Partners such as families, their social worker, local authority commissioners and resources teams, family information services, service providers from a range of sectors and brokers will all participate in the delivery of support and service through a personal budget. Therefore, in evaluating Made to Measure, it may also be advantageous to consider how the Made to Measure projects are situated within that system. A better understanding of this will assist in the potential future roll out of the programme.

The wider system

Figure 1 shows the key stakeholders identified by the Made to measure pilots. Two contrasting local authorities have been identified to host Made to Measure. The local authorities were selected to test the effectiveness of the pilot against different levels of provision. These differences were evident during the data collection. Table 2 summarises the differences between the two hosting local authorities.

Figure 1: Key Stakeholders in Made to Measure

- *Disabled children and young people and their families*
All disabled children, young people and their families who access short break services through a personal budget or direct payment may be a stakeholder in the pilot. The level of interest in the pilot may vary according to the extent to which families wish to pool their budget.
- *Local authorities*
At present the key stakeholder from the hosting local authorities are the Children's Services short break service commissioner. Interest in the pilot may extend to other Children's Services personnel, and colleagues from Education and Health services as the pilot progresses.
- *Short Break service providers*
Independent and voluntary service providers may be commissioned through a pooled budget to deliver a service.
- *Brokers*
Brokers work with families who have been given a personal budget to assist and support the family with how they might use their budget. Brokers may wish to signpost parents to Made to Measure to ensure they can use the personal budget to access the services and support they feel they need.

Table 2: Background information on the two hosting local authorities

	Trafford Council	Plymouth City Council
Demographic and background information	<p>Trafford is a medium sized metropolitan district council within a conurbation of a large urban area in the North West of England.</p> <p>The estimated population of children and young people is 51,800 with approximately 3,900 disabled children and young people.</p>	<p>Plymouth is a medium sized unitary authority, consisting of an urban development located in an otherwise rural area.</p> <p>It has an estimated population of 50,900 children and young people aged up to 17, and an estimated 3,000 children and young people with a disability.</p>
Short breaks Market	<p>Short break activities are well provided for and they want to stimulate more provision to strengthen local community engagement.</p> <p>The authority is part of a collaboration of authorities in the area. These authorities have developed a Framework for the commissioning of short breaks.</p> <p>The site is one of the SEND pathfinder sites.</p>	<p>Plymouth reported a relatively underdeveloped market offering limited services for families with disabled children in 2008.</p> <p>However, this has changed with significant market development work taking place over the period of the Aiming High grant.</p>
Approach to personalisation	<p>Personal budgets have been provided since the DfE pilot programme.</p> <p>All families whose needs are such that they require social care are offered a personal budget. The allocation of personal budgets are determined using a RAS (Resource allocation score).</p> <p>A range of other support services are available for those families who do not require social care support.</p>	<p>Personal budgets are not yet available in Plymouth but will be from September 2014. Direct Payments are available.</p> <p>Personal budgets will be available to families with higher levels of need. These may be provided on their own, or as part of a package of services. Families will only access personal budgets if they meet the criteria for targeted or specialist services.</p>
Parental involvement in commissioning	<p>Ongoing consultation is sought through:</p> <ul style="list-style-type: none"> • Children with disabilities Parents Advisory Group • Parents' forum • Special Parents in Trafford Facebook group. • Parents email list. 	<p>The authority supports a parents reference group ('Your Child, Your Voice), which is a community interest company run by parents and is involved in planning monitoring and evaluation of the short breaks services, alongside the Aiming High strategic oversight group (forum for partners) including voluntary and community providers.</p>

The most distinct difference between the two local authorities is their approach to personalisation. This is explored further in Section 3.1 below. It is not yet evident whether and in what ways the differences between the two hosting local authorities will impact the pilot. It is likely that the projects will develop different systems, processes and possibly cultures in order to adapt to the system which they are working in. To some degree this will be necessary for the success of the pilot. However, it may be advantageous to explore whether some common policies and processes are required. Such an understanding may assist new projects to be set up at a later date.

The context of change

The evaluation of the Department for Education Individual budget pilot found that while the pilots have demonstrated that personal budgets can provide a number of advantages for families, the process through which those personal budgets are delivered needs to be clarified (Thom and Prabhakar, 2011). For instance, Thom and Prabhakar (2011) note that consideration still needs to be given to how services accessed through the personal budget schemes align with existing block funding and contracts. Families and professionals alike are still 'getting used to' a new way of delivering services. The process may be slightly more familiar in Trafford compared to Plymouth. However, the implementation science literature suggests that it takes a minimum of two years for a new social care intervention to fully embed (Fixsen *et al.* 2005). Consequently, personal budgets may still feel new to some families and professionals across both the hosting local authorities.

While neither hosting local authorities reported significant difficulties in implementing the personal budget programme, it is important to recognise that Made to Measure is being implemented at a time of substantial change. Personal budgets, alongside other changes to the way services for disabled children and their families proposed in *Support and Aspiration* (Department for Education, 2011a), including the greater integration between social care, health and education services and the new 'Health, Education and Care' plan are all on the horizon for local authorities. This evaluation is also being carried out during a period of economic austerity. Spending pressures were present in the rhetoric of all the participants both explicitly and implicitly.

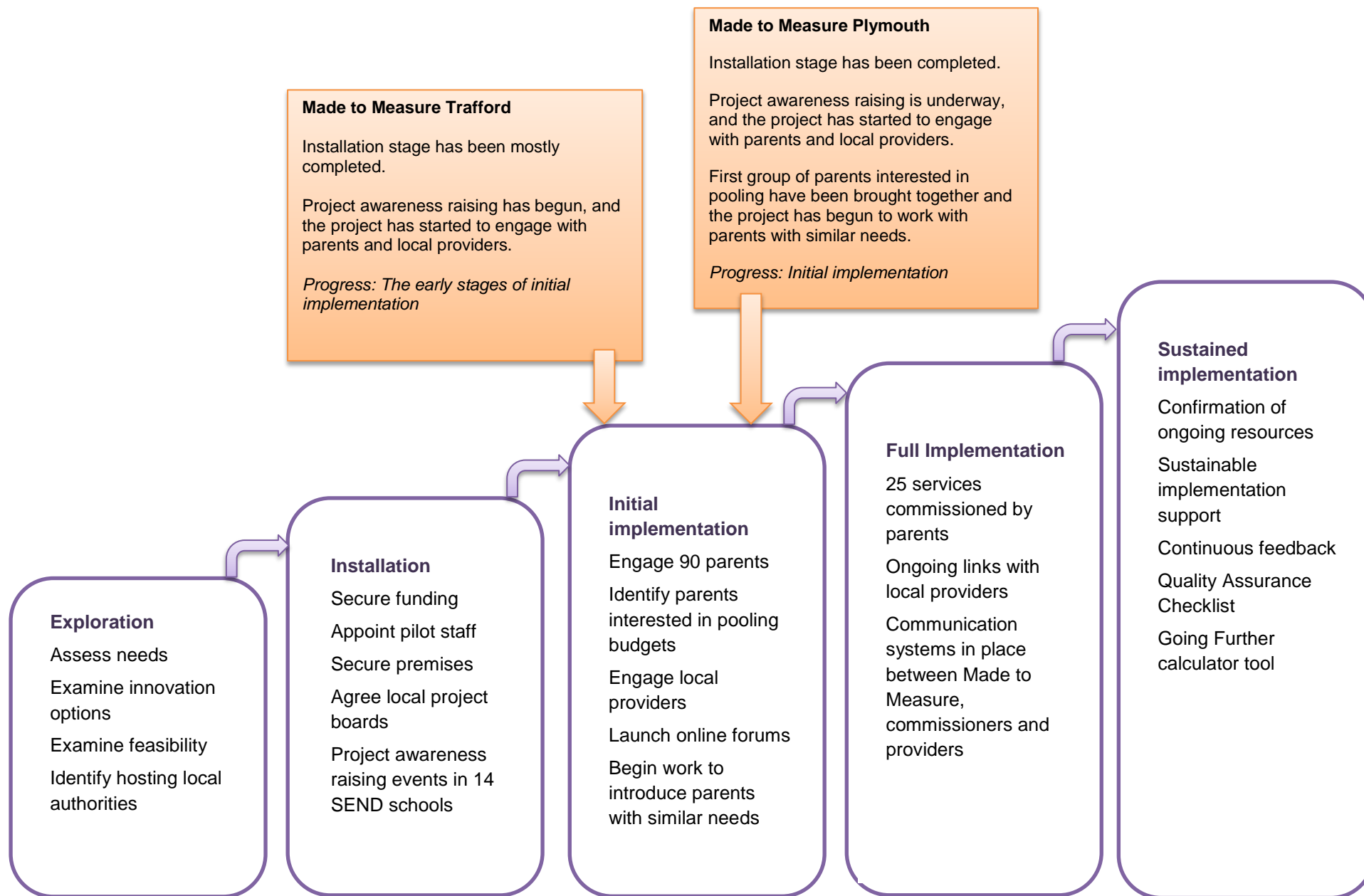
Innovation can be a greatly rewarding, but problematic process. The pooling of personal budgets is not only a developing innovation, but one which is being undertaken in a context which itself, is still under development. While it is currently unclear how this context might affect the implementation of Made to Measure, it can be anticipated that innovation may be more difficult where the supporting structures to that innovation are in flux. This process may be eased through continual communication and partnership with other stakeholders, most notably local authority commissioners, and a flexible approach which enables the projects to 'move with the times'. These two elements were evident in the data collection.

2.2 Progress to date

Fixsen *et al.* (2005) have developed a model to demonstrate the five key stages of implementation. These stages represent an 'ideal' model of implementation of new innovations. In reality these stages may overlap, be of different lengths or the steps between some stages may be more difficult than others. This model has been adapted for the Made to Measure pilot and can be used to analyse each project's progress to date². Figure 2 shows the stages of implementation for Made to Measure and the key tasks that might be undertaken in each stage. The figure also shows where each project has reached along the stages.

² This method for assessing the progress of programme has been adapted from the work of Deborah Ghate at the Colebrooke centre for evidence and implementation.

Figure 2: The stages of implementation for each local Made to Measure project
 (adapted from Metz and Bartley, 2012 and Ghate, McDermid and Trivedi, 2013)



The Installation stage

The installation stage relates to all those activities that are necessary to set up the innovation or pilot. It is during this stage that a pilot starts to move from being an idea or plan to a tangible reality. Both projects were established in this stage and the activities undertaken included:

- Recruitment of the staff team;
- Secure premises;
- Establish local project boards.

As might be expected, the two projects are advancing at different paces. The difference in pace is in part, due to considerable difficulties experienced by the Trafford project during this stage. For a number of different reasons, this project has experienced delays in establishing a full staff team, which has restricted the extent to which the project could get fully underway. The additional pressures that have been placed on this team are twofold: firstly through the restricted capacity of the reduced team to undertake the necessary activities; secondly through the additional activities necessitated through the recruitment process. It is therefore no surprise that the Trafford team are less advanced into the next stage (initial implementation) compared to Plymouth. The additional hours undertaken by the Trafford team to progress the project in the light of the staffing difficulties should be recognised and commended. The project has now established a staff team and reported that they have made good headway into the next stage. The two projects have developed a strong partnership, and have offered good support to each other during the installation stage. The support offer to Trafford by Plymouth during the difficult installation stage has been of particular value.

