

Short breaks pathfinder evaluation

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This research report was commissioned before the new UK Government took office on 11 May 2010. As a result the content may not reflect current Government policy and may make reference to the Department for Children, Schools and Families (DCSF) which has now been replaced by the Department for Education (DFE).

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

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EXECUTIVE SUMMARY

- (a) This report by the National Development Team for Inclusion (NDTi) describes the evaluation of the 21 Short Break Pathfinder sites. It was undertaken in late 2009 and early 2010 with the purpose of understanding more about how the Pathfinder sites had gone about commissioning and providing different packages of short breaks in order to inform:
- Local authority and PCT practice in the future
 - The development of Short Break policy and direction of the AHDC short break programme
 - Future Government spending proposals.
- (b) The evaluation was conducted in two phases using an approach based upon 'Realistic Evaluation'. Rather than just report on what had happened, this methodology seeks to understand *how* things have or have not worked, in *what* situations, with the *particular* groups of people and *why* those outcomes were achieved. This helps to make the learning from the evaluation transferable to other situations and settings.
- (c) The first phase involved detailed interviews with a range of stakeholders across all 21 Pathfinders – out of which initial conclusions were reached. These were then explored in more detail by further interviews and case studies in 10 of the Pathfinders – from which the final report has been produced.
- (d) The evaluation identified seven 'theories of change' that help to explain what has happened in the Pathfinder sites. In summary, these are:
1. *Parent participation*. That investment in a range of strategies to involve families as full partners in co-production results in improved outcomes and innovative short breaks.
 2. *The imprecise nature of short breaks*. The lack of national clarity about definitions of short breaks has been a double edged sword –

helping creativity in some places and situations and hindering it in others.

3. *Inclusion and ordinariness.* The increased focus on using local community settings increased feelings of inclusion but many short breaks in inclusive settings are still segregated in nature. Both this style of provision and the smaller amount of fully inclusive opportunities were significantly driven by expressed parental wishes.
 4. *Commissioning for innovation and change.* A wider range of short breaks that reflects choice is being developed where commissioning processes are being applied more flexibly.
 5. *Partnership Working.* Strong partnership working leads to significantly improved services and outcomes for people
 6. *Access and Equity.* New 'easy access' methods have broadened access for young people with less complex needs with some progress for those with more complex needs. Significant variation in access is linked to factors such as information provision.
 7. *The importance of accountability and resource protection.* The identification of national funding and the requirement to report on its usage and general progress made, directly assisted the delivery of policy at a local level.
- (e) Two further theories were identified where the evidence was less strong, and so cannot be viewed as evidence based conclusions, but which the evaluation suggests are probably the case:
8. *Participation by children and young people.* Involving children and young people in service design, development and evaluation is leading to more accessible and child-focused short breaks.
 9. *Sustainability and a lasting legacy.* The engagement with 'mainstream' services is raising the profile of disabled children and helping create a culture that has the potential to achieve long-lasting inclusion.

- (f) The report also comments on a number of other issues specifically asked in the evaluation brief, summarised as follows:
- Approaches taken to population needs analysis are highly variable and most local systems are struggling to produce accurate and usable data
 - Whilst all Pathfinders have focused to varying extents upon the five 'target groups' identified in the Full Service Offer as meriting particular attention, the way in which that has been done and recorded does not make it possible to clearly and accurately state how provision to those groups of people has changed.
 - There is no 'local model' of short breaks provision emerging (though this may do in the future as more is learnt about what young people and families want and they have better information). Rather, there is a local commissioning led model emerging, linked to personalisation, which does have the potential for replication across areas.
 - There is evidence that short breaks are becoming more tailored and flexible to individual needs, but limited evidence at present of widespread progress in improving access for children from 'seldom heard' groups including those from minority ethnic communities.
 - There is increased use of direct payments, though less than might be hoped for, with the success of this being clearly linked to factors such as investment in support systems - without which many families see direct payments as a burden.
 - The investment in infrastructure support to manage and deliver the Pathfinder initiative was an important element in ensuring significant progress in delivering the policy at a local level.
- (g) The main report concludes with a short discussion on the implications of these findings for future policy and its delivery.

MAIN REPORT

Section 1 Introduction

Background

1. This report for the Department for Education is the final report from the Pathfinder evaluation component of the short breaks evaluation. It is based on the work undertaken across two phases of evaluation – as described in the original tender proposal – by the National Development Team for Inclusion (NDTi)¹ and is part of a wider piece of evaluation being undertaken in partnership with the Centre for Disability Research (CeDR) at Lancaster University.

2. The report is structured in the following way:
 - A description of the process and methodology used for the work
 - A summary of the main findings that have arisen through the evaluation process (Theories of Change)
 - A description of how those findings additionally inform answers to some specific questions asked in the brief for this evaluation
 - A commentary on the policy and delivery implications of the report's conclusions.

3. We would like to place on record our appreciation of the efforts of and cooperation we received from the Pathfinder sites. The commitment of people working in the field to achieving better lives for disabled children and their families is undoubtedly a positive factor in the progress

¹ The NDTi is a not for profit policy, development and research agency concerned with promoting inclusion and equality for people who risk exclusion and need support to lead a full life. It has particular expertise in the fields of disability and ageing. The organisation's work includes:

- National and local policy development;
- Undertaking research and evaluation;
- Consultancy to organisations and partnerships to achieve change;
- The delivery of training and personal development programmes;
- Disseminating good practice through events, articles and publications.

achieved to date. At least equally, we wish to record our thanks and appreciation to the families and young disabled people who met with us, particularly in Phase Two of the work, and who shared their experiences with an honesty and openness that greatly contributed to our findings. To be regularly reminded of the challenges facing young disabled people and their families, often arising from the actions of society and indeed services themselves rather than the child's disability per se, along with the fortitude and determination with which they are addressed, is an important and often humbling experience for others to share.

The Purpose of the Evaluation

4. The overall purpose of the Pathfinder Evaluation was described by the Department for Education as being to:
 - enable local authorities and PCTs to commission and provide different packages of short breaks with better information about likely outcomes;
 - inform the development of short break policy, to be set out in statutory guidance on short breaks;
 - inform the national policy direction of the AHDC short break programme;
 - inform future Government spending proposals.

5. A number of specific questions were asked of this evaluation that would help to inform this. These were to identify:
 - different approaches used in assessing population need for short breaks, and associated strengths and weaknesses;
 - the extent to which Pathfinders are extending their short break provision to a greater number of children and how judgements regarding eligibility are altering with additional resources;
 - what pattern of provision (local area models) Pathfinders are using to extend short break services. How these models differ in terms of

the likely volume of short break provision that is to be made available. Whether, and how these approaches are increasing, or are likely to increase access to short breaks for the five target groups set out in the Full Service offer;

- how assessment processes are used amongst Pathfinders and whether the design of these processes is related to the pattern of provision secured;
- the key factors that have influenced Pathfinder approaches to extending provision, and the extent to which these include considerations around appropriate eligibility, needs analysis, value for money considerations, and consultation;
- the extent to which parents of disabled children and disabled children themselves are being involved in service planning and delivery, and the approaches to engagement used by the Pathfinders;
- any evidence that the increase in resources is leading to provision becoming more tailored and flexible, so as to better meet the specific needs of individual children and families, including those from minority ethnic groups;
- information on the approaches Pathfinders have taken to procuring additional short breaks;
- the extent to which Pathfinders are promoting direct payments in lieu of short break provision, and what support is offered to parents to enable them to effectively secure the short break provision they need

6. In order to answer these questions, the evaluation has identified a number of major underpinning conclusions that can be evidenced from the data obtained. These are described, evidenced and discussed in Section Three of this report. The specific questions summarised above are then commented upon in Section Four where they have not already been covered directly within Section Three.

7. It is important to emphasise from the outset that the brief of this evaluation was primarily concerned with understanding the organisational and systemic delivery of the Pathfinder initiative i.e. how the Pathfinders went about improving short breaks and the extent to which the approaches used are being successful. There are thus three things that this evaluation is **not** concerned with and does not draw conclusions about:

- The impact upon individual young people and their families. Naturally, we needed to understand elements of this in order to draw out our conclusions, but this question is being addressed through the related element of research being undertaken by Lancaster University. Thus this report does not explicitly seek to draw conclusions about how the lives of young disabled people and their families have been affected by the Short Breaks Pathfinder initiative.
- Individual Pathfinder sites. Our evaluation is of the programme as a whole and the similarities and differences in the approaches taken between and across the 21 sites. We did not seek to evaluate, and we do not report upon, the performance of individual Pathfinder sites.
- The Pathfinder Support Programme delivered by Together for Disabled Children (TDC). It was not our role to evaluate and comment upon the support received by the Pathfinder sites.

Section Two

The Evaluation Methodology

Realist Evaluation

8. The methodology is based on a realist style of evaluation, as described by Pawson and Tilley², which is particularly suited to measuring change in social programmes. This uses both qualitative and quantitative data and focuses on outcomes. It goes beyond asking “Does this programme work?” to ask: “*How* does this programme work, in this particular situation, with these groups of people and why?” It also involves local people as **participants** in the process rather than just as **passive givers** of information. Thus, it helps to promote both understanding and ownership of the research conclusions. This methodology is specifically designed to evaluate medium and long-term change programmes, and initiatives involving multi-sectoral and multidisciplinary partnerships to demonstrate impact – such as the Short Break Pathfinders.
9. This method of evaluation recognises that no project can be delivered in the same way twice or in the same circumstances, and that this has important implications for policy and the spread of best practice. Instead, it surfaces the underlying assumptions, or theories, in the project and tests and refines those theories. It does this through taking account of the circumstances of the project and the mechanisms used to bring about the desired outcomes. This is crucial in those programmes which seek to shift attitudes and underlying beliefs, improve practice, delivery and experience, and inform future policies/strategies and their implementation (including long term investment plans).
10. In addition, the ‘realist evaluation’ design is favoured over other evaluation designs because the outcomes of change programmes such as the Aiming High for Disabled Children Programme may be long-term

² Pawson R. & Tilley N. (*Realistic Evaluation* 1997), London: Sage Publications

and are likely to be influenced by a range of external variables for which it is not possible, or necessarily desirable, to control.

11. There are three key types of information that were gathered, analysed and synthesised to answer this fundamental question of “what works”:

- **Contexts** - the external and internal environments that have a bearing on the project’s success, and which influence its impact(s) on its target populations and other stakeholders/partners
- **Mechanisms** - the delivery structures, processes, systems and activities designed to work towards and deliver the project’s aims and objectives. (e.g. the variety of different types for short breaks provision available/being developed; the range of places where short breaks are provided and experienced; the funding and partnership arrangements involved, etc).
- **Outcomes** - the impacts and differences that the project has made to or contributed for target populations and other stakeholders, including disabled children, their families, commissioners and the range of providers from different sectors/agencies, DfE etc., insofar as they inform the specific questions being asked in this evaluation - given the primary work on outcomes for individuals and families is being carried out in the parallel study by Lancaster University

In broad terms, the evaluation was designed in two phases.

Phase One

12. Phase One was concerned with gaining a broad understanding of issues across all the Pathfinder sites and from relevant national perspectives. This encompassed the following elements:
13. A review of relevant national documentation including data collected from the Pathfinder sites known as the LAIMP, and meetings and telephone interviews were held with key national stakeholders, in particular the Department for Education and Together for Disabled

Children (TDC), to obtain a national perspective of the development and operation of the Pathfinder programme.

14. A series of interviews, meetings and interactions with stakeholders from the 21 Pathfinder sites. There were four NDTi field evaluators, each taking responsibility for five Pathfinder sites (one taking six). These were essentially grouped on a geographical basis for ease of access and management of travel time and costs. Prior to this, a semi-structured agenda was designed to ensure that the evaluation team covered what were felt to be core issues whilst also allowing the freedom and flexibility to explore other issues and areas felt to be important to the local stakeholders. (This is contained in Appendix I.)
15. In this context, information was obtained from a total of approximately 575 people during Phase One from the Pathfinder sites as summarised in Table 1 below. We have intentionally differentiated the nature of the interactions as described above. i.e. with some people detailed interviews took place. With others a shorter meeting occurred, which did not cover the breadth of issues we were concerned with but which nonetheless elicited important data. In addition, some observations and interactions occurred (e.g. observation of short breaks taking place) which provided additional understanding and knowledge to the evaluation team about the nature of local change.

Table 1.

	Interview	Discussion	Observation
LA Commissioners	43	9	5
PCT Commissioners	15	1	
Providers	46	58	
Families	51	53	Circa 100
Young people	3	33	Circa 130
Others (e.g. Family Support Officers)	15	14	

16. Two points should be made at this juncture of the report.
- Whilst the overwhelming majority of Pathfinder sites engaged fully in the evaluation process, we were only able to engage with 18 sites to a depth sufficient to give us confidence in the data obtained to fully incorporate it into the analysis. This does not give us any cause for concern about the resultant findings given (i) the high level of consensus and support for our findings across the Pathfinder sites in particular through the Feedback Workshops, and (ii) the limited data we obtained from the other three sites did not give any indications of contrary information.
 - Whilst there were a small number of notable exceptions where PCT's were making a significant contribution to the Pathfinder, it proved difficult to engage with a minority of Primary Care Trusts. In five cases no interaction with the PCT was possible. In one other it was very limited. In other Pathfinders, the identified PCT officer had limited involvement in the work and/or had only recently been allocated to it with limited time provided for this activity. Although many PCT officers were forthcoming in wanting to help, their detailed knowledge about the work was often limited and they were unclear about the PCT's particular contribution to short breaks and the Pathfinder initiative. This, in itself, is important data in terms of the NHS's role across the Pathfinders. It does, however, mean that the NHS commissioner perspective has been under-represented – though it is probably represented in a proportionate way to the NHS's actual (rather than intended) engagement with the Pathfinder programme.
17. The data from these sources was then analysed using the frameworks described in Realistic Evaluation. In particular, Context, Mechanism, Outcome models were developed (CMO models) for each site. These are at the heart of the analysis (see Appendix III) and describe what actions or interventions took place, the context in which they operated and the outcomes they appeared to be resulting in. With pairs of the evaluators working together (essentially split north and south), emerging 'theories of change' were developed. These described the major things we were starting to identify as actions or interventions that

had either helped or hindered the delivery of the Short Breaks agenda, along with an explanation about why and their impact. It is important to note that whilst the two pairs of evaluators worked separately, there was a high degree of synergy between their emerging theories – which increased our confidence in their likely accuracy. The north and south analyses each identified seven theories, six of which were common i.e. resulting in a total of eight different emerging theories of change.

18. All Pathfinder sites were then invited to send representatives to one of two workshops where these emerging theories were shared; 46 people from 20 Pathfinders attended. These people covered the full range of stakeholders described above other than young disabled people themselves. Participants were essentially asked three questions in relation to each emerging theory of change:
 - Does this reflect your experiences as a Pathfinder site?
 - How would you like to ‘tweak’, amend or change it?
 - What examples can you offer to either illustrate or contradict the emerging theory?

19. Whilst a number of refinements to the emerging theories were made through this process, it is important to note that **all** the emerging theories described by the NDTi evaluators were endorsed by **all** Pathfinder representatives as being accurate and valid. Additional information was provided to help describe and elaborate upon them as well as to further evidence the theories and illustrate their importance. In addition, one further theory was identified through the workshop discussions (Theory 7 – Paragraphs 85-88).

20. It is also worth noting that the clear view from workshop participants was that the workshop process in itself was a positive experience for them, in terms of:
 - Providing an opportunity to network and discuss issues with people from other Pathfinder sites – something they wished to have had greater opportunity to do.

- Contributing at an early stage to the analysis and conclusions from the evaluation – increasing their sense of ownership of the outcomes.
 - Stimulating their own thinking through debate around the ‘emerging theories’ and providing ideas to take back for implementation in their Pathfinder work.
21. The final element of Phase One involved the evaluation team reviewing and amending the emerging theories of change in the light of comments from the workshops and identifying any further issues that merited additional investigation during Phase Two. These emerging theories were then written up in an interim report that was presented to the DfE and DH and the multi-stakeholder Steering Group for this evaluation. The report was also shared, on a confidential basis, with lead officers from the 21 Pathfinder Sites. The DfE subsequently made this report publicly available³. **It is important to emphasise that the interim report has now been superseded, both in content and conclusions, by this report.**

Phase Two

22. Phase Two of the Evaluation was designed to test out these emerging theories in more detail through:
- Further discussions with key national players.
 - Further discussions with key local stakeholders in ten of the 21 Pathfinder sites.
 - ‘Case Studies’ of three families in each of ten Pathfinder sites in order to test out the real experiences of young people and their families in relation to the emergent theories.

