



Department  
for Education



Social Science in Government

# Mapping user experiences of the Education, Health and Care process: a qualitative study

Research report

April 2016

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ASK Research

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## Acknowledgements

The authors would like to thank Gav Cross for his invaluable input and advice on the project and for running the workshops. Our thanks are also extended to Clarissa White for her help with carrying out interviews and analysing transcripts.

We are grateful for the support of the DfE team, especially Roz Harper, Michael Dale and their policy colleagues, as well as the Advisory Group members, Gareth James from Department of Health (DH), Beatrice Andrews from the Cabinet Office and Liz Malcolm, Principal Educational Psychologist in Wandsworth.

We are indebted to the four authorities who took part in the research for helping us to understand their local journeys and for fully embracing all aspects of the project.

Thanks are also extended to our web design team who have shown the utmost patience in helping us to build, develop and amend the online tool.

We are especially grateful to the parents and young people who gave up their time to talk us through their experiences, come to workshops and give us their opinions. We appreciate how busy their lives are and so we are very thankful for how much they helped us.

## About the authors

Amy Skipp has been involved in SEND research for over 15 years. She was involved in the Early Support project, the Newborn Hearing Screening Programme implementation and was Head of Research and Policy at the National Deaf Children's Society. Since then Amy has worked as a Research Director (qualitative lead) in the Children, Young People and Families team at NatCen Social Research, and as Head of Research at Gingerbread, before establishing ASK Research, specialising in qualitative research with socially disadvantaged groups. Dr Vicky Hopwood is a freelance researcher and evaluator, with over 20 years' experience of delivering social research for central and local government as well as the voluntary sector. Much of her research has involved consulting with those with SEN and disabilities as well as with hard-to-reach groups.

Our project colleagues have a wealth of experience. Gav Cross delivers training on Independent Support, Key Working, service development and Working in Partnership with Families. Clarissa White works with the National Children's Bureau, amongst other organisations. She led the process evaluation of the Troubled Families programme.

# Executive summary

## Introduction and background

This report presents the findings from a small-scale qualitative study commissioned by the Department for Education (DfE) to examine user satisfaction with the Education, Health and Care (EHC) process for children and young people with Special Educational Needs and Disabilities (SEND). The study was undertaken by ASK Research. It was conducted from May to December 2015 – during the first year of the national implementation of the new EHC process, which began in September 2014.

We interviewed 77 parents and 15 young people with SEND and worked with over 120 professionals from four local authority areas in England. The findings in this report relate only to those four areas, but it could be assumed that some of the issues explored might be found in other local authorities. Authorities would need to gather their own user feedback in order to identify their own priorities.

There were two overarching aims of this study:

1. to map children, young people and families' experience of the EHC process and determine their satisfaction with the service in the local area; and
2. to explore the extent to which the approaches employed to capture user feedback in the course of the study can help local areas and others to gather user satisfaction and make improvements to their service.

The specific questions we addressed were:

1. How are EHC assessment, planning and provision processes implemented by local authorities and delivery partners? What are the key aspects/encounters with regard to service user satisfaction and how do these vary by group?
2. What are the key issues driving user dissatisfaction and satisfaction for different groups in relation to these processes? How feasible is it to make revisions to services to improve user experience? If problems appear inherent/ intractable can this be challenged through innovation?
3. What practical and effective actions can local authorities take to improve user experiences in reference to key aspects of services and drivers of dissatisfaction? What good practice can be replicated and what innovative solutions can be reached in partnership with local authorities and delivery partners?
4. What methods can local authorities use to research and gain productive feedback themselves to improve user experiences? How best can this information be presented and disseminated to local authorities so that they will make good use of it?

## Families' experiences

Our research found broad similarities in how the process is being delivered in the four participating areas as well as some subtle differences. Overall parents reported being satisfied with the new approach. In interviews they generally reported that they liked:

- the new philosophy behind the reforms - which promote:
  - being involved - with a person-centred approach, in which their opinions are listened to and respected;
  - their child being at heart of process;
  - professionals taking a multi-agency approach; and
  - developing an holistic view of their child;
- individual staff working with them throughout the EHC process - who:
  - make all the difference to their experience and satisfaction;
  - go the extra mile to inform and support them;
  - keep the family informed and involved in the process; and
  - seek to really understand the family and child's needs.

Our analysis suggests that there are ten factors which influence family satisfaction with their local EHC process. These are the extent to which services have:

- accessible referral routes;
- holistic needs assessment driven by children, young person and families' needs and aspirations;
- suitable support to meet educational needs;
- consideration of longer term ambitions and future implications;
- effectively actioned plans;
- a monitoring and reviewing process in place;
- clear and transparent information;
- joined up working within and between the education, health and care sectors and families;
- parental and young people involvement; and
- support (emotional, social and legal) provided to children, young people and families.

The detailed parents' experiences of the EHC process in this small sample revealed a number of areas where services were still working towards consistently delivering practice in line with the Code. There were several examples of:

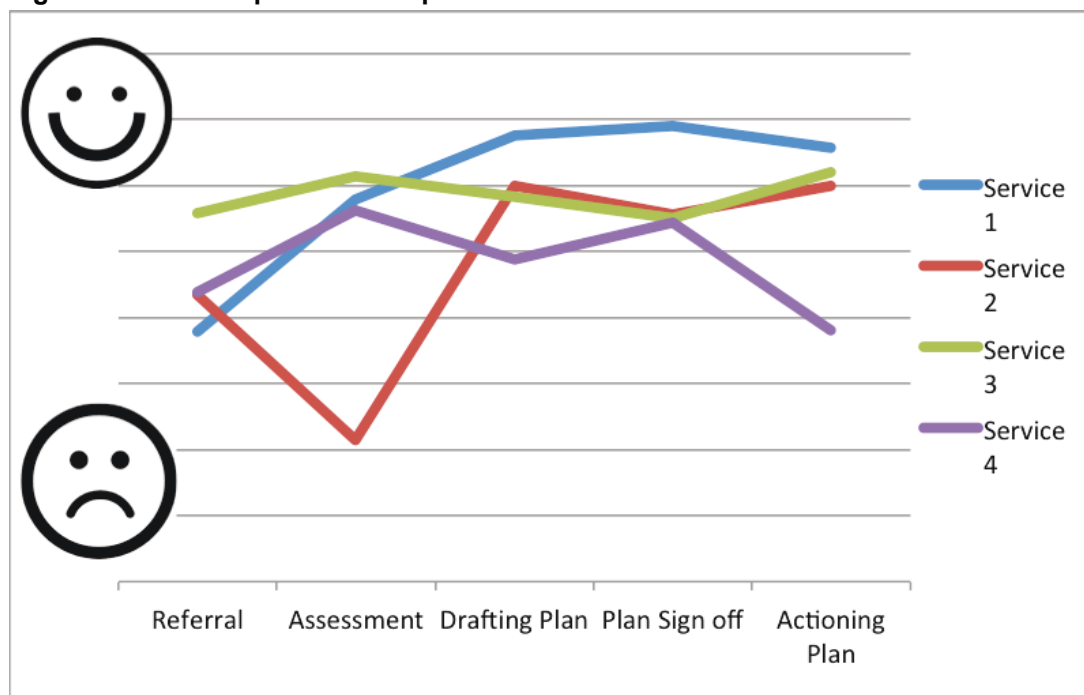
- children and young people not having their needs identified early;
- a lack of appropriate Health and Care input;
- plans not being SMART (specific, measurable, attainable, relevant and timely) or outcome-focussed;
- panels overruling co-produced multi-agency needs assessments; and
- tensions around provision or placement issues.

Also, many parents had very little understanding of the new process and wider SEND reforms.

## Getting feedback from families

We mapped parents' satisfaction with their journeys through the EHC process.

Figure 1: Visual map of the EHC process



We found that averaging parents' scores indicated overall satisfaction with the EHC process. However, there were a wide range of responses and our in-depth conversations with parents revealed several important issues that must be taken into account in measuring and interpreting parental satisfaction:

- parents scored elements of the process (referral, assessment, etc.) differently to how they scored the overall process;
- they wanted to articulate the differences in services and support they had received from individual practitioners and services;
- parental satisfaction and understanding of the SEND system and wider reforms are intrinsically linked. We gained feedback from many families who expressed high levels of satisfaction despite the service they described appearing not to be fully in line with the Code.

Local authorities could see the benefit in monitoring feedback over time and mapping change. Practitioners found these visual maps useful as they quickly showed areas of relative strength and weakness within the EHC process. They could therefore start discussions about practice in these areas. In order to consider suitable changes to their service delivery, they also needed the detail provided from our qualitative work. From this they were able to consider the steps to be taken to develop their services.

## Education, health and care service development

Based on hearing the feedback from local families, service providers were asked to consider possible next steps for their service improvement and development. Examples of these steps were:

**Service 1** to hold multi-agency training events to agree local processes and develop information for parents. These will cover agreeing outcomes and producing high quality plans. They will look to set up a Quality Assurance (QA) review with another service to get further input, advice and validation from external providers.

**Service 2** to assess their local placements. By carrying out a mapping exercise, they will seek to plan better use of existing resources (e.g. by looking at intake restrictions), increase capacity and bring about a strategic response to identified gaps in need. They would like to develop a long-term matching of provision to need.

**Service 3** to internally review their 'panel process'. Panel procedures are to be reviewed (and revised where needed). They will consider what panels are for, how to check decisions with parents (including the possibility of having a parent representative on the panel), staff availability to attend meetings, the role of the caseworker and supporting submissions. They want to establish clear guidance for practitioners and families and produce clear information on the process. Decision letters will be simplified to state clearly how decisions were reached and next steps.

**Service 4** to develop templates for information sharing across professions. These will be developed from multi-agency meetings, which will seek to agree a joined up process



across education, health and care services. Commissioners and parent group representatives will be involved in this.

However, practitioners (at the multi-agency workshops) identified some barriers to delivering services in a way that might lead to higher parental satisfaction:

- **Structural** – such as how education, health and care services work together to deliver despite different support criteria, processes and priorities, and funding streams;
- **Procedural** – such as how referral routes are made accessible whilst managing case flow; or how placements and support provision are agreed equitably across the local authority;
- **Skills-based** – such as how caseworkers, teachers, health and care practitioners are enabled to feed into plans and delivery of support meaningfully;
- **Resource-based** – such as how the reforms are delivered fully and to a high quality within current time, resource and funding constraints.

From this study we have developed a website<sup>1</sup> for practitioners and families detailing our findings, the personal stories of families, service checklists (based on provision that led to higher or lower parental satisfaction), and tools and considerations for collecting feedback on families' experiences of the EHC process locally.

## Recommendations

In terms of next steps to take based on the findings of this research, we propose:

- R1. Local authorities should routinely collect and analyse user feedback in order to improve services and understand how effectively the local area meets the needs and improves the outcomes of children and young people who have special educational needs and/or disabilities
- R2. When gathering their own feedback from local families, local authorities should be able to evidence that:
  - this is more than a 'tick box exercise';

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<sup>1</sup> <https://ehcpjourneys.com/>

- they have consulted with a wide range of families and not just the established parent forums;
- they have been able to generate quality feedback that results in meaningful, robust and actionable changes to practice; and
- they are reflecting back changes they are making (such as with a 'you said, we did' format).

R3. There is a need to draw up guidance on how best to effectively elicit and act upon the views of children and young people with SEND within the feedback process.

R4. Good practice for service delivery and acting on feedback needs to be shared. We hope that the website will be widely disseminated to support this.

R5. There would be great benefit in adding examples of innovative practice as well as ways to overcome barriers to the website in order to share ideas across services.

R6. There is a need to monitor use of the website to understand who is using it, how it is being used and what impact it is having.

R7. Local authorities involved in this study should be revisited over the longer term to assess how they took forward their proposed changes and the impacts of these. Lessons learnt should feed into advice on the website.