At the time of the data collection, both projects had established a full staff team consisting of one full time service manager, two part time facilitators and one administrator. Permanent premises had been secured. The membership of the local project boards had been agreed and had begun to meet regularly. Both projects had engaged with the SEND schools in the hosting local authority.

Initial implementation

As Figure 2 shows, both projects are in the initial implementation stage. As might be expected given the staffing difficulties encountered by Trafford, this project has just entered the initial implementation stage, while Plymouth is further advanced.

However, it should be noted that Trafford secured a full staff team in December 2013. Since that date they report interest in the pilot has advanced at pace. Fixsen *et al.* (2005) note that innovations generally take a minimum of two years to journey from initial conception to full and sustained implementation. This time frame should be borne in mind when considering the progress that each project has made in the first nine months of the pilot. Given the two year timeframe hypothesised by Fixsen *et al.* (2005), it can be stated that both projects are making good progress.

The initial implementation stage is the point at which the activities related to the innovation commence: staff are in place, people are trained in and begin to apply the innovation. Engaging parents in the pilot and enthusing them about the potential for pooling budgets is essential to the pilot and a key focus of this stage. Table 3 shows the numbers of parents engaged in both projects. Section 3.3 explores parental engagement in more detail. Engaging professionals from both local authorities and providers is also an essential element to the success of Made to Measure. The Trafford project have made good links with the seven SEND schools and two SEND Parent Liaison Officers, two local parent groups and the Brokers working across Trafford. More events are planned to engage all stakeholders in the pilot. The provision of training has provided the project with good opportunities to create links with all stakeholders. Plymouth has also made good links with six of the seven SEND schools in the area and has continued to contact parents through a range of means. The project facilitators have attended 12 parent groups. In addition the online forum had been launched in both localities and parents are beginning to use it. The use of the forum will be explored in future evaluation reports.

Both projects have established good links with the hosting local authority, which is represented on the local project boards. It was evident that communication between the Made to Measure projects and the local authorities was regular and ongoing. Providers are also represented on both local project boards, and both projects reported they have started to build facilitative relationships with local providers.

Supporting the continued engagement of all stakeholders in the pilot will be an essential component for the projects as they progress. Table 3 below shows that both projects had made progress towards the objective of engaging 180 parents in the pilot.

Table 3: Parental engagement by project¹

	Number of interested parents²	Number of engaged parents³
Plymouth	173	52
Trafford	42	26
Total	215	78

¹ Figures correct on 12th February 2014

² Those parents who are attending groups or accessing the forum, who are showing general interest in the project, but are not actively discussing ways that they would like to pool their budgets

³ Those parents who have asked to be kept informed about the pilot, are actively engaged with Made to Measure facilitators to discuss the pilot further.

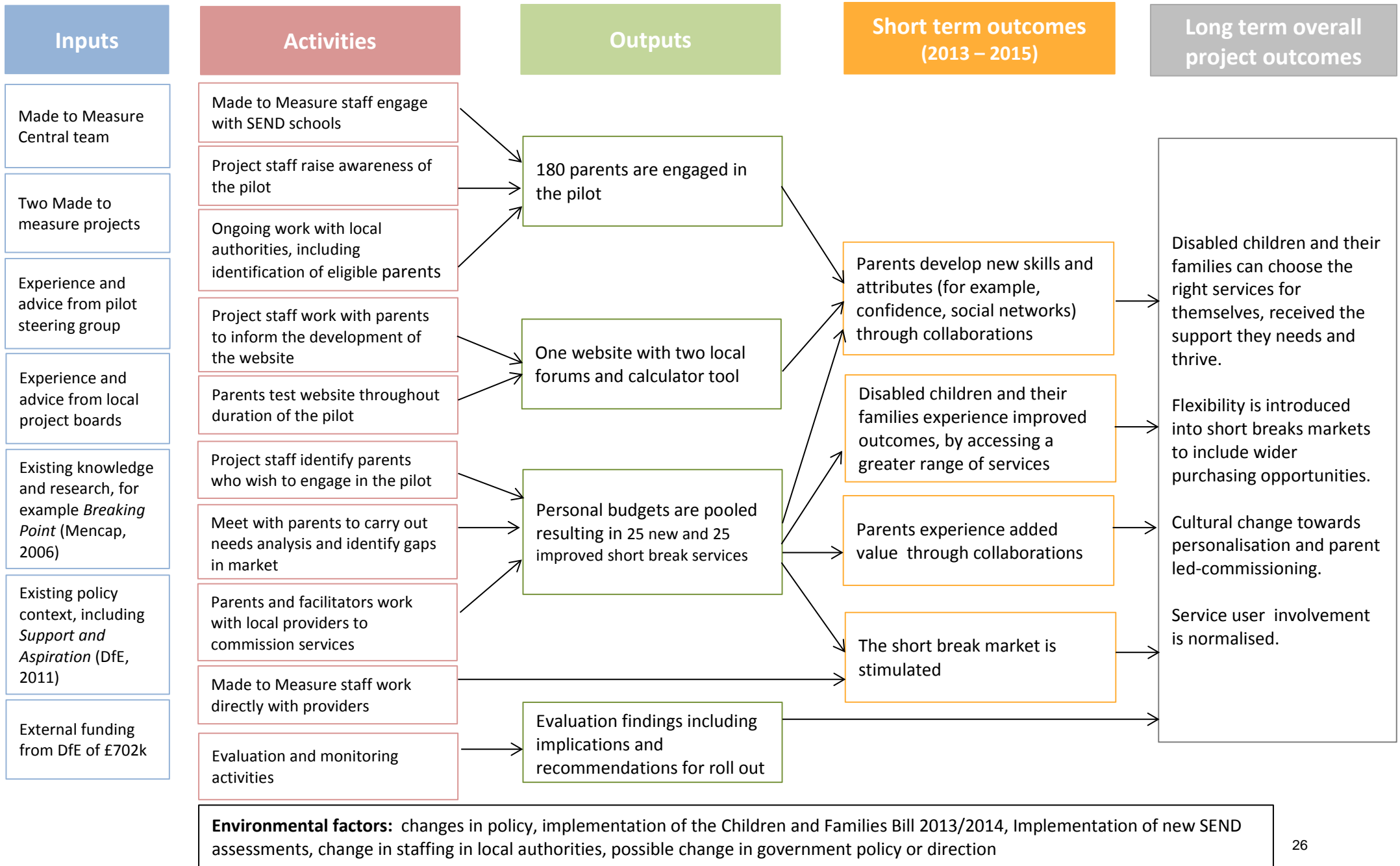
It is in the initial implementation stage, through the initial use of the innovation, where challenges may be encountered and solved (Fixsen *et al.* 2005). Encountering such difficulties are to be expected in this stage of an innovation and identifying them and finding solutions at as early a stage as possible will benefit the projects.

2.3 The mechanism for change: the Made to Measure logic model

In light of the realistic evaluation approach which seeks to explore the mechanisms by which interventions work, the findings of this data collection have been brought together to develop a logic model for Made to Measure. A logic model is designed to hypothesise how the inputs, activities and outputs link to the desired outcomes. Moreover, by identifying the key elements of the pilot, the differences between *how* the elements have been implemented between the two projects can be more clearly explored. This logic model is designed to assist in establishing ‘what works, under what circumstances and why’ (Pawson and Tilly, 1997).

The logic model is shown in Figure 3. It will be used to evaluate the outcomes in subsequent data collections.

Figure 3: The Made to Measure logic model



2.4 Summary of Section 2

The evaluation found that the context within which Made to Measure is being implemented is a complex one, with many national and local changes, along with uncertainties relating to budgetary constraints. The extent to which the variations between the two hosting local authorities impact on the way in which Made to Measure is implemented and the impact that it has, will be considered throughout the evaluation.

It is evident that both projects have made substantive progress in the first nine months of the pilot. While these months have not been without their difficulties, it was evident from the data collection that the project staff and professionals from stakeholder organisations have worked hard to develop effective relationships and to advance the pilot. While the Trafford project has been hindered by staffing difficulties, these delays should lessen now that they have a full complement of staff.

Both projects are in the initial implementation stage. This stage is an exciting one, as staff will start to explore the realities of pooling budgets. It is in this stage that difficulties and questions about how the pilot will be implemented can arise. While this is to be expected, the remainder of this report attempts to identify some of these difficulties to assist the projects as they progress.

3. The short breaks market

Central to Made to Measure is the improvement of the short breaks market. In order to fully evaluate the impact of the pilot on the short breaks market it is first necessary to examine the short breaks market upon commencement of the pilot.

The short breaks market not only comprises the number and types of services available: the extent to which these services offer good quality and lead to positive outcomes for disabled children and their families should also be considered.

Moreover, previous research has demonstrated that families' levels of satisfaction in short break provision, and the costs of that provision, is influenced by the way in which those services are accessed (Holmes, McDermid and Sempik, 2010). This section will bring together the findings of the mapping exercise, the focus groups with parents of disabled children and the set up interviews with professionals, to explore the availability of short breaks in each hosting local authority, how they are accessed and parents' views on the short breaks market overall.

3.1 Overview of the service provision

Previous research undertaken by CCFR has found a variety of commissioning arrangements for the provision of short break services (Holmes, McDermid and Sempik, 2010). A complex picture of short break services has been identified across England. The two hosting local authorities are no exception to this, whereby each has developed a short breaks offer designed in response to local need and procedures.

Local authorities offer short break services to families who fall into two broad groups (Holmes, McDermid and Sempik, 2010; Department for Education, 2011b):

Group 1: Families of disabled children with lower levels of need are provided short breaks through a 'local offer'. These services can be accessed directly (with no assessment or referral) or through a 'light touch' referral.

Group 2: Families whose needs are such that they meet the threshold for social care support are provided targeted or specialist support. In the majority of cases these families require an assessment such as an Initial or Core assessment.

In addition to the services that are commissioned by local authorities, a range of services may also be provided independently of local authorities. These may include charities and voluntary organisations, or other providers (such as health and education) offering services for disabled children and their families. Families may access these services directly. Some information about these services may be accessed through the family information service.

The structure of short break services, and the needs of families, in reality is more complex than this, but has been simplified for the purposes of this evaluation. Personal budgets and direct payments are typically provided to families who fall into Group 2, with higher level of needs. In the majority of cases, the families who access Made to Measure will therefore, be in this group.

Both local authorities have developed 'tiered' service provision, to ensure that short break services are available for families with different levels of need. Services and assessment systems have been developed to ensure that the right kinds of services are available for the right families. Table 4 summarises the short breaks offer in both hosting local authorities.

Table 4: Summary of the short breaks offer in both hosting local authorities.