³ Short Breaks Pathfinder Initiative – Interim Report.
<http://publications.dcsf.gov.uk/default.aspx?PageFunction=productdetails&PageMode=publications&ProductId=DCSF-RR223&>

23. Meetings and telephone interviews were held with the Department for Education, Department of Health, TDC National Officers and TDC Regional leads. The prime foci of these meetings varied between participants but were essentially concerned with (i) exploring their perceptions of the emerging theories of change and making any necessary refinements and (ii) contributing to the further development of the 'logic model' (see Appendix IV) to ensure it appropriately reflected the national perspective on the Short Breaks Pathfinder initiative.
24. The ten Pathfinder sites were chosen for Phase Two on the twin basis of (i) the ten sites between them containing a reasonable spread of data and findings across the whole set of emerging theories, and (ii) retaining a geographical and local authority 'type' spread as far as possible.
25. The meetings and interviews with local stakeholders were particularly focused on helping us to apply the conclusions from the emerging theories to the specific questions asked by DfE in the evaluation brief. A semi-structured interview format was used for these and this is contained in Appendix II.
26. Three families were then identified in each of the ten sites for 'case study' interviews. The way this was done varied between sites, in some cases the local authority directly supported identification and brokered contacts; in others it was done through independent means such as a Parent Participation Forum. We sought, in each location, to obtain a breadth of family/young person experience in terms such as (i) the complexity of the child's needs and demand placed upon services and age and (ii) the extent to which families were (or were not) also those actively involved in local planning and service delivery. Where possible all these interviews were done face to face, though a number were done as extensive telephone interviews for reasons of practicality and availability of the interviewees.

27. Again, a semi-structured approach was used, broadly based upon that used with other local stakeholders. However, given the nature of parents often wishing to talk in detail about their experiences with services – this had to be used very flexibly. In addition to parents and the young person wherever possible, interviews were also held with a mixture of allocated care managers, keyworkers and service providers – as summarised below in Table 2. It is worth noting that the number of care managers interviewed is lower than the number of families for three main reasons, (i) as more flexible access to short breaks emerges, some families do not have allocated social workers/care managers, (ii) some families explicitly asked that their care manager was not spoken to and (iii) in some of the Pathfinders a combination of staff sickness and leave over the period of Phase Two meant some staff could not be interviewed.

Table 2.

Phase Two Interview Numbers from Pathfinder Sites

	Number Interviewed
LA Commissioners	13
PCT Commissioners	9
Care managers/keyworkers	17
Providers	10
Families	32
Young people	17
Others (e.g. Family Support Officers)	15

28. All this data was then further analysed by the Team. The key conclusions were then presented to another workshop for the Pathfinder sites in order to test the final conclusions with representatives in a similar way to that described in Phase One – with a similar endorsement of the main conclusions and suggestions for ‘tweaks’ in the associated descriptions. Following that, further analysis has taken place, in particular in relation to the available national information with final reference to the most recent LAIMP data (the

regular statistical reports by Pathfinders to the Department), and this final report has been produced.

Section Three Theories of Change

29. The following theories of change have been derived from the evidence obtained across all Phases of the work. They describe what we have identified as consistent themes across the sites, themes that illustrate how the Pathfinder initiative has affected practice and delivery, and crucially why that appears to be the case and/or what it was that was done that resulted in this happening. In each case, sample evidence is offered to illustrate how and why the particular conclusions have been drawn. This is contained in italics under the relevant text. Those sentences in quotes are direct comments from participants or submitted documents. Other sentences are the evaluators' summaries of evidence. Given the commitment not to be evaluating and reporting on individual Pathfinder sites, locations and sources for the data are not directly stated in this report. From these theories, we have been able to draw conclusions about (i) answers to the specific questions contained in the evaluation brief (also partly covered in Section Four) and (ii) what might need to happen elsewhere in the country in order to maximize the impact and effectiveness of the development and delivery of short breaks (Section Five).
30. These theories are, in themselves, split in two. Some theories we have strong confidence in and we believe should be used to inform both national and local practice. For two others, whilst some evidence exists and we believe, on balance, that the conclusions are likely to be correct, the evidence is not sufficiently strong for us to state that in a robust and definitive manner and so we offer them still as 'emergent' theories that could inform future practice but which will also need further testing out over time.

Theory 1. Parent Participation.

- 31 **The growing participation of parents in decision-making mechanisms and arenas is a general trend across Pathfinder sites. Where undertaken effectively and in ways that recognise the**

disparate nature of families and the ways in which they wish to interact with services, this co-production has led to some innovative short breaks which address specific local needs and utilise local community groups and resources.

32. Parental participation has been a central concern of all Pathfinder sites. We have found evidence of a relationship between (a) the extent to which Pathfinders (and families) can describe and evidence short break developments that are meeting with the approval of families and young people and (b) the breadth and depth of their investment in family participation – in both systemic and resource terms. Key to this is their recognition that families are different and have different expectations and thus there is a need to adopt a range of different, but complementary approaches.
33. In particular, we have identified that when the Pathfinder directly and significantly invests in support for parent participation, there appears to be evidence of some innovative short breaks which address localised difficulties and utilise local community groups. In other words, parental involvement does seem to be connected with different types of short breaks that are particularly responsive to community inclusion. These connections, whilst being incremental in nature, appear to be influenced by a number of different elements:

In (Pathfinder), the extensive participation by parents in the decision making processes (for example around capital spending and the commissioning process) has resulted in 11 new services and facilities (now being developed) across different localities. Some of these new options appear to be relatively innovative, such as the Befriending scheme to support access to community activities or the agency commissioned to provide personal assistants to assist access into community activities.

In (Pathfinder) the whole approach of the dedicated short breaks team is based on working very closely with families to identify their needs. This partnership with parents is resulting in many varied approaches to

utilising local mainstream services, with appropriate support to facilitate access.

In (Pathfinder) parents on the steering group came up with the initiative to supply the workforce development manager with parent-led training sessions for mainstream providers

34. An important dimension is time and history. Those sites that had established parental involvement mechanisms prior to the Every Disabled Child Matters policy, were generally able to evidence greater degrees of progress and satisfaction – in part because of the time it takes to establish trust and confidence between services and families. In those Pathfinders with less history, parent forums and networks are nonetheless beginning to give some parents a ‘voice’ (where that didn’t exist before) and greater consultation is taking place. Where active parent groups and networks already existed, there are now more informed and aware parents who are helping to guide the short break strategy.

‘It used to feel like them and us, now it feels we are both batting on the same side’

‘Twenty years ago kids were hidden away. Five years ago parents were hidden away. Now that’s all changed’

A parent described a ‘proper partnership’ with professionals and the ‘mutual respect’ that had developed over time so that contact between senior officers and parents was ‘frequent and positive – even when we do not agree’

35. Progress was clearly linked to investment in developing and hearing the parental voice – both financial and officer time and attitude - it does not just happen unless the local authority and partners support its development and recognize the work involved in making it happen.

(Pathfinder site) has employed a Parent Forum Coordinator (there are 4 active Parent Forum Groups across the County). This has helped to 'pull together' various strands of work and has enhanced the impact, particularly improving communication and helping the groups act for themselves. Parents commented: 'A big problem has always been about finding out what is going on because the information is so scattered about. (The Coordinator) has really helped sort this and is working with us to find out what works best for different parents because we're not all the same. At the moment, we're looking at different ways to 'get the word out' - not just to those in the know'

There has been significant investment in the structural dimensions of parental support. For example, an outreach worker targets those not taking up short breaks which provides information that shapes service development.

'(The family support service) act on our behalf...I have a strong sense that they understand us and can and will advocate on our behalf. I don't always agree with everything they say but we know they're there if we need them. They've done great things to get more family activities - there was a waiting list before'

(Pathfinder site) has been slow in securing investment in parental participation – only starting to recruit posts in 2010. The evaluation team was only able to identify low levels of participation and interviews with families focused on them describing what did not work rather than what did work.

36. These approaches can lead to the Pathfinder team actively listening and genuinely valuing parents - beyond consultation – in other words they are seen as continual partners and not as people to be consulted and involved only when needed. Importantly, where progress is at its most positive, parents and families will be found at almost all levels and places where their view could be heard with openness, two way trust and multi-layered communication

An NDTi evaluator attended a meeting which included a discussion on eligibility criteria and equity of access for a particular service and the initial officer recommendation was changed to a different outcome directly because of parental comments.

'It's about putting the needs of families with disabled children higher up the pecking order moving from consultation to participation... we've been consulted to death!!'

'Parents are no longer told there is no services – we are asked about needs and changes, looking at outcomes rather than outputs'

(Location) Parent Forum groups invite Professionals and Providers to their meetings on a regular basis. They prepare the questions and get feedback/explore issues together. 'We've seen genuine changes as a result of this. We've had the Head of Leisure Services and the Short breaks person recently. Sometimes it's about hearing what's going on but we are starting to feel like we are included and they are listening to what we have to say'(Parent)

One Pathfinder has adopted the principle that families are involved in everything – all training events, all relevant interviews, all consultation meetings. Families clearly reported feeling involved. Senior officers reported 'they keep us very grounded they keep us honest and on our toes hold us to account it is a very healthy relationship'

In one Pathfinder some parental representatives felt pressure to be publicly supportive about progress in order to maintain the momentum of the Pathfinder – pressure subsequently acknowledged to the evaluation team by the lead officer. Families we spoke to clearly expressed a lack of comfort about this as it compromised their independence as the voice of parents.

37. Whilst recognising the importance of involving families across the spectrum, it is also evident that many parents want there to be a clear

purpose and focus behind involvement rather than involvement for involvement's sake and this approach can often be most productive

A consultation on playgrounds led directly to improvements/ investment in equipment and training for park staff - a parent member of the Provider Group commented that it was the fact that 'something happened as a result that really pricked up parents ears'

'Families are keen to be involved when there is something practical involved – 'fun days' or workshops seem to work best'

*'We do have to feel like something is happening as a result of this. Otherwise the membership will dry up - it's not just a talking shop. We know it's difficult and that money is tight. We just want people to be honest and open. We were talking at the last meeting about how we could get clearer information to people about what they can have. Us parents had loads of ideas- we got a letter back after the meeting from (senior officer) telling us what they were trying, that meant a lot'
(Parent)*

(Location) Pathfinder has worked with a group of parents to establish a set of 10 'success criteria' to apply when evaluating new bids. Within the revised commissioning process, bids go to the LA and to the Parents Group. Although the LA has the final say, far greater emphasis is now being placed on the parents' views.

38. Where parental involvement works alongside a 'visionary' officer(s) there appears to be increased impact.

In one site with a history of limited parental engagement a real sense of purpose, driven by lead officers, of the need to proactively engage parents and involve them as equal partners right at the beginning of Aiming High led to a sea change in the extent to which parents were engaged. This clear vision accelerated the pace of change and parents very quickly became active members of all aspects of the short break work.

In (Pathfinder) the vision of the lead officer and project manager have led to the creation of a dynamic AHDC team and more importantly a positive and focused partnership between parents across the city. The impact of this combination can be seen in many aspects of the Pathfinder initiative, from the significant effort given to getting information to families; to some creative consultation and listening events (e.g. a “Have your Say – Hear My Voice” Consultation event with Deaf children and families”); to the range of new providers entering the market; to the impressive range of short break options offered. The energy and vision of the two officers appears to have shaped the Pathfinder initiative and stamped a flexible, “can do” mark onto the rest of the team, which has given a huge lift and motivation to parents, both in groups and individually.

39. There did not, however, appear to be many successful initiatives, at this stage of the Pathfinders, to reach seldom heard parents. Many sites had identified issues to be addressed such as language barriers, inappropriate diets, lack of Asian workers, gender issues (matching worker & child), recognition of traveller issues etc., but actions to address them were generally in their early stages and the evaluation team was offered little evidence of specific progress in addressing them. (See also paragraphs 81 and 109 on black and ethnic minority communities).

(Pathfinder) has developed a service specification that involves requiring the provider to specifically do outreach work within the BME community to identify the needs and wishes of the family and young person, feed this into service planning and provide the family with information about support options.

(Pathfinder) had commissioned an external advisor to assist them on this issue, including consideration of use of the internet and IT more effectively.

(Pathfinder) has dedicated parent consultants for Somali and Kurdish families, as these have been identified as the hardest to reach in their area.

(Pathfinder) has a dedicated post to research the needs of far-flung communities. However, the site was not able at this stage to report any outcomes achieved.

40. We would, however, express a reservation about the breadth of parental involvement in the coproduction described above. There are, perhaps, three broad groups of parents; (i) those who have chosen to be involved in consultation and representation (ii) those who have additionally decided to become engaged in innovative forms of service provision, and (iii) the vast majority of parents who have neither the time nor desire to engage in these activities and focus primarily on their caring responsibilities and the rest of their lives. The progress noted on parental engagement is largely limited to the first two of these groups, and we are not clear about how the benefits of direct participation are being experienced by the third (and largest) group of parents. Whilst it is clear that having a parental voice within services is bringing vicarious benefit to all parents through influencing the range and style of short breaks available, some families reported a concern that they felt pressurized into getting involved – as otherwise they might miss out and not know what is on offer.
41. A key issue that this relates to is that of the provision of information and advice – an issue that impacts upon most of the other ‘theories’ that are commented upon in this section. What most families reported mattered to them was the availability of clear, concise information that described what they could expect in terms of short breaks – in part through staff advice and information but (particularly given comments we make later on about self-assessment and rapid access services) written materials are crucial. In several Pathfinders there has been impressive progress in the provision of such information but in others it has been more limited with some sites only producing initial information in early 2010 and/or information being couched in terms of entitlements which, for

families not well-versed in service-speak or the opportunities arising from the Short Breaks policy, are not easily understandable in terms of what it might mean specifically for them and their child. Parental involvement and coproduction was strongest in those places that had progressed furthest, and earliest, in providing information and advice in a range of different ways.

42. On both consultation/involvement and the provision of advice and information, a key factor appears to be the use of a range of different and complementary approaches that will enable families to engage with the method that best suits their lifestyles and caring responsibilities.

'We don't want to go to meetings - we haven't got the time/energy - but we do want a say. Having a named person who knows us and we speak to regularly really helps us. We feel like we are partners without having to do all the legwork. We talked to (keyworker) about what we would like over the holidays and we know it got taken to the meeting they have with all the providers' (Parent)

'We felt like we had to accept every invitation. We do want to be involved but we also felt that we would miss out if we weren't in the 'inner circle'. We value being involved in theory but not really in practice. We just haven't got the time. It's a luxury....we're about survival!. We don't want forms, questionnaires, meetings....we're in the process of extracting ourselves from things. We do want to know what's going on though but just in more flexible ways.' (Parent)

Parents who were actively involved reported a 'need to buddy parents to help them speak at meetings, let alone hold a post'

'I do go to all the meetings/events because I feel I have to be a constant presence but I don't feel heard. I attended all the consultation meetings but they were very 'tame'. I've heard it many times before' (Parent)

(Pathfinder) has undertaken a wide range of consultation activity with parents. This has included 7 Parent and Provider events across the county, 4 'Programme for Change' Fun Days, and individual Interviews with parents. Further targeted consultation such as 'Involving Children and Young People and their families in shaping services' and specific work with the Asian Mothers' Group. This has accrued a detailed list of wants/wishes/views on existing services that is now being used to inform service development. A number of developments are taking place that are clearly based on parental feedback (e.g. inclusion of siblings, more things on offer in the school holidays)

(Pathfinder) has invested in developing a brokerage model which provides members of staff to work alongside families to help them explore possibilities and represent their views rather than require the parents to take on that responsibility directly (unless they want to).

One Pathfinder has focused much attention on its relationship with one family led organisation which has developed positively. However, parents not linked into that structure appeared unaware of much basic information and described the 'foregone conclusion' of that particular organisation receiving contracts as the preferred provider.

One Pathfinder relies mainly upon meetings – which families report they hear little follow-up from and also find difficult to engage with, wanting other 'smarter' ways of communicating (e.g. e-mail) that don't involve them giving up work/caring responsibilities to engage.

'We've consulted to death in the past. There was definitely a little scepticism in the beginning, 'here we go, another initiative', but we do seem to be learning how to do it better, in different ways. Many of the parents I know are not interested in the running of things, they just want to know, what they can have, when will we get the break, will my child like it, do I have to jump through loads of hoops to get it. We weave consultation/participation into events now so that there is something practical for people/a reason to come along ... it's fun! (Local Authority Officer)

Theory 2. The imprecise nature of Short Breaks: when is an activity or experience a short break?

43. **A lack of national specificity and clarity, combined with evolving guidance on priorities has resulted in a huge variety of service responses, and a significant diversity of understanding amongst parents, young people and professionals in respect of short breaks. This has been helpful in many places, allowing creativity and innovation, but in others has resulted in more limited aspirations with families being unaware of what might be possible.**
44. We have found a huge variety of support services and responses to the Short Breaks initiative - almost any activity or experience can be seen to provide a short break from ordinary or everyday responsibilities and difficulties. The flexibility of the concept (initiative) allied with the lack of national policy specificity around definitions has been positively exploited by most Pathfinder areas and led to innovative and creative responses in the spirit of 'prevention'. However, those Pathfinders who appear less developed have found the lack of definition an obstacle as they have not known how to interpret national expectations.

