Evaluation of the Special Educational Needs and Disability (SEND) Pathfinder Programme

Impact Research report: Qualitative research with families (second cohort)

Research report

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Executive summary

This report presents the findings from stage two of the evaluation of the Special Educational Needs and Disability (SEN and Disability) Pathfinder Programme commissioned by the Department for Education in September 2011.

The report is based on qualitative research conducted with 31 families between January 2014 and early March 2014 who participated in the new Education, Health and Care (EHC) planning pathway and as a result, received an EHC plan.

The qualitative research was undertaken by OPM (Office for Public Management) which was commissioned as part of a consortium of organisations led by SQW and including Ipsos MORI and BPSR (Bryson Purdon Social Research). This forms part of the impact evaluation work and therefore seeks to complement and provide further depth to the parent carer survey that is being undertaken with pathfinder and comparator families

The evaluation was commissioned in two stages to mirror the phases of the evolving programme:

- **Stage one** – **evaluated the first 18 months of the programme** and focused on understanding the approaches adopted to deliver the new processes and the experiences and outcomes of the initial cohort of participating families. A series of reports detailing the findings from this stage of the evaluation are available on the government publications website[1].
- **Stage two** – **evaluating the second 18 months of the programme** (April 2013 – September 2014) built on the findings from the initial evaluation to understand the progress made by pathfinders as they roll out the new processes, and the experiences and outcomes of the second cohort of participating families.

Methodology

The families in the stage two sample were drawn from seven pathfinder areas, which began implementing the pathfinder in September 2011. The children and young people in the sample had a wide range of additional support needs varying in severity and complexity. Many had multiple conditions. The gender split of children and young people in the sample was almost even. About two thirds of children and young people in the sample identified as White, with the rest identified as belonging to Black and Minority Ethnic Groups.

Recruitment involved OPM sending out invitation letters, making follow up telephone calls and issuing confirmation letters. Fifteen interviews were conducted face to face at the family's home; the rest (16) were conducted by telephone. Interviews tended to last

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[1] https://www.gov.uk/government/collections/send-pathfinders#evaluation-of-the-send-pathfinders

between 50 minutes and 1.5 hours. All interviews were recorded and transcribed, except in a small number of cases where the participant did not wish to be recorded.

The majority of the interviews were conducted with the mother of the child or young person only. Five children and young people were present for the interview with the support of their parent.

Key findings

Understanding and expectations of the pathfinder

Parents appeared to have been referred through a more diverse range of entry points compared to last year's cohort, which may suggest a more embedded referral processes within the areas. There also appeared to be a more consistent approach to referring families in the second cohort. This typically involved a face to face referral followed by a home visit, which families appreciated as an opportunity to get information and ask questions face to face.

Most parents joined the pathfinder with a clear understanding that this was a pilot initiative testing a new approach to planning support for their child or young person, and many knew that it would be replacing the SEN statutory assessment. The majority of participants were positive about the prospect of being involved in the pathfinder and very few had concerns or worries prior to joining. These findings suggest that they received a clear and reassuring introduction to the pathfinder.

Reasons for joining the pathfinder varied but most commonly, participants hoped that their child or young person's needs would be placed at the centre of the process. They also hoped that it would: help to bring education, health and social care professionals together around the child, enable long term planning and give them a greater say in support planning for their child or young person.

Assessment and support planning

Experiences of the assessment and support planning process were quite varied and differences between cases were not clearly linked to specific pathfinder areas. In the vast majority of cases families were assigned a key worker.

Generally, it was less common to have new assessments to inform support planning, than to draw on existing assessments. There was usually a wide range of professionals involved in providing reports and/or attending meetings. Most participants had further meetings, either just with their lead person or attended by multiple professionals, at which they discussed and agreed outcomes and actions to be included in the plan.

In the second cohort, families more consistently took part in support planning after the 'assessment' stage. This was a positive development because parents felt that the plan was less useful when it lacked a support planning element.

The period following the drafting of the plan was the point at which it was most common for parents to experience a gap in communication with their key worker, which could lead to anxiety for parents. A small number were unsure whether or not their plan had been signed off. Participants also reported dissatisfaction when they were unclear on their options in the support planning stages, encountered delays or a lack of updates, or where the process was not well led.

Joint working by professionals was identified as taking place principally during assessment and planning meetings where participants felt they benefited from professionals sharing of ideas for supporting the child or young person and encouraging professional accountability. These meetings also enabled professionals to build relationships as a basis for working together.

Where joint working was not felt to have taken place the main examples were non-attendance at meetings by professionals who they wanted to attend, or poor communication between professionals outside of meetings.

The vast majority of participants felt that their experience had been child- or family-centred and this was a key factor in terms of families' levels of satisfaction with the process. Families valued instances where they had been encouraged and enabled to give their input into the plan. In one example a young person aged 16 worked with her key worker to create a PowerPoint presentation about herself, which she delivered to professionals at the planning meeting. The young person enjoyed it and felt she could express herself more confidently than she might otherwise have done.

The role of the key worker

The majority of participants were aware of a professional they considered to be the 'main person' involved with their EHC plan. In most cases key workers were either in an existing local authority role or in the pathfinder team. The majority of families were assigned a key worker, with only a very small number given a choice or told they could change their key worker if they wished.

While there were variations in the role of the key worker, in most cases they dedicated considerable time and energy to the process. Participants noted the following elements of the role:

- Leading the process (e.g. collating paperwork, arranging multi professional meetings)
- Providing information and advocacy
- Conducting one-to-one meetings with families
- Supporting multi-agency meetings
- Leading the drafting of the plan

Key workers were important in determining participants' overall level of satisfaction with the process and outcomes of the plan. Feeling well supported by their key worker was

often identified by families as a key factor affecting their level of satisfaction with the overall process.

Key workers were felt to be effective where they:

- ✓ knew the child or young person

- ✓ knew the 'system' and how to 'get things done'

- ✓ synthesised different strands of information into a coherent package

- ✓ provided advice, information and advocacy

- ✓ exercised judgement of families' support needs

- ✓ influenced other professionals using their status and knowledge

- ✓ were good listeners and were attentive to the wishes of families

- ✓ built rapport with, and provided reassurance to families

- ✓ were fair and impartial and brought a fresh perspective

- ✓ took responsibility for putting the completed plan into action

The role of the key worker was deemed less effective when they:

- ✗ were unresponsive when contacted

- ✗ lacked confidence and skills to work with other professionals on an equal footing

- ✗ were not attuned to the detail or terminology of information provided by professionals

Satisfaction with the process of getting a plan

Participants reflected on what had been satisfying or not about the process of getting an EHC plan and their reasons for this. There was widespread recognition that they had joined a pilot, and acknowledgment that the process was likely to improve as it became embedded.

Table 1 - Satisfaction and dissatisfaction with process

Satisfaction with the process	Dissatisfaction with the process
✓ Being at the centre of the process	✗ Not knowing the options
✓ User-friendly, non-burdensome process	✗ Delays
✓ Feeling supported through the process	✗ Shortfalls in the organisation and running of planning meetings
✓ Developing a fuller understanding of the child or young person	✗ The time and energy required
✓ Learning more about available services and support	✗ Parents capacity to take part
✓ Improving multi- agency working	✗ Lack of support
✓ Creating a single, comprehensive plan	✗ Lack of buy-in from professionals
	✗ Not sharing and following the plan
	✗ Lack of clarity on the next steps

Views on the completed plan document

The current design of the plan appears to be working well based on families' feedback. They reported liking the structure of the plan, finding it clear and easy to navigate, and they liked the efforts made to convey the child or young person's personality and individuality.

Parents were generally able to describe the four broad categories of content in the plan: information about the child or young person; service and support they were currently receiving or required; outcomes and goals; and actions to achieve outcomes.

The formatting and level of detail varied to some extent and plans used a number of approaches to structure the information, for example, the name of the plan, key headings, photos, and the way in which action plans were set out. Parents valued the specificity of goals and actions which made clear who, what and when would happen.

Once the plan is complete, it continues to be common for participants to have questions about its use and next steps. This includes the arrangements for sharing and updating plans, professional accountability and the legal status of the document, as well as its relationship with the Statement.

Delivery of services

Many families did not gain new services by taking part in the pathfinder because they were not needed. In some cases families benefited from changes to the way they were supported at school or at home by their parents. It is important to include both services *and* support in considering how to meet children and young people's needs.

In some cases having choice was not deemed necessary because families were already happy with their services or were happy to accept the advice of their child's school. Parents appreciated being able to exercise choice where they felt they had the ability to make a judgement on services, such as selecting a school or carer or considering options around transitions. But they wanted support in doing this and did not want to feel they were left to take important decisions alone.

Throughout the process of the pathfinder, parents wanted to be kept informed with progress in terms of trying to gain new services or support. Even if services were not being delivered, parents were more content when they knew that actions were underway; that someone was accountable and that there was a defined timescale in place.

Sufficiency of and satisfaction with support and services

Many participants had not received new services, because they were happy with their current services. Some reported increases in their existing services (such as additional hours of respite or carer time), or new services that were suggested during the planning process. Others had new support, rather than formal services – such as a school agreeing to work differently with a child.

A few families secured new or increased Direct Payments through the plan, which increased their ability to choose services and support. Families who had Direct Payments valued the element of choice this offered, but noted that families needed advice and information about the availability of local services to enable them to choose how to use their Direct Payment.

Participants who had received the services in their plan were mostly happy with them; often these were participants who had already been happy with their services and not required any change. Another group of satisfied parents were those whose child had started a new school where their needs could be met.

There were parents who were unsatisfied because they wanted more hours of a certain service, or because they had not received services that were included in the plan. A few participants had outstanding needs that were not addressed within their plan.

Comparisons with previous processes and with expectations

Parents compared the process of getting an EHC plan favourably with that of getting support under the previous system, which for most was the Statement. When reflecting on previous assessment and planning processes, participants recalled a more

fragmented 'system' which was difficult to navigate, not equitable and where services were poorly joined-up.

EHC plans were strongly preferred to Statements because of their wider scope and more holistic package of care and goals, including aspects of support beyond education: health, social care and the wider family. However, parents felt that the Statement benefited from having a clear legal status and better transferability if they were to re-locate.

Expectations that the plan would be a family-centred process, involving a range of professionals, were widely met. Expectations of securing additional services and support were less consistently met, suggesting that key workers should take care not to raise expectations unduly.

Outcomes experienced

Just under half of families reported experiencing outcomes as a result of joining the pathfinder, which is a similar proportion who experienced the same in the first cohort. It should be noted that not all families needed new services and therefore did not expect new outcomes. There were also families for whom outcomes were anticipated but not yet realised. Outcomes tended to be specific to individual children and young people, depending on their needs, but included improvements in relation to education, health, social interaction and overall wellbeing.

The biggest single process that led to a positive outcome for children was moving to a new school, which about a sixth of participants in the qualitative research had experienced. However in most cases parents were unsure of the exact role of the plan in this.

Where children or young people were receiving an increase in support and services, this had often led to improved outcomes for them and their families, delivered for example, through additional therapies or a personal assistant. Positive outcomes were also experienced from the informal support provision in the plan through the process of setting goals and applying consistent approaches from professional and family to achieve them. Young people felt empowered where they had the opportunity to give their opinions and in some cases they, rather than their parents, took the lead in the process.

In terms of outcomes for parents, it was common for them to derive reassurance from having the plan in place and seeing their child or young person thrive. In some cases parents also gained confidence in their own ability to support their child, and felt that the process had helped them to have a more accurate understanding and clearer expectations around their child's progress.

There were very few cases where participants experienced any negative outcomes. However, a few reported a reduction in existing services, causing parents to feel less able to cope, or increased levels of anxiety and stress caused by uncertainty around the

future of services. This was more common for families in the second cohort, who also reported less access to clubs and activities.

Conclusions and recommendations

This section summarises what appeared to work well and less well about the pathfinder for the second cohort of families who took part in the qualitative research and offers some recommendations for areas moving towards implementation in 2014.

It was difficult to draw firm conclusions from the qualitative research findings due to the very wide variety of experiences reported by participants, and the complex web of factors influencing these experiences. The process appeared highly variable from case to case across both age groups and pathfinder areas, making comparison and evaluation of different approaches more challenging.

Key findings from the second cohort

In terms of expectations, in the second cohort there was slightly more consistent *awareness of the pathfinder as a pilot* process, and clarity on its intended status as a *replacement for the educational Statement*, than was found amongst the first cohort. Generally more families had *clear expectations* at the outset, suggesting that areas have become more effective and consistent in introducing the EHC plan to families. The key worker was central to ensuring families' understanding of the plan, and time spent upfront explaining and answering questions was well spent in terms of families feeling reassured and positive about it.

There was more mention by families in the second cohort of the scope of the EHC plan as including the *needs of the whole family*, as well as those specifically of the child or young person. This was an aspect which families found very attractive, as part of a 'holistic' approach to meeting need. However, key workers should be careful not to raise expectations around what support may be available for wider family members, bearing in mind available resources.

In terms of process, families noted the value of *involving children and young people* as much as possible in the planning process. There were several examples of innovative practice in the second cohort in which older young people were supported to play a central role in developing their plan. Seeking young people's input into their plan was seen as an opportunity for empowering young people and helping to develop their ability to express their needs and views, which is increasingly important as they move towards adulthood and greater independence. Therefore the process should seek to involve young people meaningfully and make the most of this opportunity.

Multi-agency meetings were common for the second cohort and widely perceived as effective. Families thought that much value was added from bringing professionals together to share and develop an understanding of the child or young person's needs and support options. Also more consistent (although not uniform) in the second cohort were *plans that included actions*, as well as identifying needs. And the inclusion of supporting actions was key to families' finding the plans useful and worthwhile.

The importance of the *key worker* emerged strongly from the second cohort. The key worker role, where played well, had a great impact on families' experiences of the process. Key workers who were supportive, accessible and effective in driving change, and who kept families informed and reassured, were highly praised. Generally key workers were seen to be providing information and support effectively, suggesting that the role may be becoming more embedded in some areas. However, key workers need clear accountability structures to be in place to clarify the roles and obligations of other professionals and agencies, in order to play their role well.

A key area for improvement by areas was around ensuring families had clarity on the *timescales and process for review* of the plan, which was consistently lacking.

In terms of services and outcomes, it is important that the plan considers both *services*, in the sense of formal services delivered by professionals, and *support* for children, young people and families, in the sense of supportive actions and strategies implemented by schools and parents in collaboration with professionals. There were benefits to be gained from these kinds of actions by schools and families, such as implementing consistent routines and more appropriate techniques and practice.

Parents in the second cohort expressed *anxiety around cuts to funding* for local services for their child or young person, in the context of the wider climate of austerity. Prior to involvement in the pathfinder, participants had already experienced the effects of this in terms of reduced access to services and changes to the professionals supporting them. There was a sense of reduced access to non-statutory services such as leisure and social activities.

Recommendations for implementation in September 2014

Based on the qualitative research we offer a number of suggestions to DfE and local areas that are developing the means to meet the requirements of the SEN and disability reforms. These relate to supporting families, professionals and commissioners to improve the experience of the EHC planning process and resultant EHC plan, and to generate positive outcomes from it.

1. Families. Professionals can effectively prepare and support families in making an EHC plan by:

- Assigning a key worker to establish and develop a supportive, responsive and ongoing relationship with families. The key worker should 'hold' the process so that families do not feel that the burden of involving professionals is on them.

- Setting out clear and detailed expectations about what children, young people and families will get from the process and why they should take part. Resource and other constraints should be explained: families will not necessarily get everything they want.

- Letting families know what is expected from them, including what kind of time and effort they will need to put in. Linked to this, what provision is available for parents

who need extra support to participate (e.g. an advocate, or extra time with the key worker).

- Communicating and adhering to timelines for producing an EHC plan, and clear steps along the way. In particular, the process and timescale for updating or review of the plan, as many parents were unclear on this.

- Ensuring families understand the legal status of the EHC plan, so that they know what it means in terms of their ability to secure services

- Ensuring that families are kept informed throughout the process: of which professionals are involved and how, what is happening 'behind the scenes', and the causes of any delays or changes. This will help to mitigate parents' anxiety.

- Providing information on what services are available to children, young people and families, for example a 'brochure' of services in different categories. This may be developed as part of areas' Local Offers.

2. Professionals. Families' experiences of the pathfinder may be improved if professionals are better prepared and equipped to support them, by:

- Setting clear expectations for the main professionals involved, including skill requirements, time commitment and logistics. This would promote a more consistent approach and lead to a more equitable experience for participants.

- Designing and delivering training packages for professionals, for example, how to get the best out of support planning meetings.

- Providing templates and example plans so that a consistent format is used and a clear standard of quality set. The existing formats have worked well for participants so far.

- Developing approaches and processes which allow families with different needs and capacity to take part and benefit equally from the process.

- Developing processes and guidance for key workers on involving children and young people directly in the process.

3. Commissioners. Commissioners may be better supported in their roles by understanding and clarifying:

- The necessary infrastructure and protocols required to:

    - share and update plans securely and efficiently.
    - provide quality assurance of draft plans so that they are completed to a satisfactory standard.

- The legal status of the plan, and whether it can hold agencies to account to deliver services.

- The most appropriate mechanisms for ensuring accountability and buy-in from professionals, such as memorandums of understanding, guidance or statutory regulation, cost benefit data, case studies.

Next steps

Follow up interviews, taking place 6-18 months after the initial interview, will be conducted with a sample of families during 2014, in order to explore their experiences in this longer term time frame.

The sample will be drawn from participants who took part in the qualitative research in the first cohort in 2013 (reported in July 2013), and the second cohort in early 2014 (reported in this report, March 2014).

1: Introduction

The evaluation

OPM was commissioned as part of a consortium of organisations led by SQW and including Ipsos MORI and Bryson Purdon Social Research (BPSR) by the Department for Education in September 2011 to undertake the evaluation of the Special Educational Needs and Disability (SEN and Disability) Pathfinder Programme. The evaluation was commissioned in two stages to mirror the phases of the evolving programme:

- **Stage one** - **evaluated the first 18 months of the programme** and focused on understanding the approaches adopted to deliver the new processes and the experiences and outcomes of the initial cohort of participating families. A series of reports detailing the findings from this stage of the evaluation are available on the government publications website[2]

- **Stage two** – **is evaluating the second 18 months of the programme** (April 2013 – September 2014) to build on the findings from the initial evaluation to understand the progress made by pathfinders as they roll out the new processes, and the experiences and outcomes of the second cohort of participating families. An assessment of local areas' (both pathfinder and non-pathfinder) readiness to meet the forthcoming Special Educational Needs (SEN) reforms and a review of the effectiveness of the pathfinder champions has also been undertaken.