	Trafford Council	Plymouth City Council
The services available and how they are accessed: Group 1	<p>A range of targeted support services are available through the local offer.</p> <p>These can be accessed through a range of routes.</p>	<p>Up to 10 days holiday activities and three hours per week leisure activities can be directly accessed through a brokerage service.</p>
The services available and how they are accessed: Group 2	<p>All families wishing to access short breaks have an assessment and are given a RAS (Resource allocation score), which will determine which services they can access.</p> <p>Families whose RAS score is over 150 are offered a personal budget with broker support.</p>	<p>Targeted services are available through either a CAF or self-assessment.</p> <p>Specialist services are available through either an initial or core assessment and then agreed through the resource panel.</p> <p>Some families are offered a direct payment.</p>
Needs analysis and areas for continued improvement	<p>Access to services including access to buildings, age restrictions on some services, cultural barriers, and transport.</p> <p>Information about how to access services and eligibility.</p> <p>Need for greater coordination between services.</p> <p>Limited knowledge across workforce about disabilities.</p> <p>Parents do not feel safe leaving their children in universal settings.</p>	<p>Continuing Workforce development in universal services</p> <p>Joint funded care.</p> <p>Enabling services.</p> <p>Transition services.</p> <p>Inclusion services.</p>

One key distinction between the local authorities, is the extent to which personal budgets have been implemented. Trafford Council is a pathfinder site, and participated in the Department for Education pilot to introduce personal budgets. The vast majority of families who fall into Group 2 access support through personal budgets. Short break services are still available through traditional direct access routes. However this approach is likely to reduce over time and all new families will be encouraged to access services through a personal budget. By contrast, personal

budgets are not available in Plymouth, but will be available to some families from September 2014. Direct Payments were provided to approximately 90 families. The majority of those families used the direct payments to purchase personal assistants. Other types of services are still available and accessed through traditional direct access routes.

It is not yet evident whether, and in what ways, these differences in the length of time the authorities have been delivering personal budgets will impact Made to Measure. However, this will be an essential aspect to consider as both projects advance and begin to bring the first groups of parents together to pool their budgets. It was evident that both local authorities are committed to the principle of pooling personal budgets. However, all the professionals interviewed acknowledge that the process of pooling and how Made to Measure would intersect wider changes within the authorities is still to be clarified. It is evident that the Made to Measure projects and the local authority representatives have developed good working relationships and ongoing communication. This will be essential to maintain and build upon as the projects and personal budgets progress.

Parents' views on personalisation

The evaluation explored parents' views on personalisation. There were some very strong feelings about personal budgets among some of the focus group participants, with a small number (3:12%) feeling that they had been '*unfairly*' treated. Feelings were strongest amongst those focus group participants who felt that a personal budget had been '*forced*' upon them (4:16%) in place of access to services through traditional means. A small number of parents (4:16%) reported that they felt that the move to personalisation was a 'cost cutting' exercise, but not necessarily in the interests of families. A little under half (11:44%) of the focus group participants reported that there is a lack of information about personal budgets in general, including the assessment process and the criteria for how much budget is allocated. A quarter of the focus group participants (6:45%) highlighted concerns regarding the timescales relating to personal budgets, including the time between referral and initial contact and between completing the assessment and having the personal

budget at the family's disposal (*c.f.* Johnson, Thom, and Prabhakar, 2011; Brawn and Rogers, 2012).

The view among a number of the focus group participants (9:36%) was that local and national policies relating support and services for disabled children and their families were 'ever changing'. This context made it difficult for parents to plan beyond the 12 month timescale of their care plan. One parent reflected the view of a number (3:12%) saying "*If it's working why can't they just leave it alone?*" (Parent 13). Another commented: "*There have been so many changes within social services over the last few years that people just don't know [how to access short break provision]*" (Parent 23). A few parents from Plymouth (4:16%) expressed concerns about what would happen to their allocation once personal budgets were introduced.

The strength of feeling among a small, but significant, number of parents regarding personal budgets was apparent, with parents feeling let down by the system that they looked to for support. This was most (but not exclusively) apparent in the areas where personal budgets were replacing traditional methods of accessing services. Even those parents who did not feel as impassioned about personalisation expressed substantive concerns about it. Those focus group participants in receipt of direct payments were less critical of personalisation. These parents reported having more flexibility regarding how their money could be spent than those who received a personal budget. It is unclear from the data gathered at this stage of the evaluation if this reflects differences between direct payments and personal budgets *per se*, or differences in practice and culture between the two hosting local authorities.

It is important to note, that these parents were dissatisfied about the personalisation agenda in general, rather than the idea of pooling their budgets. However, it will be important for the Made to Measure projects to recognise this as they progress. No pilot operates in a vacuum and the Made to Measure pilot is necessarily linked to the wider personalisation agenda. It may be advantageous to consider how parents' broader views and experiences of personalisation may impact the extent to which they wish to engage with Made to Measure and to recognise when parents are disinterested in *pooling* personal budgets or personalisation as a whole. This will be

important to ensure that project staff do not become discouraged where parents are in fact, expressing concerns about wider issues.

An unintended consequence of parents expressing their wider views on personalisation may be that the projects could provide an opportunity for feedback loops and communication between parents and local authority representatives. The Made to Measure team have considered whether this is an appropriate role for the pilot to take from the outset and will continue to review as the pilot progresses. One of the projects is gathering parents' views about personalisation more generally and are exploring different ways these views might be fed back to the local authority.

3.2 The availability of services

The mapping exercise identified a wide variety of services. The types of services identified were diverse, and included an array of activities, personal care and more traditional types of 'respite'. Different types of services were available for families with different levels of need. However, a number of similarities between the types of services were identified, which made it possible to identify a set of generic service types, based on previous work carried out by CCFR (Holmes, McDermid and Sempik, 2010).

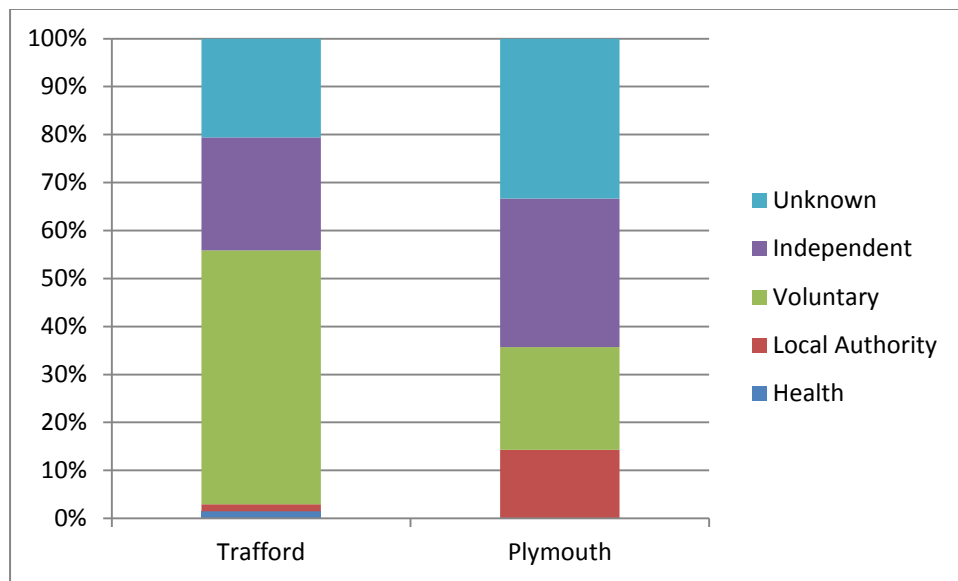
The complexity of the short breaks market was compounded by the variations which were identified within each service type. These included:

- The way the services was accessed;
- The target group (variations in relation to age and need);
- The number of hours the session runs for;
- The location;
- The number and type of professionals delivering the service and the capacity;
- The provider.

Research carried out by CCFR suggests that local authorities are delivering fewer services. Short break services are increasingly commissioned to voluntary and independent providers (Holmes, McDermid and Sempik, 2010; McDermid and

Holmes, 2012). The findings of this evaluation support this view. In total, seven services (six in Plymouth) were provided by the local authority and one was provided by health. The remainder were provided by voluntary and independent providers. It was not possible to gather data on the type of provider for all the services identified. However, of those that were identified 16 different independent providers, and 23 different voluntary providers were cited. Figure 4 shows the proportion of services by provider in both local authorities.

Figure 4: The proportion of services by provider in both local authorities



This finding suggests that providers are a central to improving the short breaks market as a whole and are therefore key stakeholders in Made to Measure. The projects have already begun to engage with providers to fully execute pooled budgets.

In total 68 services were identified in Trafford, and 42 services were identified in Plymouth. Table 5 summarises the number of services identified by local authority and whether they were identified as being part of the local core offer, social care provision, or independent from the local authority commissioning programme. This last group were identified using the local Family information Service. Anonymised versions of the templates for each local authority area are included in Appendix A.

Table 5: Summary of the services available by local authority

Service Type	Number of services identified								
	Trafford				Plymouth				Total
	Local core offer	Social Care	FIS ¹	Total	Local core offer	Social Care	FIS ¹	Total	
Access to universal services	2			2		1		1	3
Befriending	2	1	1	4				0	4
Day Care		6		6		1		1	7
Equipment				0		1		1	1
Family Support	2			2				0	2
Groups: Afterschool				0		2		2	2
Groups: Arts and Drama			3	3	3			3	6
Groups: Independence			1	1				0	1
Groups: Other	3		5	8	1		1	2	10
Groups: Sports and outdoor activities				0	6			6	6
Groups: Youth	4		3	7	1	3	1	5	12
Mental health support			2	2				0	2
One to one support		1	10	11		5	2	7	18
Overnight: family based		2	1	3		2		2	5
Overnight: residential		7	2	9		2	1	3	12
Support and Advice				0			2	2	2
Support for parents			1	1			1	1	2
Therapeutic			6	6			1	1	7
Transitions			2	2		2		2	4
Weekend and holiday groups	1			1		3		3	4
Total	68				42				110

¹ Services identified through the Family Information Service, but are not commissioned directly by the local authority.

As Table 5 shows, the most frequently identified services were one to one support (which include personal assistants and domiciliary care) and overnight residential. This finding reflects the views of parents, who reported that these two services are the most valued.

In addition to the types of service available, information was also gathered about who each service catered for, based on age and impairment type. Information was only partially available for the majority of the services. Of those services where information was available regarding the age range of the service (n=56), almost half (30:53%) were provided for older children and young people (aged 11 – 18). Only two services stated that they were specifically aimed at younger disabled children (under 10), one of those was provided for under fives. Just under half stated that they were provided for all ages. The data suggests that there is a lack of services provided specifically for younger disabled children. However, this finding should be verified, due to partial data. Those services that either did not state an age range, or stated a wide age range, may cater for younger children.

Thirty five services stated that they were aimed at children with a specific need or impairment. Of those, over a third (15:43%) reported that they were provided for children with complex needs, and a third (12:34%) stated that they were aimed at children and young people with a diagnosis of Autism Spectrum Disorder (ASD). The extent to which families would prefer services supporting children with specific needs and impairments, or mixed ability groups is discussed further below. However, these findings should be treated with some caution, due to the gaps in data.