In (Pathfinder) the use of an outcomes framework for deciding on funding and service provision, based significantly on parental and child wishes, has enabled there to be a creative approach to designing innovative packages of care where the outcome rather than the input (i.e. service design) is the determining factor.

In (Pathfinder site) the AHDC lead reported that families were primarily wanting traditional bed based respite services and this was the main demand. The families and young people met during the evaluation told a different story, stating they wanted activities linked into their communities and friends.

In (Pathfinder) there is little evidence of a variety of service responses being available or developed. This is also a Pathfinder that has

invested little in the provision of information or support to families. Families met during the evaluation were not generally proposing innovative ways of having their short break needs met.

45. As previously noted, this lack of specificity has perhaps not been helpful to many PCTs, who have often found it more problematic to make sense of being a Pathfinder and deliver change and innovation beyond the area of palliative care. PCT officers reported an underlying difficulty with regard to their efforts to conceptualise the role of the NHS in relation to short breaks.

In (Pathfinder) aligned PCT/LA budgets are in practice only supporting 5 children, with all other packages funded separately. Flexible use of resources has got bogged down in social care and Continuing health care criteria issues

In (Pathfinder) several children with very complex needs appear to have very limited contact with the NHS – for example in one site there is no funding for incontinence pull ups (only pads) for larger children and in another the pull ups funded were ineffective and the parent had to jump through numerous hurdles to access ones which actually worked. In another site the mother of a boy who uses a wheelchair had received no training or guidance in relation to lifting/moving /handling.

In (Pathfinder) the PCT part-funded a complex health needs co-ordinator post and another officer is a core member of the commissioning group. The process for arranging complex packages of care has improved significantly as a result. The PCT is well engaged with the short breaks agenda and commissioning/providing relevant things such as equipment, therapies and specific forms of care and support.

'The PCT just don't get it – they are not even contributing any thinking, we need a multi agency training policy, they will help deliver it but not with accreditation or monitoring.'

In (Pathfinder) the lack of involvement and financial contribution from the PCT has reached the stage of it being raised by the local MP.

46. Possibly the greatest impact of the overall lack of clarity has been experienced by families and their understanding of what a short break is and what they might be able to gain access to. Often parents, young people and practitioners are uncertain about the developing range of options that may or may not be available - and this uncertainty has created some confusion and impacted on the take up of short breaks. For example, some families do not recognise the innovative supports they were receiving as being short breaks and emerging from the Pathfinder work. This confusion may reflect a communication gap that is gradually narrowing; but it is nevertheless difficult to convey a concept or idea that is very broadly defined or described.

'I don't like the term –who is a short break for? It used to be very clear (child) had respite to give others in the family the chance to regroup. I understand that in a lot of families that might not work and the child might feel pushed around but it is vital for the three of us to have time together. It feels as though the whole pendulum has swung in the opposite direction.' (Parent)

'The terminology is difficult (it should be respite) –a lot of parents don't recognise this is relevant to them. It sounds as though you are having a weekend away in a luxury hotel. I think it sounds a commercial thing by Government and don't see it as a Council service or an entitlement' (parent)

'We see short breaks as the opportunity for our son to have fun and the family to have a chance to be 'normal' both with and without him'. (parent)

'It is good for our daughter to have peaceful chilled time at home when she can completely relax –made a big difference to pressure points in the family' (parent)

47. The consequence of this variation is that the types of support that families and young people value are available in some Pathfinders and not available in others, because of one or both of (i) it not being conceptualised that using resources in that way equates to a short break (ii) interpretation of guidance specifically excluding the use of Pathfinder resources in that way. For example, the guidance around use of Pathfinder capital monies stated that they should not be used to substitute for public expenditure to meet Disability Discrimination Act (DDA) requirements that should be funded through other routes. One resource that regularly tops consultation lists with families is that of fully accessible public toilets including changing facilities (without which, many disabled young people find it difficult to leave their house for long periods of time). Some Pathfinders refused to allow Pathfinder capital money to be used for this purpose because of the guidance (i.e. it was a DDA compliance issue), whilst others took the view that as this was a priority for families then it could and should be used to make such adaptations.

(Pathfinder) felt it was very clear what it could/could not spend short breaks money on and stuck closely to those rules e.g. it would not purchase a hoist for a swimming pool which was done in a number of other Pathfinder sites.

In (Pathfinder) one young girl had been supported to buy a tricycle with short breaks funding. This meant when she did things like go to the park with her parents, she could move around on her own, within parental sight, giving her parents a few minutes break from continual interaction - "I love my bike hundreds!" (child)

'I thought you had to go away – I don't want that. I didn't know you could have as much choice as you can' (Parent)

I feel like Oliver Twist asking for a begging bowl (when asking for a holiday). I feel I would be frowned upon because that is not what parents do'

Some Pathfinders stated that short breaks money could be more effectively spent on other types of support, such as behavioural support or sleep advice, which would reduce need/demand for short breaks. Some other sites just spent short breaks money on those things anyway.

In (Pathfinder) several parents met were unclear about what a short break may or may not be – despite the authority instigating several new options and being flexible in interpretation. Most of these parents had gone through the self-assessment route to services, thus having less interaction with staff who could explain short break options to them – suggesting the issue is a lack of information rather than a lack of specificity.

Theory 3. Inclusion and Ordinarity

48. **The increased use of ordinary community facilities and investment of resources in ‘opening up’ local community settings to make them more welcoming is increasingly contributing to people’s feelings of inclusion and belonging. This is best understood as a journey to inclusion, with many young people and families still choosing short breaks within mainstream community resources that are delivered mainly or exclusively for young people with disabilities.**
49. Disabled children and young people being supported to access mainstream community opportunities is a central expectation of the Short Breaks initiative and something all Pathfinders are working on. There are a great many examples across all Pathfinder sites of new types of short breaks emerging that, in one way or another, involve the child or young person utilising or engaging with community resources and activities. There is also some evidence that this trend is increased when direct payments are used to employ PAs and other supporters who appear more willing to explore mainstream community options.

'We went to our local Children's Centre last summer holidays to a play scheme there. We had two afternoons a week. It was great to see (child) with other children but they really thought about him too (I could tell they knew what they were doing). It was small groups, with the same staff and the same toys- they took time to find out about his routines. There were a few issues but we worked through them. We so appreciated it and just felt normal. I painted the dining room one day; we spoke with each other (rare). We're going again for the Easter hols' (Parent)

'The choice of services is so much more greater now. All we really wanted was for (child) to be able to go to things like other kids. She goes to Brownies now and to a swimming class at the local leisure centre. It might have been us that were a bit over protective but I don't think it was just that. I know the short breaks people have been working with different people to get our kids in and I can see it (slowly) beginning to work. (Parent)

'I used to see all these things going on at the Children's Centre but just thought, great but it's for ordinary children, what about my child, he won't fit in, they won't have the right support, they won't be able to cope. It's changing now though. We started going over the summer holidays after they put in some training for the staff to cope with (child). It's taken me ages to let go. I still get really stressed but I can see that they're thinking more about us now'. (Parent)

50. We have, however, found only limited evidence of substantial progress in terms of **fully** inclusive and mainstream opportunities being developed. On the whole, the process of Pathfinders actively listening to children and young people and their families about what feeling included means to them has resulted in the development of short break provision that is located within mainstream resources and locations, **but** is often an activity that involves either exclusively disabled children and young people - or sometimes primarily disabled children and their non-disabled siblings. In other words, it is not fully inclusive (which we would define as at least 50% non disabled participation if not the 95%

non-disabled figure that is widely recognised in the education field). Additionally, many of the activities involve an activity that we would describe as 'tourism' i.e. using and visiting the types of places and resources that we all use when visiting new places (such as shops, cafes and leisure centres) rather than places and activities that involve ongoing interaction with other local young citizens. This whole area is perhaps something that merits more detailed consideration in the future in terms of data collection and regulation.

We do use ordinary places but just at different times. A place we go regularly is a local soft play area / activity centre. They let us use the facility (just for us). It's good for the whole family. (Family Support group).

In (Pathfinder site) the summer programme involved groups of children with disabilities holding activities linked to those of 'mainstream' youth programmes and events – with some youth groups actively encouraging disabled young people to join and the residential stays away involving "buddying" with other young people. These young disabled people were clearly proud of "their" club and the things that they were achieving, as well as evidently making friends and socialising.

"Inclusion means the activity being open to all. My only niggle about (named service), though it met (child's) needs completely, it was aimed specifically at disabled children. We'd fought to get him out of the special school and into mainstream. We've tried so hard to give him a life in the real world. I'm almost backing down on that by saying there's this lovely place he can go to. Don't get me wrong, what they do is good. But nothing has been done at (named services) that is inclusive. My other kids wouldn't have gone along. It was going against what we've set out for (child). He's always got to be reminded not to copy bad behaviour. It clashes. (Parent)

51. This is an important finding in that it could be described as a 'third way' in what has often been an acrimonious debate around inclusion between those who believe inclusion puts disabled children at risk and

those who believe that full inclusion is the only appropriate goal. We will not repeat those arguments and evidence in this report, suffice to say that we met with families (and to a lesser extent officers) who held all views strongly – on one hand making the case and giving examples about how inclusive breaks had failed their child and only specialist segregated services could cope, and on the other telling stories of success and achieving and complaints about how segregated services that were available failed to meet their children's needs and wishes.

52. On the whole (but note paragraph 54) we could find only limited evidence of children and young people feeling that they belonged and were cherished in fully inclusive and integrated activities and settings, whereas they felt comfortable and valued in activities that were largely segregated but in inclusive settings.

In (Pathfinder) joint action with the youth services has led to one youth centre open weekly for disabled young people but others also invited. More and more non-disabled children are coming, with around 30 children attending things like drum workshops and guitar sessions.

'The service is serving as a direct link between the parents/children and some of the mainstream services. Although we do use specialist services, there is an aim to help the child use their local community facilities (if it's right). We've now got growing relationships with them and can support both parties' needs.' (Local Authority Officer)

'I want him to know about cerebral pleasures and learning and not just going to Sainsbury's and shopping' (parent)

53. However, there are three important caveats to be applied before this finding is interpreted as evidence to support a shift away from the aspiration of inclusive short breaks.
54. Firstly, there is some evidence – from one Pathfinder site in particular, though the examples given below come from a number of locations – of progress towards and benefits from fully inclusive short breaks.

What is interesting is to identify what it is in this location and elsewhere that has enabled inclusion to be taken further. Whilst it is difficult to draw conclusions from (primarily) one location, our work suggest the following are important factors:

- Leadership within the Pathfinder that is explicitly committed to achieving inclusion as a primary objective
- Clear local policy and strategy statements that state how this will be achieved and judged
- Through this, the creation of a culture whereby all parts of the system understand this is how they are expected to operate and the language of the service is the language of inclusion
- The development of a local evidence base that can demonstrate the positive outcomes arising from inclusive practice

(Pathfinder) has worked closely with the local youth service. They have used Pathfinder money to fund new Access and Inclusion Workers (1 per locality) and to pay for additional support when necessary from existing youth workers. These Access and Inclusion workers have used their dedicated time to support individuals to take part in mainstream (and specialist) youth activities and have also facilitated group activities aimed at mixed cohorts of disabled and non disabled young people. Their role is to enable disabled young people to take part in a wide range of activities. The youth services (using these workers and others) have also enabled disabled young people to attend residential trips away with integrated groups to London, Barcelona and even Cuba!

In (Pathfinder) there has been limited progress towards inclusive activities and families rarely even mentioned the concept. Inclusion is not a central part of either the action being taken, nor the language and mind-set of lead officers (with limited thinking beyond issues of physical access).

A short breaks brokerage service is run by a charity in (Pathfinder). They find out what mainstream activities providers can offer, then

support young people to go there (examples include fishing, golfing, surfing, water skiing and an orchestra) Staff identify any barriers to access such as safety, confidence, or staff knowledge and then take the child on 1:1 visits to work out how to address the issues. The intention is to eventually use direct payments to help fund this work.

(Pathfinder) has established an Inclusion Grant system. Providers can fill in a very short form to get extra support to enable a child to access funding without going to a panel where the objective is full mainstream access. Team managers are responsible for budgets but within that can apply discretion.

55. Secondly, there is a clear picture that wider benefits are developed within mainstream services and resources from disabled children being present (albeit in segregated activities). For example some mainstream staff reported increased confidence in their own skills and working with disabled young people brought additional job satisfaction. This reinforces a belief stated by many Pathfinder sites that segregated activities within inclusive settings need to be seen as a stage on a journey that could and possibly should lead to fully integrated short breaks once the willingness and commitment of both parties (i.e. disabled children and families and staff and participants in mainstream activities) is achieved to a greater extent. Participants consistently reported raised expectations, with regard to increased choice and being able to access ordinary services and facilities, and there is no reason to believe that this will not continue.

In (Pathfinder) parents have identified significant improvements in the approach and attitude of mainstream services.

The significant increase in the use of ordinary community bases / amenities is helping people to feel valued and welcomed in ordinary (and good) facilities. The groups are most often disabled only groups but some more varied (e.g. siblings) options are emerging. It is reported that the views of staff in universal settings are changing and attitudes are progressing. (Some staff were met and indeed appeared

very positive). Offering the “taster” sessions to young people and parents to try out amenities with targeted and tuned in staff has also helped build confidence in ordinary provision

56. Thirdly the most successful strategies, even when they appear to be essentially separate or “stepping stone” in nature, are those that focus on friendship and shared experience rather than dogmatically seeking integration (or non-integration), and are associated with action to help open up wider, mainstream opportunities.

‘The changing attitude of providers is very exciting, the message is really getting out there. There is a complete shift from why they can’t to how can we support them to do this?’ (Parent)

‘There has been a degree of resistance from families with low expectations about what their disabled child can do, but this is now changing as they see the changes in their child’s development and enthusiasm.’ Some are now saying ‘ we didn’t understand what we could do with our child’ (Local Authority Officer)

57. A number of other factors can be identified from our evaluation that are important components of inclusion and ordinariness becoming central to short breaks. Firstly, investing in workforce development – both the mainstream workforce who are not accustomed to working with and supporting disabled children and elements of the disabled children’s workforce who will have worked for many years from a presumption of separation.

‘It’s not just about facilities, it’s about changing hearts and minds - that takes so long to do’ (PCT Officer)

In (Pathfinder) sports and arts inclusion work has involved training mainstream staff. The first session involved 90 sports and play centre staff and the 2nd session was with music staff. The aim was to increase confidence and understanding amongst mainstream staff of working with children with disabilities.

In (Pathfinder) behavioural support workers have been funded through Aiming High monies to work with individuals to ensure successful community access – accompanying young people and training and skilling up others

One Pathfinder which acknowledged that its commitment to inclusive outcomes had made limited progress also stated it had not engaged in workforce development to support this agenda 'It just became absorbed into all the other workstreams'.

(Pathfinder) have been working closely with a range of mainstream services to raise awareness of the needs of disabled children, including staff training on issues such as behaviour management, supporting the needs of children with ASD as well as training around the use of equipment and specific needs of children with complex health needs. They report a 'real shift' in the impact this has had. Feedback from services indicate increased confidence and feedback from parents describes feelings of safety and happy to leave their child (e.g. significant increase in the number of children using the holiday play schemes with summer 09 having the highest referrals ever).

58. Investment in physical resources (such as equipment and facilities) was a significant factor in enabling full access – either from the perspective of adapting mainstream resources or from that of individualised supports to disabled young people that they can take with them and use wherever. (see also Para 49).

(Pathfinder) has invested heavily in 'opening up' the local parks and playgrounds to meet the needs of all children. Detailed feedback from parents and children established a 'room for improvement' list of priorities. Many of these have now been actioned and usage (and feedback) has increased significantly.

New initiatives with the Extended Schools and Early Years Service have involved short break capital monies being used to upgrade a

children's centre to be fully accessible and offer all mixed activities.

The same service (ESEY) has subsequently bid, entirely independently, for a holiday childcare project for disabled children, having increased their understanding and awareness as members of the Children Disability Partnership.

59. Investment in staff to facilitate access to community services (either in their own right or as advisors and supporters to locality/cluster teams) has increased the numbers of young people participating, reduced some types of specialist provision and achieved positive feedback from parents and children.

In (Pathfinder) short breaks co-coordinators have as part of their role to 'gently' engage families through providing information about how support for individual children in inclusive activities will be provided.