This report

This report presents the findings from qualitative research conducted with 31 families that had participated in the new Education, Health and Care (EHC) planning pathway and as a result, received an EHC plan across seven pathfinder areas. This research forms part of the impact evaluation work and therefore seeks to complement and provide further depth to the parent carer survey that is being undertaken with pathfinder and comparator families

The 31 families that took part started and completed the process between January and November 2013. This second cohort of families was drawn from a different set of areas than those that participated in the qualitative research undertaken during stage one of the evaluation (i.e. the first cohort of families)[3]. For comparative purposes, no changes were made to the research approach, which is set out in more detail in the methodology section of this report [Annex A].

In each section, we note any differences that were observed between families' experiences in the second cohort as compared to the first cohort. However, readers should note that this research is not based on representative samples and therefore we

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[2] https://www.gov.uk/government/collections/send-pathfinders#evaluation-of-the-send-pathfinders

[3] The main findings from the qualitative research with the first cohort of families were presented in the Stage One Impact Evaluation Report, which can be found at https://www.gov.uk/government/publications/impact-evaluation-of-the-send-pathfinder-programme

are unable to draw direct comparisons between the two cohorts or generalise from these findings about changes in the EHC plan process over time.

The report includes a number of anonymised case studies, to provide additional insights into the experiences of families. The case studies have been chosen simply to illustrate a range of participants' experiences (see Annex A). They are not intended to be 'representative' or showcase 'typical' experiences, as experiences were very varied and influenced by a large number of factors.

The process of making an EHC plan

The process of making an EHC plan differed across areas; there was no definitive process across all participants. However, it may be helpful to be aware of the broad stages of the process, which were:

- Referral (entering the pathfinder)
- Assessment and supporting planning (drawing on existing assessments of need such as the educational Statement and in some cases being referred for new assessments, and then drafting the plan)
- Sign-off (reviewing and editing the draft plan to produce a final version)
- Review (most plans had yet to be reviewed at the time of the research).

2: Methodology

Detailed information about our methodology is set out at Annex A below and covers the following stages: recruitment, sampling, data collection, analysis and reporting. However the following challenges relating to method and data should be borne in mind while reading the findings.

Overview of methodology

The cohort of families in this sample was drawn from seven pathfinder areas, which began implementing the pathfinder in September 2011. A target sample was drawn from the list of families eligible to participate in the evaluation, with the aim of getting a cross section across the different age groups and pathfinder areas.

This report is based on the findings from a final sample of 31 families, covering 33 children and young people (two families each had two children participating in the pathfinder). The split by age group was: 0-5 years (n=12), 5-16 years (n=14) and 16-25 years (n=7).

Fieldwork took place between January 2014 and early March 2014. Fifteen interviews were conducted face to face at the family's home; the rest (16) were conducted by telephone. The vast majority of the interviews were conducted with the parent/s/carer of the child or young person only. Five children and young people were present for the interview with the support of their parent/carer.

All interviews were recorded and transcribed, except in a small number of cases where the participant did not wish to be recorded.

Challenges relating to methods and data

There were a number of limitations to the methods and data which affected the completeness of the data and the extent to which we could draw conclusions from it. It is recommended that readers of this report keep these points in mind as they read the findings. The limitations were as follows:

- Participants' often **poor understanding** of the process and purpose of the pathfinder. Some participants were vague as to what the EHC plan was, what it was for and what had taken place in relation to it. A few did not know the term 'EHC plan' or 'single plan', or have a clear understanding of the terms 'assessment' or 'support planning'.

- Participants' **difficulty in remembering** details of their experience of the pathfinder. Even participants who were confident as to what the EHC plan process was about were often unable to recall specific details associated with the process. For example, they sometimes forgot whether letters received, meetings attended or conversations with professionals were related to the EHC plan or another process around their child's care. Details such as who had attended a meeting, in what order certain stages of the process occurred, how many conversations had

taken place and for how long had frequently been forgotten or participants were not sure whether they had known them in the first place. This was often a result of the fact that participants reported attending a great many meetings with a variety of professionals and receiving lots of mail concerning their child and therefore found it difficult to keep track of which of these were associated with the pathfinder.

- Participants being at **different stages** in the process. Delays in the finalisation of the EHC plan for many families impacted their ability to talk about outcomes. Some were still in the process of drafting their plan, some had not yet seen their plan, others had finalised their plan but were still waiting to receive services and support.

- As well as being at different stages in the pathfinder process, there were so many other **variations in individual circumstances** of participating families that it was very difficult in the analysis to find patterns or ascribe cause and effect to different outcomes and experiences. Experiences varied not only according to a child or young person's age group and their pathfinder area (indeed there was often huge variation within age groups and areas), but to the nature of their additional needs, their family circumstances, their school, their existing provision of support and services and their relationships with professionals.

- More so than in the qualitative research last year, the above points were compounded by the fact that **a smaller number of interviewees were spread over a larger number of pathfinder areas**, making it more difficult to identify when there were genuine differences between areas and when differences were related to individuals' extremely varied circumstances, as described.
  - 2014: 33 children and young people in seven areas
  - 2013: 46 children and young people in seven areas but including two areas with only one family in each, therefore the majority (44) spread across five areas.

These limitations highlight the fact that **a qualitative approach that is open and semi-structured has been invaluable in exploring and plotting participants' experiences of taking part in the pathfinder**. It was necessary for our researchers to continually probe and prompt participants, repeat questions for clarity, use the interview guide flexibly and examine any documentation associated with the pathfinder to develop an accurate understanding of the families' participation in the pathfinder. A more structured approach would have struggled to capture the diversity of the participants' often nuanced experiences of the pathfinder.

3: Understanding and expectations of the pathfinder

KEY FINDINGS

- Although parents joined the pathfinder through a diverse range of entry points, there appeared to be a more consistent approach to referring for families in the second cohort than the first. This typically involved a face to face referral followed by a home visit, which families appreciated as an opportunity to get information and ask questions face to face.

- Most parents joined the pathfinder with a clear understanding that this was a pilot initiative testing a new approach to planning support for their child or young person, and many knew that this approach would be replacing the SEN statutory assessment. This suggests that areas communicated these aspects effectively to families at the outset.

- The majority of parents joined the pathfinder with clear expectations relating to: joint professional working, smooth transitions, long term planning, and a parent/child centred process.

- The majority of parents reported they were positive about the prospect of being involved in the pathfinder and very few had concerns or worries prior to joining, indicating that they received a clear and reassuring introduction to the pathfinder.

Routes into the pathfinder

Parents were informed of and invited to join the pathfinder process by a variety of agencies. Most commonly they were referred to the pathfinder by an education professional (for example, a school SENCO); a health professional; a social worker; or an early years professional (for example, a portage worker). Existing channels of support were key sources of referrals, as were professionals involved in transitions into, between, and out of educational settings. .

Some general trends across the age groups could be identified, as shown in the following table:

Table 2 - Routes into the pathfinder by age

0-5 years	5-16 years	16-25 years
• Referrals made by **specialist professionals already supporting the child** such as the school SENCO or a portage worker. • For parents of children aged 0-5 who were pre-school age and with complex health needs, it was common to hear about the **pathfinder through a health professional** such as a health visitor or specialist consultant. • Often identified at the point at which they were considered eligible to participate in the **Special Educational Needs (SEN) statutory assessment** and/or as part of the process to facilitate the **transition from pre-school to school education**.	• Common to be identified through a **professional at school** such as the home-school liaison officer or school SENCO. • Three were invited to join the process directly by the local authority through a **letter or phone call**. • Two were told about the pathfinder by their **child's social worker**. • Two parents found out about the pathfinder through involvement in a **local parent forum**. • After hearing about the pathfinder, most received a home visit from a professional who explained the purpose and process of the pathfinder.	• For parents of young people aged 16-25 who remained in formal education it was common to hear about the pathfinder through their **child's school**. • One was invited by the school to attend **an introductory meeting with other parents** in the area. • Two parents were told about the pathfinder by their **child's social worker**. • Several parents learned about the pathfinder at a point of **transition** for their child - for example, transitioning from children's to adult's social care or from school to a post-16 education setting.

Across the age groups:

- A minority of parents were **less certain about how or when** their child or young person had been referred

- A few parents felt they had been invited to get involved because they were particularly well known by the professionals involved in the new process or perceived to be 'articulate' and therefore more suitable to help pilot a new system.

With the second cohort of families it was more difficult to identify any patterns of referrals across pathfinder areas than with the first. This may reflect the fact the pathfinder areas in the second cohort were referring children and young people from different age groups; and/or may imply that areas have a wider variety of referral routes.

Although a more diverse range of entry points were identified, there appeared to be a more consistent approach to referring than we heard about from the previous cohort. It was more common for parents to be told about the pathfinder face to face by a recognised professional, rather than by letter or phone call directly from the local authority, or to find out about the process independently. This was also far more commonly followed up with a personal visit to the family home where the purpose and process of the pathfinder was explained further, rather than at a joint meeting with other parents.

Understanding of the purpose of the pathfinder and expectations of it

Most parents had a clear understanding that the pathfinder was a **pilot initiative**, testing a new approach to planning support for their child or young person. Many noted that this process would **replace the SEN statutory assessment**, and a small number knew this transition would begin in September 2014. Most parents appeared to have a fairly clear and consistent understanding of the purpose of the EHC plan as compared to that of the Statement, as follows:

- *Parents of children who did not previously have a Statement* understood that they were taking part in the pathfinder as an alternative to the SEN statutory assessment process

- *Parents of children who had an existing Statement* generally understood that the pathfinder would be replacing this Statement on completion

- *Parents of young people aged 16-25* tended not to describe the purpose of the pathfinder in relation to the Statement, but focused on planning for post-16 education and adulthood.

There were a small number of parents who began the pathfinder process **without a detailed understanding of its purpose**, including the relationship between the pathfinder and other support planning mechanisms such as the Statement. These parents tended to have only a broad understanding that the pathfinder was 'something new' and 'something that would help their child'. Although they had been given an initial explanation and introduction to the pathfinder, they had either found this to be confusing, overwhelming, or had since forgotten the details.

The vast majority of participants joined the pathfinder with the **expectation that the process would lead to improvements** in how their child or young person was supported. A small number expected the process to result in similar support to that gained through a Statement.

Understanding of the purpose largely shaped expectations of the pathfinder. Parents who were unclear about the purpose of the pathfinder tended to have fewer, or more general, expectations.

General reasons for joining the pathfinder included:

- The EHC plan would **replace the Statement** at some point in the future, and therefore a transfer to the new process was inevitable.

- When the pathfinder coincided with a **transition**, this was a point where it would be least disruptive to introduce a new process.

- The pathfinder was 'recommended' by a trusted **professional**.

- Some simply felt they had **'nothing to lose'** by taking part.

The majority of participants had clearer expectations, including:

- To have their child or young person's needs **accurately reflected** and their best interests at the centre of decisions:

  'I just hope that it's not about the funding, and it's not about the money, and it's not about the people. They strip all that away and it is just about the child.' (Mum, Area M, 0-5)

- To facilitate **smooth transitions** into, between, and out of schools, and access the most appropriate educational setting.

- To have **professionals working together** creating more joined up support; for both parents and professionals to gain a clearer understanding of the different agencies.

- To have **education, health, and social care assessments within one plan** so parents do not need to repeat information, and professionals understand the child or young person more completely and quickly.

- For the family to have a strong presence in the process and **directly to influence** it.

- To facilitate **long term planning** beyond school and education, to support independent living for young people up to age 25 (a few thought the upper age limit was 18 or 19).

Individual parents had these specific hopes:

- To gain additional **support for the wider family**, including siblings.

- To gain access to support and services in the community, where the child could enjoy **social opportunities** such as activities and clubs.

- The 'EHC plan' or 'single plan' would hold **less stigma** than a Statement.

- It would be a mechanism for gaining additional **funding** or to transfer funding between health, education and social care.

- The pilot would **benefit other families** of children with additional needs in the long term:

  'We've got a lot out of the system and thought we'd owed it to them to try the new thing out. It wouldn't do [child] harm.' (Mum, Area P, 5-16)

Across and within the age groups, participants had varying expectations; however, some general trends could be identified as shown below:

Table 3 - Expectations of the pathfinder by age group

0-5	5-16	16-25
• To simplify the transition from pre-school to school education • Parents to be fully involved in the process and decisions made about support	• To give the young person a voice in support planning • Professionals would work better together and the system would become simpler to navigate	• To give the young person a voice in support planning • To enable long term planning for support outside of education

Across the age groups:

• Parents of children or young people with very complex needs expected the pathfinder to bring education, health and social care assessments together in one place to reduce repetition.

• They expected their child or young person's carers or other professionals involved with their care to have a more comprehensive understanding of them as a result of reading the plan.

Concerns about taking part

Parents were generally very positive about the prospect of being involved in the new process and very few had concerns or worries prior to joining the pathfinder.

A small number of parents questioned the **extent to which the process would be child/family- centred**. For example, the idea that *parents would have a greater say in their child's support* prompted one person to challenge whether parents always know what is best for their child, and emphasise the need to maintain a balance between parent and professional opinion. Another was sceptical about the plan being written in the child's *own voice*, because their child was unable to communicate verbally.

A few parents were anxious that their **child should not be disadvantaged** in any way by taking part in the new process. There were some initial concerns around the legal status of the plan compared to the Statement, and whether there could be a gap in provision should the plan fail to replace the Statement as a legal document:

'I didn't want my child to [be in] nowhere land where he's not on a Statement. You've got to be very careful if you give up something, then he [could] suffer from it because the gateways to support might be closed if you are not on a Statement. (Dad, Area O, 16-25)

One parent, conscious of the upcoming general elections and the **frequency of educational reforms** in recent years, was concerned that a future government may withdraw the pathfinder process. This was worrying in terms of long term planning to facilitate their child's transition to adulthood.

Unlike families in the first cohort, in the second cohort no parents had concerns at the outset about the practicalities of the process (such as attending meetings and completing paperwork).

Understanding of the process of the pathfinder

Participants' understanding of the **process** was varied. While a minority displayed little understanding, many had received a clear introduction to the pathfinder:

'She explained what would happen, how it would work, what would happen next, who she would contact, reports that she would need to put in- to collate the final plan that she needed obviously input from everyone that was involved in [child's] care.' (Mum, Area L, 0-5)

Clarity on process and timescales

In general, the following aspects of the process were clearer to participants, who thought:

- there would be **meetings** of parents and professionals together
- families would provide **written input** about their child
- **one document** would be created, pulling together all assessments and plans

The following aspects were less clear:

- frequency and **timescales** of meetings
- **broader timeline** for the process, including timescales for overall delivery.

There was little **distinction between 'assessment' and 'planning'** processes for most families.

There were no notable differences in understanding of the process between pathfinder areas. One difference between the first and second cohorts was their perceptions of the knowledge and understanding of professionals leading the process: in the second cohort, it was far less common for participants to describe professionals as lacking understanding about the process.

Summary

Circumstances in which parents found out about the pathfinder varied both across and within areas. Parents were informed of and invited to join the pathfinder process through a number of different agencies including education and early years, health and social care. Parents appeared to have been referred through a more diverse range of entry points compared to last year's cohort which may suggest more embedded referral processes within the areas. Furthermore, there appeared to be a more consistent approach to referring in this cohort, compared to the previous cohort.

Parents' understanding of the purpose largely shaped their expectations of the pathfinder; parents who were unclear about the purpose of the pathfinder tended to have fewer, or more general, expectations. The reasons why participants joined the pathfinder were varied but most commonly they hoped that their child or young person's needs would be placed at the centre of the process, and that it would help to bring education, health and social care professionals together around the child, enabling long term

planning and giving them a greater say in support planning for their child or young person.

Few participants had concerns prior to joining the pathfinder; a finding which is consistent with findings from the first cohort. A small number were uncertain whether the programme would be truly child/family-centred, while others were anxious that their child would not be disadvantaged in any way by taking part.

4: Experiences of assessment and support planning

KEY FINDINGS

- It was less common for families to have new assessments than to draw on existing assessments to inform support planning. New assessments were more common when children were at the point of diagnosis or recently diagnosed (usually 0-5), or when approaching transition from school (16-25).

- Parents in the second cohort tended to have a more collaborative role alongside professionals in drawing up the 'about me' section than the first cohort, where a number of parents completed this section by themselves. This support was generally appreciated by parents.

- The period following the drafting of the plan was the point at which it was most common for parents to experience a gap in communication with their key worker, which could lead to anxiety for parents.

- Very few participants from the second cohort reported that they had no further experience of support planning after the 'assessment' stage (in comparison to the first cohort, in which more participants felt they did not have any further support after this stage).

- Key workers were important in determining participants' overall level of satisfaction with the process and outcomes of the plan. They affected the extent to which participants understood the process, were kept up to date with progress and enjoyed a child-centred experience.

- In terms of joint working, a key aim of the pathfinder, participants focused on how professionals worked together at meetings and the benefits of multi-agency attendance.

- Joint working in multi-agency meetings led to the following benefits: sharing ideas about how to support the child; greater professional accountability; building relationships between professionals and between professional and parents.

- The vast majority of participants felt that their experience had been child- or family-centred. This was achieved largely by the quality of professionals' communications and interactions with them.

- Where children and young people were encouraged and enabled to give their input into the plan this was well received by families. There were several examples of good or innovative practice in involving young people directly in planning.

Assessment and planning

Experiences of the assessment and support planning process were quite varied by individuals and differences were not clearly linked to specific pathfinder areas. We have

not attempted to describe the exact process in each area, or in relation to each age group, because participants had varied levels of understanding and recollection around who was who, their roles, the exact sequence and purpose of each step of the process.

Participants did not always make a clear distinction between assessment and support planning as a two-part process, perhaps because the process often drew on existing assessments and in some areas the two ran together.