Without comprehensive data it is difficult to assess the extent to which the short breaks market in each area is meeting the needs of the disabled children population. The lack of information about the services is explored further below. However, the mapping exercise does present a complex picture of short break services for disabled children and their families, with a diversity in service provision.

3.3 Parents' views on the short breaks market

Overall, the focus group participants' views were mixed regarding the short breaks market in their local authority area. It was evident that the short breaks were an

important source for support for their disabled children and their families. In accordance with other studies, the evaluation found that one to one support, such as those provided by personal assistants and overnight respite were the most highly valued services among the focus group participants (Johnson, Thom, and Prabhakar, 2011; Scope, 2012). The focus group participants reported that personal assistants helped with both personal care, assisted in duties such as lifting and changing, and enabled families to go out and access activities. For some parents, they could not access activities without the support of a personal assistant. Parents also reported that overnight stays ensure that parents were given a '*decent night's sleep*' and the break they needed to continue with their caring responsibilities (*c.f.* McDermid *et al.* 2011).

The general feeling among all the focus group participants, however, was that the range of services on offer within the hosting local authorities is insufficient. This finding supports previous research undertaken by Scope (Brawn and Rogers, 2012; *c.f.* Mencap, 2006; Holmes, McDermid and Sempik, 2010). The focus group participants reported that services were felt to be limited in respect to the types of services and activities on offer, the needs and impairments they catered for, the age catered for (with a bias towards older children), and the times and locations of the services. When asked what factors they take into consideration when choosing a service, they all agreed that choice was limited and would choose the 'next best' fit, rather than having the option to adequately match the service accessed to the needs of their child. The focus group participants reported that a 'one size fits all' approach was taken when commissioning short break services, and greater diversity in both the types of provision, and the needs of children should be taken into consideration.

Gaps in current service provision

The role of the Made to Measure facilitators is to enable parents to explore their thoughts and ideas about what services they would like to access and how they would like to spend their personal budgets. Consequently, both projects have been working with parents to identify gaps in service provision. The gaps identified by parents will be used to inform possible pools and to inform the projects' work with providers.

The focus groups also explored parents' views on the gaps in service provision. Particular gaps were identified in relation to afterschool and school holiday activities, services for children with physical disabilities and occasional one off care for, for example, dentist appointments. Two after school clubs were identified in the mapping exercise. However, these were only available in one local authority. Only one service reported that it provided support specifically for children with physical impairment. However, due to lack of data it is not possible to identify how many of the services identified cater for children with physical impairments.

In addition to the types of services on offer, the majority of focus group participants (21:84%) reported that their budget allocation was very limited, especially for the very highly sought after support including personal assistants and overnight respite care. As a result, parents reported that they did not feel able to take as much advantage of the services that were available as they would have liked, or felt that they needed. Only four focus group participants reported that they had sufficient budget to meet the needs of their family. Just over a quarter of the focus group participants (7:28%) reported that they paid directly for additional services.

While a number of gaps in the types of services were identified, more frequently discussed among focus group participants were the deficiencies in the short breaks that were already available. Common themes identified included:

- A shortage of *knowledge and understanding* about children's needs demonstrated by the staff providing short breaks, including personal assistants. Finding personal assistants with the appropriate knowledge, skills and competencies was a difficult task for some focus group participants;
- *Lack of staff* at services. A number of focus group participants reported that their child needed one to one support to enable them to access the services that are available;
- Services that provided both a *fun activity for the child and a break for the carer* were difficult to find. For example, services that were provided for a long

enough time period to enable the parent to go and do an activity of their choice while their child was attending the activity were rare;

- *Transport and accessibility* to get to the services raised as an issue.

Consequently, while a range of services might be available within an area, there are a number of factors that parents of disabled children may have to take into consideration. All of the focus group participants expressed the need to carefully consider whether the service met their child's, and their families', needs. Balancing all the factors that families have to consider when choosing which service to access may result in constraints of the amount of choice for parents in reality. The sufficiency of services available within a given area must not only be measured by the number of services available; in addition the extent to which these factors listed above are present should also be taken into consideration. It may be possible for this information to inform the projects' work with providers.

The Made to Measure pilot aims to improve 25 existing services (as rated by families) through the timeframe of the pilot. Addressing the wrap around' factors listed above may be central in achieving this aim. Both projects have begun to work towards this: for example, exploring how personal assistants can be pooled to increase staff ratios, and assisting parents to find activities to attend while their children attend services that are provided for a short time. The findings of the focus groups suggest that, for some families, these issues may be the deciding factor as to whether they can attend a service or not. For these families, pooling budgets to provide transport (for instance) may result in substantial outcomes.

Moreover, it is interesting to note that gaps identified by the focus group participants overlap with those identified by the local authorities in three key areas: Access to services (including transport), Information about the services; and skills and knowledge of the workforce. The Made to Measure projects may wish to explore how the pooled budget programme can contribute to filling those gaps and to improved added value within the short breaks markets.

3.4 Summary of Section 3

Both hosting local authorities provide a range of services for disabled children and their families. The short breaks market is complex, with considerable variations in the types of services available, the children and young people they seek to support and the range of providers active in the market. The mapping exercise will be repeated in subsequent data collections to explore whether changes in the market have taken place since Made to Measure commenced.

The evaluation suggests that the focus group participants also find the short break provision complex. While a number of gaps in the type of provision were highlighted, it was evident that a number of other factors, such as transport, number of staff available at the service, and the skills and knowledge of those staff, are very important factors for parents choosing to access short breaks. Despite the fact that one to one and overnight residential services were the most frequently identified services in the mapping exercise, focus group participants reported wanting more of both of these services.

Some parents expressed a degree of dissatisfaction with personal budgets themselves. It may be advantageous for the Made to Measure projects to be aware of this as they progress, and ensure that those families who may benefit from pooling their budget, but are discouraged by their views of personal budget *per se*, are enabled to participate in the pilot.

4. Pooling personal budgets

This section explores the emerging findings regarding pooling personal budgets. The parents' initial views and interest in pooling budgets, the anticipated advantages and disadvantages of pooling, along with some of the practical and implementation issues identified by both parents and professionals are explored.

4.1 Initial interest in the pilot: impact and advantages

Improvements to the range of services available

Overall the focus group participants were positive towards the idea of pooling budgets. Those parents who had expressed dissatisfaction about personal budgets in general, were the least positive about the pilot. Just under half (11:44%) of focus group participants believed that pooling budgets would facilitate access to a wider range of services, designed around the needs of their children and their families. In addition the focus group participants reported that the pilot should provide opportunities to make modest changes to existing services which will add value; making a big difference to the families. During the focus groups a number of different ideas about how pooled budgets could be used were identified. These were:

- Sharing the costs of an extra staff member or personal assistant to facilitate improved access to services;
- Sharing the cost of specialist equipment such as hoists;
- Developing a 'pool' of personal assistants for groups of children with similar needs to enable them to attend a range of activities.

A small number of focus group participants (4:16%) reported that pooling budgets should enable budgets to '*stretch further*' (Parent 23) and increase opportunities to try new activities. The participants of one focus group all felt that bringing parents together to 'brainstorm' ideas may increase the range of services on offer and provide opportunities for families to use their personal budgets in a more creative way.

The evaluation also found evidence of support and commitment to the principle of pooling budgets expressed by the stakeholder interviews. While the interviews were

not without their questions regarding the practicalities of pooling budgets (explored further below), the interviewees reported that pooled budgets had the potential to facilitate families to gain access to an improved range of short break services.

As noted above, the projects are both in the early initial implementation stages. Therefore at the time of the data collection, no personal budgets had been pooled. However, engaging parents in the pilot and the principle of pooling personal budgets is an essential first step towards full implementation. It was evident from the focus groups that the majority of parents were at least interested in exploring the idea further, with other focus group participants expressing more interest and engagement in the pilot. As Figure 3 shows, engaging parents is the first step in pooling budgets. It is therefore possible to argue that both projects had made substantial progress towards achieving the ultimate goal of facilitating 25 new and 25 improved services by the end of the pilot.

Supportive networks

The lack of information about services and how to access them was frequently cited throughout all of the focus groups as a source of frustration and a barrier to accessing the services (*c.f.* Johnson, Thom, and Prabhakar, 2011; Welch *et al.* 2011). The focus group participants reported that the main source of information was other parents. For example, one focus group participant said “*The only way you find out anything is through other parents*” (Parent 23).

It was evident that both projects had already had a positive impact on parents through the development of networks and relationships between families. These networks had facilitated information sharing. On a number of occasions in the focus groups themselves, parents shared information with one another, and a number of recommendations for services, contact numbers and email addresses were exchanged during and after the focus group sessions. Conversations continued between parents after focus group sessions. Word of mouth was considered to be a powerful tool, and parents exchanged information about good and bad experiences at different providers. Consequently, the focus group participants (4:16%) were also of the view that the pilot would help to improve the quality of services overall, through

families 'voting with their feet' on the recommendations and experiences of other families.

It is evident that any group that brings parents of disabled children together to share information and to provide informal peer support is valuable (McDermid *et al.* 2011). There is great potential for parents to develop supportive networks through the pilot, even for those parents who do not go on to pool budgets, they may well pool other kinds of 'resources' such as information, emotional support and social capital. The informal approach of the Made to Measure project staff, may facilitate these kinds of relationships and networks to develop. Moreover, research among practitioners has found that professionals are more likely to collaborate on a formal or informal basis, when a pre-existing relationship exists (Holmes *et al.* 2012). It is possible to hypothesise that parents may be more inclined to pool financial resources where personal relationships are fostered. The Made to Measure projects may wish to consider practical ways in which they could build on the positive work which has already been done, and continue to facilitate the building of supportive networks.

Choice and control

The green paper *Support and Aspiration* (Department for Education, 2011a), includes an expectation that parents and young people should be given greater control and choice over the support and services that they receive (Johnson, Thom, and Prabhakar, 2011). As shown in Figure 3, it is anticipated that Made to Measure will assist parents of disabled children to achieve this aim.

The baseline finding is that at the time of the data collection very few parents feel able to exercise choice and control over the short break services that they and their families receive (*c.f.* Johnson, Thom, and Prabhakar, 2011; Welch *et al.* 2011; Brawn and Rogers, 2012). A substantive proportion of the focus group participants (17:68%) felt that their views were not taken into consideration, both in relation to the individual packages of care they receive and the services that are currently commissioned in their area. One parent stated "*Nobody ever listens to us. Ever.*" (Parent 13). The perceived lack of choice is in part, limited by the perceived inadequate range of services available in both localities. For example, one parent reflected the views of a

number: when asked what factors are taken into consideration when choosing which short break to attend, answered “*What choice?!*” (Parent 23).

The extent to which the focus group participants felt able to exercise choice and control was limited by their own knowledge and experience. A number of parents (7:28%) reported that they were either unclear about the process for accessing personal budgets to improve the choice of services available to them, or wanted to question their allocation. However, these parents did not feel able to do so due to lack of information or confidence. As one parent noted “*Unless you are bolshie enough to challenge it, you won’t. I was lucky that I had that [background] knowledge*” (Parent 21). Information sharing between parents and through the Made to Measure project staff may help parents feel better equipped to exercise more choice and control over the services and support they receive.