60. Some issues exist that appear to be continuing obstacles to inclusion and 'ordinariness', are: (i) Parents not having sufficient information about the range of services available/ the experience and qualifications of staff/ the equipment, etc to generate trust and confidence in accessing mainstream community services; (ii) 'Traditional views' amongst specialist staff (iii) type of disability and/or diagnostic label – in particular there was less progress towards inclusion for young people on the autistic spectrum across most Pathfinders, in some cases leading parents to suggest that there was active exclusion.

'Families don't really want to use the services everyone else uses (local authority officer)

One Pathfinder had to resist pressure from a Special School consortium to take control of the budget at the outset as they were best positioned to provide for children and young people.

In (Pathfinder) a parent described how after a few weeks of attending youth group funded by Aiming High, they were asked that she should not attend as they could not cope with her behaviour and were worried

that she would hurt another child or herself. This youth group was “new” to disabled young people and lacked knowledge of managing difficult or anti-social behaviours and how to get help or support around this. However, the girl concerned was successfully attending other youth / activity groups without such issues arising.

One senior local authority officer report on eligibility for inclusive provision “we have to be selective – some of them can’t handle it,” but neither they nor their staff were able to describe what criteria are used to select.

61. Similarly, the limited ways of identifying and measuring success (see also paragraph 67) make it difficult to demonstrate to families the potential benefits arising from fully inclusive short breaks - ‘the better it is working the more invisible the families will become’.

In (Pathfinder) the lead reported that data on mainstream access (from host providers) cannot be captured beyond the number of children and hours. No information on quality or outcomes is collated.

Theory 4. Commissioning for Innovation and Change

62. **The development of an assertive, values-led, but less mechanistic and prescriptive approach to commissioning, has enabled new and different providers of short break options to enter the market and is slowly leading to a wider range of short break provision that is having a positive impact on whole families.**
63. A common picture across Pathfinder sites was that people were demanding and looking for different types of short break provision from those that had traditionally been on offer. Frequently, these were felt to be best delivered from sources other than the traditional providers of short breaks and this often provided a challenge to the ways in which services were commissioned.

64. We have found that those Pathfinders who were able to be most flexible in their commissioning processes have derived the greatest benefit from consequently opening up their provider market to a more mixed economy of providers (some of whom may not have participated in this area before). Small, local (and often family led) provision appeared to be well placed to provide the innovative and community focused options that often emerged from consultation with families and young people. Such people and organisations can be either unwilling or unskilled at entering into complex tendering processes and the associated bureaucracy of contract placing and compliance, but if greater flexibility is shown then the evidence is that young people and families are benefitting from more appropriate services and supports and some early indications of cost-effectiveness for commissioners.

In (Pathfinder) most investment had previously been in residential, high cost, low volume services. Commissioning has sought to focus on small scale provision, including through use of in-house brokers, as a result of which several new, different types of small scale provision is available (such as supporting 'chaotic' families with household tasks to enable them to spend time with their children). The Pathfinder report that some of this change, such as purchasing sleep management advice, has reduced the demand for residential short breaks.

In (Pathfinder), new services commissioned include elements such as adaptation of foster carer homes, befriending services for accessing universal services music and drama groups. The early indications are that these things are connected with a reduction in out of County placements and reduced travel time for families to get to service provision.

65. Our conclusion is that the development of commissioning processes that prioritise an understanding and knowledge of factors such as community connections, values, flexibility and outcomes above the ability to comply with often complex tendering processes, appears to be an important factor in enabling the types of short breaks wanted by families and young people become a reality. The ability and willingness

of commissioning processes and personnel to invite and value the particular contributions of potential local community providers and engage with them as partners is clearly linked with local progress.

(Pathfinder) significantly expanded its range of providers, with eight contracts being awarded to different organisations. This was the result of assertive lobbying of the procurement function and emphasis of the national required delivery timescales – along with having a short breaks lead with knowledge of commissioning processes.

The commissioning/tendering approach has been more ‘speculative’ looking for providers with the right kind of values rather than a prescriptive list of what to provide. This involved ‘putting out feelers’ to test what was potentially available (based on what parents/CYP were telling them), adopting a process where providers brought their ideas to the table (much more outcome focused). A decision to actively seek involvement from smaller local providers included offering ongoing support with smaller organisations around capacity building and sustainability. This has led to the commissioning of a much broader menu of options that are firmly grounded in the ethos of Aiming High and inclusion.

‘Whilst large scale joint commissioning processes can support efficiencies and economies of scale, there is a real danger that we will lose the flexibility to support development and innovation. We need both!’ (Commissioner)

(Pathfinder) has stuck largely with traditional approaches to commissioning. For example, a sixty page tender document for a summer holiday activity service. Providers reported particular difficulties with being asked to respond to tenders at short notice that they had had no involvement in developing and which contained broad, non-specific outcomes. Timescales for delivering different styles of provision were described as unrealistic. Where more ‘negotiated’ contracts were developed (e.g. summer play-schemes) the commissioning process tended to be cumbersome and not completed in time to recruit staff,

secure CRB clearance and plan the activity before summer holidays started, Some providers progressed at financial risk with a promise from Pathfinder Leads that the money would come through eventually.

A voluntary organisation commissioned to run a consultation with young people about short breaks starting in April 2009 did not get the money until October 09 – describing the ‘ridiculous hoops the contracts department wanted us to jump through’.

In (Pathfinder) the commissioning structures actively involve parents and providers and have led to the production of a Marketing & Purchasing Plan which drives all Aiming High commissioning. Each service commissioned goes through market consultation days - with parents and providers testing specification/outcomes/costs. Subsequent monthly contract monitoring meetings with providers ensure any issues are quickly addressed and parental views are also fed into the process and changes are made as required. All involved feel this process has ensured final specifications are realistic and relevant and that providers have clear understanding of expectations with an outcome focused approach. It has also stimulated joint working between voluntary sector organisations.

In (Pathfinder) Short Break Coordinators help to access individual and often mainstream services for families. Many individual packages are in place but there are frustrations with procurement services within the local authority. Financial reporting is described as inflexible with many hoops to jump through, and an overall feeling that the more creative the service the more bureaucratic the process to put it into place. For example, the complexity of the process and arrangements to try and pay £170 for a boy with autism to attend a tennis academy over the summer holidays resulted in a frustrating and disproportionate administrative process.

66. Linked to this, we identified that strategies to engage potential (non specialist) providers in the tendering process, accompanied by support to develop capacity and infrastructure within organisations were

beginning to stimulate the market. These approaches can be counter to standardised requirements for commissioning local services, creating tensions between proactive commissioning and restrictive procurement processes. However, it was clear from the evaluation that, without this strategic support, some potential innovative providers would have been deterred from coming forward.

In (Pathfinder) the Pathfinder lead and colleagues have invested considerable time and energy in developing new links and encouraging involvement with mainstream providers in an attempt to open up the market. There are now more smaller, locally based providers involved, some being new to disabled children and some large national providers have withdrawn as they were unable to meet the new, flexible requirements.

(Pathfinder) has invested in training units and toolkits for generic providers (such as on moving and handling and working with people who challenge) in order to improve access to mainstream settings.

'We are a local wrestling club. We saw the invitation to provide 'short breaks' and thought nothing of it at first because we hadn't worked directly in this area before, but we knew that our values and way of working was what the advert described so we gave them a call. The support we got before, during and after has really helped us. We've been really truthful about what our fears and concerns were and asked for help when we weren't sure about something. It's been absolutely brilliant, we've got young people doing wrestling (some of them with significant health needs) and they love it! There have been so many knock ons from this. We knew it was a bit of an experiment when we started but it's paid off' (Provider)

67. The other key commissioning issue relates to outcomes measurement. Almost all Pathfinder sites are struggling to find effective ways of measuring and reporting on the more innovative services and supports. In part this is because some of the most valued services are in effect almost 'invisible' in conventional terms (as discussed under Theory 2)

and thus are not easily identified and measured by existing performance systems. For example, a young person engaging in the same community activities as their non-disabled peers is a 'natural' activity and thus applying measurement and recording to that process can be both difficult and intrusive. Similarly, some of the ways in which families are choosing to use resources are not readily identifiable and understandable as short breaks in the conventional sense and are thus evading outcomes monitoring systems either intentionally or unintentionally.

(Pathfinder) has established a Community Lead Professional Team that is entirely based on identifying measurable outcomes with parents e.g. parents need 2 unbroken nights sleep in a week / child needs to have made 2 friends by November. Support packages are put in place with outcome requirements to achieve these things, of which there are currently 200 plus such packages with no residential services. The average costs are £1500 compared with £11,000 for specialist team services – though there are differing views on the comparability of need. The focus is on looking at parents and strengths within the family and the supports around them and then identifies gaps. A significant number of support plans don't cost anything extra apart from CLPT team time as they help find what available locally and work out how to access it. The aim is to support family independence and access natural community support.

(Pathfinder) is piloting reviews individual outcomes within services, in order that once outcomes have been achieved the services either comes to an end or new objectives are set. This approach does, however, cause concerns for some families who are concerned with stability as the prime objective.

Theory 5: Partnership Working.

68. **Where there is a history of joint working within and across the local authority, PCT and voluntary sector, along with current**

evidence of a common vision, this can lead to significant improvements in (a) the delivery of services and (b) the lives of individual children and young people.

69. There is an additional appendix on Partnership working (Appendix V) and so there is limited comment on this point at this stage of the report. However, there are a number of points worth outlining in brief:
70. Generally, the strongest progress was being made by Pathfinders where there was a prior history of partnership working between key agencies – starting from scratch when the Pathfinder initiative was announced caused predictable difficulties and tensions until the partnership had a chance to grow and mature.
71. As previously noted, many sites had difficulty in fully engaging with the PCT. Where this was possible, there were clear benefits in terms of impetus behind the work, but the more common picture was one of a lack of clarity about the NHS's involvement and in some places tension that led to difficulties. The evaluation identified three main factors influencing this position:
- The lack of explicit priority given to the short breaks initiative within national NHS priorities (certainly as understood by the NHS at a local level) meant that resources in the form of staff time were only significantly allocated by the PCT where an individual (usually senior) officer took a personal interest in the policy initiative. Two consequences of this in many Pathfinders were (i) frequent changes in the lead officer linking into the Pathfinder initiatives and a resultant limited knowledge base about short breaks, and (ii) involvement in the Pathfinder frequently being something that PCT officials squeezed into their workload in the face of other priorities and thus something that tended to fall by the wayside when pressures grew.
 - The non-ringfencing of the PCT's financial allocation for short breaks and Pathfinder involvement meant that in many cases the resources notionally available and described in national documents did not get through at a local level. In its most extreme cases, some

Pathfinders reported no financial contribution to Pathfinder initiatives from the PCT.

- In some Pathfinders, the lack of specific guidance on the nature of short breaks contributed to particular difficulties in understanding the role of the NHS in short breaks. The implicit logic within guidance that the NHS should be contributing health skills to an overall package of short breaks was not understood by all and instead some places found themselves engaged in more old fashioned debates about identifying the discrete packages that were 'health short breaks' and provided and funded just by the NHS (such as palliative care), rather than looking at how health skills contributed to a 'mixed economy' of provision e.g. through support around behavioural management within mainstream settings.

'On paper it's a partnership approach, it was a joint bid that the PCT 'signed off' and would say that they were 'up for it'. It's not that they're obstructive but just not really 'present'. The Senior Leaders from the PCT don't often attend the steering groups. They have identified some funding but nothing substantial. Their priority seems to be around palliative care. The lack of ringfencing is a major issue (for us and them). There certainly needs to be some levers to ensure this changes' (Pathfinder Lead)

'We are very involved but haven't always brought money to the table' (PCT Lead)

72. Beyond the NHS partnership, where local authority departments such as leisure, youth and extended schools services are involved as partners in both planning and delivery of the Pathfinder programme, this has resulted in creative approaches to increasing the accessibility of services, the numbers of children and young people participating, and generated positive feedback from children, young people and their families.

73. As previously noted, partnership with the local voluntary sector appears to be particularly important to the development of a range of innovative provision. The earlier section on commissioning commented upon the benefits that appear to be being gained from engaging a plurality of providers in developments and planning.

‘Other authorities just want to provide services, (Pathfinder) is trying to get it’s teeth around outcomes’ also ‘how can we more both help each other to move forward?’ ‘We meet with all domiciliary providers and Project lead to share what’s working, what’s not, liaising and identifying training events.’ ‘We feel our knowledge and expertise is valued’.
(Provider).

In (Pathfinder) the active steps taken to engage with parents individually and collectively helped to encourage voluntary sector organisations that were parent focused to engage with the Pathfinder initiative with more confidence.

Theory 6. Access and Equity.

74. **In most places there has been an increase in the numbers of children and young people (significantly those with less complex needs) accessing short breaks as a result of authorities introducing an entitlement model alongside eligibility criteria. There has been some progress towards greater access for those young people and families with more complex needs through targeting of people perceived to be in greater need – though this is variable both in the methods used and the progress made. The range and choice of breaks people actually access is significantly affected by factors such as information provision and staff knowledge.**
75. Many sites have successfully increased the number of people receiving short breaks through adopting an easy access system. Families can apply for a defined amount of short break support through a process

that is much quicker and simpler than a traditional assessment process. This is generally based upon the concept of 'entitlement' i.e. if families can demonstrate through simple methods (such as tiered receipt of DLA) that they have a need for support, then they get an immediate entitlement to access short breaks. Numerous parents described to the evaluation team how these 'quicker, simpler' routes to short breaks were positive from their perspective.

"The good thing about it (the process) is it is flexible and quick...you get a quick decision even if it is not good! You don't have to go through an assessment process... I just spoke to a Pathfinder worker and filled in a form and she said she would ring back...(and she did!). (Parent)

In (Pathfinder site) they have piloted a self assessment process for accessing short breaks (though not through direct payments). This was in response to parents' wishes about a quicker process and not wanting a full assessment. People can apply if they are on the Middle or Higher rate of DLA and not already receiving services. There are limitations with regard to complex family situations (difficult on the form) and this has not helped those already receiving services, but overall the impact appears positive. The Pathfinder report 70-80 new families now receiving short breaks via this system.

'It used to be that the word amongst parents was that in order to access holiday schemes you had to phone up the social worker and break down on the phone. That's changed now' (Parent)

(Pathfinder site) has made limited progress on access. Assessments through the social work service remain the main route of access, though some families are also able to access other services in unplanned ways. The Authority's own data indicates that 500 families are known but not receiving any form of short break – though some may be getting unplanned short break access.

76. The services people access through this route are often (but not always) available through pre-commissioned services delivered through

the voluntary sector. There are also some innovative approaches being used to enable families to access this support in alternative ways – for example through making vouchers available that can be cashed in a variety of places.

In (Pathfinder) there is an inclusion grant form that enables providers to fill in a very short form to get extra support to enable a child to access services focused on inclusion very quickly.

(Pathfinder site) are developing a social screening tool that parents will complete on line. A score will be generated on basis of barriers faced and a certain score will automatically generate a ticket for certain services.

The local offer in (Pathfinder site) is delivered by relying on a website and using self-referral followed by choose-and-book. Parents reported this had the advantage is the instant matching of need to provision, but had difficulties such as no possibility of “tasting” before booking and problems for those families without web access. The Aiming High lead reported this was addressed through “word of mouth”.

77. Many Pathfinder sites then have a second tier of assessment process that families go through in order to obtain more intensive short break support and/or access direct payments (see also paragraphs 110-113). In some places this appears to be working well, but in others the system used is becoming, in their own words, overly complex and bureaucratic.

In (Pathfinder site) developing a dual access system has enabled more people to receive short breaks. It has been possible for Pathfinder to identify disabled young people who are not receiving short breaks and to target these people (without full social care assessment) with information and an Outreach worker (Group A). The other benefit to parents has been the fact that decisions are made quickly and parents know whether or not they have a place on an activity.

'Short Breaks themselves have become assessment drivers, huge panels around table –often feels disproportionate to parents' needs.'

In (Pathfinder) the system operates on the basis of four levels of need. The lower two are available through grant funded voluntary sector services. The self-referral system is used to identify people who might be eligible for the higher tiers and the resultant commissioned services (or direct payments – which are not available for lower tier support). Follow-up is by telephone call or home visit. "So we're assessing people without them realising it." (Local Authority Officer)

78. In some (but by no means all) Pathfinder sites, there is a particular drive to change services (in particular for those with more complex needs) from what might be called 'high cost low volume' to something more along the lines of lower cost higher volume. This has generally been done through reviewing commissioning arrangements and seeking to move from block contracts to more individualised purchasing arrangements.