Assessment

It was less common to have new assessments than to draw on existing ones. Where children and young people had a **Statement**, this was used as a source of information to inform support planning. Children who had not yet entered education (0-5) tended not to have a Statement so their plans drew on reports from other professionals. Parents saw the Statement as a sensible source of information for the plan, except where the Statement was not up to date.

Other existing assessments included those of other education, health and care professionals depending on the child or young person's individual needs. In one area (L) the key worker coordinated a large number of reports from different professionals; the key workers' effort in requesting and chasing these up was appreciated by participants in this area.

New assessments were most common in two situations. One of these was when children had recently received a diagnosis (usually in the 0-5 age group), and therefore required assessment to identify their needs. The other was when a young person was approaching transition from education to the next stage (16-25); in these cases new assessments were conducted to inform the planning of support for the next stage. These participants were clear that this was the case and were glad to receive new assessments in order to provide up to date information to inform planning.

In some cases a new assessment was undertaken after an initial meeting between the key worker and the family, in order to inform subsequent planning. Sometimes assessments were listed as an action or goal within the plan. This was helpful where parents had wanted a specific assessment for some time but had not been able to get a referral for it.

Planning   **Assessment**

Parental involvement in assessment and planning

Most parents had a meeting with a professional, who was most often the person they considered to be their key worker. A small number were sent a blank plan document in advance of this meeting, so that they could start entering information into the 'about me' section.

✓ This helped parents to understand what would be discussed at the meeting and to envisage the completed plan.

At this initial meeting, key workers either began to fill in the plan template then and there or took notes to write up later. The discussions enabled the professional to write an 'about me' section, describing the child or young person. In the first cohort of families, a small number of participants completed this section by themselves; parents in the second cohort tended to have a more collaborative role in doing this with the key worker. This was generally appreciated by parents as it meant they did not have to write it entirely by themselves.

Parents were happy to give their input on this 'about me' aspect of the plan, and there was little sense of concern about getting the right information into the plan. Perhaps this was because most understood that they would go on to have a support planning meeting, and/or that their key worker would be drawing on other reports; there were few parents who felt that their input was the *only* source for the plan. It may suggest that there was a better balance between professional and parent input for the second cohort, compared to the first cohort in which a number of families felt they had developed their own plans.

Support planning

Approaches to support planning ranged across and within areas, but by far the most common experience was to have a further meeting or meetings which were used to further discuss and generate content for the plan. These meetings usually took place at school, with a) just their lead person or b) more commonly, multiple professionals.

After the plan was drafted, participants had the opportunity to comment on a draft of the plan. Parents thought this was a useful step in the process for helping to correct any inaccuracies. Following this stage, a small number of participants were not sure whether or not their plan had been 'signed off', or what this meant, or what would happen next, suggesting a possible gap in communications by key workers at this point in the process.

There were accounts from families in the first cohort of the draft plan being 'sent away' to be written by 'someone else'; this was not reported by any participants in the second cohort, suggesting that families experienced a more 'seamless' process.

Also less evident from the second cohort were participants who had no further experience of support planning after the 'assessment' stage, which produced a descriptive document giving information about the child or young person. Very few interviewees felt that this was their situation in the second cohort, which is a positive development because these parents felt that the plan was less useful because it lacked a support planning element.

Even more than for the first cohort, it was difficult to identify a definitive or typical process in each area; participants had often had different experiences within the same area.

The key worker

Professional role of the key worker

The majority of participants were aware of a **professional they considered to be the 'main person'** involved with their EHC plan[4].

Key workers were either in an existing **local authority** role (e.g. social work, early years/portage, transition worker) or in the **pathfinder** team. Few participants identified their key worker as being based in a **school/college role**.

Transition support professionals were mentioned by families with an older child (16-25, or approaching 16). Often this professional was new to the family, which made it difficult to identify whether changes after the process were due to the EHC plan, or whether the transition worker would have supported them at this stage anyway.

There was variation within areas: within an area some families identified the pathfinder lead as their key worker while others referred to a different professional. In the second cohort it appeared to be slightly more common for the key worker to be a professional new to the family than it was for the first cohort.

Amongst those who were less clear about their key worker:

- A small number of participants **did not know their professional role**, identifying them only by name, or as someone from the school, the pathfinder, or the council. Participants often seemed less clear about the person's role when they were someone based at the council or in the pathfinder team.

- A couple of parents were aware of **several** important people leading their plan. One family had two key workers because the pathfinder lead had initially been so involved with the family, they thought it would be beneficial for her to act as a second key worker; the parent was happy to have this extra support on board.

- A few thought that they **did not have a key worker** or lead person.

Choice of key worker

The majority of families were assigned a key worker, with only a very small number given a choice or told they could change their key worker if they wished. Generally participants were not concerned with having a choice as long as they felt their key worker was effective in their role (qualities associated with effective key workers are described

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[4] Descriptions of the key worker role can be found in the evaluation's Thematic Report on Key working and workforce development (January 2014). Available at: https://www.gov.uk/government/publications/send-pathfinder-key-working-and-workforce-development-part-1 (accessed 24.03.2014)

below). Where they had a choice, participants preferred that the key worker **knew their child or young person**. Having the right **skills and knowledge** was also deemed important, although this was talked about in hindsight rather than at the time of choosing.

One young person chose someone **similar in age**, who knew her case. Because the role of the key worker was described to the young person, she felt able to pick the right person.

The role played by the key worker

There were variations in the role of the key worker. Usually they were reported to give considerable **time and energy** to the overall process. Participants observed the following elements to the role and they valued where their key worker had been present throughout these elements:

- **Leading the process**: collating relevant paperwork; liaising with other professionals; arranging multi-agency meetings; chairing and attending meetings; and observing the child or young person at home or other settings.

- **Providing information and advocacy**: acting as main point of contact for information, progress updates and advice; advocating for families by articulating their needs and views; mediating between families and professionals; and resolving process issues:

  'If ever I felt there were any subjects that I couldn't bring up, she would make sure that I was kept... in the conversation. When sometimes people tend to talk to each other about what was going on, she would make sure that I was brought into it.' *(Mum, Area P, 5-16)*

- **One-to-one meetings with families**: most key workers met with families, usually at their homes, to explore issues and options with the family.

- **Supporting multi-agency meetings**: arranging multi-agency meetings, at which most were active contributors. A minority had a less active role, for example, note taking, which parents found less useful.

- **Drafting the plan**: taking charge of the drafting process, synthesising different strands of evidence and making edits following participants' comments.

Effectiveness of the key worker

Key workers were important in determining participants' overall level of satisfaction with the process and outcomes of the plan. They affected the extent to which participants understood the process, were kept up to date with progress and enjoyed a child-centred experience.

Parents emphasised the importance of having the 'right' person with appropriate skills and knowledge. Key workers were felt to be **effective** where they:

- ✓ **knew the child or young person**

- ✓ **knew the 'system'**, for example, available options and 'how to get things done'

✓ **synthesised different strands of information** into a coherent package

✓ **provided advice, information and advocacy**:

> *'Key workers need to have knowledge of how systems work, you can't expect them to be an expert in everything but you need to know when you may be being fobbed off and when people are being reasonable.' (Dad, Area P, 5-16)*

✓ **exercised judgement** of families' support needs (when to take a collaborative role, a 'hands off' or a 'hand holding' one)

✓ **influenced others**, using their professional status and knowledge to drive progress

✓ were **good listeners** and were **attentive to the wishes** of families:

> *'She's been a comfort to me...because she knew what she was on about and… you could tell she genuinely cares for the children that she has to work with.' (Mum, Area M, 0-5)*

✓ **built rapport** with families, and provided **reassurance** during an unfamiliar process:

> *'If I hadn't had that understanding, I know that [our key worker] would have given me tips. She's very approachable, so it's not a problem to go and ask her anything.' (Mum, Area P, 5-16)*

✓ were **fair and impartial** and brought a **fresh perspective**:

> *'Sometimes as parents we can bury our head in the sand… sometimes you don't want to face reality...[having] someone like [the key worker] that very tactfully can say, look it's not working out but these are the other options, is very helpful.' (Mum, Area L, 0-5)*

✓ **took responsibility** for putting the completed plan into action.

The role of the key worker was **less effective** when they:

✖ were **unresponsive** when contacted

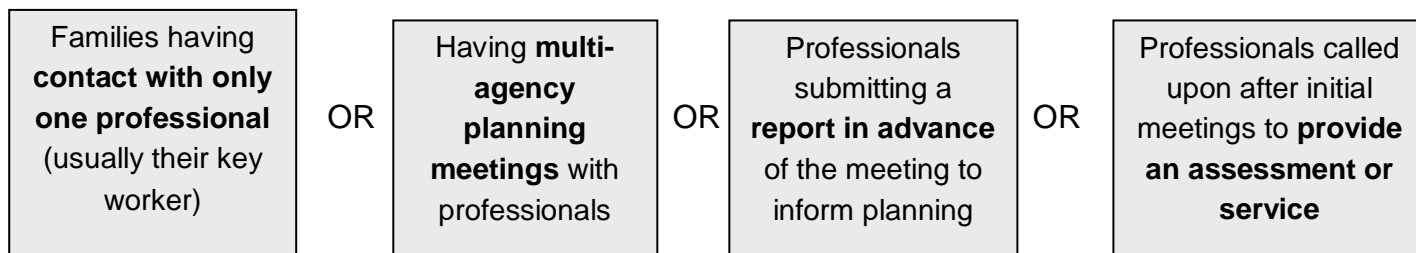✖ **lacked confidence and skills** to work on an equal footing with other professionals:

> *'She didn't seem to be the professional there...it was like she was a minute-taker really and then everybody would look at the notes she'd taken.' (Mum, Area P, 16-25)*

✖ were not **attuned to the detail or terminology** of information provided by professionals.

Joint working

Professionals involved

Participants reported a range of experiences in terms of the number of professionals involved in the process and what role they played, for example:

Families having **contact with only one professional** (usually their key worker)	OR	Having **multi-agency planning meetings** with professionals	OR	Professionals submitting a **report in advance** of the meeting to inform planning	OR	Professionals called upon after initial meetings to **provide an assessment or service**

Some factors influenced participants' level of awareness and clarity on who had been involved:

- *Where professionals attended meetings with the family*, participants were clear about their role, especially if they were already known to the family.

- *Where professionals did not attend meetings*, participants were not always sure who was involved, perhaps suggesting a need for greater transparency in this situation.

Participants sometimes knew or assumed that **professionals had a role 'behind the scenes'** – submitting a report to, or talking with, the key worker. In a small number of cases, parents themselves brought reports from relevant professionals to meetings so knew what these were. They were happy to do so if they already had these reports anyway (i.e. they were not asked to obtain them specially).

The involvement of professionals varied according to the **nature of the child or young person's needs**. Those professionals who had the most significant role in their support or care had the greatest role, for example, if the key need was around communication, a speech and language therapy professional was involved. Parents generally found this acceptable; they did not necessarily expect that all of the professionals would attend meetings and appreciated that some, particularly health specialists, could not attend due to their workload.

Involvement of professionals varied more by individuals than by area. Most participants reported the involvement of a range of professionals; only a very few had contact with only one professional. The only area in which we could identify a fairly consistent process was Area L, in which all participants received a visit from a social worker to check that the home environment was suitable for the child or young person, and a number of reports were requested by the key worker from different professionals, to inform the plan. As a general rule parents appreciated the involvement of multiple professionals but understood the constraints on this happening in practice.

Joint working by professionals

In terms of joint working, a key aim of the pathfinder, participants focused on how professionals **worked together at meetings** and the benefits of multi-agency

attendance. There were a limited number of comments on evidence of joint working taking place **outside of these meetings**.

Joint working in multi-agency meetings

Positive experience of multi-agency meetings

Participants generally found multi agency meetings a positive and valuable experience. They felt that professionals communicated well and listened to each other's views. Benefits of this included:

✓ **Sharing ideas** about how best to support the child or young person:

'And like [paediatrician] would bring up that [Child] should be maybe doing more activities [exercise] outside of school, which is then when [key worker] would write it down as a target. And then go, 'well I can look into this', and they'd also go, 'yes we will as well', and yes, because it wasn't about one thing, it was like a general of everything, I don't know, I found it better.' (Carer, Area O, 16-25)

✓ **Opportunity for parents to meet professionals**:

'It was nice to meet people you didn't know [before], or you didn't know what their role was.' (Mum, Area P, 5-16)

Participants thought that having professionals agree to undertake actions in front of each other made them more likely to follow through on these actions, that is, there was a sense of **increased accountability**:

'Straightaway, in front of parents, [professionals] were allocated things to do...if it [hadn't been] written down and [typed up], [then] they wouldn't have known what actually happened. So everybody knew [what they were supposed to do] and they couldn't go back to saying, 'oh, I didn't know that'.' (Mum, Area P, 5-16)

The meetings also enabled professionals to **build relationships** as a basis for working together:

'I think that's good because the school need to know that it is part of the bigger world outside of the school, because like any organisation you belong to becomes insular after a while, you just think about yourself only, so to have something outside to say, 'well look you are part of this as well'. So I think from that thing, from that point it is good. And hopefully it means now that future ones, from now on, the school and the local authorities will work better together on this whole involvement and benefit from it.' (Dad, Area O, 16-25)

Participants found it helpful if professionals **prepared in advance** for the meeting:

'Everybody said what they were going to do. So they knew- It seemed to me they all knew beforehand what they have to do, what they were going to do, which they came out in the meeting and then more notes were made.' (Mum, Area P, 5-16)

Negative experience of multi-agency meetings

When participants were dissatisfied with multi agency meetings this was because **not all of the relevant professionals** attended:

'[OT] was meant to have ordered it all [special equipment for child] and it's not happened so it would have been useful to have her at the meeting to discuss that again. That's the, those are my concerns is actually getting everybody together, I don't know how that works, because it would be, it's very beneficial having everyone involved with his care in one room, but the likelihood of that happening is quite low I think.' (Mum, Area M, 0-5)

There was also one example where professionals had not turned up to the meeting as expected.

No multi-agency meetings

Some of the few participants who had *not* had a multi-agency meeting thought it would have been useful, for the reasons given above.

Others felt that it was not necessary. Instead, they or their key worker obtained the views of other professionals through reports or conversations. Others noted that there was no new information that the lead person did not already know (for example, the child's health needs had not changed).

A couple of participants said that they actively preferred not to attend a multi-agency meeting themselves, because they felt that they would have found this to be a daunting experience. They appreciated that their key worker had done this on their behalf.

Joint working outside meetings

Participants offered few examples of joint working happening as a result of the plan; this is not to say it was not occurring, but it was not highly visible to participants, again suggesting a potential need for more communication with parents as to who was involved and how. Participants who felt they had *not* seen improved joint working suggested the following evidence of this:

✘ **Insufficient information shared between professionals**. In one case the draft plan was sent by the key worker to a prospective new school, which rejected his application on the basis of the plan. The parent felt that the draft plan did not include sufficient detail to describe her son accurately, so she requested that the detailed reports which had fed into the draft were sent to the school. They offered him a place on the basis of this information.

✘ **Conflicting messages** about entitlement to services. At a multi-agency meeting one parent's request for Direct Payments was agreed; subsequently her social worker, who had not been at the meeting, told her she was not entitled. She felt that had the social worker attended the meeting, this disappointment could have been avoided.

✖ **Onus on parents** to request or chase up referrals. One parent asked at the planning meeting for a referral to a health specialist, having unsuccessfully pursued this with her GP, but, *'she just told me to ask my GP.' (Mum, Area O, 5-16).*

✖ **Lack of clarity on roles and responsibilities**, experienced by parents and professionals:

'Half the time I don't know who I am ringing for what thing. But I have to try and find out who I need to ring, where it would be nice if they actually said right, and a job description for everyone because [...] there are so many people involved.' (Mum, Area M, 0-5)

'I don't think anybody in the early stages knew what the other professionals expected of them. This could be because the pathfinder was very new to them, or because this was the first time that [organisation] had worked with [organisation].' (Mum, Area P, 16-25)

Child/family-centred focus

The vast majority felt that their experience had been child- or family-centred. Parents frequently felt that professionals were working in the interests of their child or young person:

'They were all just… they were all in [Child's] corner.' (Mum, Area Q, 5-16)

Interactions with professionals

Parents' interactions with professionals were key to their sense of a child-centred experience. Factors that made parents feel this included being:

✓ listened to during meetings

✓ able to speak freely, give their opinions and be honest about their needs and concerns

✓ able to ask questions.

Professionals fostered these positive feelings through their behaviours and practices, for example:

'There was a lot to take in but she was very thorough, she asked if we'd got any questions but she did go over it quite a few times just so that we had the basic sort of information really of what was going to happen and how the plan worked. So she was very good actually, she wanted to make sure we were, we knew exactly what was going to happen and that obviously we can contact her any time so we had her email. And we could ask her anything really. (Mum, Area L, 0-5)

Families found it helpful when professionals:

✓ Allowed enough time for discussions and took notes to show that they were listening

✓ Had a sympathetic manner

✓ Placed families' views high on the agenda, and recognised the value of parents' insights into their child or young person's needs

✓ Considered the views and needs of other family members, including siblings

✓ Were accessible between meetings (e.g. providing a mobile number)

✓ Pitched communications appropriately for the child or young person:

'They understand [Child] is different, so they might, you know, talk to her differently - not like she's a baby, but, you know, maybe for her to understand better.' [Carer, Area O, 16-25)

Direct involvement of children and young people

The majority of children and young people did not participate directly in the process, because of their age or the nature of their additional needs. However, where it was possible, this was seen as very positive and empowering, as well as yielding useful information:

'They should be allowed, you know, to say what they want to do, what they think, because I might think that he wants something completely different. If I'd gone in without him I might have said something different, whereas he's actually in there, so it's his decision.' (Mum, Area P, 5-16)

There were several **examples of good or innovative practice** in involving young people:

- A young person aged 16 worked with her key worker in Area P to create a PowerPoint presentation about herself, which they delivered to professionals at the planning meeting. It included video clips and information from her Statement. She enjoyed this and felt she could express herself more confidently than she might have done in person, and provide insights into her own views and needs:

  'It's a good model for getting the older young people, at any rate, involved in their own meetings. We actually learned things about her that we didn't know.' (Dad, Area P, 16-25)

- A young person aged 17 in Area R worked with a mentor to create his EHC plan – his mum attended one meeting, but he was 'in the driving seat'. He felt it was important that young people give their direct input. This may also have had benefits in terms of developing independent living skills, at the age when young people may be moving towards greater independence and responsibility for their own care and support.