Participants in Focus Group 3 all agreed that while there were opportunities to feedback to local authority commissioners, these views were not acted upon. However, the parents in this group did feel that providers were responsive and flexible. Both projects are working with providers to engage them with the pilot. In addition, six focus group participants reported that they already independently sought out services and spoke to providers about activities and three of the parents gave examples of providers adapting or creating a bespoke service after discussions about their children’s needs. For example, one parent reported that a surfing instructor had developed a number of sessions based on the needs of her son. These sessions had subsequently been made available for other children with similar needs. These participants were particularly positive about the potential pooling budgets might have to improve choice. It was evident that, perhaps unsurprisingly, previous positive experiences of working directly with providers to shape services influenced the focus group participants’ level of interest in pooling budgets through Made to Measure. Conversely, those parents who had previous negative experiences expressed less interest in the pilot. A number of the focus group participants (9:36%) had participated in the Department for Education personal budget pilot through the pathfinder programme (Johnson, Thom, and Prabhakar, 2011). As noted in Section 3.1, a number of these parents had considerable concerns about personal budgets overall. Despite interest in the *principle* of pooling

personal budgets, there was a sense of 'pilot fatigue' and scepticism about '*another pilot*' expressed among these focus group participants. It should be noted that this scepticism reflected previous experiences, rather than Made to Measure itself. However, such previous experience is likely to impact the extent to which families wish to engage in the pilot. It may be advantageous to consider how families' previous experiences of pilots and programmes might impact on their engagement with Made to Measure. It may be possible to invite those parents who had previously had more positive experiences to share success stories, at the forums, for example, (including through peer mentoring). This may encourage those more sceptical parents, who may well benefit from pooling their budgets, to become involved.

4.2 Moving forward: issues for consideration

Who would pooled budgets most benefit?

While there was enthusiasm among parents about the idea of pooling budgets, some initial questions about how the process might work were raised. Questions regarding the practicalities of a pilot are common at the early stages and the presence of them should not be interpreted negatively. However, it may be advantageous for the projects to be aware of parents' questions as they continue to engage potential parents in the pilot. Anticipating some of these concerns from the onset, may help to instil confidence in parents.

The general feeling across the focus groups was that, while it may be suitable for some families and some services, careful consideration should be given to when and for whom pooling is appropriate. For instance a number of the focus group participants (5:20%) reported that substantial differences in the needs and behaviours of some children may mean that it is not always appropriate or possible to pool budgets and to attend a shared activity. This issue was of particular concern for parents of children with a diagnosis of ASD. These parents reported that their children needed very specific care and it may be very difficult to bring similar children together for a shared activity. This factor may lessen as more parents sign up to the pilot, creating a greater sample from which families with similar needs might be matched. It was generally felt that pooling budgets may be more appropriate for children with physical disabilities, as it may be easier to match their needs. By

contrast, a number of participants (7:28%) felt that it was important to ensure that their children are given the opportunity to mix with children with different needs and abilities. It was felt that such opportunities would enable children to learn from each other and develop vital social skills, such as compromising, tolerance and empathy. It was felt by these focus group participants that the short break services available currently did not sufficiently enable children to mix in this way, and thought that pooling budgets might provide such opportunities.

Moreover, a small number of parents (3:12%) were apprehensive about the impact of the children on one another. For these parents, one to one support and overnight respite was felt to be the most appropriate support for their families. These parents reported that they were less interested in pooling budgets to attend new or different (group) activities. Rather these parents expressed a desire to maximise the number of personal assistant or respite hours.

It is important to bear in mind the stage at which the data were conducted. A large number of the focus group participants may have only heard about it on the same day that the focus groups were conducted. Moreover, both projects are in the initial implementation stages and are therefore still in the process of refining and clarifying many of the processes associated with pooling budgets. Therefore, it is not surprising that the participants were unfamiliar with some of the practical processes through which personal budgets might be pooled. The role of the facilitators will be to ensure that parents seeking to pool budgets are appropriately matched, either in relation to the activities or the needs of the children. The focus group participants may have been unaware of this. However, it was evident that *who* personal budgets would be pooled with and *how* was an important consideration for the focus group participants. It may be advantageous for facilitators to emphasise and clarify how parents will be brought together to pool budgets in the early stages of engagement. Such clarification may encourage those parents with concerns to continue onto the next stages of engagement.

Research into personalisation more broadly suggests that personal budgets may be more suited to some parents than others (Welch *et al.* 2011). For example, previous research into direct payments (Welch *et al.* 2011) found that the take up varied

according to social strata. In their study, Welch *et al.* (2011) found that those accessing direct payments were more likely to be more educated, white British, with a wide social network, live in less deprived areas, with a younger child. Other studies have suggested that those families who feel capable and willing to research different types of providers and take on the responsibilities of managing that budget are more likely to want a personal budget and be satisfied with it (Johnson, Thom, and Prabhakar, 2011; Welch *et al.* 2011). Likewise, the pooling of direct budgets may be better suited to some families. There was some evidence in the focus groups, that those parents who felt better informed, who had previous experience with providers and who felt more confident, were more interested in the engaging with the pilot.

It will be important to ensure that the pilot does not produce a 'virtuous circle' whereby those parents who already have access to the social and personal resources available to them are those who are primarily engaged in the pilot, at the exclusion of others. While there is no evidence of this at present, it will be advantageous to take steps to prevent it at this early stage. For example, it may be possible for the projects to review which parents have engaged in the projects to ensure a representative group of parents are signed up. It may also be possible to identify common characteristics between those parents not engaging and target engagement activities accordingly. The Made to Measure facilitators could consider how they can support those parents, who may benefit the most from the pilot, to participate. Moreover, it will be important to bear in mind that pooling will not be appropriate for all families. Parents engaging in the pilot, but not moving on to pool should not be considered 'failures' in all cases. However, it will be important to ensure that families who might benefit from a pooled budget are given all the information and support they need to do so.

The process of pooling budgets

The question of how personal budgets might be pooled was one raised by all evaluation participants. A number (5:20%) of the focus group participants noted that the idea of personal budgets was a good one, but raised concerns regarding the length and complexity of the process. As Welch *et al.* (2011) suggest, personal budgets may present already busy families with additional tasks, a view reflected by

a small number of the professionals interviewed. Some participants questioned whether pooling those budgets would add an additional layer of process onto an already complex procedure. One focus group participant said *'I can see a situation where someone might say, 'yes, that's a good idea in principle, but I just haven't got the energy to go through that again'* (Parent 23). It will be essential to ensure that the effort required to pool those personal budgets is not prohibitive for families wishing to engage. It may also be advantageous to clarify that the role of facilitators is to undertake the majority of the work required to pool budgets during initial engagement discussions to prevent parents from being discouraged from engaging in the pilot. However, it will also be important to ensure that parents are empowered to pool their budgets without over reliance on the facilitators where appropriate. The extent to which the facilitators take on the majority of the work to pool budgets is likely to emerge as the pilot progresses and may differ between families.

A number of the focus group participants (5:20%) expressed concerns about how the local authority would react to their participation in the project. A small number (3:12%) of the participants requested assurances from the local authority that their existing care packages would not be changed should they participate in the pilot. Both parents and professionals raised questions regarding the process of ensuring that the activities commissioned through pooling met the needs and aims of their care plans. There was a lack of clarity among the parents regarding the extent to which care plans underpinning direct payments and personal budgets could be changed. However, at the time of the evaluation, both projects had agreements and processes in place with the local authorities: in one of the local authorities the Made to Measure facilitators will have to seek permission from the local authorities for individual parents to use a portion of their budget for a pooled activity. The remaining authority have agreed that parents can pool up to 30% of their budget associated with an existing plan. The focus group participants expressed concerns regarding the amount of time this process would take. It may be advantageous to ensure this process is clarified with parents during initial engagement meetings. Furthermore, questions were raised regarding the extent to which the role of the Made to Measure facilitators would overlap with the Brokers, resulting in a duplication of activities for both families and professionals.

The intersection between the Made to Measure project staff and the hosting local authorities will be vital in ensuring these issues are resolved. It was evident that good working relationships between these groups were being developed and these must be built on to ensure that the process of pooling budgets does not become too onerous or time consuming for parents or professionals. It may be advantageous for the Made to Measure projects to explore with each hosting local authorities how approval for 'pooled services' can be achieved in a way that does not add to the burden for families.

Made to Measure is a pilot programme and it should therefore not be surprising that there are a number of practical considerations that need to be resolved. For instance, some parents are employers and may need to consider the legal implications of "pooling" their personal assistants with other parents on tax and insurance. Focus group participants questioned the process for ensuring the correct indemnity insurance(s) were in place for personal assistants supporting more than one child, and the additional costs associated with that insurance. Questions regarding what the mechanism for making payments would be were also raised. A further consideration for focus group participants and professionals interviewed was the issue of personal relationships and attrition. A number of participants questioned the consequences of a family pulling out of a pool. One of the projects is developing an agreement for each participant in a pool to adhere to in such circumstances. The effectiveness of this agreement will be evaluated in the next data collection. However, it should be noted that at the time of the data collection no parents had been brought together to pool budgets. It is likely that many of these practical questions will be answered as the first pools are completed.

It was evident in the focus groups that the subject of support and services can be highly emotive and emotional for some families. For some, discussing the support required touched on difficult subjects such as the levels of stress and anxiety experienced by some parents. Five parents expressed real concerns regarding their own mental health during the focus groups. For a small number of parents, seeking support was combined with guilt or frustration. While, like all families, families of disabled children will experience ups and downs, it is likely that the seeking of services will occur at times of stress (*c.f.* Holmes *et al.* 2012; Brawn and Rogers,

2012). As such, the process of pooling must be designed in such a way to reduce that level of stress. Moreover, in the process of developing a pool, some parents may need to talk frankly regarding their own personal circumstances and needs. It is thus important that systems, processes and cultures are developed in such a way to be sympathetic to the emotional nature of the subject. It was evident that the Made to Measure facilitators are sympathetic to this need and supporting parents to have open and honest conversations.

It is to be expected that the time and effort required to produce the first few pools will be disproportionate to later ones. Using extra hours for a personal assistant to cover the additional work associated with polling personal budgets has been suggested. It will be important to ensure that each pool is not as onerous as the next. Moreover, it will be important to clearly manage expectations of parents participating in the initial pools, highlighting the nature of the pilot. It will be especially important to be clear that the first pools may take longer to implement than later ones. Managing expectations will help to ensure that parents are not discouraged from the pilot in the early stages. It may also be advantageous to consider how those parents, who have successful pooled budgets, may act as advocates or peer support for those parents joining the pilot at a later date.

4.3 Summary of Section 4

It is evident that both Made to Measure projects have made good progress to engage and encourage families to participate in the pilot. Overall the focus group participants were interested in the idea of pooling and perceived it to be a useful route to access a better range of services and to exercise more choice and control than presently exercised. The projects have already begun to achieve positive outcomes for families, through bringing together parents of disabled children who have been able to share information and provide informal support.