"A conscious decision to move away from the long established pattern of residential short breaks enabled us to redirect resources away from this expensive provision to develop far more flexible and responsive provision in greater volumes. This did not involve the 'taking away' of a service but a rationalisation of the resource due to reduced level of demand. The PF money allowed us to build up options whilst still maintaining the residential options in the short term" (Pathfinder Lead)

79. We were unable to identify substantial hard evidence about the extent to which the short breaks initiative has resulted in services being more available to young people who matched the five priority groups identified in the Short Breaks Guidance. There is no doubt that many Pathfinders have targeted some of their new developments at specific groups of young people who have been identified as not being well served by existing short breaks, but the extent to which this can be quantified and covers those specific definitions or labels is unclear. The official LAIMP data does show increased numbers and provision across

all five groups but the data also shows variations over time across many Pathfinders that, in our opinion, cannot be explained by changes in provision and are more likely arising from increased accuracy in data recording. Most Pathfinders have improved their data management and collection and now have a clearer understanding of who they are delivering short breaks services to – but this is a stage on a journey and many are generally still some way from understanding the detail of who they are providing exactly what services to. Paragraphs 102-105 comment in more detail on this issue.

80. An issue that was clearly important to access and equity was that of the information available to families about both how the system operated and the range of short breaks that might be available. We identified radically varying understandings from families across different Pathfinder sites about the type and style of short breaks that they might be entitled and able to access. In part this was a question of the written or web-based information and what it did and did not explain. It was also influenced by the role played by staff and the levels of knowledge those staff had when advising and supporting families to take decisions.

In (Pathfinder) most parents heard about short breaks through special schools or word of mouth. Some parents expressed surprise at being informed by the evaluation team of local services they had no idea existed. “I have no idea how those in mainstream schools would hear about any of the activities taking place” (Parent)

Information available through a substantial printed Resource Directory with detailed listing. Prior to that families previously reported “A big mismatch between the bits and pieces of what’s available and the information about them,” and “the information is there if you’re looking for it, otherwise you’re stuck”

‘I got a leaflet saying that we could have up to 100 hours of support over the year. It spelt out examples of what we could have but stressed that they were just that. I called the number to speak with (named

worker) and we've never looked back! I felt that there really was a true menu of things that we could tap into and not something that (child) was being slotted into. If it wasn't something that (named worker) knew about, she would try and find something. We wanted (child) to have swimming lessons but with a teacher who got in the water with the children (this isn't usual for older children) and we've got on now thanks to (named worker). It was time consuming at first but I really feel like it's been an investment as they really have a good picture of (child) and us.

'Social Workers don't know what's available or understand the rules'. 'This is made much worse by frequent changes of staff and people being off sick- it's really difficult to speak with them'. 'All I'm trying to find out is what we can have. I sometimes feel like I'm being lied to (I'm probably not) but I just want to know what we're entitled to' 'I just wanted to know where there was some kind of community sports activity that we could go to burn off energy but the Social Worker didn't know of anything or who I could ask' (Parents in the same location)

'Moving it firmly out of the 'social care arena' - changing the language we use, simplifying the processes, making it clearer what's on offer and who can access the basic level of support. It features in all LA events- we've got our own logo now and nicely produced publicity material. A key function of our dedicated Parent Participation Officer is to work directly with parents to let them know what they can access and how. (Local Authority Officer)

"if you don't shout, you don't get anything", and "parents feeling they have to beg for Direct Payments". (Parents in one location)

81. The evaluation was able to identify only limited specific initiatives aimed at black and minority ethnic communities. In a minority of Pathfinders there was some limited focus on these issues – for example an initiative targeted explicitly at the Jewish community or a member of staff with that specific responsibility. (See also paragraphs 39 and 109). In a number of Pathfinders it was not recognised by lead officers as an issue that they had a need to specifically address. In a handful of

places, the approach taken was to focus on poverty as, by doing so, most of the difficult to hear/reach minority ethnic communities would be covered.

In (Pathfinder) officers were unable to evidence an awareness of need, nor mechanisms, to reach the BME population. It was stated that they were reached by methods used for the population as a whole (but no data was available to support this).

In (Pathfinder) BME parents identified potential inequity as being not ethnicity but how recently you have arrived and related factors such as knowledge of language and local systems.

82. Almost all Pathfinders operating across rural communities identified the geographical challenges that this created as a significant factor and something they were having to address. This specifically encompassed issues of travel and access to short break opportunities. In a large rural area, it can be difficult or impossible for a family to actually get to what they wish to access because of distance - meaning that either the family has less choice or the Authority needs to commission multiple resources that smaller authorities only need one of. There are also problems of recruitment, with families finding it difficult to find people for 'PA' type of work in small, rural communities. Finally, it is more difficult for parents to network with other families and/or get to organised family support opportunities and thus they risk being ill-informed about new developments and opportunities.

"Everything is available ... if you think across (Pathfinder area). But you have to drive miles just to get a couple of hours for your child" [Parent].

In (Pathfinder site) a dedicated officer has been identified for researching and initiating schemes away from the conurbations (restricted so far to one area)

(Pathfinder) has built on their existing partnership with the Community Transport service by extending the 8 schemes across the county to

move towards a more flexible offer for those children and families in the medium to high threshold. A key shift has involved a move away from an entitlement that was measured in mileage to one which is expressed in 'journeys'. This has significant implications for those people who have to travel significant distances (and so would use up their mileage allowance very quickly). All journeys are now supported by an approved escort. This is being carefully monitored and tested. Issues arising include deciding whether parents and siblings will also be allowed to use the transport.

"Because of where I live I never meet other parents" (Parent)

83. We are thus not in a position to comment in any detail on whether the approaches taken by Pathfinders have resulted in increased equity of access to services. There are perhaps two elements to this (i) equity between young people with different types of needs and (ii) equity across the country in terms of types of provision. Pathfinders themselves consistently reported a level of unease with regard to equity and felt that flexibility in eligibility criteria (by itself) would not achieve this desired outcome. The evaluation findings would endorse this view – with the other issues identified in the 'theories of change' in this report being at least as important. The national data, which should be the prime source of information to inform this question, do not provide solid information to answer access and equity questions for reasons described later and (with very limited possible exceptions) local Pathfinders have not collated and analysed information on equity of access to enable either a single or cross-location analysis of this to be undertaken – though some are making progress towards this. Thus, whilst we can confidently state that there is more open access to services than before, it is not possible to state whether this has resulted in greater equity and/or targeting on those deemed to be in greatest need. There is certainly variation across the country about types of short breaks available for reasons described elsewhere in this report and thus equity of provision across the country has not been achieved.

(Pathfinder) commissioned their own research into access which reported a year ago. One of the main conclusions stated “The majority of parents currently accessing childcare and short breaks were very satisfied with the service they were receiving ...However... Parents felt the eligibility criteria for short breaks excluded most parents and didn’t reflect the individual needs of parents”. Since this report the Pathfinder have promoted a quicker access route and this may have had an impact but the parents met during the evaluation were not well informed about the range of options available and therefore were still not able to access easily.

‘Short breaks need to be focused on those in greatest need. It used to be families who really needed it and families under pressure, now it feels like every half dick Herbert is jumping on short break bandwagon and some children less needy than my two other children are getting it’.
(Parent)

84. Almost all Pathfinder sites stated that they are waiting for and expecting some further national guidance and/or clarity on this issue and so local innovation and initiative has perhaps been suppressed because of this expectation.

Theory 7. The Importance of Accountability and Resource Protection

85. **The clear identification of the Pathfinder Funds provided through the local authority, along with the requirement to report nationally on their usage, was a positive factor in empowering Pathfinder leads to protect resources and engage key stakeholders and thus help achieve the policy objectives**
86. We found that the clear identification of the funds channeled through the local authority for the Pathfinder initiative enabled Pathfinder leads to argue for their explicit use on this initiative, whereas otherwise there was a strong belief that a large proportion of them would have been lost to other local authority purposes. As previously noted, the experience

with PCT funds was in many ways the opposite, i.e. the non-ring-fencing resulted in substantial proportions not finding their way through to short breaks, thus clearly indicating that local authority officers had grounds for this belief.

All Pathfinders also talked about how empowering it has been to be able to meet providers, or potential providers and to be able to respond to their good ideas with “proper money”. Similarly, Social Work team managers described the (positive) difference it had made to their team to be able to work with families and to be able to know exactly what resource was available to offer and, perhaps more importantly, to have confidence that the resources were protected to support families with.

A number of Pathfinders reported interest in their work from Council Chief Executives that had not occurred previously and which they felt would not have been the case without the national profile.

*‘There had been a lot of discussion regarding the commissioning and children and parent outcomes. Nobody had picked it up and gone with it. Aiming High gave us the perfect opportunity to take that forward.’
(Head Extended schools and Early Years).’*

The extra money helped us to stay afloat’ (Provider)

87. The availability of this funding was also an important ‘carrot’ in encouraging elements of mainstream services (such as the Youth Service) to become actively involved in the Pathfinder work.

*‘Would be trying to provide these things anyway but Aiming High has given the youth service the opportunity to be part of the process and connect to all the other work taking place –this certainly helps the whole process strategically –certainly of benefit... it raises profile of disabled children and young people in our service and keeps the issue alive’
(Youth Service officer)*

In (Pathfinder site) AHDC lead officers described how they achieved working outside the 'disability silos' surprisingly quickly, and they attributed that to the fact that they entered discussions with other colleagues with resources available and the confidence that money would remain in place.

In (location) the Pathfinder project identified closer partnership working with the Youth Service as a key priority. Short break funding has been used (along with Youth Service funding) to support a part time development worker to look specifically at the needs of young people age 13 plus and to develop appropriate short break provision. Following consultation activities with young people (many who have very complex needs) a range of activities, innovative provision has been put in place. Numbers accessing the Youth Service activities have increased by 50%.

"We expected to meet resistance, but were surprised by the degree to which people cross-worked out of silos, very suddenly, even beginning upfront with their own resources that were already there. They came to the table with things they could offer. That was because they knew there was additional money and that it was ringfenced. It meant that joint working wasn't a threat." (Lead Officer)

88. The requirement to account for how funds had been used through the TDC processes, associated with the profile of being part of a national initiative, was a positive factor in maintaining senior level interest and engagement within local authorities. There were clear indications that, without this degree of national 'profile' and the requirement to account nationally for progress being made, those local officers leading Pathfinder work would have been less able to gain priority, attention and support for their work.

'The money was important because it forced questions to be asked which required us to produce a high profile response and raised expectations across the board.'(Lead Officer)

'Trying to do new things was hugely time consuming and exhausting – trying to sort out problems which have never been done before, keep persevering and finding a way through. A clear vision was vital otherwise we would never have made it'

Newly constructed service level agreements included the need to report outcomes with crisp professional clarity when monitoring and evaluating. In other words, it enabled even the least confident of commissioners to say “you must provide me with evaluation evidence as we have to report to the government...”

Although the reporting and monitoring was a pain at times, it definitely made sure we spent the money where it was intended and that we could show that. We would never have been able to get any posts in place without the ringfencing (Local Authority Pathfinder Lead)

Emerging Theories of Change

89. A small number of other theories of change were developed during the course of the evaluation. Whilst there is some evidence to suggest that these are a fair reflection of progress across the Pathfinder sites, unlike the preceding theories we do **not** have sufficient breadth and depth of evidence to state that these assertions are **definitely** borne out by our evaluation. We therefore offer them up as emerging theories that we believe merit consideration, and indeed further investigation, but which are not so definitive as to merit (i) explicit incorporation into policy guidance and/or (ii) specific local investments to put in place as part of delivery mechanisms as **evidence-based** decisions. This is not to say these things should not be done, and indeed we believe there is sufficient reason to argue they should be, it is purely that the label 'evidence based' would be over-stating the position from this evaluation.

Emerging Theory A. Participation by Children and Young People

90. **Involving individual children and groups of young people in service design, development and evaluation is leading to more accessible and child focused short breaks.**
91. Most areas clearly now believe in an approach based upon children's rights. This shift in culture is, we believe, often significantly arising from the work linked to EDCM and this Pathfinder initiative. However, in many places moving from this theoretical intent to delivery in practice is at a very embryonic stage – certainly less advanced than parental empowerment. Most areas have developed systems for finding out what young people want and subsequently what young people thought about their short breaks – including those who may need much support to communicate their views – though this was not the case everywhere.

In (Pathfinder) a specialist organisation was commissioned over a six-month period to work with disabled children with a wide range of needs (via special schools, open days, workshops, play schemes and children's centres). This built up a detailed picture of what children wanted (e.g. to spend time with friends away from parents, go places to meet friends and wanted to be able to take their siblings). This has resulted in the commissioning of increased befriending services and the opening up of services to allow siblings to attend (previously not allowed).

'I have a long and established presence within 'short breaks' but this feels different and exciting (and challenging). Although I totally supported young people's active involvement in 'recruitment' –I did have a concern that it would be tokenistic and wondered whether they would they see through 'hype' but really didn't feel it was. I was positively surprised at the insightful questions. I'm a bit embarrassed to say that but I'm just being honest' (Provider)

A Pathfinder is working closely with the Youth Service to support a team of young people to work across a range of mainstream services

and local organisations. This involves looking at services from the young people's perspective and awarding them (or not) a charter mark (based on the AH logo) which all services involved in short break provision have to have. Ongoing training and support has enabled Youth Service staff to work with children with more complex needs

(Pathfinder) runs an annual Independence Day with panel of local decision makers. They film questions beforehand so it is less intimidating for young people. 2010 theme is transition and there will be a workshop beforehand for the young people attending to increase understanding of possible issues and questions and in order to make independence day meaningful.

In (Pathfinder) all questions to local authority staff about children's participation were responded to in terms of parental participation – this was a Pathfinder with good parental involvement.

92. In a number of Pathfinder sites, there is positive progress arising from investment in providing support to enable young people to come together in groups or networks, with infrastructure and methodologies to support such groups. Such groups have placed great emphasis on promoting self-esteem and developing peer support / role modeling within the wider community.

In (Pathfinder) a group of young adults who had previously used short breaks were supported to set up a steering group to explore ways of consulting with disabled young people. They undertook a school based consultation with 150-200 children, focusing on six key questions:

- *What do you like to do in your free time?*
- *When do you like to do this?*
- *Who do you want to spend your free time with?*
- *What support do you need to do these things?*
- *Who would you really like to give you this support?*
- *What new things would you like to do in your free time?*

The findings from the consultation and the views of young people were reported back to the Aiming High Board and used to shape the overall development of the Pathfinder.

In (Pathfinder) a voluntary organisation runs 10 'Speaking Up groups' in schools for young people who need a lot of support to develop self advocacy skills. This includes work on things like group identity and assertiveness training.

93. There is some evidence to suggest that the development and participation of such groups is beginning to influence the nature of services being developed, such as the opportunity to participate in a diverse range of opportunities and a growing emphasis on shared short breaks (i.e. parent and young person together) rather than what might be called separated time breaks. However, there is much evidence to suggest that meaningful participation takes time to develop and the numbers of young people engaged in this way is still very limited, as methods of successfully working with them are still being pursued.

A Pathfinder has worked with a teacher in a local special school (who had a specialism in augmentative and alternative communication) to engage the school council to help with the selection process of new services. These were the only interviews for applying organisations that were held in this commissioning process. The approach was accessible (in a communication sensitive sense), objective and robust enough to stand up to external scrutiny. It involved:

- *Bidding companies/organisations to deliver a short presentation (up to five minutes, strictly no PowerPoint!) to a group of young people, and then to participating in a question/answer session*
- *The presentations being videoed and watched back at school by a wider group of young people who then scored presentations using a predefined set of criteria*

In (Pathfinder site) a panel of disabled young people will consider applications for short breaks and then providers are invited to attend and give a presentation in a Dragons Den format.

A Pathfinder lead stated how their views on service provision had changed after consultation with young people. They had originally intended to put money into specific services/groups, but feedback from children and young people about diversity then led to a decision to develop and set up a buddying scheme.

A Pathfinder site has established an 'Ideas Group' – a group of young people thinking of lots of ideas for young people to do ('often people – professional, parents, children themselves, have very low expectations of what disabled children can do.'). They have a principle of aiming to test boundaries about what is possible and refusing to accept limits and barriers whilst accepting all families very different.

In (Pathfinder site), a group of young disabled people said they wanted to experience skiing breaks with their non-disabled peers. The Pathfinder funded a trip to the French Alps and twelve young people took part and all needed specialist equipment and support to take part. "All had had a brilliant time, had made new friends, had laughed till they cried, and had achieved more than any of us had ever dreamed of." More trips are planned.

94. The increase in take up of Direct Payments is reported to have given young people more choice, in terms of service options, and therefore there is a real individual decision making process for them to be part of. However, progress is still limited. (See also paragraphs 110 – 113)

Emerging Theory B. Sustainability and a Lasting Legacy.

95. **Having a range of mechanisms to engage, challenge and support mainstream services is raising the profile of the needs of disabled young people and their families, and creating a culture of**

‘everybody’s business’ that has the potential to achieve long-lasting inclusion.