# 1. The study, background context, aims and approach

1. This report presents the findings from a small-scale qualitative study commissioned by the Department for Education (DfE) to examine user satisfaction with the Education, Health and Care (EHC) assessment and planning process for children and young people with Special Educational Needs and Disabilities (SEND). The study was undertaken by ASK Research. It was conducted between May 2015 and December 2015 – during the first year of national implementation of the new EHC process.

## SEND reforms and education, health and care plans

2. New duties regarding children and young people with special educational needs and disability<sup>2</sup> are contained in the Children and Families Act 2014<sup>3</sup> (the Act). These are explained in The Code of Practice<sup>4</sup>, the statutory guidance published by the DfE and the Department of Health (DH) on duties, policies and procedures relating to part 3 of the Act. These duties came into force in September 2014 and place responsibility on local areas to identify and meet the needs of children and young people with SEND aged 0 to 25. The local area includes the local authority and health commissioners and providers, together with the area's Early Years settings, schools and post-16 further education sector.
3. The Code of Practice sets out that 'where, despite the school having taken relevant and purposeful action to identify, assess and meet the SEND of the child or young person, the child or young person has not made expected progress, the school or parents should consider requesting an education, health and care needs

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<sup>2</sup> A child or young person has SEN if they have a learning difficulty or disability which calls for special educational provision to be made for them. A child or a young person has a learning difficulty or disability if they:

- have a significantly greater difficulty in learning than the majority of others of the same age, or
- have a disability which prevents or hinders them from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream Post-16 institutions

Many children and young people who have SEN may have a disability under the Equality Act 2010 – that is '...a physical or mental impairment which has a long-term and substantial adverse effect on their ability to carry out normal day-to-day activities'. SEND Code of Practice: 0-25 years, 2015

<sup>3</sup> <http://www.legislation.gov.uk/ukpga/2014/6/part/3/enacted>

<sup>4</sup> 'Special educational needs and disability code of practice: 0 to 25 years: a statutory guidance for organisations that work with and support children and young people who have special educational needs or disabilities'; Department for Education and Department of Health, May 2015; [www.gov.uk/government/publications/send-code-of-practice-0-to-25](http://www.gov.uk/government/publications/send-code-of-practice-0-to-25)

assessment'. The purpose of this assessment is to decide whether an Education, Health and Care (EHC) plan is required. The purpose of an EHC plan is to make special educational provision meet the special educational needs of the child or young person, to secure the best possible outcomes for them across education, health and social care and, as they get older, prepare them for adulthood.

4. The definition of SEND has not changed and therefore a child or young person with a statement would be expected to require an EHC plan. All transfers from existing statements are expected to be completed by April 2018.
5. The key principles in the Code of Practice are designed to support the earlier identification of need and intervention. They should involve children, young people and their families in their support and multi-agency working practices (across education, health and care services). Provision should be high quality, looking to the future and adulthood.
6. In line with the steps set out in the Code, we have split the EHC process into five steps: identification (requesting a referral and deciding whether to assess); 'assessment'; 'planning' (including the drafting and final sign off of EHC plans); 'putting the plan into action' and 'reviewing'.

## User satisfaction

7. The DfE set out an accountability framework for monitoring the progress and outcomes of the SEND reforms (DfE 2015<sup>5</sup>; DfE 2015<sup>6</sup>). This included proposals to measure success at a national level through data on improved outcomes and user experience across three broad areas:
  - positive experience of the SEND system for children, young people and families;
  - improved outcomes for children, young people and their families; and
  - effective preparation for adulthood
8. This qualitative study was commissioned to support element I of the accountability framework - to explore whether children, young people and families are having a positive experience of the EHC process part of the SEND reforms.

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<sup>5</sup> Department for Education [Accounting officer: accountability system statement for education and children's services](#) Ref: DFE-00026-2015.

<sup>6</sup> Department for Education [Special educational needs and disability: supporting local and national accountability](#) Ref: DFE-00118-2015

9. The evaluation of the SEND Pathfinder Programme (2011-2015) found that although families reported overall higher levels of satisfaction with the trialled EHC process, there remained a significant percentage who were not satisfied. There were concerns from families about insufficiently explained decisions, the need to repeatedly share information, absence of joint planning across services and the amount of preparation required for meetings. This research showed that parents were less satisfied when they lacked capacity to take part in the process, lacked support or 'buy in' from professionals, when the process was unclear and when the EHC plan was not shared or followed<sup>7</sup>. The DfE therefore wanted to explore further possible solutions for this.
10. Previous work on user journey mapping has been carried out within government by the DWP<sup>8</sup>. This explored the experiences of customers aged 18-26 years with a physical or learning disability as they moved from education towards employment, to inform the development of a new disability strategy. The primary objective of the research was to further the DWP's understanding of the barriers and catalysts that helped young adults with disabilities make the transition from education into work. The study included interviews with 12 young people and user journey maps were developed for each, detailing what led to higher or lower satisfaction at key points in the process.
11. DWP also explored claimant experience and satisfaction<sup>9</sup> using a large-scale survey approach. From this, they were able to detect statistical differences between the experiences of groups of claimants, along with barriers and drivers to satisfaction.

## Study aims and objectives

12. There were two overarching aims of this study:
  - to map children, young people and families' experience of the EHC process and determine their satisfaction with the service in the local area; and

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<sup>7</sup>[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/448157/RB471\\_SEND\\_pathfinder\\_programme\\_final\\_report\\_brief.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/448157/RB471_SEND_pathfinder_programme_final_report_brief.pdf)

<sup>8</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/221224/WP111.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/221224/WP111.pdf)

<sup>9</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/364302/rrep884-research-report-dwp-claimant-survey-2013.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/364302/rrep884-research-report-dwp-claimant-survey-2013.pdf)

- to explore the extent to which the approaches employed to capture user feedback in the course of the study can help local areas and others to gather user satisfaction and make improvements to their service.
13. The specific questions we addressed were:
- How are EHC assessment, planning and provision processes implemented by local authorities and delivery partners? What are the key aspects/encounters with regard to service user satisfaction and how do these vary by group?
  - What are the key issues driving user dissatisfaction and satisfaction for different groups in relation to these processes? How feasible is it to make revisions to services to improve user experience? If problems appear inherent/intractable can this be challenged through innovation?
  - What practical and effective actions can local authorities take to improve user experiences in reference to key aspects of services and drivers of dissatisfaction? What good practice can be replicated and what innovative solutions can be reached in partnership with local authorities and delivery partners?
  - What methods can local authorities use to research and gain productive feedback themselves to improve user experiences? How best can this information be presented and disseminated to local authorities so that they will make good use of it?
14. The primary output from the research was to be an interactive resource to help service providers develop their practice - including guidance on how to research service user experiences.

## **Methodological approach**

15. This was a small scale qualitative exploratory study. The research focused on four local authorities in England. These were purposively selected to include a broad mix by type, location and population (i.e. black, minority and ethnic groups, socio-economic profile, disability), and because of their willingness to embrace the exploratory nature of the study. The four authorities were also selected because of their higher SEND caseload volumes. This was in order to maximise opportunities to consult with families within the project timescales.
16. The research comprised three key strands of activity:
- data gathering workshops conducted with a broad range of stakeholders and practitioners in each local area. These were conducted at the start and end of the research process;

- in-depth consultations with parents/carers of children and young people with SEND. This included 67 depth telephone interviews and 10 online survey responses with open and closed questions (N = 77); and
- focus groups with young people with SEND over the age of 15 years (N = 15).

17. More detail on the methodology, sample and analysis can be found in Appendix A.

## **Workshops**

18. Two workshops were held in each local authority. One at the beginning and one at the end of the research process. The aim of the initial workshop was to determine how the EHC process was being implemented in each local area. This enabled us to contextualise family feedback and levels of satisfaction, as well as, look for examples of varied / innovative practice.

19. The purpose of the second workshop was to provide feedback to each area on what we had learned from users. We sought to determine how the feedback could be used to improve local service delivery. We also explored how well the approach to capturing and presenting user feedback employed in this study proved an effective mechanism to shape service delivery. Attendees were also asked to trial and comment on early versions of the website that we were developing to support service improvement.

20. A total of 128 professionals attended at least one of the local workshops (the majority attended both) along with parent representatives. The professional attendees included a range of education, health and social care practitioners, managers and commissioners (with the majority being education staff from SEND teams). Further details of attendees can be found in Appendix B.

## **Data collection from families and young people**

21. A total of 92 parents and young people from across the four local areas fed their experiences of the EHC process into the study.

22. Sample selection was purposive to include a broad mix of parents by:

- those new to the SEND system and those transferring from a statement;
- stage of the EHC process (including a mix of those who had completed the process and those who were still part-way through);
- child/young person age; and
- type of SEND.

Details of the sample breakdown can be found in Appendix C.

23. The telephone interviews with families involved exploring their experiences and reflections on each of the five elements of the EHC process. They were asked to score their levels of satisfaction with each element of the process. This was used to develop service user maps of satisfaction for each of the four participating local authorities. Given the limited number of users involved in this study, the intention of this scoring system was not to provide a quantitative assessment. Rather, it was used as means to provide a visual representation of satisfaction and issues across the local process.
24. Parents were also asked about their awareness of, and satisfaction with, the wider elements of the government's SEND reforms (e.g. Local Offer, Personal Budgets, Independent Support etc.) and opinions of where they felt services could be improved and how. In addition, we ascertained how families felt they would like to be consulted by their local authorities. The topic guide and recruitment materials can be found in Appendices D and E.
25. Additionally, an online survey was developed which asked parents to rate their satisfaction with the elements of the EHC process (closed-ended questions), explain their views on it and suggest ways to develop the service (open-ended questions). This survey is in Appendix F.
26. Three focus groups were held with a total of fifteen young people with SEND. They were led by a member of the research team, and supported by local staff (including teaching assistants and support workers). All groups took place in educational settings. The participants had all been issued with EHC plans and were aged between 15 and 19. They had a mix of SEND needs and varying support in place to meet their needs (including being in a range of different educational placements). The focus groups followed a similar topic guide to the parent interviews. Young people commented on the process overall and described what they liked and did not like about it.
27. Participants were recruited from records provided by each local authority. In an attempt to minimise potential bias, local authorities were asked to purposively include some families who they knew had positive experiences and some who had had a particularly negative experience within the overall sample. A larger sample was requested than needed so the research team had control over the selection of participants. The intention was to select up to 20 out of 60 parents from the lists provided. Very few parents declined to have their contact details passed on to the research team.



28. The research followed the Quality Standards for Qualitative Evaluation<sup>10</sup> and DfE's ethical procedures. Further details regarding recruitment and ethics employed in the research can be found in Appendix A.

## Outputs

29. The output from this study, along with this report, is a website<sup>11</sup> for practitioners and families detailing our study findings, service checklists (based on provision that led to higher or lower parental satisfaction), and tools and information for collecting feedback on families' experiences of the EHC process locally.
30. In this report, Section 2 sets out how implementation varies across the local authorities, feedback from users and factors affecting experiences of the EHC process. Section 3 explores potential ways to increase parental satisfaction, including identifying key barriers to implementing EHC process change. Section 4 explores the extent to which the approach for capturing user feedback employed in this study can be used by local authorities to improve services in their area and lessons learned from gathering user feedback.
31. Quotes used throughout are all taken from parent interview transcripts or survey responses. Any names have been changed, and we have not provided individual respondents' details to protect the anonymity of all participants.

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<sup>10</sup> <http://dera.ioe.ac.uk/21069/2/a-quality-framework-tcm6-38740.pdf>

<sup>11</sup> <https://ehcpjourneys.com/>

## 2. Experiences of, and satisfaction with, the EHC process

32. This section provides an overview of families' satisfaction with the EHC process in the four local areas studied. We then detail the drivers of satisfaction and dissatisfaction within each step of the process and variations within responses.
33. Our research found broad similarities in how the process is being delivered in the four participating areas. There were some subtle differences such as variation in:
  - referral approaches for families to enter the SEND process;
  - threshold levels to enter the EHC process and the extent of evidence required to support the initial referral;
  - approaches to decision-making (e.g. use, or otherwise, of decision-making panels) to determine whether or not to proceed with an assessment or to write a plan;
  - the roles, responsibilities, skills and experience levels of staff deployed at key points of the process, such as, family liaison, coordinating assessments and plan development;
  - the extent and type of involvement of a range of professionals involved in supporting the child or young person;
  - extent of signposting to independent and other support;
  - mechanisms for sharing and agreeing information and advice; and
  - determining resource and agreeing placement.
34. More detail of variations in local EHC process implementation is in Appendix G.