- Younger children and those less able to participate in discussions were occasionally involved in the design, like a child in Area M who chose stickers for the cover of the plan. Her mother felt this helped it to give more of a sense of her personality:

  'I think the more people can read about her and know her well and think, oh there really is a little person in there who has wants and needs and a sense of humour and is alive.' (Mum, Area M, 5-16)

Influencing the process

A few participants were asked to **have a say on aspects of the planning process**. They liked being asked to suggest which professionals should be involved, and to comment on the draft plan.

Child-centred plan document

A small number of parents reported that the **completed plan document itself** contributed to a child- or family-centred experience, because it reflected their views, described their child accurately and contained all of the necessary information.

Outcomes

Perceptions of the plan as child- or family-centred were also influenced by the degree to which it was enabling their needs to be met.

✓ Where additional support or services were received, participants saw this as evidence that the process was centred on their needs:

'It was us doing the talking and saying what we felt, and I know that they took it on board and they listened because we got the hydrotherapy out of it.' (Mum, Area P, 0-5)

✘ If there was no evidence that actions were underway or parents had to chase to get things done, they were less likely to feel they were 'at the centre' of the process.

The minority of participants who felt that they did not have a child or family-centred experience said professionals failed to provide information, and left them feeling 'fobbed off' and frustrated:

'No one is helping me. Everyone comes back and tells me it depends on what his needs are. And he said, 'Oh, I understand what you mean. I understand. I can understand why you're frustrated'. I said to him, 'You keep saying that', I said, 'but nothing changes'.' (Mum, Area L, 5-16)

The extent to which participants felt at the centre of the process did not vary much by pathfinder area: it was consistently positive across areas. Despite whether families had seen outcomes from the plan, they praised professionals' way of making them feel involved and important.

Summary

Participants reported a wide range experiences in terms of the process; it was more difficult with the second cohort than it was with the first to identify consistent approaches by pathfinder areas. Generally, it was less common to have new assessments to inform support planning, than to draw on existing assessments. There was usually a wide range of professionals involved in providing reports and/or attending meetings. Most participants had further meetings, either just with their lead person or attended by multiple professionals, at which they discussed and agreed outcomes and actions to be included in the plan.

The vast majority of families were assigned a key worker, (most often this was either a member of the pathfinder team, or a professional known to the family in a supportive role such as social worker or transition worker). There were however, variations in their role and level of input: while some dedicated much time and energy to the whole process and drove it forward, others focussed on discrete elements. In a minority of cases there were several professionals playing a 'key' role.

Parents linked the effectiveness of the key worker role to their knowledge of the child or young person, knowledge and experience of the 'system', their ability to ensure that the process was child centred and their ability to achieve a rapport and good working relationship with the family. It was deemed to be less effective when key workers were unresponsive when contacted or had otherwise failed to support families. Participants recognised that key workers' time could be limited, or that it was a new role for them which would take time and effort to become effective.

Joint working was identified as taking place principally during assessment and planning meetings; few participants were aware of joint working taking place outside meetings. Where multiple professionals had attended meetings together, this was found to be a valuable experience which resulted in the sharing of ideas for supporting the child or young person, and increasing the sense that the professionals were held to account. Participants who felt joint working had not occurred most commonly reported either non-attendance at meetings by professionals who they would have liked to attend, or poor communication between professionals outside of meetings.

Participants largely felt that their experience of the process had been child- or family-centred; a message that is consistent with the findings from last year. This was achieved by the quality of professionals' communications and interactions with them, for example allowing time for discussions, being accessible and recognising the value of parents' insights into their child or young person's needs. This year there were several examples of children and young people being encouraged and enabled to give their input into the plan in creative and innovative ways, which was well-received by families. Where children or families were receiving support or services as a result of the plan, and where these were making a positive difference to their lives, then participants saw this as additional evidence that the process was centred around their needs.

5: Views on the completed plan document

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KEY FINDINGS

- Parents liked the structure of the plan, finding it clear and easy to navigate. They also liked the presentation of the plan when it conveyed their child or young person's personality and individuality. Therefore the current design of the plan appears to be working well.

- There was widespread lack of clarity on arrangements for sharing the plan, timescale and process for updating or reviewing it and its relationship to the Statement. Again there is a communication issue to be addressed here.

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This section reports parents' views on the structure, content and presentation of the plan, their perceptions of how the completed plan was being used, and questions about the completed plan.

Structure, content and presentation of the plan

Most participants described a fairly typical plan, containing information about the child or young person, details of their support and services, proposed outcomes or goals, and actions to achieve these. Parents liked this structure and found it clear and helpful. In one case a plan produced by a brokerage firm was a short document which acted as a guide for people supporting the child. It contained an informal introduction to the child followed by a set of instructions and 'tips' for supporting her, but had no support planning section, so the parent felt it had limited usefulness.

Parents were generally content with the format and presentation of their plans, identifying many positive attributes as follows:

✓ **'About me'** information and instructional content sections such as **'how to support me'**, felt personal and were particularly helpful for new and busy professionals.

✓ Including **photos** of the child or young person and using **lively and active language** helped to 'bring the plan to life', and capture their personality.

✓ **Clear sections** and **headings** made the plan feel easy to navigate. Participants welcomed signposting in the document and the use of tables to present outcomes and actions which they could use to monitor progress.

✓ Plans were written in **plain English** and used **minimal jargon**.

✓ Some stressed the importance of plans incorporating a **sufficient level of detail**.

In a small number of cases participants were less positive about their plans, because:

- ✖ It seemed to be **unfinished**, for example, lacking actions or too narrowly focussed.

- ✖ It contained **too much jargon**.

- ✖ It had become **out of date** (for example, referring to out of date professional titles, or providing a snapshot of the child that was no longer relevant).

- ✖ Different information was not sufficiently **amalgamated** into the plan, for example, in one case the content appeared to have been simply copied from the Statement.

- ✖ Actions **were insufficiently detailed**, for example, the plan outlined *what* professionals should be doing, but not *how.*

Questions about the completed plan

Participants generally felt they would welcome more information about the next steps with their plan and about *how* the plan would be used. Questions and areas of uncertainty were as follows:

- **?** **Arrangements for sharing** – it was common for participants to be uncertain about how exactly the plan would be shared amongst professionals. For example, one participant asked whether it was her responsibility to do this, or whether it was an 'automatic' process.

- **?** **Status and frequency and process for updating** – participants were frequently unclear about the updating of their plan. Some assumed that it would be updated as their needs or circumstances changed; others thought it would be reviewed annually, like the Statement.

- **?** **Relationship with the Statement** – some participants were again keen to confirm whether the plan would replace the Statement or work alongside it.

- **?** **Completion and sign off** – a couple of parents were unsure whether the plan had been finalised or signed off, as they had not or did not recall being asked to sign it off or seeing a final version. However, for these parents there was no great sense of urgency around this, as their plans did not contain any new services so they were not waiting for anything.

Summary

Parents were generally able to describe the four broad categories of content in the plan: information about the child or young person; service and support currently receiving or required; outcomes and goals; actions to achieve outcomes. The majority of plans included all four of these sections and parents found it a clear, accessible, navigable and comprehensive structure.

The formatting and level of detail varied to some extent and plans used a number of approaches to structure the information e.g. the name of the plan, key headings, photos,

and way in which action plans were set out. Parents valued the specificity of goals and actions - who, what and when.

Once the plan was complete, participants continued to have some questions about its use and next steps, including around: arrangements for sharing and updating plans, professional accountability and the legal status of the document as well as its relationship with the Statement.

6: Satisfaction with the process of getting a plan

KEY FINDINGS

- There were a clear set of factors which helped parents to feel more satisfied with the process: parents were most satisfied where they felt their family was at the centre of the process, it was not burdensome for them, and they felt well supported by their key worker.

- Families also gained satisfaction from learning more about their child or young person, and about available options and services, through the process of making the plan.

- Where the young person was able to participate in making the plan and was enabled to do so by professionals, this increased satisfaction with the process.

- Parents were less satisfied where they had experienced delays, shortfalls in the organization and running of meetings, a lack of information about available options in terms of services, a lack of support for the key worker, a lack of buy-in or follow up from professionals, and a lack of clarity on next steps and plans for future review of the plan.

Participants reflected on their satisfaction with the process of getting an EHC plan, and their reasons for this. There was widespread recognition that they had joined a pilot, and many acknowledged that the process would be likely to improve and satisfaction increase as the new system became embedded, for example:

'Everybody works as well as they can, given the newness of the whole process for everybody. But like I say next year hopefully it should, everybody should be better informed and better used to what's going on and what is needed. So hopefully next year it will be better.' (Dad, Area O, 16-25)

Satisfaction with the process

Satisfaction varied considerably between participants, depending on their individual experiences. The following factors increased satisfaction with the process, detailed in the table below:

Table 4 - Satisfaction with the process

Factor increasing satisfaction	Reasons and examples
✓ **Being at the centre of the process**	As described earlier, it was common for participants to feel that the process had been empowering and inclusive. This was achieved by: • meeting professionals and being asked for their views • having the chance to discuss their child: *'It was a chance for me to sit down and talk about [Child's] condition and how various situations will affect her behaviour and her wellbeing and all this sort of thing you know what I mean? I'd never really until that point had a chance to do that with anyone properly.' (Dad, Area Q, 0-5)* • contributing their knowledge of their child or young person • participants also expressed satisfaction that, where possible, children and young people were enabled to give their input.
✓ **A user-friendly and non-burdensome process**	Participants often felt satisfied because they understood the aims and process of making the plan. There was a good level of understanding of what the plan was all about, suggesting that key workers and/or pathfinder teams had done a good job of introducing it clearly. A few participants thought the timescales had been appropriate (not too long).
✓ **Feeling supported through the process**	Many noted that they felt supported during the process and understood what was happening. The key worker often played a pivotal role in this by: • explaining things and reassuring parents • providing information about support and services • being responsive and flexible: *'I felt they were quite flexible, no matter what problems it was written down and they'd make sure it was seen to. No problem was too big or too small.' (Carer, Area O, 16-25)* Participants frequently praised the friendly and supportive manner of professionals, particularly key workers.
✓ **Developing a fuller understanding of the child or young person**	Participants praised how the process had brought together different perspectives of parents and professionals, which led to more thorough understanding of the child or young person's needs and aspirations. Several participants mentioned the value of looking beyond education, to the child's wider wellbeing and long term goals. The consideration of other family members' needs was also valued.
✓ **Learning more about available services and**	Many felt the process had allowed them to learn about the different support and services that were available, through conversations with key workers or other professionals.

Factor increasing satisfaction	Reasons and examples
support	
✓ **Improving multi-agency working**	As discussed earlier in relation to the benefits of joint working, participants often cited multi-agency meetings as a reason for satisfaction with the process.
✓ **Creating a single, comprehensive plan**	The completion of the plan was itself a source of satisfaction, for example: • Parents liked the fact it was a single document: *'Because I like the idea that everything is write down and you can just pick it up, one completed document and it's there.' (Mum, Area Q, 5-16)* • Parents felt it was personal and tailored to their child as an individual: *'[Child] does not quite fit in one box, he's got quite a few conditions that he's got a mixed condition and stuff like that it is hard to, he is more of a rare case so it is harder to pinpoint stuff and people like things, they like to put people in a box they can say yes that goes with that and… whereas this plan, it helps us because we can't put him in a box, it helps us get things that he needs that aren't part of one condition.' (Mum, Area L, 0-5)*

Source: Pathfinder evaluation team

Dissatisfaction with the process

The following led to dissatisfaction with the process, detailed in the table below:

Table 5 - Dissatisfaction with process

Factor causing dissatisfaction	Reasons and examples
✗ **Not knowing the options**	One source of dissatisfaction was where participants did not know the available options in terms of services and support.
✗ **Delays**	Several participants felt stressed and frustrated by delays in drafting or signing off the plan, during which they felt they were not getting an adequate response from their key worker. This was especially negative where it caused anxiety to the child or young person: *'Special needs children or young adults like to know what is going to be happening and I wanted to be able to talk to [Child] about what she'd be doing and who she'd be with. We were not able to do that because we didn't have anything.' (Mum, Area P, 16-25)*
✗ **Shortfalls in the organisation and running of planning**	Examples of dissatisfaction with meetings were: • A lack of preparatory work in advance meant that too much time was spent by professionals 'thrashing it out' to decide what the child

Factor causing dissatisfaction	Reasons and examples
meetings	needed. • Lack of clarity on who was in the meetings. In one meeting there were 13 professionals, not all known to the parent. • Meetings felt rushed (i.e. they required more than the time allocated) • The date of the planning meeting was moved at short notice, which meant that some professionals were unable to attend.
✖ The time and energy required	There were a small number of comments about the effort and logistics of attending meetings. For example, a working parent had to arrange their shifts around meetings, which relied on the understanding of their employer.
✖ The capacity to take part	A few participants noted other challenges in terms of parents' capacity; for example one parent felt that she had to keep the professionals to task at the meetings, which not every parent would have the confidence to do. Participants observed that some families, such as those whose child is newly- diagnosed, would require additional support to benefit from the process.
✖ Lack of support	A number of participants were dissatisfied with the level of support they had received, ranging from key workers who were difficult to get hold of, to (more unusually) a lack of clarity on who the key worker was.
✖ Lack of buy-in or cooperation from professionals	A few participants reported inadequate input from relevant professionals. There were a couple of examples where participants felt it would have been beneficial to have professionals at meetings, including a social worker and an OT.
✖ Sharing and following the plan	There were participants who were happy with the content of the plan but felt that there had been a lack of follow up work to ensure it was shared and followed up. For example: *'It was just like we'd gone through all that for it just to sit on somebody's desk somewhere, so that was actually quite annoying.' (Carer, Area N, 5-16)* In one case a parent felt that important details had not been incorporated into the plan so that when it was shared it did not present an accurate picture of her child's needs.
✖ Lack of clarity on next steps or review of plan	Many participants were unclear about when the plan would be reviewed and who, if anyone, would be accountable for ensuring actions were undertaken. Many parents were poorly informed and/or confused about timescales and accountability: *'I mean when it came out to me you know you have to, any bits that you are not happy with or you think should be added to it you put in, so one of the things I wrote on it was "not receiving Direct Payments", but of*

Factor causing dissatisfaction	Reasons and examples
	course that's never been mentioned because it was never, that part of it wasn't reviewed and I don't, and I don't know whether it was, it's going to be, the whole thing is going to be reviewed, the health bit of it is going to be reviewed in July or whenever it is because that would be 12 months into it.' (Mum, Area Q, 5-16)

One cause of dissatisfaction mentioned by participants in the first cohort was a lack of actions in the plan. There were very few in the second cohort who reported that their plan was only a descriptive document, rather than an actual plan, suggesting that plans were more consistently including this vital planning aspect

Summary

Participants were satisfied with the process when it felt child- or family-centred, was user-friendly and non-burdensome and they were appropriately supported to contribute. Participants also noted the direct involvement of the child or young person as a source of satisfaction. Participants tended to be satisfied where it had helped parents to develop a fuller understanding of the child or young person, learn more about the available services and improve multi-agency working.

Participants were typically dissatisfied when they were unclear on their options in the support planning stages, they encountered delays and a lack of updates, the process was not being well led, there were shortfalls in the organisation and running of planning meetings and the time and energy required of parents was more than expected. There was also dissatisfaction when there was a lack of input from relevant professionals, the plan was not adequately shared and actioned, and parents did not know when it would be reviewed.

7: Delivery of services

KEY FINDINGS

- Parents appreciated having a choice in terms of services, such as choosing a school or a carer (personal assistant, buddy or one-to-one worker). They felt they were able to make a judgement of these kinds of services, as opposed to services relating to health and medical matters, where expert professional input was highly valued.

- Nonetheless, there was a need for support in choosing services, such as a professional to go with them to view potential schools or help them consider options around transitions. Parents did not want to feel they were left to take important decisions alone.

- Key workers and other professionals were key sources of information, although parents also valued printed information. A combination of face to face support and printed information may work well to support parents in choosing services.

- Many families did not gain new services because they were not needed; some benefitted instead from changes to the way they were supported at school or at home by their parents. It is important to include both services *and* support in considering how to meet children and young people's needs.

- Above all, parents wanted to be kept informed with progress in terms of trying to gain new services or support. Even if services were not being delivered, parents were more content when they knew that actions were underway, that someone was accountable and that there was a defined timescale in place.

This section outlines the kinds of services and support that participants obtained by making their EHC plan, as follows:

- **Extent of choice and information** on the availability of services
- **Changes to services and support** following the plan
- **How satisfied participants were** with their services and support.

Choosing support services

Degree of choice

Levels of choice in selecting support services varied. Factors influencing choice were:

- Many families noted that current services and support were working well and they did not need new ones, so **choice was not relevant**.

- A small number felt that having **provision in place was more important** than choice:

'We weren't worried who it was, as long as there was someone in place for him, that could help him.' (Mum, Area L, 0-5)

- That said, participants appreciated having a choice in services about which they felt **able to make a judgement**, with schools and carers the key examples of this.

- **Choice was necessarily limited** by availability of resources and amenities. Another limiting factor, reported by one parent, was that a school with academy status was not legally obliged to implement the plan (from September 2014 all Children and Families Act provisions relating to EHC plans will apply equally to schools with academy status).