96. We have found some evidence that where a Pathfinder has a clear and strategic vision for the development of short breaks provision that is communicated effectively, and championed at a senior level by someone with ‘clout’ and credibility, this is beginning to influence the development of mainstream children’s services. In particular, where partnership working with mainstream services (as described in Theory 2) has been a prime organisational focus, this is leading to the creation of a future culture that will help to ensure the inclusion of young disabled people in community life and opportunities.
97. There are a number of components that appear to be important within this development, including:
- investment in the ‘up-skilling’ and support of mainstream practitioners as part of a coherent workforce development strategy. The outcome is starting to be an evolving confidence and capability (as evidenced by families amongst others) that if retained within the service should have long term benefits.
 - The development of a strong parent ‘voice’ that, amongst other things, acts as a link between parents and political decision makers.
 - The evidencing of outcomes for both individuals and services is a major challenge but appears to be essential in demonstrating the effectiveness of the inclusive achievements of the Pathfinder programme and securing the future shift in services.

Parents described their direct involvement in the redesign of elements of a sports and leisure complex in the (Pathfinder site) that has redeveloped the site in a way that enables long term access for disabled children. This involved working with Play England and leisure services in the City.

Providers in (Pathfinder site) who were new to disabled children's provision talked about the extremely positive impact that Aiming High has had on their staff motivation and morale and how these staff had relished the challenge of learning new skills and different ways of working. This seems to be of critical importance for the future of both specialist groups based at such youth centres and also the potential inclusion of disabled young people in the mainstream activities they offer.

In (Pathfinder site) there is clear evidence of the building up of a "critical mass" of people and resources who are focused on challenging and supporting mainstream services – a large Pathfinder team (10 / 11 in total), a dynamic parent group, an active young people's peer support group and vibrant voluntary sector.

In (Pathfinder site) it was widely reported that the Play Service is much more engaged with working with Disability services and there has been a tangible shift in staff attitude. In particular, the Play Service always used to ask for extra resources to support children but they now see disabled children as children first who deserve access to play.

'Yes there have been changes and will have longer term impact.....huge injection of money, more people employed, spreading the word, more publicity, children more visible...parental expectations will drive changes –cannot just take it away' (parent)

'It is definitely happening - I feel there is much more awareness amongst providers of the needs of disabled children, but this has come from a very low base'. (Social Worker)

' I chair the local multi agency meetings for pre school children and two and a half years ago pre school services used to say they didn't feel they could meet his/her needs –we hear that much less often now.'
(Social Worker)

In (Pathfinder site) a key strand of the Short Breaks development plan includes a co-ordinated workforce development strategy that is supported at a senior level and integrates with mainstream services. The establishment of the workforce development working group and funding of a post (from SB money) to drive this forward is seen as crucial to long term sustainability and change. Outcomes so far have included the auditing of staff needs across 3 services (play work, youth service and leisure services) including senior managers. Training and workforce support has concentrated initially on those services directly involved in the provision of short term breaks but plans are developing to widen this out to support a culture where the needs and interests of disabled children and their families are seen as 'everybody's business.

In (Pathfinder site) recent restructuring across the local authority places the aspirations of Short Breaks and Aiming High within the new locality model. Newly created posts (Operational Directors) will have specific responsibility for disabled children and their families (this has been lacking) and will be required to channel information around the specific needs directly to senior managers. The aim is to integrate and sustain the short breaks initiative.

98. It should be emphasised that the evidence to support this theory is (i) quite embryonic, (ii) relies significantly on statements of belief from local people that this change is happening, and (iii) is projecting forward i.e. asserting that things will be different in the future. It is therefore more difficult to evidence. However, almost without exception, every Pathfinder site was adamant that this would be a consequence of the work they are currently doing. We can certainly evidence from a number of places that there have been shifts in skills and attitudes from mainstream, universal services that are opening up new opportunities for disabled children. Whether those things will be sustained over time in the face of difficult public finance decisions, changes in personnel who have been open to new ways of working and shifting political priorities if Short Breaks ceases to be a national and local political priority is far more difficult to be certain about.

Section Four
Other Specific Questions From the Brief

99. The information and evidence from Section Three address many of the specific questions contained within the brief for the evaluation. There are a number of issues that are not explicitly covered by the identified theories, and the following section provides additional commentary and evidence to cover those other factors.

Approaches used in assessing population needs for short breaks

100. Colleagues from Lancaster University have, as described in the tender proposal, used the DfE Autumn 2008 and Autumn 2009 School Census data to estimate the number of disabled children in each of the 21 Pathfinder areas by gender, age, ethnicity, type of impairment (SEN category) and area deprivation. From this, estimates have been derived of the proportion of children in each SEN category and broad age group who would be likely to be deemed eligible for receipt of short breaks – from which have been derived estimates of local need (the number of ‘eligible’ disabled children in each of the Pathfinder areas). This information is contained in a separate report being submitted from the research team. One key point to comment upon is that (as noted in the other report) most Pathfinder sites found it extremely difficult to provide estimates of local population by differing categories or definitions. However, many of the local Pathfinder leads we have been dealing with insisted they had undertaken significant local population analysis and were using this to help plan developments.
101. In exploring this apparent difference, it became clear that most Pathfinders had undertaken some form of population analysis – sometimes pre-dating the Short Breaks initiative. However, these varied significantly in approach and in most cases were at least partly historical i.e. data had been collected at a point in time but resources were not being applied to retain it in an updated manner. This is not necessarily a problem if the data was comprehensive to start with and its application done rigorously. Many Pathfinders described or reported

local systems that struggled with problems such as incomplete data, voluntary completion and under-resourced collection methods that undermined the accuracy of data produced.

One of the more comprehensive approaches involved pulling data together from the following sources:

- *A well developed Register of Children and Young People with Disabilities that is cross referenced with the SEN register and used to produce an annual report with information covering (inter alia) numbers, age, ethnicity, geographical/Practice location and recorded disability.*
- *National data with anticipated norms that are then applied locally to identify potential discrepancies*
- *Data from the 2001 census*
- *Numbers of people under 18 claiming DLA;*

This information was then used to inform a range of local strategies including the Strategy for Disabled Children and associated marketing and Development Plan.

Another Pathfinder had analysed numbers of children with severe disability (but not by separate groups) back in 2004, updated that with a snap shot database 2005 and since then been seeking to improve data by cross referencing with SEN and social care data. Children are defined by diagnosis not need. Whilst this information is used for commissioning purposes, in practice more emphasis is placed on feedback from team managers' assessments and consultation than on population statistics.

Target Groups in the Full Service Offer

102. The brief asked how approaches are increasing access to short breaks for the five target groups set out in the Full Service Offer .The Full Service Offer described in the Government's Short Breaks Implementation Guidance identified five 'groups' of children and young

people for whom additional attention should be given to ensure that they were not disadvantaged in accessing short breaks. These groups were:

- Children and young people on the autistic spectrum
- Children and young people with complex health needs
- Children and young people over age 11 with moving and handling needs
- Children and young people where behaviour that challenges is associated with additional impairments. (e.g. severe learning disability)
- Young people 14+

Whilst there is clearly an awareness about the expectation to focus upon these five groups, there is limited evidence either that (i) they are part of formal planning at a local level and/or that (ii) data exists on which basis sites can judge whether or not provision has genuinely increased to people described within these five groups. The problem we identified is essentially two-fold.

103. There was a lack of understanding and/or acceptance of the five categories as descriptors and the purpose behind the categorisation. In part this arose because of a valid concern that many young people would fit into more than one category of group – thus creating a coding problem. More significantly it arose from varying understandings and interpretations at a local level about how this categorisation was to be used – compounded by an understanding by most Pathfinder sites that the five were subsequently conflated into two categories covering (i) autism and challenging behaviour and (ii) complex needs as the LAIMP reporting system used these two broader groupings.
104. Most sites are clear that they are focusing, in part, on expanding provision for people described by the original five target groups, but this then became something ‘softer’ than specific plans and measurable

outcomes across all five. For example one Pathfinder initially created separate Planning Groups around each of the five categories but then, after recommendations were produced, disbanded them in order to avoid criticisms about favouritism towards specific populations and/or providers. Many Pathfinders could identify initiatives targeted at one or more groups – but generally this had arisen from local consultations that had identified a specific need rather than a policy/delivery drive driven by national requirements about the five groups.

105. Perhaps more importantly, the requirement to report into national data collection processes across these groups was rarely seen as a requirement that required accurate analysis. This reporting was seen as something that could not be done with any great accuracy (in part because of the problem of overlapping numbers) and approaches varied from trying to categorise people appropriately, through paying minimal attention to accuracy of data through to one authority coding **all** children and young people as meeting one of the five criteria. In addition, the data describes variations over time that, in our opinion, is at least partially explained by improved data collection rather than changes in levels of provision. Thus the idea of data collection aimed at evidencing increased service provision to the identified priority groups has failed to be achieved and the data cannot be relied upon to present an accurate picture. Without a separate data collection exercise that was beyond the scope of this evaluation, it is not possible to shed further light on the extent to which the Pathfinder initiative has increased provision for these identified definitions of young people and thus answer the question in the brief about how different approaches taken by Pathfinders have impacted upon this.

Local Area Models

106. The brief asked what patterns of provision (local area models) Pathfinders are using to extend short break provision. The concept of a local area model for provision is, in many ways, contradictory to the approaches being taken by the Pathfinder sites and indeed the general

direction of travel of public services. There is an emerging *commissioning* model as outlined earlier in this report which effectively takes many of the principles of personalisation and social inclusion – out of which a potential plethora of approaches to provision are emerging - alongside a major focus on increasing total numbers through introducing an ‘easy access’ route as described in paragraphs 75-76. Equally, in a number of places there is a model of *entitlement* being developed which creates a framework against which people can expect to receive funding for services, but this is clearly different to a local area model of provision – which we understand as being a ‘template’ of desirable services and support that (i) people can then choose against and/or (ii) forms a strategic commissioning framework towards which local resources are committed. Certainly some Pathfinder sites can describe a pattern of service provision, but when pressed, that is essentially driven by history rather than a pattern that has emerged as a result of the Pathfinder work to the extent that it can now be described as the desired (and replicable) local model.

107. This point is more than semantics. The interest in a local area model as we understand it is a question about whether it is possible to, within broad parameters, describe the range of quantity of short breaks services that would be expected within any authority area – which in turn would help provide frameworks for (i) national policy statements (ii) local commissioning intent and (iii) regulation and inspection. The evidence from this evaluation is that this is not emerging – for four inter-connected reasons:
- The model that is developing is based upon strategies for commissioning and personalisation rather than provision. This is wholly appropriate given national policy.
 - Families and young disabled people not only have a wide-ranging set of wishes and needs that will result in different ‘models’ of provision, but the extent to which families and young people have been genuinely involved in coproduction and then been empowered to use the available resources in different ways will result in significantly different provision existing. For example, we have commented earlier upon how different interpretations of

responsibility under the DDA has resulted in quite different service provision through short breaks funding. Similarly, the differing levels of parental understanding of what is available under short breaks, emerging at least in part from the information provided by Authorities, is resulting in different types of provision being demanded and available. Thus, unless and until there is a consistent commissioning and personalisation approach across the country that is fully operational, these variations will continue to exist

- Following this, it may be that, in the future, once families and young people are more fully empowered and commissioning has ‘bedded down’, we will begin to see significant similarities in provision across authorities – but the evidence is that we are still some way from this.
- Finally, the point has been made earlier that as families and young people increasingly choose inclusive short breaks, it becomes more difficult to both describe and identify what those are. Seeking to articulate the range of options that should be available locally as ‘disability short break provision’ in order to monitor and review, rather than seeing them as natural community activities that some disabled people engage with, risks formalising and thus negating much of the benefit that might arise from genuine mainstream integration.

Tailored and Flexible Services

108. The brief asked for evidence that the increase in resources is leading to provision becoming more tailored and flexible, so as to better meet the specific needs of individual children and families, including these from minority ethnic groups. The question of how and whether provision is becoming more tailored and flexible has been addressed throughout Section Three, as has the limited evidence of specific action around cultural diversity. The specific question about whether the increase in resources is leading to this is perhaps more complex. The data from

the evaluation points towards four inter-connected factors to inform this question (the outline evidence of which is included in Section Three):

- There is evidence that the availability of additional resources has enabled provision to become more flexible and tailored in that front line staff were able to offer additional resources, not previously available, to families as part of a conversation or 'offer' through which the families (working with professionals and providers) could identify and choose service options that were specific to their needs
- Similarly, there is evidence that the availability of additional resources facilitated the opening up of mainstream resources to disabled children, thus assisting more tailored services, in ways that would not have happened with the additional resources (e.g. matched funding, disability access works)
- Specifically it was the degree of knowledge and certainty that these resources were in some way protected or ringfenced, linked to the requirement to be nationally accountable for the work (See Paragraphs 85-88) that gave the confidence and ability to use the resources to generate additional more person centred provision
- However, these additional resources on their own would not have led to more flexible and tailored provision without them being accompanied by the new ways of working connected with personalisation and family/young person empowerment that were also part of the Pathfinder initiative. i.e. it was the combination of additional resources and new working practices/culture that resulted in more tailored and individualised options becoming available.

109. As previously noted (see para 81) there was only limited evidence of successful initiatives to address issues of flexibility to recognise the differing needs and wishes of families and young people from minority ethnic communities. Many Pathfinder sites had acknowledged this issue, and some had instigated specific actions to expand the range of options, but in general it is too early to state whether these have had

the desired impact.

In (Pathfinder site) a voluntary sector led Parent Participation Service have invested in publicity materials for carers events in a number of languages and formats and supported people to take part in workshops and events via the use of interpreters. One such conference was very successful in securing the involvement of parents from the Asian community. The same initiative has also made links with local groups such as a support group for Asian Mothers of children with disabilities and medical conditions.

The same Pathfinder has commissioned local Universities to undertake a scoping exercise in respect of the leisure needs of people with disabilities from the South Asian and other BME communities. This builds on earlier research which put forward recommendations about making leisure services more accessible to disabled people from BME communities and will involve disabled young people themselves as co-researchers. The project is essentially aiming to be “action research” in that it aims to improve access as the work progresses.

(Pathfinder) has commissioned a local youth group to undertake an outreach and consultation programme aimed at exploring the needs and aspirations of the BME community with regard to short breaks. This group has much experience in respect of provision for young Asian people in the area. The outreach work and consultation has just finished so findings are not yet known.

Direct Payments

110. The brief asked about the extent to which Pathfinders are promoting direct payments in lieu of short break provision, and what support is offered to parents to enable them to effectively secure the short break provision they need. Across Pathfinder sites, there is an increase in the use of direct payments as a mechanism for families and young people to access short breaks, as confirmed by the LAIMP data – but the

extent of this and the approaches being taken vary significantly across the country.

111. There appears to be clear evidence of an expansion of direct payments as a tool for change and empowerment. Some of the more innovative short breaks that families spoke positively about had been accessed through direct payments where direct payments are seen as an inherent part of the strategy and actively promoted and supported. Where it works families describe being very satisfied and in control and use the resources flexibly. There is also some evidence that it has also attracted service users who otherwise wouldn't have sought help because of the stigma of receiving social services.

'Every time he comes I take photos and we stick them in a book and write about what he has done –apparently he takes it to bed with him when he goes home- we are now on the 3rd book! I also take him on tube trains, out to restaurants, day trips to sea side etc. My husband and older boys take him fishing and provide valuable role models as he comes from an all female family. We all love having him here.' (PA)

One family uses Direct Payments flexibly – saving up hours to get whole 8 hour days- activities include 1:1 swimming lessons in a normal Sunday morning swimming session; weekly riding lessons; occasional play schemes in holidays, trampolining and athletics - plus babysitting for one night out per month.

'I would like her to be in our life forever' (parent about PA) 'He is the most amazing little boy and we have such fun and have met great people. I am training to be an OT so it also helps with my professional development' (PA)

A family use the direct payment to go shopping, buy clothes, watch buses, often use to pick up from activities e.g. youth club, pick him up en route to scouts and brings back – creates an extra hour 'makes a huge difference –can sit and chill with the other two'

'I often go on family outings to be an extra pair of hands, either going on rides with (young person) or looking after all the equipment so they can go together as a family. I have also been to Bullins for the weekend so I can babysit in the evenings and will also take (young person) swimming (as mum won't). I am less likely to wrap him in cotton wool and we have a real sense of adventure when we go out. It all also gives mum the chance to spend time with her other two children. It's really fun and so rewarding to be giving him opportunities he wouldn't otherwise get.' (PA)

One family had 1 day per week in the holiday for two siblings. It was complicated to arrange right play schemes so they swapped to direct payments - they attend pottery classes, tennis, tennis competitions, play schemes etc. In holidays this is sometimes used to give the mother time separately with each child. 'Just fantastic they love having mummy time'

In (Pathfinder) direct payments (linked to individual budget pilots) are explored as a possible option with all families and social workers appeared to be fully aware of and supportive to this. If families opt for this, an allocated support worker works with them to explore how to use the money and what they could have through it – with an emphasis on raising expectations (source both families and social workers)

'I wanted to be the same as everyone else and not feel any stigma, as a middle class parent it was a huge mental leap to ask for anything'
(Parent now accessing support through a direct payment)

112. There were also examples from the data collection of dissatisfied parents and limited access to direct payments where a direct payment could easily have had the effect of helping to deliver the required changes.
113. The reasons for the variations in use of direct payment appeared to be no different to those regularly reported in articles and reviews about direct payments, namely:

- A divergence between senior officers' enthusiasm for direct payments, and caution - if not obstruction - from many front line staff.
- A significant proportion of the parents we met being unaware of direct payments, despite local authority descriptions of promotion campaigns. Some information provided to families about direct payments was not in line with policy and legislation.
- A lack of clarity about effective support structures for families to access.
- Some people accepting direct payments because they felt they had little option – even though they did not really want them.