### Overall family satisfaction with the EHC process

35. Overall, parents reported being satisfied with the new approach to SEND in which the EHC process operates. In interviews parents generally reported that they liked:
  - the new philosophy behind the reforms which promote:
    - being involved - with a person-centred approach, in which their opinions are listened to and respected;
    - their child being at heart of process;
    - professionals taking a multi-agency approach; and
    - developing an holistic view of their child;

- individual staff working with them throughout the EHC process. These individuals:
  - make all the difference to their experience and satisfaction;
  - go the extra mile to inform and support them;
  - keep the family informed and involved in the process; and
  - seek to really understand the family and child's needs.

36. Parents appreciated that everyone was still getting used to the new system and a new way of working and that this might be taking time to 'bed in' fully, less than a year into the change.

*"I mean, it's all new, isn't it? We laughed about how we were all getting used to it together. They [staff] often still had to look things up."*

37. For this project user journey maps were created. This is a way to describe all the experiences a 'service user' has with an organisation and the emotional responses they provoke. It can be a useful tool to help understand how the public experiences the delivery of services, especially in terms of identifying 'moments of truth'. These are the critical points when activities or initiatives are most likely to succeed or fail<sup>12</sup>.

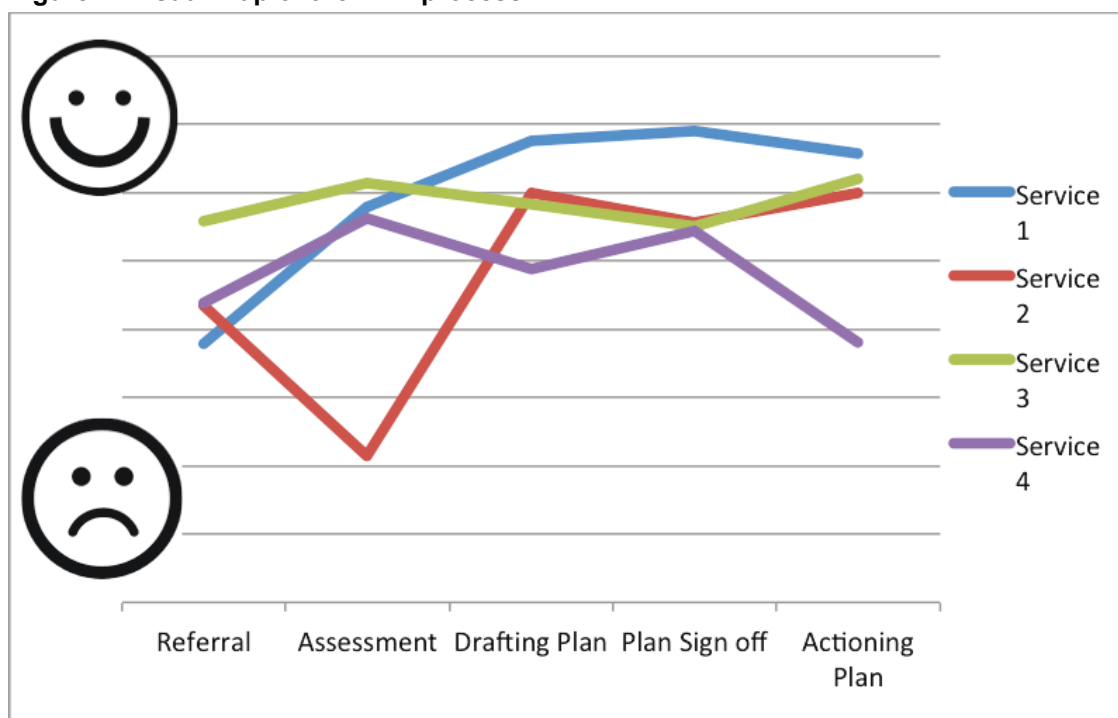
38. Parents were asked to score their satisfaction with each step of the EHC process. Mean scores were then calculated across the sample of parents in each area to give a general indication of satisfaction levels with each step of the EHC process.

39. The visual maps show which elements of the process families are more or less satisfied with. There were some variations in terms of the extent to which families were satisfied with the five key steps of the EHC process in each of the four local authority areas (see Figure 2).

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<sup>12</sup> <https://gcn.civilservice.gov.uk/guidance/customer-journey-mapping/>

Figure 2: Visual map of the EHC process



40. The detailed parents' experience of the EHC process in this sample revealed a number of areas where services were still working towards consistently delivering practice in line with the Code. These included examples of children and young people not having their needs identified early, a lack of appropriate Health and Care input, plans not being SMART (specific, measurable, attainable, relevant and timely) or outcome-focussed, panels overruling co-produced multi-agency needs assessment, and tensions around provision or placement issues. Also many parents had very little understanding of the new process and wider SEND reforms.
41. We now detail the key experiences parents reported on each step of the EHC process.

### Experiences of identification

42. The identification step of the EHC process includes what happens from the point at which it is known or suspected that a child or young person requires more support for their SEND, up to the local authority making a decision on whether or not to conduct an assessment. Parents reported the key issues that led to higher satisfaction at this stage. This included:
- early identification of children's need for additional support and steps being taken quickly to arrange appropriate intervention;

*"We had a good paediatrician who told us about the need for an EHC very early on. She's been involved with our family from 3 weeks old and helped set everything up with the nursery, liaising with education about what [my child] would need before the EHC process started."*

- advice and support with applying to enter the EHC process and to understand what the process involves;
- chance for a face to face discussion with an informed professional to discuss the process and their child's needs. This included home visits and parent events.

*"We were invited to an evening at the school with other parents. The whole team were there and they explained everything to us that was going to happen. We could ask questions and get to talk to all the staff. It was good to meet them and put faces to names. There was the SENCo from our child's school and the EHC co-ordinator and her boss. The parent partnership people were there and we were told that they could help us, but we don't think we'll need it."*

43. Issues which led to lower satisfaction with the Identification step were:

- later identification of needs. Needs were only being assessed when the child was older, struggling at, or excluded from school and presenting with education and/or behaviour issues. This was often felt to be limiting the progress being made by the child and having a negative effect on the family's' functioning and well-being;
- a lack of a clear or poorly explained process which parents did not understand, did not know who it should involve, (including their own role), or when and who their contacts were;

*"I was so depressed. I didn't know where to turn to and I had to get used to being in this position. It wasn't all out there. You really have to search for it. There was nothing that said here's the information if your child is bad at school, no leaflet. Nothing said what is happening or these are the steps. It wasn't good at all. If there was more information for parents in my situation, who didn't know what was going on, that's what's needed."*

- not having a clear self-referral process or simple paperwork to complete to contribute to the application;

*“It was such a stressful and daunting experience. He was really struggling at school, so we decided to keep him home. We had started to get a diagnosis for him, which we think will be high functioning autism. We were told about EHCs from someone and when I looked it up we decided to apply ourselves. The school said they couldn’t help as he wasn’t there any more. It’s really hard to know what to put in the forms. Then I knew I’d hear back within 6 weeks, which was nerve-racking, but I had no idea what happened after that.”*

## Experiences of assessment

44. The Code of Practice states that an EHC needs assessment should seek advice and information from a number of key professionals on a child or young person’s education, health and care needs. Based on the evidence the local authority must then decide whether there is a need to issue a plan. Key issues which led to greater satisfaction for parents with this stage were:

- appropriateness of assessment - children and young people being appropriately involved in the assessments (including being supported to feed in their opinion) and these assessments being carried out by a suitable professional (usually someone who the child knew) and suitable to the child (based on their age, needs and ability level);

*“It feels like it’s about him, so I’d say it definitely has the child’s voice in it and I think it’s so important that that is heard. It makes him feel grown up to be involved in the whole process, to be asked for his views and what he wants. The Education Psychologist saw him in his secondary school, in form time and in some lessons I think, and he spoke to his main teacher and then came round here and spoke to me. I liked that. They obviously thought it was important to hear what he was like at home and what we thought he needed.”*

- having all of the professionals attending multi-agency meetings and providing assessments of their children. This was in order that an holistic picture could be developed of all the child’s needs. Agreement could then be reached jointly on how best to support them;

*“We had regular meetings with the paediatrician and the Speech and Language therapist, Occupational Therapist and Educational Psychologist. They have all been in constant contact with us. After they assessed him, they phoned me, told me what they thought and got my opinion. I was sent a copy of every report and all the way along they told me what was going to happen next. I thought the assessment was really thorough.”*

- involving the child’s current and prospective school staff. Including staff from a placement which the child might be moving to, to ensure they were familiar with the child and family’s’ needs and could start to plan how best to support them from when the plan was agreed;
- opportunities for pre-meetings (for example before multi-agency meetings) and being provided with copies of all assessment outcomes and reports, so that they were kept informed and felt they could contribute to the multi-agency discussions;
- having time and suitable information to allow them to make informed decisions, which felt right for them now and in the future;
- building up a full and complete picture of the child, not just in an academic context but to include all their needs (such as eating, sleeping, toileting, travel and housing) which could all affect their ability to make progress;

*“It all felt much more about Jasmine than statements did. It was really good to include all her behaviour needs and health and later in life. The school set up all the referrals to lots of professionals who all wrote reports on her.”*

- being regularly and openly informed of progress (including reasons for any changes or delays) and when and how decisions were being made.

45. Issues that led to lower satisfaction with this stage included:

- assessments focusing on the child’s deficits, i.e. what the child could not do rather than including what they could achieve;
- lack of meaningful (or in some cases, any) input from Health and Social Services. This included not all of the professionals who were, or could have been, supporting the child being involved in the assessment (such as CAMHS) or those who were, not doing so in a meaningful way. Most frequently, parents reported that health professionals detailed the child’s condition and possibly needs, but did not translate this into the implications for their learning and requirement for support;

*"I was told we were all going to meet together. The school didn't send any information or tell me it was for a transfer rather than just an annual review, but I'd read up so I knew. The Coordinator just told me to prepare for a very long meeting. I wrote 7 pages about what my daughter needed. When I turned up there was the SENCo, teacher, 1 to 1 supporter and EHCP coordinator. None of them had prepared reports or filled out any of the forms they were meant to. The SENCo only stayed 5 minutes and there was no Ed Psych there. Others hadn't sent in their reports. The meeting ended up being abandoned as none of the required documentation was there. That was when we looked for legal advice. We didn't know what else to do, they just didn't seem to be taking it seriously."*

- parents having to be proactive in driving the assessment process forward. Some told us they had to suggest who should be involved, tell them what they needed to provide, and coordinate the process;

*"We did all the ringing. I'd found all about it on the internet and really wanted this to make things better for [my son]. They didn't contact everyone for reports, so I did it all. I told them what we needed and when by. I had to keep it all going and make sure it was right."*

- results of assessments coming as a surprise to the parents;

*"They said he had the abilities of a six year old, which came as a real shock to us. He's 15 and nothing's ever been picked up or mentioned to us before. When we told the schools, right from primary, we thought he was struggling they just said he needed to pay more attention. All that time we've lost..."*

- issues with the availability of suitable staff leading to delays in the time taken for assessments to be completed and reported on (and therefore the overall length of the process);

*"We were told there would be a delay as the Ed Psych had a backlog and nothing could be done without them. We were told we could get a private assessment instead if we were worried. We asked the paediatrician to write a report and sent him all the details. But he didn't offer much direction. There was nothing in there about school or what help was actually needed."*



- panels taking decisions which appeared to be in conflict with the parents' understanding of what their child needed. Decisions were not in line with discussions that had taken place with other professionals. There was little or no explanation as to the decision-making process (including what parents could do if they disagreed).