While it was widely acknowledged that pooling personal budgets is a simple idea, it was also noted that there are some complexities to consider and resolve. Concerns were raised regarding the practical implications of pooling budgets, how the process

would work in reality and the time taken to pool budgets. There were also questions regarding who might benefit most from pooling budgets and how the Made to Measure pilots might help to support parents in this process. It may also be valuable to consider the current national and local context within which the projects are being implemented and the impact which local procedures and families experiences may facilitate or inhibit participation. While some concerns were raised regarding how personal budgets might be pooled and by whom, it is also important to recognise that the pilots are in the early stages. As such, there are still ample opportunities to resolve these concerns as the first few groups of parents are brought together.

5. Conclusion

5.1 Summary of key findings and implications

It is evident that the two Made to Measure projects have made substantial progress in the first nine months of the pilot. Both projects have begun to engage parents and professionals and there is evidence of commitment and enthusiasm for the principle of pooling budgets from both of these groups. Parents and professionals both anticipate that pooling budgets will:

- Facilitate the expansion of the short breaks market to provide a better range of services to meet the needs of disabled children and their families;
- Add value to existing services;
- Support parents of disabled children to exercise more choice and control;
- Facilitate the creation of networks between parents to share information and support one another.

The extent to which pooled budgets achieve these aims will be examined in subsequent data collections. The Made to Measure projects have started to create links with stakeholder groups including commissioners and providers. These networks will be essential to the projects as they progress. While neither project has pooled budgets to date, it is evident that the essential ground work that will facilitate pooling is well underway.

It is evident that the context within which Made to Measure is being implemented is a complex one. The short breaks market is highly diverse, and the practice and policy environment within which short breaks are presently being delivered is experiencing substantial changes. There was also some evidence to 'pilot' fatigue among some focus group participants, who were more reluctant to engage with Made to Measure. It is anticipated that implementing a new way of working may be more difficult where the supporting structures to that innovation are in flux. It was evident that both local authorities are committed to the principle of pooling personal budgets. However, all the professionals interviewed acknowledge that the process of pooling and how Made to Measure intersects with wider changes within the sector is still to be clarified. This process may be eased through continual communication and partnership with

other stakeholders, most notably local authority commissioners, to enable personal budgets and the pooling of those budgets to develop in a way that is complimentary.

Moreover, this evaluation has found evidence that some parents in receipt of personal budgets are dissatisfied with them. Those parents who had concerns about their personal budget appeared to be the most cautious about engaging with the Made to Measure. It may be important to recognise the distinction between parents' disinterest in pooling personal budgets or personalisation as a whole to prevent project staff from becoming discouraged.

The two hosting local authorities are distinctive, most notably, in regard to their experience with personal budgets. The distinctive features of the hosting local authorities will present opportunities for the pilot to understand how pooling might be achieved and the impact it might have in different contexts. However, it should be borne in mind that Made to Measure is one pilot. The emergence of two different projects may present difficulties with any future roll out. Innovations need clear and distinct characteristics practices and features. This enables potential users to easily understand what the innovation is and whether they wish to use it. Moreover, future users may not wish to start from scratch as the two projects have. The most successful innovations are those that have clear and distinct features, but also allow for flexibility in how those features are implemented. It may be advantageous to consider which elements of the pilot should be unique to the project and which should be common across the pilot.

Both projects are in the initial implementation stage. As is common in this stage a number of questions regarding how pooled budgets are delivered have been raised by both parents and professionals. These questions include:

- Who pooling budgets might be most suitable for;
- Practical considerations such as how payments might be made;
- How to address attrition among parents in a pool;
- How long the process might take;
- Whether it will result in duplication of work among professionals.

It is to be expected that the time and effort required to produce the first few pools will be disproportionate to later ones. It will be important to ensure that each pool is not as onerous as the next. Moreover, it will be important to clearly manage expectations of parents participating in the initial pools, highlighting the nature of the pilot. It will be especially important to be clear that the first pools may take longer to implement than later ones. Managing expectations will help to ensure that parents are not discouraged from the pilot in the early stages.

Pooled budgets may not be suitable for all families of disabled children, parents engaging in the pilot, but not moving on to pool should not be considered 'failures' in all cases. However, it will be important to ensure that families who might benefit from a pooled budget are given all the information and support they need to do so.

Despite some of the practical questions that have been raised by participants of the evaluation it was evident that Made to Measure has already begun to have a positive impact on some families. The Made to Measure meetings provided opportunities for parents of disabled children to meet together, share ideas, information and experiences. There is great potential for parents to continue to develop valuable supportive networks through the pilot, even for those parents who do not go on to pool budgets, they may well pool other kinds of 'resources' such as information, emotional support and social capital. Moreover, it is possible to hypothesise that parents may be more inclined to pool financial resources where personal relationships are fostered.

The successful delivery of personal budgets is, to some degree, dependent on a healthy short breaks market; families require the services on which to spend their personal budgets to be available. Welch *et al.* (2011) found that the uptake of direct payments was better in areas where there were more voluntary and independent providers active. They state that improvement in the uptake of personal budgets must be linked to improvements in the availability of services. As Welch *et al.* suggest: "*Given the diversity of family requirements direct payments cannot yet be relied upon to produce either a pool of suitable care workers, or a market place of short break provision, and it seems likely that statutory agencies will need to*

maintain some strategic responsibilities for ensuring the availability, sufficiency, and quality of short breaks, however they are funded” (2011:907).

In total 68 services were identified in Trafford, and 42 services were identified in Plymouth. Participants identified a number of gaps in the types of service current available. However, both parents and local authorities identified gaps in relation to:

- *Transport and accessibility* to get to the services;
- *Knowledge and understanding* about children’s needs demonstrated by the staff providing short breaks;
- *Lack of staff* at services;
- Services that provided both a *fun activity for the child and a break for the carer.*

The findings of the focus groups suggest that, for some families, these issues may be the deciding factor as to whether they can attend a service or not. For these families, pooling budgets to provide transport (for instance) may result in substantial outcomes. The Made to Measure projects have an opportunity to enhance services and the short breaks market as a whole, by considering how budgets might be pooled to add value to existing services through the provision of transport, additional staff and staff training.

While not without its difficulties, the Made to Measure pilot presents parents with a unique opportunity to ensure that the short breaks market is sufficient to meet their needs. The ability to shape that market may ensure that parents can spend their budget in the way that will best meet their needs, and therefore, lead to the best outcomes. If the Made to Measure projects are able to respond to the questions about how the pooling process might work in practical terms, Made to Measure has the potential to lead to positive outcomes for disabled children and their families. The extent to which this is achieved will be explored in the next evaluation report.

5.2 Summary of recommendations

- In order to facilitate future roll out, it may be advantageous to consider which elements of the pilot should be unique to the projects and which should be common across the pilot. The development of a shared set of characteristics, policies and procedures may assist the projects as they advance;
- It will be advantageous to continue to build on the links with commissioners and providers. Continual communication and partnership with other stakeholders may enable personalisation and the pooling of those budgets to develop in a way that is complimentary;
- The processes associated with pooling personal budgets should be developed in a way that are facilitative to both families and the professionals working with them. It will be essential to ensure that the effort required to pool those personal budgets is not prohibitive for families wishing to engage and the professionals supporting them;
- It will be important to clearly manage expectations of parents participating in the initial pools. These first pools may take longer to set up than later ones, as some of the practical issues are addressed. Managing expectations will help to ensure that parents are not discouraged from the pilot in the early stages;
- The Made to Measure pilot team may wish to consider whether it is appropriate for the projects to provide an opportunity for feedback loops and communication between parents and local authority representatives, where parents are expressing dissatisfaction with their personal budget and the services available;
- It may be advantageous for the projects to consider how personal budgets could be pooled to address the additional 'wrap around' factors, such as transport, or the provision of extra staff at existing activities. These factors may result in added value and in some cases facilitate those families unable to attend services at present, to do so;

- Enabling parents who have had positive experiences with providers, or participate in the first few pools to share their views and experiences, may encourage those parents with questions about pooling to participate in the pilot. Moreover, facilitating peer support between parents, may prevent the occurrence of a 'virtuous circle' whereby those parents who are more knowledgeable and confident engage in the pilot, at the exclusion of others;
- It may be advantageous for facilitators to clarify how parents will be brought together to pool budgets in the early stages of engagement. Such clarification may encourage those parents with concerns regarding who their budgets might be pooled with to continue onto the next stages of engagement.

References

Brawn, E. and Rogers, C. (2012) *Keeping us close, ensuring good inclusive and accessible local services for disabled children and their families*. London: Scope.

Carlin, J. and Cramer, H. (2007) *Creative Responses to Changing Needs? Fourth National Survey of Short Break Services for Disabled Children in the UK*. Bristol: Shared Care Network.

Department for Education (2011a) *Support and aspiration: a new approach to special educational needs and disability*. London: Department for Education.

Department for Education (2011b) *Short breaks for carers of disabled children: departmental advice for local authorities*. London: Department for Education.

Fixsen, D. L., Naoom, S. F., Blase, K. A., Friedman, R. M. and Wallace, F. (2005). *Implementation Research: A Synthesis of the Literature*. Tampa, FL: University of South Florida, Louis de la Parte Florida Mental Health Institute, The National Implementation Research Network (FMHI Publication #231).

<http://nirn.fpg.unc.edu/resources/implementation-research-synthesis-literature>

Ghate, D., McDermid, S., Trivedi, H. (2013) *Implementing Head, Heart, Hands – the first year Evaluation of Head, Heart, Hands – second interim report to The Fostering Network*. London: The Colebrooke Centre for Evidence on Implementation [Report unpublished].

Hamlyn, B., Grant, C., Fong, B., and Moran, J. (2010) *Parental experience of services for disabled children. Report to the Department for Children Schools, and Families*. London: Department for Children, Schools and Families.

Hatton, C., Collins, M., Welch, V., Robertson, J., Emerson, E., Langer, S. and Wells, E. (2011) *The Impact of Short Breaks on Families with a Disabled Child Over Time; the second report from the quantitative study*. London: Department for Education

Holmes, L., McDermid, S., Padley, M. and Soper, J. (2012) *Exploration of the costs and impact of the Common Assessment Framework. Report to the Department for Education*. London: Department for Education.

Holmes, L., McDermid, S. and Sempik, J. (2010) *The costs of short break provision. Report to the Department for Children, Schools and Families*. London: Department for Children, Schools and Families.

HM Treasury and Department for Education and Skills (2007) *Aiming high for disabled children: Better Support for families*. London: HM Treasury and DfES.

Johnson, R., Thom, G. and Prabhakar, M. (2011) *Individual Budgets for families with disabled children. Final evaluation report*. London: Department for Education.

McDermid, S. (2010) *The costs of short breaks: resource pack for service providers*, Loughborough: Centre for Child and Family Research, Loughborough University.