Direct payments

While a number of participants came to the pathfinder process with Direct Payments already in place, for three participants the pathfinder process had enabled them to secure Direct Payments for the first time or to increase their payments. For the families receiving them, Direct Payments were considered an important part of the support package, enabling them to have a choice of services:

'All we wanted was to carry on with the Direct Payment; we were not looking for a drastic change in support.' (Mum, Area P, 0-5)

One participant was frustrated having previously received Direct Payments and then, on moving to a different local authority area, no longer being entitled to them. This reduced her child's level of choice:

'[With Direct Payments], [Child] could do what she wanted to do, whereas now she goes to this club and she has to do what everybody else is doing, either that or she doesn't go.' (Mum, Area Q, 5-16)

Having a choice over the individual professional delivering the care was also considered to be a significant factor in the quality of care received by the child/young person. There were examples where Direct Payments were used to secure the most appropriate carer including:

- A trusted family member to provide overnight respite

- A professional trained to deliver the child's medication

- A carer of a similar age to the young person, enabling them to undertake fun, active and age-appropriate activities

However, Direct Payments were only useful in circumstances when the family had sufficient availability of care locally, and knowledge of care options. For example, one family living in a rural area were unable to recruit a carer and would have welcomed more support and guidance around this.

Information on available services

Need for information

Information on available services was not always needed by parents, for example when a) they did not need new services or b) they were content to let the school lead on support and services.

Participants requiring new services, such as at transition points, generally felt that they wanted information and advice in order to make choices or to enable them to give their informed opinions.

It was noted by a few parents that some may have greater need of information and help than others. These were parents with limited English, and parents who are new to 'the system':

'I reckon if you spoke to [parents of] older children they would probably have better information for you because they would have had the Statement for a while and probably understand it better because when you, I think I am still quite new in this whole journey with [my child].' (Mum, Area M, 0-5)

Sources and sufficiency of information

Experiences of gaining information on available services were reported as follows:

✓ **Multi-agency meetings** were a useful source of information, as having more professionals in the room brought a range of knowledge about local services.

✓ The **key worker** was a good source of information; in some cases the key worker was felt to have gone 'above and beyond' by researching and signposting families to services.

✗ A small number would have liked **printed information** to read at home when they had time.

✗ Participants who would have liked to have more information and support mentioned:

- choosing a school – several were given a list of potential schools and asked to choose one, but would have liked support in this, such as a professional to accompany them on visits to schools (particularly parents of 0-5s choosing their child's first school).

- availability of local leisure and social activities,

  '…where we could go and get extra… just to help [Child] to get out of home and do a bit more socialising.' (Mum, Area P, 5-16)

More rarely, parents gained information by **word of mouth** from other parents, parent support groups, voluntary groups or disability charities, and internet research. This was often associated with a sense of dissatisfaction, because they felt they had had to do the work themselves.

It was not possible to categorise experiences of choosing support by area or age group; key factors in determining levels of choice and information were, as mentioned, need for new services, their availability, how proactive parents were, and how well-informed their key worker was.

It is likely that the SEN Local Offer, which all local authorities are currently developing and will have in place from September 2014, will help to clarify the availability of services locally.

New services and support

Attribution of new services to the plan

Assessing the difference that the plan made in terms of services and support was complicated by the following factors:

- *Participants were not always able to quantify services*, for example how many hours of a service per week their child received, especially when services were delivered at school.

- *Participants did not know whether they would have got a new service regardless of the plan*, again particularly for services in school:

  'I think the physio and the OT [occupational therapist] work hand in hand at the school so I think she'd have probably ended up with it anyway.' (Mum, Area Q, 5-16)

- *Transition was concurrent with the plan.* For children transitioning, it was not always clear whether things would have gone differently had they not had an EHC plan. Several families made their plan at the same time as the child moved to a new school, which naturally resulted in changes to services and support provided at school.

- *Other changes were concurrent with the plan.* Examples included a family who moved area and one who lost a parent. This family had a Team Around the Child (TAC) and did not know whether the plan had driven changes, or the professionals already working with them.

Families did not tend to *cease* receiving any services or support; in relation to *changes*, the following experiences were reported.

1. No new services

Circumstances in which families did not receive new services were as follows:

- **Happy with existing services and support** - families who did not need anything additional to their existing package.

- **Expecting new services soon** - families who had not *yet* received new services or support, but hoped to soon. Examples included a home visit to help with toilet training; respite care; classroom assistant support; educational psychology assessment and accessing a group for deaf children.

A small number had not been told whether or when they would be receiving the hoped-for services. A couple of parents had been made aware of a service they could apply for, but had not yet done so (an example of this was respite care for a sibling)

- **Anticipating future services** - one family thought that the EHC plan may prove useful in future when planning services in adulthood.

2. Increase in existing services

Examples where participants had an increase in the amount of an existing service were:

- Increase in number of **sessions** (of hydrotherapy; of an exercise class)

- Increase in carer/respite **hours** (three families had an increase, while one had a reduction in hours but which were then delivered by a more specialist professional).

3. New services

Which new services families received **depended on the child or young person's needs**, and examples each given by one or two families included: DLA and/or Direct Payments; local leisure/social activities; a 'buddy' to go on shopping or cinema trips with; a carer to accompany a child on a visit to family abroad; and school transport (when starting at a new school).

Some of these families noted that they would not have known about some of these services, had they not been suggested by professionals during the planning process, highlighting the usefulness of the planning process for identifying new services.

Where the plan coincided with a **change in educational setting**:

- Parents felt unable to say whether the plan had a role in this; usually the transition was underway before the plan process began.

- There was just one parent who felt that the EHC plan had been instrumental in obtaining a school place. The school saw the draft plan and accompanying professionals' reports, then came to observe the child before making their decision.

New services tended to be less directly associated with education or health, compared to those reported by the previous cohort when some children and young people accessed new services such as occupational therapy or educational psychology.

4. New support

Some families got additional *support*, in a more informal sense, as opposed to *services*. This included practical actions to be undertaken by parents or schools; these were important to families as they had the potential to make a difference. Examples included:

- **Parents learning to support their child or young person**, such as by implementing approaches at home that are consistent with those used at school (for example, using PECS Picture Exchange Communication System).

- **Schools making adjustments or adopting techniques** to support learning, such as moving the pupil to a quieter class, allowing extra exam time, providing a scribe reader, and supporting the development of 'life skills', for example, with travel training.

In the first cohort of families, more participants talked about degree of **parental engagement** with their child or young person's needs and services, and **parents' confidence, skills, time and energy**, influencing their likelihood of accessing services. In the second cohort, there seemed to be less evidence of this; we could hypothesise that this indicated that key workers were driving the process more effectively, so that parents' personal effectiveness was less significant.

Sufficiency of and satisfaction with support and services

Participants who had received or expected to receive the services in their plan were happy with this; naturally where they had not, they were less satisfied. Some participants had outstanding needs that were not addressed within their plan. It was difficult to isolate patterns in the findings because of the great number of variables affecting each participant's individual situation, but this section gives a sense how far services were being delivered.

1. Receiving the support and services in their plan

The majority of participants (over two thirds) were receiving the support and services in their plan:

✓ Around a third of participants reported **no change** to previous services and support because none was required. However, a few parents felt that having these documented in the plan offered a sense of security that services would continue in the future:

'I think we are happy that we actually got [services] in the first place [i.e. before the plan] to be honest. We just wanted to make sure there was, it was someone there concrete to help him with the physio, with the speech and then we were happy that they would be there on a regular basis, on a continual basis really.' (Mum, Area L, 0-5)

✓ About a sixth of children and young people had **moved school** to one providing better services and support (as noted on the previous page, only one family clearly attributed this move to the plan; for others the transition had already been underway).

Generally participants receiving services were happy with these, except where:

✗ They were **not satisfied with the amount of a service** they were receiving – including respite, with parents wanting more hours. One parent felt that her young person did not have enough hours at college. A parent who had reduced respite felt unable to challenge this:

'We feel like we didn't want to push it because mentally, we just couldn't be bothered.' (Mum, Area P, 0-5)

A small number noted that while they were happy with their services, they had chased up professionals themselves to get this result. This may imply that the system is still being embedded and/or accountability structures still being developed to ensure deliverability of actions in plans.

A few reported that while actions in the plan had been implemented and they were happy with this, they were not sure what would happen next. One parent said that the plan only applied while her child was in nursery; on starting school, they would have a Statement instead. She would like to add new actions into the plan but was unsure of its status.

2. Not receiving the support and services in their plan

There were a range of support and services included in plans, but not actioned. These were **specific to individuals** and ranged from small to quite significant services, including: travel training, toilet training, day club, sensory therapy, educational psychology assessment, respite for a sibling, and an appropriate school placement:

'Poor little fella wants to go to school and all these bits of paper that they've spent weeks and months doing is just a waste of time really.' (Mum, Area L, 0-5)

✓ If parents were aware that actions were underway to put services in place, they were generally happy with this – showing the importance of keeping families informed:

'None of it has been delivered but I do know it's in hand because I've had phone calls from people saying, 'I haven't been able to get it to you but I haven't forgotten about this', which is nice. I feel like it's not just on the backburner or I'll do that later. Somebody is doing something about it.' (Mum, Area P, 5-16)

✗ When they didn't know when or whether things were being actioned, this led to frustration and disappointment. For example, one family's key worker had left post and not been replaced, therefore they did not know what would happen regarding their plan.

In a few cases it was reported that a **school was not acting on their commitments** in the plan, such as making changes to the way that they work with the child or young person in school.

3. Support and services not in the plan but still wanted

A couple of participants continued to feel that they needed some services or support that were not included in their plan. Examples were specific to individual families and included Direct Payments and specialist health services.

A small number of participants could not specify what was lacking, but simply felt that they had not received anything and were unhappy with this:

'I've just got one thing to say to that: what support?' (Mum, Area L, 5-16)

A few parents noted the limitations imposed by availability of local provision:

'No matter what plan you have in place, it's whether or not they are going to have the places and spaces for him to attend things and do things.' (Dad, Area O, 16-25)

Summary

When it came to choice of services, many did not feel they needed a choice because they were already happy with their services or were happy to accept the advice of their child's school. Parents appreciated being able to choose where they felt they had the ability to make a judgement on services, such as choosing a school or carer, but wanted support in doing this.

A few families secured new or increased Direct Payments through the plan which increased their ability to choose services and support. Families who had Direct Payments valued the element of choice this offered, but noted that families needed advice and information about availability of services locally to enable them to choose how to use their Direct Payment.

Participants generally felt that their key workers and other professionals had been a good source of information and guidance in choosing services, especially at meetings. However, some would have liked more information to help them make informed choices.

Many participants had not received new services, because they were happy with their current services. Some were awaiting services which were included in their plan but not yet in place. Some had increases in their existing services (such as additional hours of respite or carer time), or new services that were suggested during the planning process. Others had new support, rather than formal services – such as a school agreeing to work differently with a child.

Types of services and support varied according to individual needs. Attribution of new services to the plan was complicated by factors such as transition or other changes of circumstances.

Participants who had received the services in their plan were mostly happy with them; often these were participants who had already been happy with their services and not required any change; another group of satisfied parents were those whose child had started a new school where their needs could be met.

There were parents who were unsatisfied because they wanted more hours of a certain service, or because they had not received services that were included in the plan. A few participants had outstanding needs that were not addressed within their plan.

8: Comparisons with previous processes and with expectations

KEY FINDINGS

- Parents compared the process of getting an EHC plan favourably with that of getting support under the previous system, which for most was the Statement.

- EHC plans were strongly preferred to Statements for their wider scope, including aspects of support beyond education: health, social care and the wider family.

- However, on the matter of legal status of documents, parents preferred the Statement for its clear legal status. They were keen to understand whether the plan had or would in future have the same legal status as the Statement currently has. This aspect needs to be more clearly and consistently conveyed to parents as uncertainty on this point was widespread.

- Expectations that the plan would be a family-centred process, involving a range of professionals were widely met, while expectations of securing additional services and support were less consistently met, suggesting that key workers should take care not to unduly raise expectations.

This section describes how families perceived the EHC plan process in comparison to their experiences of previous assessments and plans, and in comparison to their original expectations

Comparison with previous assessments and plans

Comparison to previous overall system

Participants reflected on the overall 'system' *prior* to the pathfinder, and observed that:

- It was a more **fragmented** system in which professionals worked independently of each other, and were less likely to share information and work collaboratively.

- Information was **less accessible** (e.g. more use of jargon) and felt less 'owned' by families.

- The most **confident and knowledgeable** families got the best support and services.

- Processes were not **family-centred** and provided fewer opportunities for **co-production**.

Comparison to Statement

Many participants compared the process and outcomes of the Statement to those of the EHC plan (with the exception of parents of 0-5s who did not have a Statement).

Participants identified key strengths of each process compared to the other, outlined in the following table:

Table 6 - Advantages of EHC plan and Statement

Advantages of EHC plan	Advantages of SEN Statement
• Broader and more holistic (not limited to education, and drawing on the input of more professionals including health) • More accessible and free of jargon • More detailed and specific on goals and actions • More involvement of families in the process • More regularly updated (in theory) • Efficient use of time through multi agency meetings (professionals' and parents') • Enables more long-term planning (0-25)	• Clear legal status with impact 'guaranteed' • Transferability from area to area if family moves • Updated annually

Source: Pathfinder evaluation team

A small number of participants compared the EHC plan favourably to **health plans** and **individual education plans** (IEPs), which tended to be fairly instructive, and focus on specific needs:

'We had a health plan which was completely sort of based around [Child's] seizures, so we had the health plan. If this happens, you call 999 or if this happens you go to the children's assessment unit, type of thing.' (Mum, Area M, 0-5)

Comparison of experiences compared to original expectations

The pathfinder was fairly consistent in meeting participants' expectations of the *process*. When it came to the expectation of receiving additional services and support, the results were more mixed:

- One of the most common expectations of the pathfinder was a more **family-centred process**: *in nearly all cases this was fulfilled.*

- Where the motivation was securing **additional services and support**: *results were mixed, with roughly equal numbers saying this was achieved or not.*

- Where (less commonly) participants hoped for more **joined-up working by professionals**: *achieved in some cases; others felt it was too early to say.*

- In cases where the main expectation was to obtain a new **school or college placement**: *largely achieved although, as explained, participants were unsure of the plan's role in this.*

The following table shows why participants felt their expectations were exceeded or not met:

Table 7 - Why expectations were exceeded or not met

Exceeded expectations	Did not meet expectations
Participants felt the pathfinder had exceeded their expectations where they: ✓ Quickly received new services ✓ Got services and support that they hadn't expected ✓ Learnt more about their child ✓ Were at the centre of the process and empowered by taking part ✓ Saw engagement of a range of professionals ✓ Experienced the process as efficient and user friendly, which compared favourably to the Statement process	Where the process was worse than expected participants pointed to: ✕ Lack of clarity about the status of the plan (including when it would be finalised and reviewed) ✕ Process required time and effort and did not lead to tangible benefits. ✕ Lack of broad scope and holistic focus anticipated ✕ Professionals were not sharing and working towards the goals and actions of the plan ✕ Plan had not been updated to reflect changes.

Source: Pathfinder evaluation team

Participants in the second cohort were less likely than those in the first cohort to report that the onus was on them to produce the plan and take forward actions. However, participants raised questions about whether the new approach would be feasible in terms of resources when rolled out to all eligible children and young people.

Summary

Comparing experiences of the EHC plan to those of other assessment and planning processes, participants often recalled a more fragmented 'system' in the past, where professionals tended to work more independently and where information and documents were not shared. Many felt that prior to the pathfinder, information and support was scarce and they had to 'fight' for services. They described a system which was difficult to navigate, not equitable and where services were poorly joined up.

Comparing the plan to the Statement, parents felt that plan offered a more rounded and holistic package of care and goals. Statements were often seen as more narrowly focused on educational needs. When creating the plan participants were more likely to feel 'at the centre' of the planning process, compared to Statements. However some participants liked the clear legal status of the Statement and its 'transferability' if they were to relocate.

Participants mostly had clearly stated expectations about joining the pathfinder. Where their expectation was around being part of a better process, that was more family centred and with more engaged professionals, the pathfinder achieved high levels of success. However where the main expectation was around securing additional services and support, the pathfinder had mixed success, with roughly equal numbers saying that this

expectation had or had not been achieved. The pathfinder exceeded expectations when it led to new services and support straightaway, especially those which parents had not thought of before. Participants also felt that their expectations had been met where the process was efficient and user friendly, and where professionals had made particular efforts to ensure that they were listened to and genuinely involved.

9: Outcomes experienced

KEY FINDINGS

- Just under half of families reported experiencing improved outcomes; this number should be taken in the context that not all families needed new services and therefore did not expect new outcomes. There were also families for whom outcomes were also anticipated but not yet realised.

- Outcomes tended to be specific to individual children and young people depending on their needs, but included improvements in relation to education, health, social interaction and overall wellbeing.

- The biggest single process that is likely to lead to positive outcomes for children was moving to a new school, which about a sixth of participants in the qualitative research had experienced. However in most cases parents were unsure of the exact role of the plan in this, suggesting that the extent to which the plan drove changes in education setting was not clearly articulated to parents by professionals involved.

- Parents derived reassurance from having the plan in place and seeing their child or young person thrive. They also gained confidence in their own ability to support their child, suggesting that this is an important and worthwhile aspect of the plan.

This section outlines the kinds of outcomes experienced by children and young people and their families as a result of the pathfinder. This includes outcomes resulting from changes to their services (for example, additional hours of therapies, respite care) and support, as well as outcomes resulting from participating in the process.

Extent of outcomes

A little under half of participants reported outcomes for child or family (which was consistent with families in the first cohort).

Factors which influenced whether or not a participant could identify an outcome were:

- **Whether the plan had led to any changes in their service or support**. When it did not lead to changes, families were less likely to feel the pathfinder had led to outcomes.

- **How recently the plan had been finalised** - around a quarter of participants perceived that their plans were unfinished or said they were very recently finalised. For others, additional support written into the plan had not yet been delivered. These families felt it was too soon to see outcomes but thought they may occur in future.

- **The timing of services and support outlined in the plan** - some plans focused on forward planning, including support and services not intended to come into

immediate effect. This was the case for young people planning a future transition at 16.

As noted already, it was not always possible to attribute outcomes to the plan. It was sometimes unclear to parents whether outcomes would have happened anyway, through an alternative process or a change in educational setting.

We were unable to compare the extent to which outcomes had been achieved between pathfinder **areas** due to the greater influence of the wide range of factors specific to each child/young person (such as: the level of child's needs; previous support received; timing of service delivery).