*“Jordan’s on a statement now. A letter came saying that our case was going to panel. These are the ones that make the decision. But this was before anyone had come out and seen him, or talked to us or anything. So this decision is just off of what I put in the form. What if I didn’t do it right? I’ve heard you can’t go back to them for another 6 months. I don’t know if they can take his statement away.”*

## Experiences of planning

46. The planning step of the EHC process involves taking all of the information from the assessments and, where these find more support is needed, putting this into an actionable plan. A draft plan is shared with parents for them to agree or suggest changes. Once agreed, it is then re-issued with placement details included (i.e. the name of the nursery, school or college the child or young person will attend) as the final plan. Parents reported being more satisfied with this step of the EHC experience when:

- the plans developed were SMART, explicit about the support needed, what for, how success would be measured and contained aspirational outcomes;
- plans were co-produced between parents and the multi-agency team. These were an accurate reflection of their child, family and their needs and had been agreed jointly;

*“We wrote the plan together, all sat round a table. We all said what we thought and it was put straight into the plan. Couldn’t have been simpler.”*

- they were given sufficient chance to comment on the draft version, discuss its contents and agree changes when necessary;
- their child/young person and parents' views and wishes were captured and reflected in the document;

*“Everything about the plan is spot on. It’s great. Our family story was written by me with our family worker and shows our dreams for Sonny. That he’ll go shopping, have his own money, be his own person and live as independent a life as possible. I feel it sets out how he’s going to develop and how we’ll be supported.”*

- the plans considered the short and long-term implications of the child’s SEND on both them and their family;
- placement visits were arranged for parents to look around the provision available to their child. This helped them make informed decisions about the most suitable support for their child and get to speak to staff there. Some parents appreciated being accompanied on these visits by a member of the SEN team or an Independent Supporter (IS), so they could discuss their thoughts with someone.

47. Parents who were less satisfied with the planning stage described the key issues as being:

- the plan being a lengthy, inaccessible document or one which had not been tailored specifically to their child or family circumstances. Some were simply a copy and paste from other people’s plans;
- inconsistent or conflicting advice being in the document which made it difficult to agree clear actions;
- delays in getting the final plan issued and implemented, due to disagreement over content, placement discussions or other reasons which were not explained to the parents;

*“There was no school named on the plan. We were told to sign it and then this would be sorted. I didn’t know that wasn’t right then. They said that’s what they do around here because this bit can take so long because it’s about sorting out the money. They said if I didn’t agree with anything I could take it to tribunal. It was so much to take in, I felt overwhelmed to be honest. There’s nothing SMART on it. It doesn’t set out what actual support he needs or from who. It doesn’t say he needs watching because he might run off. They’ve suggested two schools but I think we should wait and see if he’s diagnosed with autism before we say which is best. One school have said they want to assess him themselves. It seems like doing the plan hasn’t got us anywhere.”*

- the parents views and/or those of the child/young person not being adequately captured and reflected in the document, or not given sufficient weight in final decisions;

*“I took the time to read through and consider the draft plan. I made comments on it and sent these back to the council. The plan was then re-issued in its original state with none of the comments or changes. I’d just been ignored!”*

- noticing inconsistency across plans produced locally, or in other areas, which led parents to think their plan may have not been of adequate quality or content;

*“I signed off the plan but now I’ve seen what’s in other people’s plans I’m actually very concerned. The main issue is that it does not state what actual support Charley needs now and in the future. So when she starts primary school in September there is no provision stated and the support won’t be in place to meet her needs. It states she has got speech and language issues but does not state what sessions she should have to address that.”*

- educational aspirations reflected in the document being low, with a predominant focus on behavioural, social and emotional development;
- issues around agreeing placement decisions, including:
  - parents’ wishes not being met;
  - process delays occurred if schools entered into negotiation with the local authority about meeting the child’s needs, the type and level of support required and who would provide the funding.

*“The panel had recommended a special school placement that I’d been quite clear I did not agree with. So I ‘appealed’ the decision, not formally appealed - just filled in a form making the case as to why the panel’s recommendation was wrong. Another Ed Psych came out and after having met my son agreed and a new report was done. We’re waiting now to see what’s agreed on the final plan.”*

## Experiences of putting plans into action

48. Some parents interviewed had not yet had their plan implemented or felt unable to comment on how well it was being carried out. Often this was because it was not

to start until the coming academic year. Key drivers of satisfaction with this stage of the process were:

- having the detailed support put in place quickly after the final signing off of the plan;
- having a clear plan so that it is obvious what actions need to be taken, with everyone in agreement;

*“Everything’s happened exactly as they said it would. On top of that the school are really good at keeping us up to date with how she’s getting on and they’ve said we can go in and talk to them if ever we need to.”*

- clear monitoring and reviewing processes set out so that everyone involved knew what they were working towards, how to know if this is happening and what action to take if not.

49. Factors leading to lower dissatisfaction were generally the reverse of those which parents identified as leading to higher satisfaction. They included where:

- further discussions and agreements took place after the final plan was signed off, meaning action was delayed;
- issues occurred around placement, funding, resources and support availability that meant there was a delay (or lack of) implementing the actions set out;

*“We’d been through the whole plan and process and finally they found a school who said they’d take him. So he’s got to go there and be assessed again so that they can see what his needs are and how they think they will support him. It sounds odd after what we’ve been through but they’re saying they’ll look at other support he might need that’s not in the plan.”*

- plans were not clearly set out and so it was not obvious what action should be taken and who was responsible for making this happen. Similarly without this clarity it was not easy for parents to know what should have been happening and what to do if they felt this was not the case.

*“I’m still waiting to hear what will happen now I’ve signed it. There’s only one course that he can do at college apparently... so we’ll just have to see how that goes. I’d asked for some people to come round and talk to him about his next steps, jobs and a place to live but I’ve not heard anything from anyone.”*

## Experiences of reviewing

50. The review step concerns how implementation of the plan is being checked, with steps in place setting out how the plan will be reviewed and modified. None of the parents we interviewed had yet reached the reviewing step, but they did raise some issues about what they expected to happen:

- some parents saw the EHC plan as a live document (based on the way it had originally been developed) and so assumed it would be frequently updated;
- parents were satisfied when the professionals working with them were keeping them informed about the implementation of the plan and the progress their child was making;
- some parents had had it clearly set out for them how the document would be reviewed and amended (usually through an annual review, although the detail of who would be involved in this and what form it would take had not been specified).

51. However, some parents had concerns that:

- they did not understand how they would know whether the plan was being implemented as stated or how they would know if it was having a positive effect on their child and their learning. They also did not know what to do if they had concerns about the support being (or not being) provided;
- some had had no information or discussions when the plan was issued about any review process, and some who had previously had statements for their child were unsure about whether the annual review process would still be in place;
- some parents reported being unhappy about the contents of the plan after it was issued and the way it was being put into action but they had no knowledge of how to raise or challenge this. A few were considering (or engaged in) tribunals, although most said this was because their concerns were not being dealt with earlier or 'lower down' the complaints system. Very few parents had heard of dispute resolution services.

## Experiences of support

52. It is set out in the Code that families should be supported throughout the EHC process. The Code states parents and young people should be referred to Information, Advice and Support services (IASS); Independent Support (IS); and parent carer groups are suggested as a way to get feedback from local families.

53. A key finding from our interviews was that parents really wanted unbiased, independent support and advice. They described how stressful and daunting the

process could be, especially if it coincided with a diagnosis of condition and/or was happening at the same time as the child or young person was presenting with behavioural and emotional issues. Those who had found and used support were generally positive about the help they received.

54. Parents told us:

- they wanted more help and information about the EHC process and their child's needs and, in particular, someone to talk to about their family's needs;
- even when very good support was being provided by the SEN team, parents could still want the advice of someone independent from the process. This was both as a means to check that what they were being told was right, and to get the perspective of someone who had seen other parents go through the process. There was seen as benefit to this being someone who was 'not part of the local authority';

*"I got lots of information from the service but it made a real difference to hear it from a local woman whose son was older than mine, but with the same sort of needs. She'd got a plan and told me about local schools and what questions to ask."*

- local groups and parent forums were seen as a good source of emotional support and advice. Parents wanted to be told these groups exist;
- many were confused about the process, especially in the early stages when they needed the most information and help. Very few in our research were aware of the IAS service, and, if they have heard about them, were not aware of what exactly this service could help them with. Those who had used these services spoke incredibly highly of them, especially in terms of understanding the families' experience;

*"All this paperwork kept being sent to me, but it went over my head to be honest. This is all new to me and I don't know anyone else who's been through it. It'd be really good if someone could explain it to me, like in a way that I get it. I'm dyslexic and I'm better when things are explained to me. I just put all this paperwork in a drawer in the kitchen."*

- often parents were in need of someone to talk to regarding their situation and to assist decision-making. Few parents in this research had knowledge of the Independent Support service;

*“What I liked about it was having someone on my side. There were all these professionals sat together but the IS person was there to help me, to advise me and stand up for me. They all work for the council, so I thought it might’ve been a bit us against them, but she helped me with it all.”*

- some parents want information provided in a range of ways; discussing information, advice and options, made relevant to their family and needs, was highly valued by all families.

55. Extracts from parent interviews and detailed family case studies, illustrating all of the points detailed here can be found on the website.

### **Sub-group variation**

56. Most of these issues were not specific to a particular group of families, or local authority, but across a wide section of them. However our analysis of responses did show some variation by groups of parents, based mainly on their child’s age;

57. Parents of children identified as needing extra support, and entering the EHC process at a younger age were generally more satisfied with the support they received. They spoke of having good relationships with their caseworker, them being understanding and good at explaining the process, and supporting the parents through the process. Parents also talked more of professionals working together and collaboratively agreeing the child’s needs and arranging intervention earlier than did the parents of older children.

*“The lady from the Early Years service was really good, a lifeline for us. She helped us through the whole process and all the services we’d need. She helps us day to day, like when Mia wasn’t sleeping she got us a meeting with paediatrics at the local hospital. We trust her. I don’t know how I’d cope without her.”*

58. Likewise, parents of primary school children were less likely to express concerns about the amount of time it had taken to get a referral for additional support assessed for their child than parents of older children. Although there were examples of families feeling they urgently wanted more help for their primary-aged child, these were fewer than amongst the parents of secondary-aged children and young people.

59. Examples of good multi-agency meetings came from parents whose children were secondary or college-aged and where the process had been led by an experienced transition worker.

60. Parents whose children had previously had a statement had a good understanding of how the EHC process differed, and in many cases, had higher expectations of what the new process would be like and could offer them. They often spoke about how much better the EHC process was in terms of building up a more holistic picture of their child and how they and their child were more listened to and at the heart of the whole process. However, this higher expectation sometimes led to them being less satisfied with their actual experience of the EHC process overall. Most commonly this was because the ethos of the new system did not translate into practice, such as getting quality input from Health and Care services.

*“We’d read all about how everyone would be at this meeting and we’d sort it all out in one go. I really wanted it to be better. But surprise surprise the CAMHS team still can’t make time to provide anything useful and the paediatrician still can’t communicate with us like humans. On paper it looked great, but the reality is still the same as before.”*

61. However, a common theme across the parents of young people aged over 16 years was the concern about suitable provision availability. In some areas all young people with SEND are recommended to complete a ‘Life Skills course’. Many parents felt this did not meet their child’s needs adequately.

*“She wants to work in a vets so needs to do sciences. They’re suggesting she does three mornings a week about how to get on a bus or count money. It’s as if they assume she’s never been to school in all this time.”*

62. In addition post-16 provision was often not full time. This led to issues for the family in terms of transport and also caring needs.