McDermid, S. and Holmes, L. (2012) *Cost comparisons of short break services for disabled children and their families. Report to Action for Children*. Loughborough: Centre for Child and Family Research, Loughborough University.

McDermid, S., Soper, J., Lushey, C., Lawson, D. and Holmes, L. (2011) *Evaluation of the Impact of Action for Children Short break Services on Outcomes for Children - Final Report: Report to Action for Children June 2011*. Loughborough: Centre for Child and Family Research, Loughborough University.

Mencap, (2006) *Breaking point – families still need a break*. London: Mencap.

Metz, A. and Bartley, L. (2012) *Active implementation frameworks for programme success: how to use implementation science to improve outcomes for children*. Nation Implementation Network: Chapel Hill, North Carolina [online] available at: <http://www.zerotothree.org/about-us/areas-of-expertise/reflective-practice-program-development/metz-revised.pdf>

Pawson, R. and Tilly, N. (1997) *Realistic Evaluation*. London: Sage.

Prabhakar, M., Thom, G., Hurstfield, J. and Parashar, U. (2008) *Individual budgets for families with disabled children. Scoping Study. Research Report DFE – RR024*. SQW Consulting.

Robinson, C., Jackson, P. and Townsley, R. (2001) Short breaks for families caring for a disabled child with complex health needs. *Child and Family Social Work* 6, 1, 67-75.

Thom, G. and Prabhakar, M (2011) *Individual Budgets for families with disabled children. Implications and Recommendations*. London: Department for Education.

Ward, H., Holmes, L., Dyson, P. and McDermid, S. (2008) *The Costs and Consequences of Child Welfare Interventions: Mapping Children in Need Services*. Loughborough: Centre for Child and Family Research, Loughborough University.

Welch, V., Hatton, C., Emerson, E., Collins, M., Robertson, J., Langer, S. and Wells, E. (2011) Using direct payments to fund short breaks for families with disabled children. *Child: care health and development* 38, 6, 900-909.

Welch, V., Hatton, C., Wells, E., Collins, M., Langer, S., Robertson, J. and Emerson, E. (2010) *The Impact of Short Break Provision on Families with a Disabled Child: Report One of the Quantitative Phase*. London: Department for Education.

Appendices

Appendix A: Mapping Plymouth

Name of Service	Service Type	Description of service	Access Group: Needs	Access Group: Age	Provider (LA, Vol, Independent)	Referral route
Local offer services Commissioned or provided by Plymouth City Council						
Drama and visual arts workshops	Group Based Activity: Arts		Not Specified	Not Specified	Unknown - Provider 1	Self-assessment through brokerage service
Youth Sailing	Group Based Activity: Sports and outdoor	1/2 day sailing for up to 6 children and young people, in two age groups	Not Specified	Not Specified	Unknown - Provider 2	Self-assessment through brokerage service
Sports Activities	Group Based Activity: Sports and outdoor	Sports activities	Not Specified	Not Specified	Unknown - Provider 3	Self-assessment through brokerage service
Outdoors Activities	Group Based Activity: Sports and outdoor	Horticultural and outdoors activities	ASD/Aspergers	Not Specified	Unknown - Provider 4	Self-assessment through brokerage service
Children's Sailing	Group Based Activity: Sports and outdoor	1 day sailing for up to 6 children and young people, in two age groups	Not Specified	Not Specified	Unknown - Provider 5	Self-assessment through brokerage service
The Beckly Centre	Group Based Activity: Other	Social and community based activities	Not Specified	Not Specified	Unknown - Provider 6	Self-assessment through brokerage service
Youth group	Group Based Activity: Youth Group	Holiday play scheme activities and beach days	Not Specified	Not Specified	Voluntary - Provider 1	Self-assessment through brokerage service
Creative dance	Group Based Activity: Arts	Creative dance workshops	Not Specified	Not Specified	Unknown - Provider 7	Self-assessment through brokerage service
Sports Activities	Group Based Activity: Sports and outdoor	Sports activities	Not Specified	Not Specified	Voluntary - Provider 2	Self-assessment through brokerage service
Music zone	Group Based Activity: Arts	Multi-sensory and instrumental workshops	Not Specified	Not Specified	Unknown - Provider 8	Self-assessment through brokerage service
Outdoors Activities	Group Based Activity: Sports and outdoor	Outdoor activities (Canoeing, climbing, moorland walking, forest schools, sports)	Not Specified	Not Specified	Unknown - Provider 9	Self-assessment through brokerage service
Targeted services (Eligibility 1): Commissioned or provided by Plymouth City Council						
Short Break Equipment loan	Practical/Equipment	Equipment can be accessed for short periods by groups and individuals	Not Specified	Not Specified	LA	Self assessment or CAF
Youth Service Groups	Group Based Activity: Youth Group	Two youth groups for disabled young people to experience activities that they would not otherwise have opportunities to experience	Not Specified	12 - 25 years	LA Youth service	Self assessment or CAF
Youth Group 1	Group Based Activity: Youth Group	Social activities	Not Specified	12 - 18 years	Unknown - Provider 10	Self assessment or CAF
Youth Group 2	Group Based Activity: Youth Group	Group that young people can attend with a friend or sibling	ASD/Aspergers	Not Specified	Unknown - Provider 11	Self assessment or CAF
Mentoring	Transitions activities	Mentoring programme for young people to explore their hopes and aspirations. Time limited intervention	Not Specified	13 - 18 years	LA Youth service	Self assessment or CAF
Transitions club	Transitions activities	Weekly evening activity (3 hours) designed to develop young people's independence skills	Not Specified	16 - 25 years	Independent - Provider 1	Self assessment or CAF
Specialist services (eligibility 2): Commissioned or provided by Plymouth City Council						
Domiciliary and nursing care: 1	One to one support	Provision of personal care, and domiciliary care	Children and young people with severe and complex needs	Not Specified	Independent Provider - 10	IA/CA and resource panel via SPOC
Domiciliary and nursing care: 2	One to one support	Provision of personal care, and domiciliary care	Children and young people with severe and complex needs	Not Specified	Independent Provider - 11	IA/CA and resource panel via SPOC
Domiciliary and nursing care: 3	One to one support	Provision of personal care, and domiciliary care	Children and young people with severe and complex needs	Not Specified	Independent Provider - 12	IA/CA and resource panel via SPOC
Domiciliary and nursing care: 4	One to one support	Provision of personal care, and domiciliary care	Children and young people with severe and complex needs	Not Specified	Independent Provider - 13	IA/CA and resource panel via SPOC
Domiciliary and nursing care: 5	One to one support	Provision of personal care, and domiciliary care	Children and young people with severe and complex needs	Not Specified	Voluntary - Provider 7	IA/CA and resource panel via SPOC
Family based foster care: in house carers	Overnight: family based	Provision of overnight short breaks in a family setting	Children and young people with severe and complex needs	Not Specified	Local Authority	IA/CA and resource panel via SPOC
Family based foster care: Other providers	Overnight: family based	Provision of overnight short breaks in a family setting	Children and young people with severe and complex needs	Not Specified	Independent - Provider 2	IA/CA and resource panel via SPOC
Adventure breaks service	Holiday and weekend Activities	Offers families a weekend break (Saturday)	Children and young people with severe and complex needs	Not Specified	Independent - Provider 3	IA/CA and resource panel via SPOC
Residential: Overnight - Provider 1	Overnight: residential	Provision of overnight short breaks in a residential setting	Children and young people with severe and complex needs	Not Specified	Independent - Provider 4	IA/CA and resource panel via SPOC
Residential: After School - Provider 1	Group Based Activities: After School		Children and young people with severe and complex needs	Not Specified	Independent - Provider 5	IA/CA and resource panel via SPOC
Residential: Overnight - Provider 2	Overnight: residential		Not Specified	Not Specified	Unknown - Provider 12	IA/CA and resource panel via SPOC
Residential: Day Care - Provider 2	Day Care		Not Specified	Not Specified	Unknown - Provider 12	
Groups	Holiday and weekend Activities	Provision of weekend activities in a nurturing environment	Children and young people with severe and complex needs	Not Specified	Independent - Provider 6	IA/CA and resource panel via SPOC
After school club	Group Based Activities: After School	2 weekly after school groups	Children and young people with severe and complex needs	8 - 15 years	Independent - Provider 7	IA/CA and resource panel via SPOC
Saturday club	Weekend activities	Saturday morning drop in session	Children and young people with severe and complex needs	Not Specified	Independent - Provider 8	IA/CA and resource panel via SPOC
Inclusion Works	Access to universal provision	Assists children and young people with disabilities access universal and community services	Children and young people with severe and complex needs	0 - 18 years	Local Authority	Self-assessment through brokerage service

Appendix A: Mapping Plymouth (continued)

Name of Service	Service Type	Description of service	Access Group: Needs	Access Group: Age	Provider (LA, Vol, Independent)	Referral route
Additional services not commissioned by Plymouth City Council - from Family Information Service						
Autism and Cerebral Palsy Support and therapy	Therapeutic	and special training to children with autism and cerebral palsy. Six free sessions with a small donation	Autism and Cerebral Palsy	Not Specified	Voluntary - Provider 3	Not Specified
Residential provision	Overnight: residential	Specialist residential provision	Learning Disabilities	8 - 18 years	Independent: Provider 9	Not Specified
Cool2Care	One to one support	Personal assistants	Not Specified	Not Specified	Unknown - Provider 13	No referral required
REACH project	Support and Advice	Contact and support for health workers and families with children having any form of hand or arm deficiency	Children with physical disabilities: arm or hand deficient	Not Specified	Voluntary - Provider 3	Not Specified
Plymouth and district DEAF children's society	Group Based Activity: Other	Various activities	Hearing impaired	Not Specified	Voluntary - Provider 4	Not Specified
Plymouth and district DEAF children's society: Parental support	Support and Advice	Support and advice for parents	Hearing impaired	Not Specified	Voluntary - Provider 4	Not Specified
Wednesdayz	Group Based Activity: Youth Group	Youth clubs for the whole family and art and craft sessions	Any child with Attention Deficient Hyperactivity Disorder (ADHD) and/or Autistic Spectrum Disorder (ASD) and Behavioural, Social and Emotional Difficulties (BSED)	Not Specified	Voluntary - Provider 5	Not Specified
Communication Interaction Team: Plymouth City Council	One to one support	Support children and young people with communication and interaction needs, their parents and teachers including children on the Autistic Spectrum and those with speech and language	Interaction and communication difficulties	Not Specified	Local Authority	Not Specified
Friends and families of special children	Parent support	Provides support for families and adult carers to meet other people in similar situations.	Not Specified	Not Specified	Voluntary - Provider 6	Not Specified