In terms of trends across **age groups**, parents of *younger children (0-5)* often reported that it was too soon to comment on outcomes or that they could not attribute new support to the pathfinder. Parents of children in the *middle age range (5-16)* felt that their child's support had remained largely the same. Parents of *young people (16-25)* more commonly reported outcomes resulting from an increase in services or a transition in educational setting.

Child and young person outcomes

The pathfinder was seen to improve outcomes for some children and young people, through the provision of services and support and the process of making a plan. Positive outcomes related to children and young people's health and wellbeing, opportunities for social contact, independence, confidence and education.

New or increased services
New and increased services commonly led to improved outcomes, for example:

✔ Where the plan supported a **transition** to more appropriate education setting. This included from mainstream to specialist education and vice versa, and moving classes within the school:

'She's just more focused in her work. She's asking more questions about things.' *(Mum, Area P, 5-16)*

✔ When children gained new or increased support or services (commonly, but not exclusively, at school) this led to improvements in **health and wellbeing**:

'Now [child] has hydrotherapy once a week, before it was twice a term. It's an improvement in that she gets pleasure out of it, and she is a person who doesn't get much pleasure in life.' (Mum, Area P, 0-5)

Additional one to one support drove **learning and development**, for example in speech and language, reading and writing.

✔ When children and young people received new or an increase in Direct Payments and these were used to access **new experiences** (for example, spending the night

away from home) and **fun activities** (swimming, playing pool, going to the gym); and to build independence, confidence and life skills:

'Sometimes they go out to a café and have lunch. That's part of [being independent], you know like go through the menu, picking out the choices and then paying for your own meal.' (Mum, Area P, 16-25)

However, few participants reported gaining access to community clubs and activities, as some had hoped to at the outset. Some noted there had been a reduction in the provision of opportunities for children with additional needs generally.

Improvements in existing support

As well as the formal delivery of services, some children and young people experienced other positive outcomes. Action planning could:

✔ **Improve the techniques and strategies used by parents** to support their child to become more independent:

'Like with the washing machine or anything she needs help with and I ask her first off have you tried yourself, and if she says yes then that's when I offer her help, but when she says no I say well I'd like to see you do it first before I go helping you.' (Carer, Area O, 16-25)

✔ **Drive progress towards outcomes in an area of existing support** by setting out clear objectives for learning and development as well as **'softer' outcomes** relating to social interaction:

'[An outcome to] encourage friendship and how that was going to be achieved and it's obviously been achieved because the other children absolutely love him, he keeps getting all these party invitations.' (Mum, Area L, 0-5)

✔ **Improve consistency of care** between different professionals and therefore drive progress towards a common goal. For example, all school staff working with a child whose goal was to 'develop social skills, make friends and initiate peer interactions' were instructed to give the child independent time with peers without an adult present.

Other outcomes

Less frequently, the *process* of making an EHC plan led to positive outcomes for the child or young person, for example:

✔ When the child or young person could attend meetings and voice their own opinions, this built their **confidence around professionals** and ability to express their views:

'As the meetings went along I felt like she was hosting it, you know, because she got more comfortable with everyone there.' (Carer, Area O, 16-25)

Taking real ownership of the process was an **empowering** experience for some young people:

'*It's my plan.*' *(Young person, Area R, 16-25)*

✓ A few young people reported that the plan led to a reduction in the time spent explaining and repeating information to new professionals supporting them.

Parental and family outcomes

Where children experienced improved outcomes this in turn had a positive impact for their parents and wider family, as parents were happiest when they saw their child engaging with the world and achieving. Some parents reported feeling more able to cope, less stressed and more reassured that their child or young person's needs were being met or would be met in the future.

New or increased services

New or increased services had a direct positive impact for those families who received them. An example experienced by several families was:

✓ When their child was **in an education setting most suited to their needs,** parents experienced improved relationships, performance at work, and mental health.

'Twelve months ago my life was on pause until we got it sorted out. Now we're just much more relaxed. I think both of us at one point were at the point of losing our jobs.' (Dad, Area Q, 5-16)

Other examples were specific to one or two individual families, for example:

✓ **Better supported** and therefore feeling more able to cope, having gained extra respite or support from a personal assistant. One parent felt less worried about their child's safety, because they spent more of their independent time with a personal assistant or 'buddy'.

✓ More **confident in their child's care,** when they had **choice** over who delivered it. One child's parents chose a care team who are trained to administer her medication; now they feel secure enough to spend time away from the home when she is in their care.

✓ **Reduced financial burden**, through access to Disability Living Allowance, Carers Allowance or increased Direct Payments.

Improvements in existing support

Goals and outcomes in the plan, and details of how these would be achieved, by whom, and by when, gave parents:

✓ **Peace of mind** that their child was receiving effective care:

'It's reassurance…to know that people are trying their best. And it is all written down for you black and white you know what [child] needs to meet, when she should meet it.' (Mum, Area M, 0-5)

✓ A clear **understanding of the needs** of their child or young person, and more **accurate expectations** around their progress.

Other outcomes

The *process* of making the EHC plan also led to positive outcomes for parents and families, including the following which were each reported by a small number of parents:

✓ **Reassured that 'things were happening'** and professionals were accountable:

'Sometimes you feel they're not going to do anything about it. But because I'm getting feedback, you know it's not being forgotten and it's a positive outcome.' (Mum, Area P, 5-16)

✓ **Became more confident as carers**:

'I'm confident that we're going the right way you know what I mean? And, you know, onwards and upwards, I can see her maturing and growing and, you know, I can see that she's easier to deal with.' (Dad, Area Q, 5-16)

✓ **Less burden and effort**, including less repetition of information to new professionals and time spent chasing professionals and keeping track of paperwork; better connection to professionals, particularly the key worker as a single point of contact, and having to attend fewer appointments as multi agency meetings allowed professionals to discuss issues:

'You're not having to repeat the information over and over again and it can be quite depressing having to go back over, like, the history of your child's disability or illness.' (Mum, Area P, 5-16)

✓ **Empowered by the process** of making the EHC plan, through which they had become better informed and able to influence the care of their child or young person.

There were a number of positive outcomes identified by families in the second cohort, which were not reported by the previous cohort. Similarly to those listed above, these were 'softer' types of outcome, further suggesting that some parents benefitted from increased confidence and reassurance as the pathfinder process became more embedded. These were as follows:

✓ Felt **more secure in their package of care**. In the context of reduced local support and services, it was thought the plan would 'justify' their care package by evidencing need.

✓ Gained a more **positive outlook on the future,** where the pathfinder process initiated thinking around long term goals and aspirations.

✔ Welcomed the opportunity for their **child to be more involved** in their support planning, enabling parents to 'let go' and feel more relaxed:

'When your child has additional needs, you tend to be overprotective and you want to make everything right and do everything for them…you need to step back, which, for me last year was a huge learning curve.' (Mum, Area R, 16-25)

'It feels like I make all the decisions for them so it's nice for them to have some input.' (Mum, Area P, 5-16)

Negative outcomes

It was far more exceptional for participants to have experienced any negative outcomes from the pathfinder. A very small number reported these as follows:

✘ Reassessment led to a *reduction* **in existing support** and parents feeling less able to cope when respite was reduced from 6 hours to 5, for example.

✘ Uncertainty and **anxiety over the future** of services and support:

'This is only September to July so it is only nine months of the year…then you know in September they might say [college] are not going to be involved anymore and then all we'll have left is the Direct Payments.' (Mum, Area P, 16-25)

Summary

Just under half of participants reported experiencing some kind of outcome or outcomes (for child or young person, and/or parent and family) from their participation in the pathfinder (consistent with the extent to which outcomes were experienced by families in the first cohort). Reporting of outcomes depended on: whether the EHC plan had led to any changes in services or support; how recently it had been finalised and the timing of services and support outlined in the plan.

Where children or young people were receiving an increase in support and services, this had often led to improved outcomes, for example through additional therapies, one to one support, or a personal assistant. Positive outcomes were also experienced from the informal support provision in the plan through the process of setting goals and applying consistent approaches from professional and family to achieve them. Young people felt empowered by the opportunity to give their opinions and in some cases, take a lead on the process.

Outcomes for children and young people had a positive impact for parents and wider families too, as parents were happiest when they saw their child doing well. Other outcomes resulted from services that impacted directly on parents and families, for example families felt better supported when they received more respite care, particularly when they were able to choose who delivered this care. When the plan helped facilitate a child's transition into an educational setting most suited to their needs, it led to a range of

positive impacts for parents including improved relationships, performance at work, and mental health.

Other outcomes for parents were the reassurance that their child or young person's carers understood their needs and were providing high quality, consistent and comprehensive care; and having a more accurate understanding and expectations around their child's progress.

It was far more exceptional for participants to experience any negative outcomes, but a few reported a reduction in existing services or increased levels of anxiety and stress caused by uncertainty around the future of services, more so for the second cohort than we saw with the previous cohort. Compared to the previous cohort, families in the second cohort also reported less access to clubs and activities.

10: Conclusions

This section summarises what appeared to work well and less well about the pathfinder for the second cohort of families who took part in the qualitative research and offers some recommendations for areas moving towards implementation in 2014.

It was difficult to draw firm conclusions from the qualitative research findings due to the differences between cohort samples (including characteristics and geography), the very wide variety of experiences reported by participants, and the complex web of factors influencing these experiences. The process appeared highly variable from case to case across both age groups and pathfinder areas, making comparison and evaluation of different approaches more challenging. However, read alongside the other strands of the evaluation, including the thematic case studies and parent-carer survey, the qualitative research adds context and richness to the overall findings.

Key findings from the second cohort

In terms of expectations, in the second cohort there was slightly more consistent *awareness of the pathfinder as a pilot* process, and clarity on its intended status as a *replacement for the educational Statement*, than we found amongst the first cohort. Generally more families had *clear expectations* at the outset, suggesting that areas have developed more effective and consistent processes and narratives for introducing the EHC plan to families. The key worker was central to ensuring families' understanding of the plan, and time spent upfront explaining and answering questions was well spent in terms of families feeling reassured and positive about it. Providing a blank plan template to the family in advance of the planning meeting also helped to show them what would be involved. However, it is important to note that these perceptions of change occurring between cohorts are based on a small sample of participants and therefore we cannot generalise from these findings.

There was more mention by families in the second cohort of the scope of the EHC plan as including the *needs of the whole family*, as well as those specifically of the child or young person. This was an aspect which families found very attractive, as part of a 'holistic' approach to meeting need. However, key workers should be careful not to raise expectations around what support may be available for wider family members, bearing in mind available resources.

In terms of process, families noted the value of *involving children and young people* as much as possible in the planning process. There were several examples of innovative practice in the second cohort in which older young people were supported to play a central role in developing their plan. Seeking young people's input into their plan was seen as an opportunity for empowering young people and helping to develop their ability to express their needs and views, which is increasingly important as they move towards adulthood and greater independence. Therefore the process should seek to involve young people meaningfully and make the most of this opportunity.

Multi agency meetings were common for the second cohort and widely perceived as effective; families thought that much value was added from bringing professionals together to share and develop an understanding of the child or young person's needs and support options. Also more consistent (although not uniform) in the second cohort were *plans that included actions*, as well as identifying needs. Plans containing specific outcomes and actions (as opposed to only description of needs) were key to families' finding them useful and worthwhile.

The importance of the *key worker* emerged strongly from the second cohort. The key worker role, where played well, had a great impact on families' experiences of the process. Key workers who were supportive, accessible and effective in driving change, and who kept families informed and reassured, were highly praised. Generally (not always) key workers were seen to be providing information and support well, suggesting that the role may be becoming more embedded in some areas. However, key workers need clear accountability structures to be in place to clarify the roles and obligations of other professionals and agencies, in order to play their role effectively.

A key area for improvement by areas was around ensuring families had clarity on the *timescales and process for review* of the plan, which was consistently lacking.

In terms of services and outcomes, it is important that the plan considers both *services*, in the sense of formal services delivered by professionals, and *support* for children, young people and families, in the sense of supportive actions and strategies implemented by schools and parents in collaboration with professionals. There were benefits to be gained from these kinds of actions by schools and families, such as implementing consistent routines and techniques.

Parents in the second cohort expressed *anxiety around cuts to funding* for local services for their child or young person, in the context of the wider climate of austerity. Prior to involvement in the pathfinder, participants had already experienced the effects of this in terms of reduced access to services and changes to the professionals supporting them. There was a sense of reduced access to non-statutory services such as leisure and social activities. There was also anxiety and *uncertainty about the future* in respect of a) anticipated further cuts to local budgets and b) potential further changes to policy, planning processes and entitlement criteria.

Recommendations for implementation in September 2014

Based on the qualitative research we offer a number of suggestions to DfE and local areas that are developing the means to meet the requirements of the SEN&D reforms. These relate to supporting families, professionals and commissioners to improve the experience of the EHC planning process and resultant EHC plan, and to generate positive outcomes from it.

1. Families. Professionals can effectively prepare and support families in making an EHC plan by:

- Assigning a key worker to establish and develop a supportive, responsive and ongoing relationship with families. The key worker should 'hold' the process so that families do not feel that the burden of involving professionals is on them.

- Setting out clear and detailed expectations about what children, young people and families will get from the process and why they should take part. Resource and other constraints should be explained: families will not necessarily get everything they want.

- Letting families know what is expected from them, including what kind of time and effort they will need to put in. Linked to this, what provision is available for parents who need extra support to participate (e.g. an advocate, or extra time with the key worker).

- Communicating and adhering to timelines for producing an EHC plan, and clear steps along the way. In particular, the process and timescale for updating or review of the plan, as many parents were unclear on this.

- Ensuring families understand the legal status of the EHC plan, so that they know what it means in terms of their ability to secure services

- Ensuring that families are kept informed throughout the process: of which professionals are involved and how, what is happening 'behind the scenes', and the causes of any delays or changes. This will help to mitigate parents' anxiety.

- Providing information on what services are available to children, young people and families, for example a 'brochure' of services in different categories. This may be developed as part of areas' Local Offers.

2. Professionals. Families' experiences of the pathfinder may be improved if professionals are better prepared and equipped to support them, by:

- Setting clear expectations for the main professionals involved, including skill requirements, time commitment and logistics. This would promote a more consistent approach and lead to a more equitable experience for participants.

- Designing and delivering training packages for professionals, for example, how to get the best out of support planning meetings.

- Providing templates and example plans so that a consistent format is used and a clear standard of quality set. The existing formats have worked well for participants so far.

- Developing approaches and processes which allow families with different needs and capacity to take part and benefit equally from the process.

- Developing processes and guidance for key workers on involving children and young people directly in the process, perhaps building on examples from the second cohort in which young people felt they had been supported to participate constructively and gained benefits from this process, as well as from the outcomes of the plan.

3. Commissioners. Commissioners may be better supported in their roles by understanding and clarifying:

- The necessary infrastructure and protocols required to:
    - share and update plans securely and efficiently
    - provide quality assurance of draft plans so that they are completed to a satisfactory standard.
- The legal status of the plan, and whether it can hold agencies to account to deliver services.
- The most appropriate mechanisms for ensuring accountability and buy-in from professionals, such as memorandums of understanding, guidance or statutory regulation, cost benefit data, case studies.

Next steps

Follow up interviews, taking place 6-18 months after the initial interview, will be conducted with a sample of families during 2014, in order to explore their experiences in this longer term time frame.

The sample will be drawn from participants who took part in the qualitative research in the first cohort in 2013 (reported in July 2013), and the second cohort in early 2014 (reported in this report, March 2014).

Annex A: Methodology

Recruitment of families

Recruitment of families for participation in the research started in December 2013 and continued through until the end of February 2014. OPM were sent the contact details, demographics, basic information about the child's additional needs and timeline of pathfinder participation of families in a single list by SQW via a secure data transfer network, once they had completed their education, health and care (EHC) plans. OPM researchers identified families to invite to participate based on comparing the target sample agreed with SQW with the sample achieved to date.

This was followed by conversations with pathfinder leads which aimed to find out more about these families, including details of the child or young person's special needs, whether the child or young person would be able to participate and what support may be needed, and their participation in the pathfinder to date. These conversations helped ensure that we were able to tailor our research methods and approach to the needs of the families involved. For example, pathfinder leads often suggested that an easy read version of the questions be sent in advance so that parents and carers could work with their children to understand the context and purpose of the research before the interview. Families were then sent invitation letters and this was followed by recruitment calls and confirmation letters.

Sample of participating families

The cohort of families in this sample was drawn from seven pathfinder areas, which began implementing the pathfinder in September 2011.

Target and final sample by age group and area

The target sample initially agreed with SQW in conjunction with DfE is presented in the table below. This was constructed based on the list of families eligible to participate, with the aim of getting a cross section across the different age groups. We have anonymised the pathfinder areas using a letter code for each.

Table 8 - Target sample of families

Area	0-5 years	5-16 years	16-25 years	Total
L	3	1	0	4
M	5	2	0	7
N	0	2	0	2
O	2	0	3	5
P	1	3	1	5
Q	0	2	3	5
R	1	1	5	7
Total	12	11	12	35

Source: Pathfinder evaluation team

All families were offered the option of a face to face or telephone interview. Wherever practical, a face to face interview was held, but some of the pathfinder areas were geographically distant from OPM's base. In these areas, and in cases where the child or young person was not able to or did not wish to participate in the interview, telephone interviews were scheduled instead of face to face, as long as parents were happy to participate on this basis. Target sample and associated number of children and young people therefore could not be achieved within the reporting timescales.

The final sample achieved is presented in Table 9.

Table 9 - Actual sample of families

Area	0-5 years	5-16 years	16-25 years	Total
L	3	1	0	4
M	4	1	0	5
N	0	3	0	3
O	2	1	4	7
P	2	5	1	8
Q	1	3	0	4
R	0	0	2	2
Total	*12*	*14*	*7*	*31*

Source: Pathfinder evaluation team

This report is based on the findings from a final sample of 31 families, covering 33 children and young people (two families each had two children participating in the pathfinder). The sample falls short of the original target by two children and young people, reflecting challenges in recruiting participants and completing interviews within the reporting timescales.

Other characteristics of the sample

Type of additional needs: The children and young people in the sample had a wide range of additional support needs varying in severity and complexity. Many had multiple conditions. When asked to describe their child's additional needs, participants described their child as having autism only (10), a learning disability only (9), learning and physical disabilities (6), a physical disability only (5), autism and learning and physical disabilities (2), or autism and a learning disability (1).