*“What no one seems to worry about is that he’s only going to be going to college a couple of days a week. That might be fine for another 17 year old, but he can’t be left on his own when he’s not in school, needs taking and getting. I don’t know if I can keep working, if I can fit my hours around his timetable or whatever. I thought there would have been more help rather than just saying he does this at college. They know he needs someone with him the whole time so who do they think is going to do that?”*

63. One group who were less satisfied with the way the EHC process had worked for them were those whose journey had stopped without an assessment or plan being issued. This means that it was decided that their child did not need the additional support offered by an EHC plan. Generally, these parents were dissatisfied by the



outcome of their application (i.e. they felt their child needed more support) and the lack of understanding of what steps they could or should take next.

*“We got a letter saying they weren’t going to assess her. I couldn’t believe it. But I went into the school and they said ‘don’t worry, we’ll just apply again but with more information this time’.”*

### 3. Factors affecting parental satisfaction

64. In this section we set out the key drivers of parental satisfaction and the perceived barriers affecting the delivery of practice leading to higher satisfaction. This section is based on parental ratings of satisfaction (from both interviews and survey responses), interpretation of parent interviews and outputs from workshop events.

65. We have drawn out the key issues which seem to underpin satisfaction across the whole EHC process. That is, the key areas parents and young people referred to when asked about their experience and levels of satisfaction. Ten common themes emerge as affecting satisfaction either positively or negatively. These are the extent to which there are:

#### I. **accessible referral routes**

with:

- simple self-referral processes (for example for parents of home educated children, excluded children, children who have not yet entered educational provision, and young people aged 18 and over who are returning to education);
- allowance for referral from different practitioners (i.e. not just schools) with clear information on who can make a referral and how they go about doing it;
- early identification and intervention as opposed to “crisis intervention”;
- a balance between the amount of evidence required from referrers and the needs of decision-makers (e.g. panel members) - in other words, with limited barriers to initial referral;

#### II. **holistic needs assessments driven by the child, young person and family’s needs and aspirations**

with:

- appropriate education, health and care advice tailored to address educational support needs;
- a person-centred approach – where all assessment and planning accurately reflects all aspects of the child, young person and family;
- details of the child/young person’s strengths and weaknesses and aspirations for now and the future;
- support for the whole family’s needs included (e.g. housing, behaviour management, respite, parental well-being as well as the child’s);

### **III. suitable support to meet educational needs**

with:

- a matching of provision to need, with outcomes and progress which can be (and are) monitored; in other words plans are SMART;
- available and accessible appropriate educational placements/provision;
- high quality support in place quickly after plan sign-off;
- wider/external provision agreed e.g. speech and language support, behavioural therapy or private providers;
- suitable educational provision with next steps set out for children and young people who are not deemed to need assessment or an EHC plan (i.e. for children and young people who do not go through the whole process);

### **IV. consideration of longer term ambitions and future implications**

with:

- a full 0-25 service - with high quality provision post-16 including full-time courses;
- post -16 information, advice and suitable support;
- plans that look to the future including the move into employment, independent living and for social interaction and Positive Activities for Young People (PAYP);
- high aspirations and clear steps for how these are to be achieved;

### **V. plans effectively put into action**

with:

- consistently high quality SMART plans which are fit for purpose being issued;
- EHC plans being clear to interpret, execute and resource to support the educational progress of children and young people with SEND;

### **VI. a monitoring and reviewing process in place**

with:

- a process for determining EHC plans are being delivered as set out i.e. an audit and quality assurance process;
- effectiveness of plans being regularly reviewed;
- all participants clear what the next steps are;

## **VII. clear and transparent information**

with:

- no jargon;
- a clearly documented process (which includes who does what and when; how decision-making works; how to evoke the complaints procedure etc.);
- straightforward paperwork and help to complete it if required;
- a balance between information overload and parents being supported to understand what is available to them;
- professionals being transparent with children/young people and their parents (for example, reasons for process delays or what decisions are based on);

## **VIII. joined up multi-agency working**

with:

- a 'multi-agency team' set up that includes all professionals who have involvement with the child, along with the family (and their advocates);
- clear processes for how this team works, roles and responsibilities;
- a common understanding developed across the team by effective information sharing, which leads to advice and support needs being jointly agreed;
- good practice and expertise being shared across child ages and professionals (e.g. The Team Around the Child and a working in partnership philosophy from Early Support, home visiting, key workers);

## **IX. parental and young people involvement**

with:

- support to effectively understand, contribute and influence (for example with pre-meetings offered to families to explain what will happen; time allowed for them to consider their options, and families provided with copies of reports and assessments etc.);
- the young person's voice effectively captured and accounted for;
- parents seen as equal partners in the process and experts on their own child/young person and family's needs;
- a non-adversarial approach with families listened to, supported and their contributions valued;

- support to make informed decisions - for example, on placement options and implications for the short and longer term;

#### **X. support provided to families**

with:

- regular signposting to suitable and experienced support;
- appropriate information and support for young people;
- an acknowledgement that parents may want, and have a right to, independent and/or circumstance-specific information, advice and support;
- awareness of emotional and social support needs to help decision-making, advise or assist parents through what may be a very stressful time.

## **Perceived barriers**

66. Our analysis of data from the workshops suggests that there are four key and interlinked barriers to the effective delivery of the EHC process. These relate to structures, procedures, skills and resources.

### **Structures**

67. Some of the features of the EHC process encountered by families that led to lower satisfaction were due to structural challenges including:

- a lack of multi-agency structures and agreed EHC processes:
  - a lack of co-terminus boundaries between health and education providers;
  - limited guidance on the implications and duties of the EHC process for non-education based providers;
  - limited organisational change to effectively include health and care within EHC process delivery;
- a lack of alignment with other organisational structures such as schools' annual cycle of applications for placement;
- perceived conflicting statutory guidance between education, health and care services causing operational problems. Health professionals, for example, feel they cannot respond to the 6 week deadlines imposed by the SEND Code of Practice. Social services are unsure whether children and young people with SEND meet the threshold for their service input;

- approach to commissioning:
  - commissioning needs to take account of cross-sector service provision;
  - commissioners are not fully engaged with the new approach so their decisions are not accounting for the additional time and expertise needed to produce sufficient outcomes.

## Procedures

68. There were clearly procedural factors affecting implementation of the new approach which included the following identified by workshop participants.

- changing previous procedures:
  - allowing easy access self-referral;
  - the use of panels - this system may have had its place previously but it now conflicts with the multi-agency and parental involvement approach;
  - plans require interpretation and translation of multiple sources of information into a plan of action with measureable outcomes;
  - the switch to looking at wider needs in an outcome-focused way is presenting a challenge to some service providers;
- multi-agency working practice:
  - actions to meet needs are not joined up with wider support packages for the family, highlighting the need for better configuration of health and care services into the EHC process;
  - there appears to be a tension with signposting families on to a wide range of additional support;
  - nurseries, schools and colleges are still seen as outside of the process and not engaged in the discussions and decisions about the local SEND approach more widely.

## Skills

69. Some identified barriers related to the skills and experience of the professionals responsible for delivering the EHC process. These included:

- different ways of working:
  - the new approach requires working in partnership with families and involving them and children and young people in decisions affecting them. This collaborative approach, along with working in joined up ways with other professionals, is proving a challenge for some practitioners.

Health practitioners, in particular, feel they are able to diagnosis conditions but can feel ill-equipped to suggest how this may be addressed in an educational context;

- reduced SEN specialism:
  - EHC plan case workers do not always have the skills and experience to be able to effectively coordinate the process, chair meetings, interpret evidence and support families. In addition some areas are using 'plan writers' whose role is simply to pull together evidence and produce a 'person-centred' document.

## Resources

70. Underpinning many of these issues were the barriers placed on services by the current limits in available resources. These were mainly:

- staff and time shortages:
  - the current workload resulting from the new approach, wider remit and referral routes, and a three year limit on transferring all existing cases is difficult for teams to manage and is leading to increased staff turnover;
  - availability of staff and their time is determining how local authorities are configuring their new services meaning less experienced staff are sometimes used, insufficient time is available to effectively carry out the EHC process and practices in line with the Code of Practice are unable to be fully implemented;
  - educational psychologists, for example, are coming under increased strain as all areas have them feed into every EHC plan. In some cases this is resulting in poorer quality input and delays in the process;
  - schools not being able to apply for all children who they think need an EHC plan because of the resources, time and effort required to make a referral;
- support availability:
  - local authorities are looking to minimise their spending rather than seeking to provide new placements or address gaps in provision;
  - with funding now being directed explicitly to placement providers for children and young people with SEND, there is an increased tension in accountability and whose duty it is to provide what. The situation is similar across education, health and care providers, with the question of who is responsible (and willing) to pay for what a common one;

- parents may not be being appropriately directed to additional support (including Independent Supporters) as this provides an additional level of scrutiny and challenge of local provision.

71. Everyone involved in service delivery seemed to be on board with the new approach but instead of completely reshaping their service they are focusing on amending their existing service and provision. We did not find many examples of innovative practice in the four areas involved in the study.

## **What does this imply for practice?**

72. In general the services being delivered as described in the Code of Practice were leading to greater levels of family satisfaction.
73. We have developed [a checklist](#) based on these findings for services to check themselves against. We also suggest some examples of [how practice leading to greater satisfaction is being implemented](#) and provide examples of resources to support this.



## 4. Getting feedback from users to shape and refine service delivery

### Introduction

74. This research was undertaken to help better understand children, young people and families' experience of the new EHC system and provide ideas that could help to improve it. Gathering feedback from families is an important part of local area approaches for self-evaluation and development. The need to capture user voice and to support children, young people and parents to participate in decisions about support is enshrined in the SEND Code of Practice. This section summarises how we captured feedback from parents and young people so that local authorities could choose to replicate our methods. It also documents lessons learned from the study and provides an assessment of how the local authorities studied might use feedback to develop their services.
75. Capturing family feedback effectively is not an easy task, particularly as children with special educational needs and disabilities and their families are a very varied group. There is no simple one-size fits all solution and we used a range of strategies.

### What did we do?

76. We mapped service provision with providers. This was important in order to be clear what we were asking for feedback on and to be able to interpret the findings - i.e. to situate the findings within the context of local delivery. Suitable questions were then developed to elicit parent and young people's experiences of the process.
77. Parents were asked to score their satisfaction with each step of the EHC process. Mean scores were then calculated across the sample of parents in each area to give a general indication of satisfaction levels with each step of the EHC process. (The results were shown in Section 2, Figure 2.1.)
78. The purpose of this exercise was not to provide a quantitative assessment of satisfaction as the sample size was not sufficient for this. It was a means of visually representing the general high and low points of families' journeys through the process.
79. User journey maps were then created. This is a way to describe all the experiences a 'service user' has with an organisation and the emotional responses they provoke.

80. We undertook in-depth qualitative telephone interviews with a sample of parents and consultations with young people. The purpose of this was to explore in detail how families were experiencing delivery within one year of implementation.
81. The topic guide explored family experiences of the overall EHC process and by each step, and their knowledge and experiences of wider elements of the SEND reforms. The topic guide we used is provided at Appendix D.
82. In order to purposively sample more parents who had had a particular experience (e.g. those who reported very high or very low satisfaction), we also developed an online survey for parental completion to quickly elicit their feedback (see Appendix F).
83. We presented the feedback in detail, at multi-agency workshops. From this, practitioners were asked to use an outcome-focussed approach to consider what actions, if any, the feedback caused them to consider.

## What did we learn?

84. In the course of engaging with families to undertake this research we learned a number of valuable lessons. We share these in order to inform the decisions service providers take about their own service evaluation and development.
85. We found a number of limitations with the sample data provided by local authorities. For example:
  - Local authority records of families were limited and most held only paper-based as opposed to electronic information;
  - records often lacked up-to-date contact details;
  - very few services hold email contacts for families, or communicate with families in this way;
  - there was little information documented in the records provided about the family i.e. stage in the EHC process, details of the child/young person, preferred means of communication etc.
86. The limited electronic management information held by local authorities involved in this study on families with SEND has implications for:
  - evaluation purposes - for example, the extent to which local authority records can be used to sample families for the purposes of a more quantitative, representative assessment, or to recruit in a wider range of ways;
  - monitoring and review - the extent of electronic information held affects the availability of information local authorities could utilise to monitor and review their services for example, referral routes, annual review meetings etc.