A family was unhappy with after school service provided by main provider (because of mix of ages and son being injured by an older boy) so they withdrew and asked for the hours to be switched to a direct payment. This was resisted and the family told 'if you are withdrawing from a service it is your choice to withdraw and you have lost entitlement'. The direct payment was eventually obtained.

In (Pathfinder) frontline social workers are the prime support mechanism for direct payments. The evidence was that direct payments were offered as an option only if a particular identified service is not available or has a waiting list

In (Pathfinder) the main focus of support with direct payments is around financial/employment arrangements. No help is available with sourcing and exploring alternative service options (i.e. brokerage)

"I wanted to explore the option of a direct payment but was told we are not eligible because we don't have a social worker" (parent who was trying to operate without using social work input from choice)

'I felt like I had to show I'd co-operated before I could be considered for more. A direct payment was the first rung of the ladder. I didn't really want it but it was all that was offered. I had to go through all that bureaucracy (payslips, NI etc) for 3 hours per week- the Teaching

Assistant we had already worked for the LA, why couldn't they just pay her? (Parent)

'It took one year from asking about a direct payment to getting the payment, nine months to do a CRB check (because of an overworked social worker). I had already asked a worker from (child's) school would she be involved. Luckily she was prepared to wait' (Parent)

"I was told 'it just gets too complicated-don't go there' by a senior manager (parent)

'I felt the process very onerous at the outset –especially finding and vetting someone to care my son, the responsibility with all paperwork. I kept putting it off then member of staff said they knew someone who would like to look after him – thank god for that as don't know if I would ever have found anybody.' (parent)

One Pathfinder has very different direct payment take-up levels between two parts of the area. In the one with the higher take up there is direct support from an independent organisation. In the other, social workers provide advice, give a leaflet and then parents are expected to organise their own support.

'I don't promote them (direct payments) that well because of the risks involved' (social worker)

'A direct payment was mentioned in early days by a social worker who said 'I am going to tell you about it just because I have to'. I decided was wasn't interested because (child's) physical disability makes it difficult' (Parent).

In (Pathfinder) direct payment uptake is only gradually increasing – there is no support service in place. One parent said ' it is an administrative nightmare, I have a Masters degree and still I struggle to administer it.'

Infrastructure Support

114. One other issue to emerge has been that of whether there is any correlation between the amount and nature of infrastructure support created in the Pathfinder sites, and their progress with the agenda. As the work progressed, it became clear to the evaluation team that there were some connections around the extent to which local sites were demonstrating positive progress in relation to each of the 'theories of change' and the extent to which the Pathfinder had actively invested in its infrastructure in terms of staff, managers and other resources directly concerned with achieving the goals of the Pathfinder.
115. We wish to re-iterate that this evaluation is not judging individual Pathfinder sites, but in order to quantify any relationship between infrastructure investment and pace of progress, the evaluation team used a simple 1-3 rating of the extent to which each Pathfinder was demonstrably achieving progress against the aims of the Short Breaks guidance and the 'theories' described in this report. We then compared this against the amount each Pathfinder had chosen to invest in its Pathfinder infrastructure. This showed some clear connections in that those sites that were best able to demonstrate progress were those that had also invested most in their infrastructure whilst those that appeared to be struggling most were generally (but not always) those who had invested least in their infrastructure and/or had delayed such investment until a year or more into the work. This **does not** mean that investment infrastructure on its own is an indicator of progress. Some Pathfinders that had invested more in infrastructure appear to be making more limited progress. However, it does seem fairly clear that without sufficient investment in infrastructure, progress will be limited.
116. We wish to emphasise that this is a somewhat crude analysis. Not only will there be several other factors beyond infrastructure investment that have influenced progress (as described above in this report) and indeed Pathfinders have invested in their infrastructure in different ways that we have not sought to differentiate between. However, the connection was so clear to the evaluation team that in our view it merits

comment – particularly when it is considered that (i) in the current financial climate investment in management and administration roles is coming increasingly under scrutiny and (ii) a number of Pathfinder sites informed us they had been advised either not to invest significantly in infrastructure and/or describe that investment in other ways in order not to attract criticism for doing so.

Section Five

Discussion and Conclusions

117. From all this evidence and analysis, there are a number of important points and conclusions to emerge that we believe merit particular comment. The framework of **context**, **mechanisms** and **outcomes** used to underpin the evaluation's analysis is particularly important in this context and so that approach will be used to describe the main conclusions in this section. The points made will be as brief as possible as the evidence in support of them is contained in the preceding sections.

Coproduction

118. There is clear evidence from the evaluation that better **outcomes** are achieved in terms of short breaks that meet family wishes, are more inclusive and meet the widely varying need and wishes of children and young people if there is significant investment in **mechanisms** that involve families at all levels of commissioning and provision. The delivery of clear, timely and relevant information (through a range of routes) is a central part of this. These mechanisms need to reflect the variety and diversity of family wishes and experiences and not rely upon a single standardised approach. They are also often more effective if focused on specific issues or processes whereby families can see and experience discernable outcomes arising from them giving up their time. This includes recognition that many families will not wish to engage in detailed activity beyond the question of their own family member's service and thus these mechanisms need to be designed around their preferred ways of operating. This work is assisted by there being a **context** of a history of family engagement (it cannot just be invented overnight), with officer level leadership demonstrating strong commitment to working with families as full partners.
119. There are a number of clear implications of this analysis, including the need to (i) sustain financial investment in family involvement including the development of a robust, independent family 'voice', (ii) recruit leadership and front line staff who genuinely believe in and are committed to family empowerment (iii) recognise the time it takes for strong family voices to

emerge and develop complementary approaches to support the family voice as this position is reached (iv) invest in person centred communication with the large body of families who will choose not to engage in formal participation mechanisms.

120. There is some evidence to support similar conclusions around co-production with children and young people, though this evidence is less clear. Nonetheless, similar points can be made about **outcomes, mechanisms and contexts**, and the resultant priorities for national and local delivery.

The Pattern and Style of Short Break Provision

121. Our colleagues from Lancaster University are undertaking the research that will specifically comment upon the quality and quantity of change in short break provision arising from this policy initiative. Our role has been to look at what it was about the way in which the Pathfinders went about their task (along with the associated national frameworks) that resulted in the different outcomes. However, we would observe that the evidence of our evaluation is such that we will be surprised if the Lancaster report does not conclude that the Pathfinder initiative resulted in improvements in both the quality and quantity of short break provision. There is clear evidence from our evaluation that many children, young people and families are experiencing better **outcomes** in terms of the range of short breaks available and their enjoyment and experience of them – though this does not appear to be either uniform across sites nor (generally) within them. One **mechanism** used by central government to help achieve this, namely allowing a wide interpretation of the definition of a short break, has been a double-edged sword. Where operating in the **context** of strong coproduction, innovative local leadership and a willingness to be flexible with the rules, this has resulted in an increasing range of short break provision that is positively received. Where these contexts are less evident, outcomes appear less positive, in particular with families not being aware that they could expect different and more person/family centred short break options.
122. The implication of this for government is that whilst allowing flexibility of interpretation of a policy is generally helpful (perhaps particularly in the early

stages of its life when delivery is predominantly being led by people strongly committed to improving outcomes), mechanisms will need to be developed for ensuring all local areas demonstrate the creativity shown by the best. It is beyond our brief to propose what those might be.

123. There are differing experiences, views and evidence in relation to the extent to which the quality of **outcomes** from short breaks is directly related to the extent to which they are inclusive with mainstream services and resources. There appears to be clear connection with the **context** within which inclusion is being progressed. In the small number of places where greatest progress towards full inclusion has been made, the clear evidence of positive outcomes is underpinned by a whole service system commitment towards mainstream inclusion. Officer leadership that believes in and is committed to such a strategy, strongly supportive family engagement, workforce development and a focus on collecting and using evidence of outcomes to encourage further inclusion are all important components. This enables the development of **mechanisms** that are person centred and work in partnership with mainstream resources. The absence of one or more of these factors appears to lead to delivery mechanisms, highly valued by families, based on partially segregated activities taking place in mainly mainstream settings.
124. The underpinning message here, both for national policy makers and local delivery agents, is that of inclusion as a continuing journey and the need to ensure key building blocks are in place – without which inclusive practice risks being delivered in a half-baked manner and thus being discredited. Inclusion is what most families and young people who experience it say that they want, and in addition to the benefits identified in this report and elsewhere for families and mainstream services, the one authority from the pathfinders that has made most progress on inclusion is also developing early evidence of its cost-effectiveness.
125. There appears to be clear evidence that where direct payments have been well developed as a **mechanism** for children and young people to access short breaks, they are resulting in **outcomes** for them and their families that are more inclusive and meet their wishes and aspirations to a greater extent.

However, this is only where the **context** in which they are being implemented is one where there is widespread commitment from front line staff as well as senior managers to the direct payment concept and, crucially, there is investment in supporting families to navigate their way through the process and use their direct payment effectively, usually through independent support services. Without these things, families tend to experience direct payments as an unwanted burden.

Flexibility Around Policy and Process

126. Some of the more positively viewed **outcomes** (as defined by the full range of stakeholders) have evolved when organisations have not allowed the formal organisational **mechanisms** to overly determine what services they develop and how they develop them. This is particularly the case in relation to commissioning. Those authorities operating in the **context** of rigid and very structured commissioning systems were less able to achieve the short break policy and outcomes that families and young people wanted than those authorities that were able and willing to be more flexible and see the achievement of those short break outcomes as the key outcome (rather than following prescribed procedures). Similarly, too rigid adherence to the DDA driven policy expectation of not funding things that other sources should fund by way of DDA compliance appears to result in families not getting the short breaks they want.
127. The key context factor thus appears to be an organisational culture that sees the over-riding driver as being the achievement of the policy outcomes as (significantly) interpreted by families and young people – and ensuring service systems are malleable enough to facilitate that happening.

Policy Priority and Partnership

128. There is clear evidence that the **context** of the Short Breaks initiative having a national political profile and additional money attached to it, linked to the **mechanisms** of national reporting with a national support programme, had a significant influence in achieving the **outcome** of improved delivery of the policy imperative. In particular, the requirements to report on progress and

account for use of the money helped to (i) engage senior players in ways that generated local organisational commitment to delivery and (ii) ensure that the resources were used for the Government's intended purpose rather than be diverted elsewhere.

129. Linked to this, this **context** had a significant impact upon the partnerships which are identified as a significant requirement to effective delivery. On the positive side it created conditions for a range of mainstream stakeholders to engage with the initiative through partnership **mechanisms** that led to more inclusive **outcomes**. However, the decision by the Department of Health not to ringfence NHS allocations nor actively monitor and prioritise NHS involvement in the Pathfinders in the way that DfE had for children's social care and education, had the clear consequence of leaving some PCT's unclear about their contribution towards the programme and enabling others to withdraw either partially or almost totally. Put bluntly, that decision had the impact of partially undermining the achievement of Government policy in locations other than where individual PCT officers personally decided to give priority to the policy.
130. The implication of this, as we probably enter a period where ringfenced national funding is radically reduced and central government adopts an increasingly 'hands off' approach, is that the policy is less likely to be successfully delivered in the future. This is particularly likely given the weak evidence we found in relation to whether long term sustainability has been achieved in relation to short breaks for disabled children having become fully embedded in the culture of how mainstream children's (and other) services are operating.

Access and Equity

131. Most Pathfinders have used additional **mechanisms** such as 'quick access' routes into service that have resulted in the **outcome of more young people and families** accessing short breaks. However, there is limited evidence that this increased quantity of access could be confirmed as achieving increased equity (either in terms of level of need within Pathfinders or geographically across them) primarily because most are operating in the **context** of weak

data and information collection systems that make it difficult for them to evidence breadth and depth of coverage across their population. This particularly makes it difficult to evidence improved equity for hard to reach communities including those from minority ethnic communities where new mechanisms are generally at too early a stage to be able to evidence outcomes.

132. Similarly, most Pathfinders are still (at best) at an early stage of introducing **mechanisms** to evidence **outcomes** achieved through short breaks – operating significantly in a **context** that has not seen the production of evidence of this nature as a priority. The production of data to meet central reporting requirements of the LAIMP appears to have assumed a greater priority – arguably without the associated benefits that would have derived from a local outcomes framework being implemented.
133. The implications of this are that, if the impact of a policy initiative is to be determined on a national (and indeed local) basis, greater emphasis needs to be placed on ensuring the robust implementation of both local population-based needs analysis and, crucially, a local outcomes framework. Had the approaches developed and implemented by the (small number) of best authorities in this respect been applied across the country at an early stage, then it could, by now, have been possible to evidence the impact on access and equity across all sites.

Investment in Planning and Administration

134. There appears to be more rapid progress towards achieving the Aiming High Short Break **outcomes** in those places that have chosen to invest some of the Pathfinder resources in creating a **context** of strong management and planning infrastructure (including roles directly working with families and front line staff). This additional resource appears to have assisted in creating created a **mechanism** that assists other developments and changes taking place more effectively.
135. The implication of this is that despite pressure to reduce spend on management, planning and support roles at a time of financial difficulty, a

decision not to invest in appropriate infrastructure is likely to reduce the likelihood of achieving policy change and better outcomes for families and young people.

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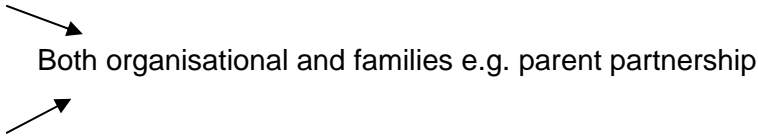
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Appendix I

Semi-Structured Interview Framework for Phase One Local Stakeholder Interviews

CONTEXTS

- What needs were you looking to address and what evidence do you have that led to that conclusion?
- How are different views and perspectives currently (or historically) obtained (incl. children's perspective + different 'groups')
- What is the current pattern of services?
- Any significant recent developments around short breaks prior to becoming a Pathfinder?
- What is the nature of organisational relationships
- Who does what 

Both organisational and families e.g. parent partnership
- Relationship quality

RATIONALE

- Why did your locality apply to be a Pathfinder – how did you think it would help – and who drove the interest?
- As a Pathfinder, why are you doing what you are doing in the way you are doing it?
- What do you define/understand as being a short break?
- What is it in people's lives that short breaks are helping to address?
- Do you have any target 'groups' e.g. minority ethnic communities, young people with complex needs, ref to five target groups?

INPUTS

- Is there an agreed strategy for being a Pathfinder and what you are going to be doing?
- If so, who developed and agreed it?

- How are you using the Pathfinder money?
- What other LA additional money is going into short breaks on top of National Pathfinder money?
- What's the PCT putting in from its additional allocation?
- What are the voluntary sector or community resources to help the programme?
- Do you have any dedicated staff allocated to the Pathfinder work?

MECHANISMS

- How are you (i) steering / managing the work (ii) taking decisions on what to do?
- How are you knowing whether it is having an impact i.e. how are you learning from the work and evaluating impact as you go along?
- What referral arrangements and eligibility criteria are being used to decide who gets short breaks?
- How are you applying and using direct payments and the developing personalisation agenda
- How are you engaging services and communities beyond traditional social services + PCT / NHS Trust?

ACTIVITIES

- What are you spending the money on?
- What will short break services look like?
- How will short breaks be organised and operated in the future and how is that different from now? i.e. what are you doing that is different in terms of what people will get or experience?

OUTPUTS

- What targets have you set for change – who set them?

- What measurable things do you want to be different? E.g. services provided, staff, training etc.

OUTCOMES

- What do you want to be different at the end of P.F. status from perspective of:
 - Children and young people
 - Families
 - Staff and providers
- How will you know whether things are different?
- Have these desired changes this already changed from what was planned at the outset of being a Pathfinder – why and how? Are new ideas emerging?

IMPACT

- Describe what you hope will be very different in 5 years time?
- How do you think being a Pathfinder will have contributed to that?