Gender: The gender split of children and young people in the final sample was almost even: 17 were male and 16 were female.

Ethnicity: About two thirds of children and young people in the sample identified as White (24), with the rest identified as belonging to Black and Minority Ethnic Groups including African (2), Caribbean (1), Mixed White and Asian (1), Mixed White and Black African (2), Mixed White and Black Caribbean (1), or other Black or Asian background (2).

Data collection

Fieldwork

Fieldwork was conducted between January 2014 and early March 2014. OPM designed two interview guides. The first was designed for use with families with 5-16 and 16-25 year old children and young people, and the second was designed for use with the parents of 0-5 year olds. Both guides focused on the following topics:

- Learning about the family and their child or young person

- Assessments and plans before the new system

- Getting involved in the pathfinder

- The assessment process

- The support planning process

- The content of the EHC plan

- How the plan was working.

The topic guide for families with 5-16 and 16-25 year olds also included easy read, easy to understand questions for use with children and young people who were able to participate in the interview.

Participants were asked to allow 1.5 to 2 hours for the interview, although in practice interviews tended to last between 50 minutes and 1.5 hours.

All interviews were recorded and transcribed, except in a small number of cases where the participant did not wish to be recorded; in these cases the interviewer took detailed notes during the interview.

Participation of family members

The majority of the interviews were conducted with the mother of the child or young person only (23). One of these was a foster mother. Five interviews took place with the father only. Two interviews were conducted with a couple (mother and father) and in these cases there was typically a lead participant and their partner 'added in' to their question responses. One interview was conducted with a sibling who was the primary carer for the child.

Five children and young people were present for the interview with the support of their parent. They were able to participate to varying degrees. For example, being unable to provide detailed verbal answers but able to indicate yes or no in response to questions, or having good communication skills but limited ability to focus on topics.

Most of the children/young people had complex additional needs and were therefore not able to take part, with this decision being taken by the parent at the point of the interview booking. Some children and young people were asked to join their parent in the interview but chose not to participate. For children aged 5 and above, parents were sent a list of

questions before the interview, which gave parents and their children the opportunity to work through these questions together and collect the child's experiences in that way.

Fifteen interviews were conducted face to face at the family's home; the rest (16) were conducted by telephone.

Interview follow-up with families

Following the interview, the interviewer sent a letter to the family to thank them for their participation, which included a summary of the key points discussed. This provided an opportunity for participants to check that their input had been captured accurately and to invite them to get in touch if they did not feel that the summary reflected the key points of the interview.

Analysis and reporting

Our analysis of the interview data took place over two stages, organisation of the data, and interpretation:

1. Organisation of the data: each transcript was analysed and the content organised under thematic headings

2. Interpretation: we looked across the interviews to explore commonalities and differences in participants' experiences.

The third stage was reporting.

1. Data organisation

Data analysis matrix

We built a data analysis **matrix template** into which the researchers inputted data from each interview transcript. Using the same template ensured the researchers across the team adopted a consistent approach to inputting data. Transcriptions from many of the interviews ran to more than 40 pages of text, so it was essential to have an effective process in place to organise the data. The matrix was structured according to the topics included in the interview discussion guide, and with the overall report structure in mind. All of the team met together to ensure a common understanding of the matrix and how to organise data within it, i.e. what type of information should be organised under each theme.

The data analysis matrix can be understood as a thematic framework or code frame, which, visually, is a table showing the themes under which data will be sorted and then analysed. We constructed the matrix in an Excel spreadsheet, with the columns referring to the themes and the rows to participants.

- Each **row** contains data relating to one family and shows: information about the interview (who participated – i.e. which parent and whether or not the young person took part – and the name of the interviewer and data coder, usually the same researcher performed both of these tasks); information about which pathfinder area and age group the family were in; and demographic and other

information about the child or young person, for example, their ethnicity, their type of disability or additional need, and their type of education setting (mainstream or special, or not in education). Each participant's row also contains their responses, sorted under themes (examples of themes are given below).

- Each **column** contains data from all of the participants, relating to a specific theme. The main themes are the topic areas in the interview topic guide, as set out above under 'Fieldwork', and these were separated into sub-themes, each with their own separate column, for example:

    - Main theme: Getting involved in the pathfinder
    - Sub themes: routes into the pathfinder; their initial understanding of what it was about and what would be involved; their expectations and hopes; any concerns or worries about getting involved.

    The themes are reflected in the headings used to structure this report.

Researchers worked from the transcriptions of the interviews, reading these and then **entering data into the cells** of the matrix, in a summarised form. The purpose of this was to distil the interviewee's response to each question into clear and relevant points to feed into the analysis. We also included direct quotes and often retained the original language used by participants, to ensure that their meaning was preserved and clear. The data in each row was identified by its unique participant identifier (e.g. D006), to enable researchers to identify and revisit the original transcript if they felt that further detail or clarity was required during the analysis phase.

2. Data analysis

After sorting the data for each participant into the relevant themes, the research team proceeded to analyse the data. The researchers read the coded information in the matrix, firstly, to identify the **key points** under each theme (for example, under the theme of 'routes into the pathfinder', the researcher identified a number of categories of responses including: via their child's school, from the pathfinder team directly, through word of mouth from another parent).

Secondly, researchers looked for **connections** between themes and different sub groups of participants, and between themes and other themes. This involved testing hypotheses, based on the researchers' experience of conducting the interviews and reading and coding the transcripts, and looking for patterns. For example, general questions such as, were there any similarities in the experiences of participants in the same pathfinder area, or within the same age group? Were there any factors more commonly associated with positive outcomes?; and specific hypotheses such as, was there a link between the role played by the key worker and whether families felt satisfied with the pathfinder process? This part of the process provides an interpretive layer to the analysis. It does not necessarily enable us to make claims of causality (that X leads to Y), but simply to identify links (that X appears to be associated with Y).

When performing the analysis, researchers read across the whole of an individual row to ensure that they understand the **context** of that individual's responses. That is, the researcher would not simply read down all of the responses in one column (e.g. 'satisfaction with the process'), but would look across rows too, in order to note the context of individual responses under this theme. This helped to make sense of any apparent inconsistencies or responses that seemed surprising.

Researchers worked closely together during the analysis process, which included regular sharing and discussion of potential hypotheses against which data could be tested, and ensured a **consistent approach** and comprehensive coverage of the issues and linkages within it.

3. Reporting

Approach

Our approach to reporting was to present the range of experiences that participants reported, and to highlight any differences by sub group (for example, age of the child or young person), and any links between themes. In writing up our findings we have been mindful to:

- Provide 'high-fidelity reportage', by including anonymised quotes from participants so that the reader has access to the authentic voices of participants

- Pay attention to 'surprise' in the findings, focusing on particularly revealing insights and evidence of contrary or negative views

- Be reflective and honest about the limitations of the research and the conclusions we can draw from it. More detail on these limitations is set out below.

Structure of this report

Each sub section of the report begins with its key findings and ends with a summary of the section. Where differences could be observed between the experiences of families in this batch of interviews and those in the 2013 batch, these are noted.

The report's concluding chapter summarises differences between the findings of this year's qualitative research and last.

Case studies

Ten case studies were included in order to illustrate in more depth the experiences of a range of participants. The selection of case studies was not intended to be representative, but aims to illustrate a range of different experiences, both positive and negative. Case studies can be found in Annex B.

Annex B: Case studies

Case studies are not intended to be 'representative' or showcase 'typical' experiences – they simply illustrate a range of different experiences. All names of families, professionals and organisations have been changed.

Case study 1

Rosie is four years old, and lives with her mum, dad and older brother in Area M. Two years ago, Rosie was diagnosed with a rare genetic disorder. Rosie is non-verbal, and uses a mobility buggy. She also has epileptic seizures – a common symptom of her condition. Rosie is a happy and sociable child, who enjoys being around other children, and going on holidays with her family. Rosie's time is split between a day nursery and a specialist child development centre, covering three days a week in total.

Rosie's mum Donna was asked to take part in the pathfinder last year. It was felt that an EHC plan would be helpful for Rosie because she has health, social care and educational needs. Donna agreed to take part in the pathfinder, hoping that an EHC plan would lead to more seamless support for Rosie and the family, and more clarity over the roles of the different professionals supporting Rosie. She was also keen to get involved in the pilot in order to help improve processes for other families. Rosie's key worker was able to clearly explain the aims and process of the pathfinder, and Donna did not have any concerns about taking part.

Before the plan could be drafted, professionals spent an intense couple of months doing assessments of Rosie's needs. Because they were all working to the same deadline it was a busy period for Rosie and Donna. They had to attend lots of appointments and were asked the same sorts of things, which felt repetitive to Donna.

The process of writing Rosie's EHC plan centred around one three-hour meeting where the content of the plan was drafted. Thirteen professionals attended the meeting – some of whom knew Rosie, and some who did not – along with Donna and her key worker. Donna felt that it was useful to gather all the different professionals together in one place, and make sure they were aware of the other people who were involved in Rosie's care. She also felt that she was fully involved in the process and listened to. Her key worker helped her to contribute in a meaningful way to the process by asking her questions, introducing her to other professionals and giving her lots of information and reassurance throughout the process.

'I feel as though I had a voice... I wouldn't have been happy had I not said my piece.'

However, the meeting was long and intensive, and there were various disagreements between the professionals about the services that Rosie needed and how these should be delivered. Donna felt that more work could have been done before the meeting, in order to speed up the process, as it took some time for everyone to get 'up to speed' on

Rosie's case. She also felt that although she was comfortable taking part in the meeting, the format and length could have been stressful and intimidating for some parents.

The completed version of Rosie's EHC plan contains aims around social inclusion and support for Rosie's leisure activities. The Plan also addresses Rosie making a successful transition to school, including information sharing between staff. Donna feels that the plan is comprehensive and detailed, and that the voices of different teams and professionals were well amalgamated in the write-up. The plan, and the assessments which took place as part of the process, were also used as the basis for Rosie's Statement, which avoided the need for more repetition.

However, Donna's major concern about the process is that no-one will take responsibility for taking the plan forward and making sure that it is implemented. She is worried that the plan doesn't contain any dates or deadlines, so there is no sense of urgency in taking it forward. At the moment, the plan is not being actioned, and Rosie's Statement is the only plan being used. However, Donna is due to attend a TAC meeting soon, and she hopes that this will be an opportunity to revisit the plan and push it forward.

Case study 2

Seventeen-year-old Alex lives with his family in Area R. Alex is dyslexic, and has hearing difficulties, for which he uses a hearing aid. He currently attends college three days a week, and also works for an advocacy organisation which supports young people in the area. He is also involved with a youth advisory group for his local council, and since establishing his own EHC plan, he has been involved in the development of the pathfinder in the area.

Alex first heard about the pathfinder through his school, which has opted to take part in the pilot. He was eager to take part in the pathfinder as he felt that an EHC plan would offer an opportunity to bring his health and educational needs into one cohesive document, whereas previously this information had felt somewhat 'bitty'. He was also keen to be actively involved in the process of establishing and planning his support.

Alex's key worker, Caroline, was also his mentor from college. She worked with Alex throughout the process of establishing his EHC plan. This involved a series of conversations and meetings between Alex and Caroline. Alex's mum, Sarah, also attended a meeting with Caroline as part of the section of the plan on family background. Caroline was able to liaise with the other professionals involved, who were mostly from health and Alex's college. She was also able to respond to any worries or concerns that Alex had along the way, and to make changes and update the plan when necessary. Alex felt he had a very good relationship with Caroline, and that she was very important in driving the process forward. It was helpful that they already knew each other, and that Caroline was familiar with Alex's background. Alex feels that it is crucial that one person works with a child or young person, rather than the young person having to work with many people.

Both Alex and his mum feel that the process of establishing the EHC plan worked very well. Alex felt that the process was truly centred on him, and that he was 'in the driving seat'. He appreciated that Caroline worked with him directly, rather than deferring to his mum. He feels that it is important that young people are actively involved in planning their support, and that the EHC plan, much more so than SEN Statements, offer the opportunity for young people to have direct input:

'The new plan is about the young person and it's going to affect the young person. It's not going to affect the parents or the professionals; it's going to affect the young people. So, I think it's more important for the young people to be asked.'

So far, Alex feels that the plan has been very useful. Caroline and the learning support team within the college have made sure that the plan is properly implemented and taken into account. The plan has helped to make the case for Alex to have a reading scribe, to negotiate extra time when he is sitting exams and to get a specialist computer program to support learning. The plan has also been useful for making sure that all staff are aware of Alex's additional needs, and how they need to communicate with him so that he can hear them - meaning that Alex doesn't have to spend so much time explaining his needs to people. Alex also felt that the plan is preferable to his previous Statement because it is a 'living document', which can be changed as and when his needs change:

'It can be easily updated. Sort of going back and just looking at it and if we needed to edit it then we could do, and that's much better, whereas the Statement obviously you have to go through an appeal process and everything to change it.'

Alex feels that taking part in the pathfinder has helped to build his confidence, and make him feel more empowered to assert his own needs. He hopes that the plan will continue to evolve to reflect his needs as he leaves school and makes the transition into adult life. He is currently planning to do an apprenticeship, along with more advocacy and voluntary work.

Case study 3

Danny is nine years old, and lives with his mum, step-dad and older brother in Area L. Danny has autism, which he calls 'lucky needs', because he was once given a free special needs pass to the local zoo. Danny has been at a mainstream school, Oldfield, since the age of four. However, because of his autism, he has struggled to keep pace with the rest of the class. Although the school have gone 'above and beyond' to support Danny, his academic level is significantly behind the rest of the class, and Danny's mum Nicola has felt for some time that he would benefit from a more specialist environment.

Nicola first heard about the pathfinder when she approached the council to request that Danny be assessed for a Statement of Special Educational Needs. The council had previously told Nicola that Danny was not eligible for an assessment since Oldfield was meeting his needs. Nicola was frustrated and appealed against the decision:

'I said, no, you can't say that. He's Year 5. His academic level is Year 1. How can you say that they are meeting his needs?'

The council agreed to assess Danny, and suggested that rather than go down the Statement route, the family could take part in the pathfinder. Nicola agreed to be part of the pathfinder because it covered educational, health and care needs, including the needs of the family, which she felt would be more beneficial than a purely education-based Statement. She hoped that they would be able to get some support for the wider family, especially for her older son who struggles to cope with Danny's autism. However, her main objective in getting involved with the pathfinder was to have Danny properly assessed, and get him into a school which could meet his needs.

Danny was assigned a key worker from the local council. Various professionals, including an educational psychologist, social worker, paediatrician and teacher were asked to submit reports, which would form the basis of Danny's plan. Nicola was also asked to write a report about Danny's history and his needs. On the basis of these reports, Nicola's key worker Dave drafted an initial plan for Danny. However, Nicola was not happy with the draft plan, which maintained that Danny should remain at Oldfield. As her main objective in the process was to get Danny a place at a more suitable school, she felt that her input was being disregarded. She was also frustrated that she had not been provided with information about special schools in the area, despite asking Dave and other professionals for the information that she needed.

'You know, and no-one was helping me. Everyone comes back and tells me it depends on what his needs are. And Dave kept saying, oh, I understand what you mean; I can understand why you're frustrated. I said to him, you keep saying that Dave, I said, but nothing changes.'

Finally, Nicola was given the information about special schools in the area, and found a special needs unit in a mainstream school called Riverside, which she thought would be suitable for Danny. However, the process of arranging Danny's place at Riverside was far from smooth. Dave initially sent a copy of the draft plan to the school, on the basis of which Riverside decided that Danny did not meet their criteria. Again, Nicola appealed the decision – she was frustrated that Dave had sent a non-finalised version of the plan to the school, and had failed to attach the supporting reports. After Nicola insisted that all Danny's reports be sent to Riverside, they decided to come and observe him at Oldfield, and finally agreed that he would be well-suited to Riverside.

Danny is now about to start at Riverside. This is a great relief to Nicola, who feels that he will finally be in an environment suited to his needs. However, she feels that the EHC plan was a difficult and complicated route to getting him there. She feels that her input was disregarded by the professionals, and that she was not given the information that she needed along the way. She feels that Dave's initial failure to provide Riverside with Danny's assessments caused unnecessary delays. She had also hoped that the plan would provide additional support, which it has not. Although she has succeeded in getting a place for Danny at a special school – her main objective – she feels that this outcome has mostly been down to her own insistence, rather than support offered by the professionals:

'I've achieved what I set out to achieve now, so I can't say my attempts weren't worth it. It's worked in the end, but it's been a job getting here.'

Case study 4

Rachel is sixteen, and lives with her mum, dad and older brother in Area P. Rachel is on the autistic spectrum, has moderate learning difficulties and a slight visual impairment. She attends a local special school where she is in a class for autistic young people. She loves art, outdoor activities, and is involved with the local church along with the rest of her family.

Rachel's family first heard about the SEND pathfinder through the local Parents' Forum. Because of Rachel's additional needs, the family had an established relationship with the local authority, who suggested that they might want to take part in the pathfinder. Rachel's parents were keen to do so, because they thought that it would be helpful to integrate services delivered by health, social care and education, and that it would be useful to have a key worker to coordinate the different people and agencies involved. Rachel's parents also felt that the family had benefitted from the 'system', and were keen to contribute to the development of services. The local authority provided Rachel's parents with a thorough overview of the process and purpose of the pathfinder, and the family had no concerns about taking part.

The process of developing an EHC plan began with several meetings between the family and a support officer from the council. Next, a key worker from a local charity was appointed to work with Rachel. Rachel was able to choose the person who would be her key worker. She chose Lindsay because she was close to her in age, and because she had worked with her before. Rachel and Lindsay worked together to create a PowerPoint presentation about Rachel which they delivered to the local authority. The presentation contained video clips as well as drawing on what Rachel had written with her parents, and what was already contained in her education statement. Rachel enjoyed making the presentation, which allowed her to express herself in a way she might not have felt confident doing in person. Rachel's dad reflected that this would be a good way for other young people to contribute to the EHC planning process:

'It's a good model for getting the older young people, at any rate, involved in their own meetings. We actually learned things about her that we didn't know.'