87. We found that calculating mean parents' scores indicated overall satisfaction but our in-depth conversations with parents revealed several important issues that must be taken into account in measuring and interpreting parental satisfaction:
- parents scored elements of the process (referral, assessment, etc.) differently to how they scored the overall process;
  - they wanted to articulate the differences in services and support they had received from individual practitioners and services;
  - parental satisfaction and understanding of the SEND system and wider reforms are intrinsically linked. We gained feedback from many families who expressed high levels of satisfaction despite the fact that:
    - the service they received may not be fully in line with the Code;
    - their children were not in education or employment because no suitable provision deemed to meet their child's needs could be secured;
    - families in similar situations reported lower levels of satisfaction.
  - gathering user feedback is only one aspect of understanding how well a local area is meeting its duties.
88. We attempted to get parents to complete the online survey by either a) sending them an email (where the service had these contact details) with the online link or b) sending them a written letter containing the online link. The links were sent to parents who we had been unable to contact by telephone. The email recruitment was more successful in areas where the local authority already used email to correspond with families. The written recruitment had limited success. Of the 55 parents we contacted by these methods, responses were only received from ten.
89. Some parents who did not have English as a first language asked to be sent the survey instead of taking part in telephone interviews and did submit their responses online.
90. Whilst interviewing parents, we found that:
- some needed to be given an explanation of services, terminology and language used to help them understand the questions;
  - in several families English was not the first language and families needed an interpreter (usually preferring to use another family member);
  - a number of parents were working and many had extensive caring duties and therefore need to be contacted outside of normal working hours and across the weekend;
  - there is a need for different approaches to ensure that hard to reach families are encouraged to provide their views. This may mean offering incentives as

well as a longer timescale to build up a relationship of trust and/or access families through trusted routes.

91. Consulting children and young people for research purposes is known to pose challenges. These issues can be magnified when these children and young people have SEND. We found:

- several innovative strategies are needed to communicate, recall is difficult and some young people with SEND have reduced cognitive ability. Communication may need to be very simple. Several strategies for eliciting responses need to be used (including drawing, or relating to pictures), which can take time. We followed good practice guidance in all our interactions<sup>13</sup>;
- it is difficult to prompt responses without knowing how the young people were involved in the process. We found that working with those who supported the young people through the process was beneficial (to make questions relevant) but this may inhibit the honesty of response. Support workers were also used to assist with appropriate communication;
- many parents had reservations about us approaching their children due to their social, communication and cognitive abilities. Although highlighting the need for the young person's voice to be heard, parents often felt that they were an acceptable route to doing this. The role of parents as gatekeepers is an understandable, yet challenging one;
- unless input from young people can be captured in a meaningful way then it runs the risk of being tokenistic and consideration must be given to the ethics of involving young people in research<sup>14</sup>.

92. We asked parents how they wanted to be consulted. Several told us they wanted to have a conversation to talk through their experiences, and put their opinions in the context of their family's circumstances. Others expressed a preference for a survey approach, which was quick and easy to fit into their lives. The majority of those who responded to the online survey said they preferred to be contacted by the service via email. Some parents suggested that feedback on family experience should be captured during the EHC process itself, and that they would value their opinions being sought as the process progressed (to improve recall and address any issues in real time). However, a number of parents wanted to speak to someone who was independent and not involved in making decisions about their family.

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<sup>13</sup> <https://www.nfer.ac.uk/nfer/schools/developing-young-researchers/NCBguidelines.pdf>

<sup>14</sup> [http://www.ncb.org.uk/media/1176052/participation\\_essays\\_final.pdf](http://www.ncb.org.uk/media/1176052/participation_essays_final.pdf)

## Presenting feedback

93. The visual maps we created were of value to the local authorities in that they quickly showed areas of relative strength and weakness within the EHC process. They could therefore start discussions about practice in these areas.
94. However, understanding what was causing these 'highs and lows' was only provided by giving the further detailed findings from the in-depth interviews. Local authorities noted that they needed this level of detail to understand what was driving varying levels of satisfaction, and therefore assess the action to be taken.
95. Local authorities were concerned that feedback was from a suitable number and wide cross-section of families. Specific measurement methods may not be suitable to collect useful information from this range of respondents. The use of mixed methods (surveys, interviews, focus groups and observation) is therefore likely to lead to better quality feedback which can inform service delivery.
96. Providing service user feedback revealed the following key issues from service providers:
  - **the value of hearing families' first-hand experiences** – many professionals at the workshops were not in regular contact with a wide range of parents or were not aware of parents' experiences of the EHC process as a whole. They also tended to focus on the specific SEND issues raised in the assessment process relevant to them and so they missed the wider family context in which this sat. They valued gaining this more holistic picture of families and felt it helped them to think through local practice more sensitively;
  - **the importance of engagement** – there has to be a genuine desire to listen to the views of parents – good and bad – and a culture of critical appraisal/self-evaluation for services to use the evidence from parental feedback to really influence improvements in service delivery. It should not be consultation for consultation's sake. Services could see that their previous attempts at gaining feedback (where these had happened) ran the risk of being too superficial or open to bias;
  - **for action planning to be effective a wide range of cross-sector participants should be encouraged to attend feedback meetings** – but attendance alone is not sufficient. Participants need to be equipped and supported to act as agents for change in their local organisations. They need to be encouraged and empowered to influence improved service delivery;
  - **senior-level buy-in** is crucial.

## How to act on feedback

97. The visual maps along with detailed feedback on service provision were presented to local authority providers and family representatives at the second workshops. They recognised the issues raised and chose key areas to focus their development planning on.
98. We encouraged them to use an outcome-focussed approach, in which they:
  - explored what was leading to the issues identified ('the story');
  - set out what outcome they wanted to achieve, what it would look like and feel for families and practitioners;
  - detailed the steps that needed to be taken, by whom and by when.
99. They set out what changes would need to take place in their service to increase parental satisfaction. It would be key to assess if and how these steps are taken and to what extent they address the issues raised. Further work will be required to assess how easily these steps can be taken and whether these affect parental satisfaction.
100. Local authorities could see the benefit in monitoring feedback over time and mapping change. However, they were concerned about the resources needed to repeat the depth of data collection carried out for this study.
101. We found that some of the feedback from parents implied the need for higher level changes that would be difficult for stakeholders to action due to the barriers detailed in Section 3.
102. Underpinning all of these suggestions was often the fact that someone needed to be ultimately responsible for gathering and overseeing the steps to be taken on feedback. However, many professionals noted the changes they could make to their own daily practice to affect parental satisfaction.

## Strategies to increase parental satisfaction

103. During the second workshop, services were asked to consider their potential next steps in response to hearing feedback. Their reactions mainly focussed on short-term strategies, which have since fed into mid- and longer-term plans of action. Examples of the types of solutions that the four services came up with are summarised below:
  - **Service 1** proposed having a SEND Reform Champion locally who would increase understanding of SEND and EHC issues across sectors at a strategic level. They would oversee accountability for reform implementation and monitor satisfaction with service delivery.

- **Service 1** will hold multi-agency training events to agree local processes and develop information for parents. This will include agreeing outcomes and producing high quality plans. They will look to set up a QA review with another service to get further input, advice and validation from external providers.
- **Service 1** suggested providing training for school governors and head teachers on the EHC process to encourage use of SEN resources and appropriate referrals. A SEN Compliance post would ensure consistency across the locality and compliance with the legal requirements.
- **Service 2** are assessing their local placements. By carrying out a mapping exercise they will seek to plan better use of existing resources (e.g. by looking at intake restrictions), increase capacity and bring about a strategic response to identified gaps in need. They would like to develop a long-term matching of provision to need.
- **Service 3** are going to internally review their Panel process. Panel procedures are to be reviewed (and revised where needed). They will consider what panels are for, how to check decisions with parents (including the possibility of having a parent representative on the panel), staff availability to attend meetings, the role of the caseworker and supporting submissions. They want to establish clear guidance for practitioners and families and produce clear information on the process. Decision letters will be simplified to state clearly how decisions were reached and next steps.
- **Service 4** are looking to develop templates for multi-agency professionals to feed into EHC plans. These will be developed from multi-agency meetings, which will seek to agree a joined-up process across education, health and care services. Commissioners and parent group representatives will be involved in this. The template is likely to ask for what evidence has been gathered about the child or young person, what outcomes are to be achieved, how this could happen and what steps the professional proposes are taken in terms of educational support.
- **Service 4** will focus on informing and up-skilling school and other support staff in their area to better meet the needs of families of children and young people with SEND. They have reconfigured their SEN team locally and will assess the skills needed for these staff to work more closely with providers, along with local parent groups.

104. Detailed examples of the types of development services set out for themselves are in Appendix H.

## 5. Limitations, discussion and recommendations

### Limitations

105. This was a small-scale study conducted during the first year of national implementation. The limited number of areas and families involved restricts the extent to which generalisations can be made. We cannot extrapolate these findings to all local authorities. Some of the findings presented will inevitably reflect the early stage of implementation and lessons learned along the way. Nevertheless, the detailed feedback captured from parents and young people provides valuable pointers for those wanting to learn from family experiences in order to improve delivery. Consultations with wider stakeholder groups for this research, as well as triangulation of our results with other research studies, suggests our key findings are in line with other issues emerging<sup>15</sup>.
106. The local authorities initially selected and approached families to take part in the study and although the sample was never intended to be representative of all cases, it is possible that local authorities could have ‘cherry-picked’ positive examples. However, we employed a range of strategies to protect against possible bias (e.g. over sampling, requesting additional sample, purposive sampling). In the event the narratives from parents reflected a range of experiences, both positive and negative.
107. Satisfaction scores collected were small-scale and therefore too small to analyse in any meaningful way. It is merely indicative of satisfaction. There are known issues with using ‘satisfaction’ as a measurement of experience with recent research evidence in the social care sector showing “the majority of participants selected a positive satisfaction rating even though both positive and negative experiences with services were described in their narratives.” Researchers suggest that “surveys provide opportunity for service users and family carers to elaborate on their satisfaction ratings. This addition will provide more scope for services to review their strengths and weaknesses.”<sup>16</sup>

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<sup>15</sup> <http://driveryouthtrust.com/index.php/joining-the-dots/>  
[http://www.ndcs.org.uk/search\\_clicks.rm?id=10785&destinationtype=2&instanceid=473176](http://www.ndcs.org.uk/search_clicks.rm?id=10785&destinationtype=2&instanceid=473176)  
<http://www.autism.org.uk/get-involved/media-centre/news/sen-report.aspx>

<sup>16</sup> Problems with measuring satisfaction with social care Rosalind Willis, Maria Evandrou, Pathik Pathak and Priya Khambhaita, Health and social care in the community, March 2015



108. We acknowledge that there are other 'users' of the EHC process, such as early education providers, schools and colleges, but the requirement from the DfE was to map the family and young person 'user journey' only.
109. We only looked at a small part of overall support for children and young people with SEND and their families, with only a small number of families with the most complex needs experiencing the EHC process. It is crucial that service providers also look at the processes that take place before children and young people enter into the process (for example, examining experiences of general SEN Support) to ensure support for all children and young people with SEND.
110. The timescale of this study was short and early on in the implementation of the new system. This meant it was not possible to find especially developed or innovative practice, nor to see how suggested service improvements were (or were not) implemented or the effect this had on family experiences.
111. The feedback from children and young people with SEND in this study is limited. Appropriately engaging them in the study and gaining productive feedback was difficult, and suggests issues for local authorities to consider when they set out to do this.
112. In reading this report, it should be acknowledged that the SEND population is a heterogeneous one. We note that the range and complexity of issues covered by the phrase 'SEND' is increasingly wide, even for the minority of the population who require additional support set out in an EHC plan. It does not always fit within one single definable category often having very different manifestations for different children and young people. We included children and young people with a wide range of special educational needs and disabilities (such as hearing impairment, emotional/mental health conditions, communication disorders, Down's Syndrome, ASD and ADHD) within this research and so are referring to the broad diversity of needs this encompasses.