Appendix A: Mapping Trafford

Name of Service	Service Type	Description of service	Access Group: Needs	Access Group: Age	Provider (LA, Vol, Independent)	Referral route
Services Commissioned by Trafford Children's Services						
Targeted Support - Accessed through the local offer						
Outdoor youth group	Group based activity: Youth group	Weekly group Alternate evenings to facilitate different needs	ASD/Aspergers	11 - 18 years	Voluntary - provider 1	CYPS referral - reviewed by Panel
Outdoor youth group 2	Group based activity: Youth group	Weekly group Alternate evenings to facilitate different needs	Complex and Additional needs	11 - 18 years	Voluntary - provider 1	CYPS referral - reviewed by Panel
Activity and City breaks	Weekend and Holiday Activities	Weekends in the school holidays	Not specified	8 - 18 years	Voluntary - provider 1	CYPS referral - reviewed by Panel
Saturday Play Sessions 1	Group based activity: other	2 hours weekly on a Saturday morning	Not specified	Under 5s	Voluntary - provider 1	CYPS referral - reviewed by Panel
Saturday Play Sessions 2	Group based activity: other	2 hours weekly on a Saturday morning	Not specified	6 - 11 years	Voluntary - provider 1	CYPS referral - reviewed by Panel
Buddying Scheme	Befriending	Up to 32 young people, weekly, 2 - 3 hours	ASD/Aspergers	11 - 19 years	Voluntary - provider 2	Open referral
Monday Youth club	Group based activity: Youth group	Weekly, 2.5 hours	Not specified	11 - 19 years	Voluntary - provider 3	CYPS referral - reviewed by Panel
Friday Youth club	Group based activity: Youth group	Weekly, 3 hours	Not specified	11 - 19 years	Voluntary - provider 3	CYPS referral - reviewed by Panel
School Holiday club	Group based activity: other	Half day or full day sessions available for 15 days in school holidays	Not specified	0 - 19 years	Voluntary - provider 4	CYPS referral - reviewed by Panel
Mentoring project	Befriending	2.5 hours weekly, over a three month period.	Additional needs	7 - 16 years	Unknown - Provider 14	CYPS referral - reviewed by Panel
Interpreting	Access to universal services	The services will be aimed at anyone who has a language or cultural barrier which prevents them or prohibits them from accessing services easily	Communication difficulties	0 - 19 years	Voluntary - provider 5	CYPS referral - reviewed by Panel
Family Support	Family Support	One to one family support	Communication difficulties	0 - 19 years	Voluntary - provider 6	CYPS referral - reviewed by Panel
Buddies	Access to universal services	Trained volunteers support families, enabling them to engage with a wide range of community services within their area	Communication difficulties	Young people	Voluntary - provider 6	CYPS referral - reviewed by Panel
Family Support	Family Support	One to one family support	Not specified	Not specified	Voluntary - provider 7	CYPS referral - reviewed by Panel
Specialist - Families with higher levels of need						
Personal Assistants	One to one support	Minimum of 2 hour sessions, package provided as appropriate	Not specified	0 - 18 years	Voluntary - provider 3	LP present to Complex and Additional Needs Panel
Overnight provision in residential: 1	Overnight: residential	Package agreed by CAN Panel	Not specified	0 - 18 years	Unknown - Provider 1	Health/social care assessment LP present to Complex and Additional Needs Panel
Overnight provision in residential: 2	Overnight: residential	Package agreed by CAN Panel	Not specified	0 - 18 years	Unknown - Provider 2	Health/social care assessment LP present to Complex and Additional Needs Panel
Overnight provision in residential: 3	Overnight: residential	Package agreed by CAN Panel	Not specified	0 - 18 years	Unknown - Provider 3	Health/social care assessment LP present to Complex and Additional Needs Panel
Overnight provision in residential: 4	Overnight: residential	Package agreed by CAN Panel	Not specified	0 - 18 years	Unknown - Provider 4	Health/social care assessment LP present to Complex and Additional Needs Panel
Overnight provision in residential: 5	Overnight: residential	Package agreed by CAN Panel	Not specified	0 - 18 years	Unknown - Provider 5	Health/social care assessment LP present to Complex and Additional Needs Panel
Overnight provision in residential: 6	Overnight: residential	Package agreed by CAN Panel	Not specified	0 - 18 years	Unknown - Provider 6	Health/social care assessment LP present to Complex and Additional Needs Panel
Overnight provision in residential: 7	Overnight: residential	Package agreed by CAN Panel	Not specified	0 - 18 years	Unknown - Provider 7	Health/social care assessment LP present to Complex and Additional Needs Panel
Home from Home carers	Overnight: family based	Package agreed by CAN Panel	Not specified	0 - 18 years	Local authority	Health/social care assessment LP present to Complex and Additional Needs Panel
Day care in a residential setting: 1	Day Care	Package agreed by CAN Panel - support provided during school holiday	Not specified	0 - 18 years	Unknown - Provider 8	Health/social care assessment LP present to Complex and Additional Needs Panel
Day care in a residential setting: 2	Day Care	Package agreed by CAN Panel - support provided during school holiday	Not specified	0 - 18 years	Unknown - Provider 9	Health/social care assessment LP present to Complex and Additional Needs Panel
Day care in a residential setting: 3	Day Care	Package agreed by CAN Panel - support provided during school holiday	Not specified	0 - 18 years	Unknown - Provider 10	Health/social care assessment LP present to Complex and Additional Needs Panel
Day care in a residential setting: 4	Day Care	Package agreed by CAN Panel - support provided during school holiday	Not specified	0 - 18 years	Unknown - Provider 11	Health/social care assessment LP present to Complex and Additional Needs Panel
Day care in a residential setting: 5	Day Care	Package agreed by CAN Panel - support provided during school holiday	Not specified	0 - 18 years	Unknown - Provider 12	Health/social care assessment LP present to Complex and Additional Needs Panel
Day care in a residential setting: 6	Day Care	Package agreed by CAN Panel - support provided during school holiday	Not specified	0 - 18 years	Unknown - Provider 13	Health/social care assessment LP present to Complex and Additional Needs Panel
Home Support Service - health trained carers	Overnight: family based	Package agreed by CAN Panel	Not specified	0 - 18 years	Health	Health/social care assessment LP present to Complex and Additional Needs Panel
Buddying Scheme	Befriending		Not specified	11 - 18 years	Voluntary - provider 2	Health/social care assessment LP present to Complex and Additional Needs Panel

Appendix A: Mapping Trafford (continued)

Name of Service	Service Type	Description of service	Access Group: Needs	Access Group: Age	Provider (LA, Vol, Independent)	Referral route
Additional services not commissioned by Trafford Council - from Family Information Service						
Work in Schools	Mental health support	Emotional support for mental health difficulties	Not specified	13 - 25 years	Voluntary - provider 8	Self referral, professional referral
Therapy sessions	Mental health support	Emotional support for mental health difficulties	Not specified	13 - 25 years	Voluntary - provider 8	Self referral, professional referral
Disabled young people's project: One to One support	One to one support		Not specified	13 - 15 years	Voluntary - provider 8	Self referral, professional referral
Disabled young people's project: Arts and Drama Group	Group based activity: Arts	Arts and Drama Group	Not specified	13 - 15 years	Voluntary - provider 8	Self referral, professional referral
Groups	Group Based Activity: Other	Targeted - not solely, but open to - disabled children	Not specified	13 - 15 years	Voluntary - provider 8	Self referral, professional referral
Informal support	One to one support	Informal support to young people experiencing difficulties	Not specified	13 - 15 years	Voluntary - provider 8	Self referral, professional referral
Inside out	One to one support	Informal support to young people experiencing difficulties	LGBT young people	not stated	Voluntary - provider 8	Self referral, professional referral
Black and Asian young people's counselling service	One to one support	Counselling	Not specified	13 - 25 years	Voluntary - provider 8	Self referral, professional referral
Art Therapy	Therapeutic support	Art Therapy	Not specified	13 - 25 years	Voluntary - provider 15	Self referral, professional referral
Autism information and Family Support Project	Support for parents and carers	Support once a month on a Saturday morning	ASD/Aspergers	Not specified	Voluntary - provider 9	
Aspirations project	Group based activity: Youth group	Various: groups, drop ins, social groups, one to one support, sport and physical activities	ASD/Aspergers	Young people	Voluntary - provider 9	
Aspirations Activities	Group based activities	Leisure opportunities	ASD/Aspergers		Voluntary - provider 9	
Autism life skills project	Group based activity: Independence skills	Life skills and social opportunities	ASD/Aspergers	Young people	Voluntary - provider 9	
The Counselling and Family Centre - REACH OUT service	Therapeutic support	Counselling in homes	Not specified	Young people	Voluntary - provider 10	
Counselling and Family Centre	Therapeutic support	Counselling	Not specified	6 - 17 years	Voluntary - Provider 16	
Art Excel	Therapeutic support	Art Therapy	Not specified	Not specified	Voluntary - Provider 17	
Craft Club	Group Based Activities: Arts	Craft group	Not specified	Not specified	Voluntary - Provider 17	
Sign Circle: genie	Group based activity: Other	Group for all the family, learn new topics each week. Story sessions and songs	Deaf or hearing impaired	Not specified	Voluntary - provider 11	No referral required
Groups and Drop ins: genie	Group based activity: Youth group	Various groups	ASD/Aspergers	Over 10	Voluntary - provider 11	Self referral, professional referral
Respite	Overnight: residential	Overnight: residential	Not specified	Not specified	Independent - Provider 1	
Befriending	Befriending	Befriending	Not specified	Not specified	Independent - Provider 1	
Holiday support	Group based activity: Other	Group based activity: Other	Not specified	Not specified	Independent - Provider 1	
Play and social support	Group based activity: Other	Group based activity: Other	Not specified	Not specified	Independent - Provider 1	
Arts crafts and social activities	Group based activity: Arts	Group based activity: Arts	Not specified	Not specified	Independent - Provider 1	
Gastrostomy and PEG care	Therapeutic support	Therapeutic support	Not specified	Not specified	Independent - Provider 1	
School and Homework support	One to one support	One to one support	Not specified	Not specified	Independent - Provider 1	
Chaperone and Transport	One to one support	One to one support	Not specified	Not specified	Independent - Provider 1	
Contact supervision	One to one support	One to one support	Not specified	Not specified	Independent - Provider 1	
care for carers	One to one support	Respite care: personal care, emergency support, specialist care	Carers of disabled children	Not specified	Voluntary - Provider 13	Referral required
short break respite care: family based	Overnight: family based	Overnight: family based	Not specified	5 - 17 years	Independent - Provider 2	Referral required
short break respite care: Residential	Overnight: residential	Overnight: family based	Not specified	5 - 17 years	Independent - Provider 2	Referral required
Residential transition service	Transitions	Transitions	Not specified	Young people	Independent - Provider 2	Referral required
Farm project	Group based activity: Other	Provides a range of flexible education and social activities	Not specified	Young people	Independent - Provider 3	Referral required
Community Supported living	Transitions	Transitions	ASD/Aspergers	Young people	Independent - Provider 3	Referral required
Domiciliary care	One to one support	Domiciliary care, ranging from 4 to 24 hours support	Not specified	Not specified	Independent - Provider 3	Referral required
outreach support and babysitting service	One to one support	Various activities and babysitting	Not specified	Not specified	Independent - Provider 3	Referral required
Stockies social club	Group based activity: Youth group	Specialist youth club	Not specified	11 - 19 years	Voluntary - Provider 14	