Rachel and Lindsay then delivered the presentation at an annual review meeting for her Statement. The presentation, Rachel's existing Statement, and various previous assessments were drawn on to form a draft plan. The plan contains goals around doing well at school, particularly in her art GCSE, plans for further education and eventual career aspirations. There is also a section about living independently, and what would need to happen to make this a possibility.

It was some time before the plan was finalised by the council. A lack of personnel due to sick leave and job cuts meant that it took two months, rather than the two weeks the family had expected, for the council to produce the final plan for the family to sign off. Rachel's dad David had to put pressure on the two SEN coordinators at the council before the Plan was satisfactorily completed. He was disappointed by this delay, after a process which had started so positively:

'I know the Local Authority are under huge pressure… But if they can't get the final plan out when they have dedicated pilot funding, then that doesn't bode well for the future.'

However, despite this delay, overall the family felt that being involved with the Pathfinder had been a positive experience. Unlike Rachel's previous Statement, which would 'expire' at the end of Rachel's school career, the plan looks to the future, with goals linked to her long term career aspirations and the support needed from social services to support her into adult life. Above all, the family felt that Rachel had more 'ownership' over the finished plan than her previous statement, having had more input into its development. Although it is currently too early to really be able to gauge the effects of the plan, Rachel and her family are optimistic that it will make a positive different in their lives and support Rachel's educational success and transition to adulthood.

While the process felt thorough and 'owned' by Rachel, the family remarked on the huge amount of staff time that went into working with them to produce plan to an appropriately high standard. They questioned whether the amount of time that staff spent on it would be available to all children who go through the process if it was to be rolled out more widely.

Case study 5

Four-year-old Beth lives with her mum and dad in Area P. Beth was a premature baby, and as a result has a lot of health needs – she has cerebral palsy, is registered blind and has had multiple surgeries. Beth attends a special nursery school full time. When she is not at nursery, she likes swimming and going on the swings, and often goes on trips with her family to the Lake District.

Beth's mum, Josephine, was introduced to the SEND Pathfinder by her specialist health visitor. Josephine's understood the pathfinder to be a way of reorganising funding that would allow the family to move money from different funding streams to pay for the package of support that Beth needed. Josephine's main motivation for taking part in the Pathfinder was to fund respite care two nights a week from the Community Team, which the family had come to depend on, and which they were in danger of losing. Josephine was also keen that professionals involved in Beth's care should work together and be aware of what others were doing with Beth and the family.

The family was assigned a key worker to assist them with the process of establishing an EHC plan for Beth. Along with the key worker, Josephine went to a meeting a Beth's school, which was attended by the different professionals involved in Beth's care. At the

meeting, they drew on various existing assessments and new professional opinion, along with notes written by Josephine, in order to develop a draft document about Beth's support needs. The chair of the meeting – whose role Josephine was not entirely clear on - also took responsibility for writing up the notes from the meeting and circulating these among the family and the professionals. However, after this a long period went by during which the family heard nothing more about the pathfinder, and were not able to get in contact with the person responsible for drafting the plan. This was disappointing for Beth's parents, as up until this point they had found the process to be smooth, efficient and centered around Beth's needs.

Josephine has felt slightly frustrated by the process of putting the plan together, and not entirely satisfied with the final product. When the plan was finally written up, no-one asked her to check and sign off the draft copy before it was finalised. There were a number of inaccuracies contained in the plan which she could have clarified, but she did not have an opportunity to do so. She feels that her key worker should have gone through Beth's plan and the outcomes before it was finalised.

She also feels that the process has been disjointed; it was worrying for her that at Beth's plan review meeting only education professionals were present and other professionals who play key roles in Beth's care had not been invited. She is also concerned that no-one is responsible for updating the plan or making sure that actions from the plan are followed up:

'The end result needs to be checked off with the parent and there needs to be a named person review the plan to check for inaccuracies.'

After going through the pathfinder process Beth's care was reduced slightly as a result of being reassessed for the plan; this was disappointing, as no one had told her there was a possibility of receiving less care. She is also disappointed because, having been told at the beginning of the process that Beth's care would be a yearly package, Beth then underwent a six month review. Josephine was worried that when the plan was reviewed Beth's care package might be reduced further. Fortunately, at the plan review the care package was amended back to the original package, although this will again be reviewed this in six months, which is tiresome for the family.

As a result of the pathfinder Josephine is now able to choose who delivers their care. Unlike the workers who used to care for Beth, these professionals are trained to administer Beth's medication, which means her parents feel confident enough to leave the house while Beth is in their care. Josephine feels she now has more control over the care the family receives as a result of the pathfinder – but she wishes it had been a more transparent and joined up process to reach this point.

Case study 6

Liam is 16 and lives with his parents and older sister in Area Q. Aged 10, Liam suffered complications following an infection, and he developed learning difficulties and epilepsy

as a result. These conditions affect his short term memory and learning at school, and having seizures can cause him to fall and injure himself. He has regular appointments with a specialist consultant to monitor his epilepsy medication. Liam has a wide range of interests from attending rugby matches with his dad, Ken, to playing badminton, and enjoying TV and computer games.

Liam attended a mainstream high school until the beginning of this academic year, when he moved to a special school for sixth form. He was approaching this transition when the family were told about the pathfinder by the council's SEN team, who knew Ken and Liam's mum as local headteachers as well as parents of a disabled child. They were happy to get involved and thought that the transition to a new school would be a good point in time to try this new way of planning support to best meet Liam's needs and to ensure that they as parents had a say in it.

The family were assigned a key worker from the SEN team; they were offered the option to change if they wanted to, but they were happy with the person assigned to them. They had a meeting at Liam's new school, the special college, which was attended by Ken, the key worker, school staff including the pastoral manager, assistant head and the school's person responsible for attending all reviews. Liam attended for part of the time. Drawing on Liam's Statement, a report from the educational psychologist, and statements from school staff who had taught and observed Liam in class, they worked together to enter information into the plan, under headings such as Liam's likes and dislikes, hopes for the future, how he was settling in at school, short and long term goals and actions and timescales around achieving these.

Ken was happy with who attended the planning meeting. He wouldn't have expected Liam's health professionals to be able to attend because of their workload, and in any case this it wasn't necessary - Ken could feed in the most up to date information on that side of Liam's care, and because the special school have expertise in epilepsy they did not need a health specialist there to inform them about it.

It was a positive process because Ken felt that those present listened well to him and to each other, and that Liam's needs and preferences were placed at the centre of the process:

'Well it was all the questions or all the statements, or even all the sections that are about, what did we want? What were our needs? What did Liam want to do? Is there anything that we can do more? Is there anything we can do better? Is there is anything we are not doing? All of those types of things were part of it.'

After the meeting, the family were sent a draft of the plan, asked whether they were happy with it and offered the opportunity to talk it through. They were happy and so a final version was produced. They were also sent a questionnaire which they could complete and return in order to give their views of the experience of creating the plan (since they had no negative feedback to give, Ken didn't bother to do this).

Ken is very happy with the support and care that Liam is receiving at his new school. Reflecting on the planning process, it's difficult for Ken to say what difference the plan

has made because the school, as a special school, is well-equipped to meet Liam's needs and would probably be doing so even had the plan not been in place. Another factor which Ken thinks is key in accessing appropriate support is that he and his wife are knowledgeable about dealing with 'the system', and confident about asking for what they want.

'Our main thing was Liam's starting a new college, was he able to do things that he wasn't able to do before? Do they cater for his needs? Yes they do. I suppose if there wasn't a care plan, [this] school would still do those things anyway.'

However, Ken feels that the plan process and the support of a key worker may have more of an important role in different circumstances, for parents who are less competent in this respect and where schools are less responsive. Whether it's a plan or a Statement, the important thing for Ken is that a system is in place to ensure support and that professionals are supportive and flexible in implementing it:

'I think it's right to have the system in place to support people, and it needs a structure. If it provides a structure to be able to follow, and as long as that has the people involved that are flexible, then that system would work, but whether that is a better system than a statementing system, [I don't know]. The same thing applies - as long the people there are open and willing to discuss and think about the needs of the child.'

Case study 7

Theo is 18 and lives with his adoptive father, Graham, Graham's partner and their two younger children in Area O. A neurological condition means that Theo experiences a range of additional needs included limited mobility, visual impairment and a learning disability. He currently studies full time at college during the week and spends time with family at the weekends. Theo likes to draw and is a good artist. He is also getting more interested in technology and gadgets like the iPad.

Theo got an SEN Statement three or four years ago, but the process was rather slow and didn't lead to Theo getting the support that Graham thought he needed. So Graham was keen to hear more about the pathfinder when he found out about it from a social worker last year. He was told that getting the plan would be quicker than the Statement, and would offer the opportunity for a more holistic assessment of Theo's needs, for example, they would be able to discuss future accommodation for Theo. As a parent, Graham was keen to try anything that could lead to better support for Theo, and also felt that even if the pathfinder didn't benefit Theo directly, perhaps it would help other people with disabilities in the future.

Theo and Graham had around three meetings which covered assessment and support planning, and the process was led by the social worker. The social worker and her colleague visited the home and talked with Theo and Graham, each separately and then together. The social worker also asked for Graham's consent to talk to Theo's teachers about him.

In addition to talking about Theo's needs and what he wanted for the future, these meetings also focused on support planning. They discussed options for Theo after college, such as participating in art projects or apprenticeships. Following the meetings, the social worker created a care plan which was sent to Graham to comment on, before being submitted to the council for approval. Graham didn't have any comments but was pleased to be given this opportunity. The plan was approved in less than a month – very quickly, compared to the timescales around the updating of Theo's Statement which is overdue by two years.

Graham was very happy with the whole process and the people involved. He felt that the professionals involved were kind, friendly and had a lot of empathy for Theo. They involved Theo well, by asking his opinion and encouraging him to speak for himself about what he wanted and needed. The social worker offered them plenty of information and guidance about the types of support that Theo was entitled to and about options for future activities; things that Graham would not otherwise have been aware of.

The two main outcomes included in the plan included Theo being able to go on an accompanied vacation to his country of birth, and to have access to a carer for 30 hours a month, which can be used flexibly over the week. This is an increase on his previous carer support which was for 24 hours a month. The increased hours mean that Theo is able to go out (accompanied by the carer) more, giving him the independence which is getting more important as he gets older. Having the carer with Theo also provides Graham with the reassurance that he is safe; he doesn't like Theo going out alone as he is vulnerable to the negative influence of and even violence by other young people in the area.

The plan will be reviewed in autumn and at that point Graham expects that they will talk about adding new activities or types of support, depending on Theo's needs at that point in time.

Case study 8

Ben is 5 and lives with his parents and younger sister in Area L. Ben has complex needs including autism and mild cerebral palsy. He has limited fine motor skills and a developmental age of around two. He has occasional seizures, and is likely to receive a diagnosis of epilepsy in the future. Before the plan, Ben was in a mainstream nursery where he had one to one support and was also receiving support from a range of health professionals including a paediatrician, physiotherapist and speech therapist.

Ben's mum Natalie heard about the plan from the SENCO at the school which was attached to Ben's nursery. She hoped that the plan would enable them to access the support which Ben needed to progress into the school:

'We were worried at the time do we put him in mainstream or do we put him in a special school. We wanted to put him in mainstream because we know he does very well at copying and he works well with watching regular children and learning from them and

learning from adults. So we wanted to keep with that, but obviously we were a bit anxious as to how his needs were met.'

The assessment coordinator at the council, Claire, then contacted Natalie with more information about what would be involved. Claire explained that the plan was instead of a Statement and that it would cover not only education but broader care and support needs. Natalie appreciated the time that Claire took to explain everything thoroughly:

'There was a lot to take in but she was very thorough and she asked if we'd got any questions but she did go over it quite a few times, just so that we had the basic sort of information really, of what was going to happen and how the plan worked […] and obviously we can contact her any time, we had her email. And we could ask her anything really. So it was very good.'

Claire gathered together reports from all of the professionals involved in Ben's care, including his paediatrician, the respite organisation and carer who takes him out, his physiotherapist, speech therapist and educational psychologist. Claire chased up the reports to make sure that she had all the information to complete the plan. Then Natalie and Ben's dad met with Claire, the SENCO and Ben's one to one support person from nursery, to input into the plan and decide what services and support to include in it.

As part of the process, a social worker visited the family at home; although Natalie felt a little apprehensive about this idea, she was reassured by Claire that it was a routine part of the process, and the social worker too was friendly and reassuring.

Another concern that Natalie had initially was that if they didn't get the plan agreed, there could be a risk that Ben would not get the support he needs, but the SENCO assured her that the school would be able to provide this support anyway. The plan was seen as offering a level of security, as it would guarantee that Ben would continue to receive the support he already got.

Natalie found that the professionals involved in creating the plan were also interested in the needs of the wider family – Claire suggested including respite for Ben's younger sister, to enable Natalie and her husband to spend time with Ben.

Ben is receiving all of the support he needs and the plan is in place in order to secure these services for the future. He is thriving at school and getting stronger as a result of the physiotherapy. Natalie is very happy with how the school supports Ben and responds to her requests for information and help, such as keeping a daily diary so that she knows what Ben's been doing at school. There are a couple of outstanding needs which Natalie is still trying to get addressed: they haven't received respite for their other child yet, nor the incontinence pads which Ben needs now that he has outgrown the nappies available from the supermarket. Otherwise the plan is working well, and making it has helped Natalie to feel that everyone is supportive and working together to care for Ben as an individual:

'Ben does not quite fit in one box, he's got quite a few conditions that he's got a mixed condition and stuff like that it is hard to, he is more of a rare case so it is harder to

pinpoint stuff and people like things, they like to put people in a box they can say yes that goes with that and… whereas this plan, it helps us because we can't put him in a box, it helps us get things that he needs that aren't part of one condition.'

Case study 9

Ten-year-old George lives with his mum, dad, two sisters and older brother in Area O. He likes trampolining, going to the park and playing computer games. George is severely autistic and is non-verbal. He currently goes to a mainstream where he has extra one-on-one support from a special needs teacher.

George's parents Julian and Lisa first heard about the pathfinder from their social worker Clara. She explained that the EHC plan was intended to give parents and children more involvement in planning their support. They weren't sure what to expect from the pathfinder, but hoped that it would make it easier to get support for George and the rest of the family. They were especially keen to be able to access fun activities to keep George occupied, since his access to the local Toy Library and his support from his social worker had been cut.

Clara acted as George's key worker, supporting the family through the process of developing the Single Plan. She came to visit the family at home and brought a blank plan template, which they filled in together. Afterwards, Clara wrote up what had been drafted and emailed it to Lisa and Julian. The draft contained some inaccuracies including that George wore glasses and had had an operation, which made his parents think that Clara had confused him with another child. Julian made some corrections to the draft plan, and sent it back to Clara.

This was followed by a meeting at George's school, attended by Lisa and Julian, Clara, George's teacher and the deputy head. They all went through the plan together – however, disappointingly Clara had not picked up the changes Julian had made to the draft plan, so the mistakes were still there. This was frustrating as it involved another round of corrections which slowed down the process. However, George's parents felt that the meeting generally worked well because it was a chance for everyone to share ideas about what would help to support George. They also felt that their views were listened to, particularly by Clara:

'She wasn't putting words into our mouth; she was simply asking us questions and we answered them and she wrote it down.'

George's final plan contains information about his medical history, his needs, school and family, along with aims and goals around his education and health. The plan also states that the family and school should work more closely together to support George in a consistent way, for example around toilet training and using PECS (picture exchange communication system).

However, George's parents feel that the plan is not particularly helpful as it doesn't give them access to any additional support and services. The family have been advised to get some items that will help at home, such as a black-out blind to help George sleep and a scooter for exercise, but they will have to pay for these themselves. They had hoped that the plan would include something which would enable them to take a holiday since they were in need of a break, but they were told there was no funding available for this. Lisa sees the plan as more of a 'wish list' of things they would like for George than a plan for changes which will actually happen. She thinks that in practice, the plan is no different to the Statement:

'It's just like the Statement. I can't see things changing. I just think it will be the same thing.'

Case study 10

Anita is three years old – soon to be four. She lives with her mum, dad and three siblings in Area O. She has Down's Syndrome and has recently moved from nursery into a mainstream school. Her mum, Sana, is keen to see how she settles into this setting and to decide if it's the right one for her. Anita has had a tough year going in and out of hospital for surgery on her adenoids and tonsils. When she's not at school she enjoys playing with her toys, dancing with her brother and two sisters and being read to.

Sana first heard about the pathfinder from Anita's portage worker last year, around the same time that she was going through the Statementing process. Sana does not remember all the details of what the portage worker told her about the pathfinder but she felt that it would be good to get involved as it would give the family more of a say about Anita and the whole families' needs.

The process of putting together the EHC plan together involved the portage worker (who acted as her key worker) coming to their house and speaking with Sana about three times. When they met, Sana spoke about what she wanted for Anita, what Sana's goals are for her, and how to make sure she is happy and comfortable. Sana worked with the portage worker to fill out the plan together and they also consulted with one of practitioners at the nursery that Anita was attending at the time.

Sana was really happy with this process and felt involved and listened to. She particularly liked being able to work on the plan with the portage worker because she had known her for a very long time. It was felt that she did a good job talking mum through the plan and how it needed to be completed. The family preferred the plan to the Statement (which was being completed around the same time) because it took a more holistic view of Anita's needs rather than focusing solely on education.

'I preferred the plan…because the Statement is just about the education and what they just want, you know, really, so. And this one is about what the family want. What's better for the children. What's better for Anita in her environment.'

In terms of content, the plan includes a description of Anita and what she likes to do and a number of outcomes and goals focusing on family, friends, community, education and

health, for example to play with other children, to be able to wash and dress, to stay healthy, to develop her passion for music. The support to help meet these outcomes will be actioned by the people and agencies who are already working with Anita. This includes her school, her portage worker, her speech and language therapist and her family. The plan doesn't include any new support from outside agencies.

As the plan has not resulted in any new or different support from what had already been identified in the Statement, it hasn't really made any difference yet. Sana hasn't really referred to the plan since it has been completed and she has not been monitoring whether, for example, Anita's school has been delivering the actions included in the plan. Sana is not very clear about what next steps are with regards to the plan and doesn't think that this was explained to her the portage worker.

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

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