## Discussion

113. The overall findings of this research suggest parents in the four areas studied are reasonably satisfied with the EHC process. They like the shift in approach, the inclusivity of families and the multi-agency approach. The EHC process is seen as being more positive than the previous process for statements.
114. However, it is clear from their detailed experiences that some areas were still working towards consistently delivering practice fully in line with the Code.
115. Support is very much needed but is not being routinely accessed. When parents were accessing support services they spoke very highly of it. However, this support was not being automatically offered to all parents entering into the EHC

process. It is positive that funding for the Independent Support service has been made available. In our view, this sort of provision will always be needed by some families (not just during the implementation of the new process). There needs to a system in place to ensure this support is benefitting all families. Support services also need to be separate from the local authority providers, to ensure they represent the best interests of parents and can provide some level of challenge and accountability to providers in the local area.

116. Some providers are struggling to shift towards an outcome-focussed approach. Some plans are not made SMART and there are issues with professionals focussing their assessment and EHC input on outcomes and appropriate support to achieve these. This issue is likely to become greater as the programme of reform moves forward and more families begin to review the impact of their plans.
117. In this research post-16 provision is a noticeable gap, with little or no mention of services for young people aged over 19 years. Again, as the current caseload of young people gets older, provision in later years and support to move into work and adulthood will come into sharper focus.
118. Overall, our research evidence shows that some families' awareness and understanding of the wider SEND system is low. In addition, in terms of the EHC process being inclusive of parents, children and young people, some parents are having to be excessively proactive. Although it is clearly the tendency of some parents to find out information for themselves and ensure the process is working as they believe it should, some parents are having to lead the process and lead the professionals themselves. In some areas there appeared to be an interpretation that the new approach should involve parents being more active, and this was placing additional pressure on parents.
119. Getting 'service user feedback' is a valuable means of assessing what is working and where action is required to improve practice. Capturing feedback from parents should be part and parcel of local area processes for self-evaluation. We found in this research that parents are keen to explain their experiences, rate service features and consider how services could be improved. Ensuring feedback is effectively gathered from families requires multiple methods to be employed. It should also be part of a wider dialogue about achieving the 'best possible' outcomes for all children and young people. This requires a shift from gauging parental satisfaction with the EHC process to satisfaction with achieving effective support, progress and life outcomes for families.
120. We found that quantitative measures of satisfaction alone were not sufficient to inform service delivery and parents did not feel they could accurately reflect the nuance of their experience with a simple score.

121. It was beyond the remit of this study to assess what impact the changes services suggested they would take had on the experiences of local families. However, we saw that understanding the detail of families' journeys did encourage providers to refine their services. Some took immediate action based on the feedback we presented. All of them started a dialogue about our findings and how best to proceed in shaping their service delivery. We believe it will take them time to digest what they heard and consider how best to implement change.
122. Our study was only small scale and involved a small sample of families. However hearing real families' voices and views certainly acted as a powerful catalyst for change. We have developed a website that provides detail of family journeys of the EHC process and provides parents' own experiences. Feedback from professionals suggests this will act as an important training tool for all staff engaged in the EHC process as well as a reminder of how practice affects service users.
123. We have set out a checklist of service provision against the ten factors affecting satisfaction. We have linked this to examples of local practice and helpful examples and other resources. We have also set out our ideas for collecting feedback which we hope will be used by local authorities to contribute to their self-evaluation process
124. We have identified some 'quick wins' (for example, making information clear and easy to understand, using templates to ensure consistent information provision for plans) but hope that services will also look at some of the issues which might need a longer term approach, such as how they will overcome local barriers to developing practice. Our hope is that the resource we have produced will be well-used and help to support a wide range of families and practitioners with their journeys through the EHC process.

## Recommendations

- R1. Local authorities should routinely collect and analyse user feedback in order to improve services and understand how effectively the local area meets the needs and improves the outcomes of children and young people who have special educational needs and/or disabilities.
- R2. When gathering their own feedback from local families, local authorities should be able to evidence that:
  - this is more than a 'tick box exercise';
  - they have consulted with a wide range of families and not just the established parent forums;

- they have been able to generate quality feedback that results in meaningful, robust and actionable changes to practice;
- they are reflecting back changes they are making (such as with a 'you said, we did' format).

R3. There is a need to draw up guidance on how best to effectively elicit and act upon the views of children and young people with SEND within the feedback process.

R4. Good practice for service delivery and acting on feedback needs to be shared. We hope that the website will be widely disseminated to support this.

R5. There would be great benefit in adding examples of innovative practice as well as ways to overcome barriers to the website in order to share ideas across services.

R6. There is a need to monitor use of the website to understand who is using it, how it is being used and what impact it is having.

R7. Local authorities involved in this study should be revisited over the longer term to assess how they took forward their proposed changes and the impacts of these. Lessons learnt should feed into advice on the website.

# Appendices

## Appendix A: Methods

This research report and the EHCP Journeys website is developed from in-depth narrative interviews with 92 families going through the Education, Health and Care (EHC) assessment of needs and planning process during 2015. This was the first year of the national implementation of the EHC process. The interviews concentrated on the family journey through the EHC process from the point of referral to putting the plan into action. We did not identify families who had had their plan reviewed to date. This is due to the fact that plans had been only in been in place for a short time. This appendix provides further detail on the methodology employed.

### Ethics and quality

The research was carried out in line with the DfE ethical procedures.

Recruitment of areas took place between May and June 2015; recruitment of families was between June and September 2015.

Participation was entirely voluntary. Participants gave informed consent to take part and were free to withdraw their consent from the research at any time.

To protect the anonymity of participants, all names have been changed, along with other key features (such as gender), which might otherwise reveal their identity. Anonymity of participants was also protected when we fed our findings back to the local areas during the workshops).

Narrative stories produced (in written and verbal forms) are based on the creation of composite case studies in order to convey the issues whilst protecting anonymity of the participants.

In line with DfE ethical procedures all data was held securely and unidentifiably. To ensure quality standards in qualitative research, all work was carried out in accordance with national guidance (2002).

### Methods

This is a qualitative exploratory study, based on:

1. in-depth, semi-structured interviews and a journey mapping exercise with families going through the EHC process in four local authority areas in England;
2. focus groups with young people with SEND;

3. stakeholder feedback from two workshops held in each area at the start and end of the research process. The workshops helped to provide a contextual narrative on the family journey through the EHC process in their local areas at the start of the research (workshop one). They also provided a form of respondent validation as stakeholders were afforded an opportunity to comment on the feedback received from families overall and in their local authority area at the end of the research (workshop two).

This is a small-scale qualitative study. The prevalence of views and experiences arising from the data is therefore not reported.

## **Sampling and participants**

### **Local authorities**

Directors of Children's Services in twenty local authorities in four parts of England were approached to take part in the study by the DfE. The sample frame for area was developed in consultation with the DfE policy group. Ten agreed to take part (with three of the original sample declining due to capacity issues and the rest not responding within the two week deadline).

Four local authorities in England were selected to take part. The local authorities were intentionally selected to include a broad mix by type, location and population (BME, socio-economic profile, disability) and because of their willingness to embrace the exploratory nature of the study. The four authorities included were also selected because of higher SEND caseload volumes.

### **Families and young people**

A total of 92 families and young people contributed to the study that had experience of the EHC process in the four participating areas. This included seventy-seven parents and fifteen young people. The research is qualitative and therefore cannot seek to be representative of all the experiences of families going through the EHC process. However, a range of strategies were adopted to maximise the rigour of the methods employed (e.g. using a defined sampling strategy, respondent validation via workshops and peer review, triangulation with external sources of research).

Access to families was negotiated through local authorities. The SEND team within each local authority was asked to select around 60 families. Local authorities were instructed to include a range of ages, needs, parent engagement and/or likely experiences. They were also asked to include families at different stages of the EHC process and a mix of families who had received a "no" or who had dropped out at various points of the process. The selection of 60 families also included a mix of those transferring from statements and new cases.

All 60 families in each local authority were sent a letter asking them to opt out of their contact details being passed on to the research team. Families were given two weeks to opt out. Few families contacted the local authority to opt-out at this stage.

The intention was to recruit 20 families and 5 young people from each of the local authorities from the (circa) 60 families whose details were passed to the research team. We requested details for more families than were required in an attempt to address concerns that local authorities may only select positive examples. We also needed to ensure that we had a sample of sufficient size from which to recruit families. Families were provided with a free telephone number through which they could contact the research team for further information at any stage of the research.

The local authority passed on all contact details for families who had not opted out to the research team. The research team sent a letter detailing the research to all families informing them they would be contacted by telephone.

Sample selection of families was both opportunistic and purposive. Criterion sampling was used to ensure the achieved sample included a broad mix by:

- families new to the SEND system and those transferring from a statement;
- age of the child/young person with SEND;
- stage of the EHC process (including a mix of those who had completed the process and those who were still part-way through);
- type of SEND.

Families in the sample were contacted between 1 and 5 times to request participation. Some of the telephone numbers received were out of date or unobtainable numbers.

Recruitment of families took place during the day, evenings and at weekends to maximise opportunities for families to take part. The research team provided more detail on the project, recruited according to the principles of informed consent and arranged a suitable time for interview by telephone.

Once contacted by telephone, few families declined to take part. The main reason for opt-out was not wanting to jeopardize the service received (despite guarantees around confidentiality). However, some were unavailable at the time the interview was scheduled and were not contactable despite further follow up.

## Interviews

A total of 77 narrative interviews with parents of children and young people with a disability or special education needs were conducted between June and October 2015, with similar numbers in each local authority. Each interview lasted between 35 and 95 minutes. Interviews followed a semi-structured interview topic guide but were conducted in a way that suited the interviewee. Interviews were conducted by telephone by three experienced social researchers and audio-recorded when respondents gave their permission.

Interviews aimed to cover:

- **expectations –**
  - how prepared they were
  - what they thought was going to happen
  - how they felt
  - how transitions were managed
- **satisfaction –**
  - what happened at/between process points
  - how involved they were in the process
  - outcomes
  - what they thought of the outcomes
  - how practitioners explained details to them
  - expectations for next steps
  - information provision
  - Personalised Budget support
  - experience of raising concerns/complaints
- **impact on family –**
  - how the process made them feel
  - what decisions they had to make
  - how they made decisions
  - what effect this had on their family members and arrangements
  - the child's opinions
  - any resolutions required



- knowledge and uptake of the Local Offer
- **recommendations for improvement –**
  - areas of need
  - what needs to change and how it would look in future
  - suggestions for development

Following involvement, participants were sent £20 worth of high street shopping vouchers to thank them for taking part. They were also sent details of issues raised in the interviews, including details of the Local Offer, Personal Budgets and were signposted to sources of support such as their local Parent Forum, IAS service, IS service and national information and support on EHC plans including CDC, CAF, NNPCF and IPSEA.

A total of 15 young people took part in small focus group exploration. The young people were recruited via school and college placements. They had all had an EHC plan put in place since the new system was introduced. Three groups were held in three local authorities.

Parents were asked (by letter) for their agreement for us to talk to the young people and informed of the issues we intended to cover. Young people themselves were asked to give verbal consent to taking part in the groups.

Staff from the provider also attended the groups to assist with communication and group management.

Groups lasted between 40 to 60 minutes. Young people were asked about:

- **their plans** – what they thought of them;
- **the process** – what they had fed in and how they had been involved;
- **their suggestions for improvement.**

All young people were given £10 vouchers for online shopping to thank them for their participation. Notes were taken from the focus groups with all contributions being recorded anonymously. These notes fed into the overall analysis.