Appendix II

Semi-Structured Interview Framework for Phase Two Local Stakeholder Interviews

Overall Planning

- What has been done in terms of population based needs analysis that then informs planning decisions. How has such work been used to inform service developments?
- How are Pathfinders identifying the particular 'needs' as defined by types of disability and how linking to service development strategies in particular how are they targeting the 5 target groups?
- Are there any specific targets or actions around quantifying the increase in short breaks arising from being a Pathfinder?
- Do strategies exist for workforce development, in particular around non professional roles linked to short breaks?
- How is sustainability on non traditional short breaks ensured?

Resources

- What has each site committed over the period of time in terms of staff and infrastructure to make the Pathfinder effective.
- Have authorities gathered any data to tell them about the **cost effectiveness** of new developments?
- Have any of the PF sites done any form of financial analysis of the costs of new approaches to short term breaks vis a vis perceived (or actual) changes in outcomes.

Emerging Theories Evidence

The imprecise nature of Short Breaks: when is an activity or experience not a short break?

- Any more evidence to support or contradict?

- Actual methods being used to define and quantify?
- Any explicit evidence of links between theory and changed services/outcomes?
- Any learning and exchange between this theory and wider policy initiatives e.g. EDCM & PPF?
- Any specifics around ethnic minorities and 5 target groups?

Access & Equity

- Any more evidence to support or contradict?
- Actual methods being used? Assessment procedures – how are they affecting provision and take up? Evidence of their impact.
- Any explicit evidence of links between theory and changed services/outcomes?
- Any learning and exchange between this theory and wider policy initiatives e.g. EDCM & PPF?
- Any specifics around ethnic minorities and 5 target groups?

Inclusion & Ordinariness.

- Any more evidence to support or contradict?
- Actual methods being used to promote full inclusion?
- Any explicit evidence of links between theory and changed services/outcomes?
- Any learning and exchange between this theory and wider policy initiatives e.g. EDCM & PPF?
- Any specifics around ethnic minorities , 5 target groups and different age groups e.g. differences between teenagers and young children??

Commissioning.

- Any more evidence to support or contradict?
- Specifically follow up Direct Payments- how have they been promoted and with what success? What support is available to/ provided for, parents in managing the arrangements and how do they find out about it? Test out views of senior managers, front line staff; levels of parent awareness.
- Actual methods being used?
- Any explicit evidence of links between theory and changed services/outcomes?
- Any learning and exchange between this theory and wider policy initiatives e.g. EDCM & PPF?
- Any specifics around ethnic minorities and 5 target groups?

Partnership Working.

Utilising the NDTi partnership readiness framework:

- Any more evidence to support or contradict?
- Actual methods being used?
- Any explicit evidence of links between theory and changed services/outcomes?
- Any learning and exchange between this theory and wider policy initiatives e.g. EDCM & PPF?
- Any specifics around ethnic minorities and 5 target groups?

Parent Participation.

- Any more evidence to support or contradict?
- Any differences between different groups of parents that are involved in different ways?
- Actual methods being used?

- Any explicit evidence of links between theory and changed services/outcomes?
- Any learning and exchange between this theory and wider policy initiatives e.g. EDCM & PPF?
- Any specifics around ethnic minorities and 5 target groups?

Participation by Children & Young People.

- Any more evidence to support or contradict?
- Actual methods being used?
- What specifically ensures it is the children's voice and not the family voice being heard?
- Any explicit evidence of links between theory and changed services/outcomes?
- Any learning and exchange between this theory and wider policy initiatives e.g. EDCM & PPF?
- Any specifics around ethnic minorities and 5 target groups?

Sustainability.

- Any more evidence to support or contradict?
- What evaluation has taken place to verify claims?
- Actual methods being used?
- Any explicit evidence of links between theory and changed services/outcomes?
- Any learning and exchange between this theory and wider policy initiatives e.g. EDCM & PPF?
- Any specifics around ethnic minorities and 5 target groups?

The importance of Accountability & Resource Protection:

- Any more evidence to support or contradict?
- Actual methods being used?
- Any explicit evidence of links between theory and changed services/outcomes?
- Any learning and exchange between this theory and wider policy initiatives e.g. EDCM & PPF?
- Any specifics around ethnic minorities and 5 target groups?

Appendix III

Outline of CMO Framework from Realistic Evaluation

DATA & ANALYSIS		
ELEMENT	INFORMATION	POSSIBLE DATA
CONTEXTS	National-Regional-Local-Individual: demographic; socio-economic; policy & system; partnerships; history of work/experience	Census; various indices; local policy docs; project related materials; governance arrgts; identified aims & outcomes; local evaluations; previous studies
MECHANISMS	Resources available; how allocated; new & existing roles; new & existing services/support; ways of working; structures & systems	Data as above. Interviews with project leads/teams & focus groups with key stakeholders (find out WHY); etc
Outputs	Evidence of how resources used to achieve the above; whether the above happened or not; project & stakeholder journeys to achieve this	As above; workshops to explore theories and “results” data; mapping exercises to capture journeys; etc
OUTCOMES	Identified/agreed indicators of change (what does success look like; how have partners agreed what to measure & use to indicate change has happened?)	As above; survey data; interviews; tracked sample using interviews & small group discussions; Most Significant Change stories; case studies etc
IMPACT	Ditto but over longer time frame. Evidence of local, shared vision & broad aims?	Longitudinal studies covering the above.

Appendix IV

Logic Model Framework for Realistic Evaluation at Outset

Context(s):	Rationale:	Inputs:	Mechanisms:	Activities:	Outputs:	Short/ medium Term Outcomes:	Impact:
<p><i>i.e. why is this initiative being pursued and what is the policy context?</i></p> <p>Long history of short breaks being important – emphasis given by actions such as EDCM Parliamentary hearing and family responses to Children’s Plan consultations.</p> <p>Political (Ministerial) priority for progress on this – within DCSF</p>	<p><i>i.e. why has this initiative been established to operate in the way that it has?</i></p> <p>Belief that evidence is clear:</p> <ul style="list-style-type: none"> • Services not meeting needs • Parents needing break from caring • Children with complex needs not accessing short breaks <p>Other policy beliefs:</p> <ul style="list-style-type: none"> • Good short breaks are 	<p><i>i.e. What resources, policies etc are being brought to bear to help the initiative work</i></p> <p>AHDC sets the underpinning policy framework</p> <p>The National Core Offer and Full Service Offer provides the basis or definition of objectives</p> <p>£269M revenue over 3 years split across authorities plus PCT baseline</p>	<p><i>i.e. What mechanisms/systems are being put in place to help the initiative deliver?</i></p> <p>Implementation Guidance describes:</p> <ul style="list-style-type: none"> • Joint delivery (LA/PCT) with senior level support • A strategic approach to promote access to universal services • Young people and families centrally involved • Local change management capacity 	<p><i>i.e. What actions and activities are intended that will help ensure the initiative delivers?</i></p> <p>Primarily locally determined actions with some specific expectations linked to the NCO:</p> <ul style="list-style-type: none"> • Parental and young person’s involvement (co-production) • Information and advice • Changed assessment systems <p>TDC delivered</p>	<p><i>i.e. what specific outputs are expected e.g. products, indicators, different patterns of service delivery and utilisation?</i></p> <p>A substantial increase in quantity of short breaks provided</p> <p>A wider range of types and styles of short breaks</p> <p>Particular increased use and access by children in five priority groups felt to have missed out in</p>	<p><i>i.e. What changed practice, experiences, observable changed behaviour will arise for and in individuals and organisations</i></p> <p>A ‘step change’ in capacity, range and quality of short breaks available</p>	<p><i>i.e. what long term changed circumstances, experiences and culture will result (in part) from the initiative – recognising the influence of other initiatives being delivered in parallel</i></p> <p>Improved life chances for vulnerable/disabled young people</p> <p>Enable parents to continue caring and improved family wellbeing</p>

<p>Additional financial resources available through CSR</p> <p>Relevant lobby groups well connected and pressing for progress - thus retained policy priority</p> <p>Synergy with personalisation agenda, Life Chances and social inclusion agendas encouraged delivery.</p>	<p>preventative</p> <ul style="list-style-type: none"> • LA/PCT partnership is key • Diverse supply base is best <p>Therefore need is for:</p> <ul style="list-style-type: none"> • More breaks • Of different types • At times and in ways that suit people <p>Desire to support LA's to protect and prioritise spend and action on short breaks in favour of other priorities – hence Pathfinder concept and phasing of extra</p>	<p>growth</p> <p>£90M capital funding – not to be used to substitute for DDA compliance</p> <p>£5M in linked initiative to promote parental engagement</p> <p>Intention to provide statutory guidance</p> <p>Implementation guidance provided</p>	<ul style="list-style-type: none"> • Local workforce strategies <p>Pathfinders selected to lead early implementation – based on assessment of chance of succeeding – and systems for others to learn from them</p> <p>Data collection to evidence progress collected through systems such as the LAIMP</p> <p>'Readiness Criteria' to determine whether other sites were ready to receive resources</p> <p>Dedicated performance management systems linked to LAIMP</p>	<p>networks for learning, dissemination, best practice sharing and also provided hands on support/advice</p> <p>Commissioning development advice/support delivered through DH mechanisms</p>	<p>the past</p> <p>Increased use of universal services by disabled children</p> <p>Doubling of national spend on short breaks</p> <p>New service/support options defined by families and young people themselves</p> <p>New planning systems that involve families and young people</p>	<p>An end of some 'categories' on children/young people not getting short breaks</p> <p>Families will be able to continue to care for their children</p>	<p>Increased acceptance, on an equal basis, of young disabled people into mainstream and universal service and community opportunities</p>
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	<p>money</p> <p>Given above point, TDC function needed to provide (i) monitoring of use of extra money and (ii) support to achieve change and use resources effectively.</p>		<p>An explicit focus on groups of children/young people felt to be missing out at present</p> <p>Expectation of a rigorous local process to identify individual needs and requirements – linked to the JSNA – and new, clear, eligibility/access criteria</p>				
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Appendix V

Partnership Commentary

This appendix comments in more detail on the evaluation's findings in relation to partnership working. There is a clear evidence base about the components of effective partnership working, with particular reference to the health and social care field. This has been developed through research and evaluation over the last fifteen years or more. The particular framework being used for this evaluation is that of the Partnership Readiness Framework⁴, developed about ten years ago and subsequently used to inform a number of such partnership reviews.

The aim of this appendix is to summarise the evidence from the evaluation in relation to the key ingredients of partnership working and thus draw out the lessons for future partnerships concerned with short breaks. It does not pose the question of whether partnership working is, in itself, a desirable activity. That is taken as read given (i) the policy expectations have partnership at their core, and (ii) the breadth of stakeholders that are required if the short breaks policy is to be delivered (from different statutory authorities, through a range of providers to young people and families) are such that the need for them to work together is self-explanatory. Rather the purpose of this appendix is to consider whether the way in which the Short Breaks Pathfinders were being delivered in local areas was conducive to those essential, effective partnerships being developed.

1. **Building and agreeing a shared vision, values and principles** with a shared picture of how life should be for people who use services.

There was clear evidence in many Pathfinder sites of a clear and shared vision, underpinned by values and principles, driving the work of the Pathfinder. However, the picture is mixed and, as noted in the main body of the report, this vision was not always shared by everyone in a locality – be that the PCT, mainstream providers or, in some cases, significant family players. Those Pathfinders that were demonstrating the most cogent

⁴ Greig R and Poxton R. Partnership Readiness Framework. IAHSF: King's College. 2001

strategies for change were generally those where there had been investment in getting broad sign-up to a principle across most partners. (However, it is also notable that in one or two Pathfinders, significant progress was still being made despite one or two key partners not being fully 'signed up').

Criteria largely met in most Pathfinders

2. **Agreeing specific policy direction / shifts** that the partnership arrangements are designed to achieve

It is important here to be clear about what the key policy shifts might be. The emphasis of the Pathfinder initiative across most sites has significantly been that of a policy shift in favour of listening to the voice of families and young people and creating systems that opened up the provision of short breaks to more families. Whilst there was a desire to change the type and range of short breaks, the nature of that change was significantly dependent upon the views of families and young people (including how they used their direct payments) rather than being pre-determined (in most cases) by Council officers.

This shift in power must thus be seen, in many ways, as a fundamental outcome from the Pathfinder initiative and it is true to say that, in most Pathfinders, this was understood and signed up to by key stakeholders from the outset.

Criteria largely met in most Pathfinders

3. **Being prepared to explore new service/support options** and not being overly tied to existing services or providers.

The picture here is more varied. In some places, there was a willingness for significant change and this helped to create a positive spirit of partnership with a range of (for example) providers both old and new. Elsewhere, there remained a significant degree of commitment to existing providers – albeit with an expectation of some service change. Similarly, many (if not most) Pathfinders were open to new ideas (from families and young people in particular) about types of short breaks and this helped to bring new players

into the partnership. Others, however, were less imaginative as noted in the main report.

Criteria significantly met in many Pathfinders

4. **Being clear about boundaries** - the aspects of service and activity are inside the boundaries of the partnership arrangements, so that there is a focus on the real added value of joint working

This issue was fairly clear and simple given the defined nature of the Pathfinder initiative – with the caveat noted in the main report about the NHS contribution to short breaks.

Criteria significantly met across sites

5. **Clear links between commissioning and delivery** - being clear about roles, responsibilities and relationships between commissioning, purchasing and providing in order to derive a coherency that uses all appropriate expertise; and ensures that any tension in the system is creative.

The main body of the report comments on how creative commissioning, that saw providers as partners, was an important component in creating an effective partnership culture that supported the change agenda. Where this worked well, the partnership was widely described as productive and helpful and could be seen as a model for other authorities to emulate.

Criteria Significantly met in many sites, but not in others.

- 6 **Identifying agreed resource pools**, including pooled budgets, and agreeing to put to one side unresolved historical disagreements about financial responsibility

Generally speaking, the more structural elements of partnership working such as pooled budgets and lead commissioning have not been implemented within the Partnership sites. Instead, the emphasis has been on bringing partners together in more informal partnership, underpinned by meeting structures as appropriate. Each partner has then been encouraged to bring

their resources to the table in a spirit of partnership. The main report comments upon two particular issues in relation to this element, namely (i) the failure of many PCTs to contribute the financial resources that were expected by their local authority partners and implied through the additional resources allocated centrally to the NHS; (ii) how, in some Pathfinders, other partners such as mainstream children's services were willing to add their resources to the initiative.

Identifying and agreeing joint resource pools was not seen as a precursor to partnership working in most Pathfinders and this does not seem to have been a hindrance - other than in relation to some local authority/NHS partnership where clarity and agreement at the outset could have assisted the partnership. Conversely, the reliance upon informal agreements about resources with other partners once people had signed up to a shared vision appears to have helped those localities where progress has been made.

Criteria not explicitly met at the outset but evolved over time in most sites

7. Ensuring effective leadership, including political, strategic, service and community level commitment to the partnership agenda

This was undoubtedly a key element in progress at a local level. The main report comments upon this in a number of places. It was notable that those Pathfinders where the stakeholders we interviewed were able to describe positive progress were also those where interviewees were positive and complimentary about the leadership being provided both within their own organisation and by partners in the Pathfinder. Crucially, it was this cross-organisational leadership that was most notable – at its best involving local authority officers, NHS officers and clinicians, families, providers and other community agencies.

Criteria significantly met in many sites

8. Providing sufficient dedicated partnership development capacity rather than it being a small and marginalised part of everyone's role

Whilst capacity dedicated explicitly to partnership working was not really the issue in relation to the Pathfinder sites, we have commented in paragraphs 114-116 about how investment in planning and management capacity for the Pathfinder Initiative appears to have been an important factor. As partnership is an implicit part of the Pathfinder programme, then this, de facto, creates a capacity for Partnership working. Those Pathfinders who had invested least in this way appeared to have the least well-developed partnerships.

Criteria variably met across the Pathfinder sites

- 9. **Developing and sustaining good personal relationships**, creating opportunities and incentives for key players to nurture those relationships;
- 10. **...in order to promote mutual trust** and 'team' attitudes

Subject to the caveats noted elsewhere in the report, the Pathfinder initiative, across almost all sites, did succeed in creating a 'team spirit' in the progression of this policy initiative. At its best, this encompassed a wide and diverse range of partners who were seen as crucial and equal partners – families, young people themselves, specialist providers and mainstream providers and commissioners.

Criteria largely met across most sites.

In summary, the conditions for effective partnership working were quite well developed across most of the Pathfinder sites – significantly supported by the policy and delivery framework the sites were working to. To the extent that these factors were less evident then, with the exception of the issue about clarity of NHS role and financial contribution, our conclusion is that there was little more that could or should have been done nationally to improve the partnership 'conditions'. The greater strengthening of partnership working at a local level would, in almost all cases, be achieved through local sites paying further attention to the issues identified in the 'theories of change' described in this report e.g. a flexible approach to commissioning that engaged providers as partners, strong parental participation, etc.

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