## Analysis

All interviews were audio recorded where consent was given by the interviewee. Full notes were taken of the workshop events. All data was anonymised and treated confidentially. Where names are reported in this document, these are pseudonyms.

A 'framework approach' (2011)<sup>17</sup> was used for data management and analysis. This allows:

- case and theme based analysis and presentation;
- data reduction through summarisation and synthesis;
- retaining links to original data;
- comprehensive and transparent data analysis.

Our aim was to achieve thematic and explanatory analysis. This approach allows data management which cuts down large amount of data into themes within individual cases (i.e. key issues raised in each parental/young person interview) and makes key issues become clear across a large and detailed dataset. Each finding can still be traced back to the original raw data so that it is possible to give individual examples of key findings.

The key aim was to be able to identify general findings and consistent issues across the four areas, as well as 'local' findings where issues were only seen in one area or were specific to the local delivery of the process.

The data was coded and themed by two experienced social researchers. An analytical framework was developed. This fed into the tool development and the feedback provided to participating local authorities.

Attempts were made to ensure/address the rigour of the analysis by the employing the strategies of:

- **inter-rater reliability** - two researchers were involved in analysing the data;
- **triangulation** - we used other documentary evidence to triangulate our findings with those of other recent research studies;
- **peer review** - our emerging findings were presented to practitioners (during the workshops) and external experts (including DfE, members of the advisory group and Ofsted). The feedback obtained was fed into the final analysis.

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<sup>17</sup> Smith, J. and Firth, J. Qualitative data analysis: the framework approach (2011) *Nurse Researcher*. 18, 2, 52-62. <http://dx.doi.org/10.7748/nr2011.01.18.2.52.c8284>

## Development of family stories

The detailed family stories presented on the EHCP Journeys website have been developed from the words of families participating in the study. In order to safeguard the anonymity of participants, some personal details have been altered.

The family stories in the [online tool](#) are intended to act as a resource for those involved in delivery - to help them to hear more directly what the EHC process is like from those who are going through it.

## **Appendix B: Workshop attendees**

### **Education professionals included:**

- SEN head of service/managers;
- EHC case workers/coordinators;
- reviews officers;
- heads/deputies from mainstream, base and special schools;
- SEN coordinators;
- plan writers (administrative role brought in by local authorities to produce EHC plans);
- parent engagement officers;
- Early Years practitioners;
- portage;
- educational psychologists.

### **Health professionals included:**

- speech and language therapists;
- Children and Adult Mental Health Service (CAMHS) heads of service and practitioners;
- Therapy Leads;
- Clinical Commissioning Group (CCG) commissioners.

### **Social care professionals included:**

- social workers;
- transition team practitioners;
- short break providers/managers.

### **Also attending were:**

- Information Advice and Support Service staff / Local Offer leads;
- Independent Supporters;
- Parent Forum representatives;
- local parents.

## Appendix C: Parent interview achieved sample

### Characteristics of sample achieved

<b>Case Type</b>			
<i>Transfer from statement</i>		<i>New EHCP</i>	
37		40	
<b>Point in process</b>			
<i>Final plan</i>	<i>No plan, no longer in process</i>	<i>In progress</i>	
41	12	24	
<b>Child/YP Age</b>			
<i>0-5</i>	<i>6-10</i>	<i>11-15</i>	<i>16+</i>
19	21	15	22
<b>Child/YP Needs<sup>18</sup></b>			
<i>Behavioural, social, emotional</i>	<i>Cognition and learning</i>	<i>Communication and interaction</i>	<i>Physical or sensory</i>
29	27	22	16

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<sup>18</sup> Some parents were unable to choose just one primary need as their children had such complex SEND.

## Appendix D: Interview topic guide

### User interview topic guide

Thank you for agreeing to take part in this interview. It should take a maximum of 30-40 minutes. We appreciate you are busy - If you need to break off for any reason we can arrange to carry on at another time.

ASK Research has been commissioned by the Department for Education to find out what families think of the new Education Health and Care Plan process, and if there are any ways that your local service [NAME] can improve.

We are working with 4 areas across England to find out how the process is working so that we can suggest how services should develop in future to give the best possible support to families of children and young people with special educational needs and disabilities. Our interview today is one of 100 that we are carrying out with parents and young people.

I will ask you to score some parts of the process and then give me more detail about your experiences. I will be asking you about what's worked well with the service and support that you have received and anything that hasn't worked so well. I will be asking your opinions on any ways that services could change.

You will not be named in any reports, and while your local service are happy for us to talk to services users they will not know who has taken part and spoken to us. We will be feeding back to them what different families tell us in general about the service they provide and will not identify specific families. We hope that sharing the learning from your experiences - good and bad - will help improve the special needs support process for other children and YP. possible, I would like to record our conversation. This is for my own use only, when I come to write up my notes. The recording will not be shared with anyone outside of the research team, and it will be deleted after use. Do I have

### Consent for recording – YES/NO

Do you have any questions before I start?

### SECTION 1: Family circumstances

AIM: To understand the family and child/young person being supported by the service

*[NB: This will be used to ensure representativeness of selected sample. Check details provided by service]*

Read out...

***Can I start by getting a few details about your child who is being supported by the local service?***

**1.1 Child name**

**1.2 Child age**

**1.3 Child's School** name and type (Mainstream/Special and pre-school/nursery / primary / junior / secondary / college/ other)

**1.4 What is their main need?**

- Cognition and Learning (dyslexia, dyspraxia or learning difficulties)
- Behaviour, emotional, social (Attention Deficit Disorder/ Attention Deficit Hyperactivity Disorder)
- Communication and interaction (speech and language difficulties, communications difficulties caused by Autism or Asperger's)
- Physical or sensory (e.g. as a result of being deaf or visually impaired or having a mobility impairment)

**1.5 How would you describe the impact of their condition/disability on day-to-day life:**

- Mild
- Moderate
- Severe
- Profound or complex

**1.6 Have they previously had a statement? Have they been transferred onto an EHC Plan? Y/N**

**1.7 Can I ask who else lives in the household?**

(How many siblings (any identified needs), How many adults and resident parents?)

This is just for background to the rest of the interview

**START RECORDING**

**Section 2: The EHC Process - Assessment of the Process - What do you think of it?**

AIM: To explore what worked well and not so well and reasons for this. To suggest change

Read out...

***We understand that you are currently or have recently undergone the EHC process for your child or YP. I want to talk to you about your experienced of the process.***

## 2.1 First of all can I check where in the process you are up to?

Probe:

- Got a Plan Signed off?
- Plan is being written / drafted? (need for plan or not and if so how that plan was developed)
- Undergoing Assessment? (identified there is a need for assessment or not?)
- Only recently been Referred?

## 2.2 [So far,] thinking about the whole process that you've been through How satisfied have you been with the support you have had with your child and their special educational needs?

- *Rate it out of 5, with 5 being very satisfied and 1 being very dissatisfied*

	1. V Dis-satisfied	2. Fairly Dis-satisfied	3. Neither Satisfied nor Dis-satisfied	4. Fairly Satisfied	5. Very Satisfied
<b>Overall Process</b>					

## 2.3 Overall why you were satisfied/ not satisfied?

- Tell me what was good about it or what wasn't so good?
- Specific issues/stages or overall?

**Read out ... I'd now like to talk through the stages of the EHC process to see how satisfied you have been with each step**

## 2.4 Starting with when you first heard about SEN support or EHC plans (were referred/requested an assessment), what was the first thing that happened?

Suggested prompts:

Who were you put in touch with?

What were you told would happen?

What information were you given?



How did you feel?

Who raised the issue of your child potentially having special educational needs?

How was this handled? Did you feel involved?

How did you find out about SEND and EHC Plans?

What information were you given about the process? (what involved, timings, other help)

Who did you speak to about the process? What did they tell you about?

Was there anything else you wanted information on or to speak to someone about?

**2.5 - Using the same 1-5 scale where 1 is very dissatisfied and 5 is very satisfied, please tell me how satisfied you were with the identification / referral part of the process (when you were first in touch with services)**

	1. V Dis-satisfied	2. Fairly Dis-satisfied	3. Neither Satisfied nor Dis-satisfied	4. Fairly Satisfied	5. Very Satisfied
<b>Identification / referral</b>					

**2.6 What made you satisfied/dissatisfied with it? What was good/bad?**

**2.7 What made it good/ could have made it better?**

**2.8 Was the decision taken to assess your child? (ie continue the process)**

YES / NO

If NO:

How happy are you about this decision? Was it a mutual decision?

How will your child's needs be met? How confident are you about this?

Has your child previously had a Statement? Why do you think they are not being transferred onto an EHC Plan?

**2.9 And so the next step of the process, Using the 1-5 scale again where 1 is very dissatisfied and 5 is very satisfied, please tell me how satisfied you were with the assessment part of the process** (when people were assessing your child and/or asking what support you needed)

	1. V Dis-satisfied	2. Fairly Dis-satisfied	3. Neither Satisfied nor Dis-satisfied	4. Fairly Satisfied	5. Very Satisfied
<b>Assessment</b>					

**2.10 What made you satisfied/dissatisfied with it?**

**2.11 What happened during this step?** What was good/bad?

**2.12 What could have made it better?**

Suggested Prompts:

How much do you understand about the process? Who is involved?

What is your role? How well are you kept up-to-date on progress?

What role will you and your child play in this?

Are there any barriers to participating in the assessment?

How thorough and genuine is it?

How long will it take?

What will you get at the end of it?

**2.13 Was the decision taken to put an EHC Plan in place for your child?**

**YES /NO**

If NO:

How happy are you about this decision? Was it a mutual decision?

How will your child's needs be met? How confident are you about this?

Will this be looked at again? Might they need a Plan in future?

**2.14 And then you got a draft plan Can you tell me what happened at this stage?**

Suggested Prompts:

What is your understanding of what is currently happening?

Does the plan reflect what you and your child want and the discussions you've had so far?

How involved have you been in the process?

How involved has your child been in the process?

What is the plan likely to set out?

How long will the process take?

What will be the outcome/result of this stage?

Can you change what's in the plan?

Can you and your child say what education placement and support you want?

**2.15 Using the 1-5 scale again where 1 is very dissatisfied and 5 is very satisfied, please tell me how satisfied you were with the drafting the plan part of the process (when you were first shown the plan and could comment on and change it)**

	1. V Dis-satisfied	2. Fairly Dis-satisfied	3. Neither Satisfied nor Dis-satisfied	4. Fairly Satisfied	5. Very Satisfied
<b>Drafting the plan</b>					

**2.16 What made you satisfied/dissatisfied with it? What was good/bad?**

**2.17 What made it good / could have made it better?**

**2.18 Then you got the final plan? What happened?**

How pleased were you with what the final plan said? Did it have the changes you had suggested in it?

What were your feelings/expectations at this stage?

**2.19 Using the 1-5 scale again where 1 is very dissatisfied and 5 is very satisfied, please tell me how satisfied you were with the plan finalising part of the process (when the final version was agreed by everyone)**

	1. V Dissatisfied	2. Fairly Dissatisfied	3. Neither Satisfied nor Dissatisfied	4. Fairly Satisfied	5. Very Satisfied
<b>Plan finalising</b>					

**2.20 What made you satisfied / dissatisfied with this step?**

**2.21 What made it good / could have made it better?**

**2.22 And what has happened since then with putting the plan into action?**

Have things in the plan happened as you expected?

Has anything changed?

**2.23 Using the 1-5 scale again please tell me how satisfied you were with putting the plan into action (when what was written in the plan started to happen - such as support in school)**

	1. V Dissatisfied	2. Fairly Dissatisfied	3. Neither Satisfied nor Dissatisfied	4. Fairly Satisfied	5. Very Satisfied
<b>Putting the plan into action</b>					

**2.24 What made you satisfied/dissatisfied with it? What was good/bad?**

**2.25 What made it good / could have made it better?**

**ONLY THOSE WITH A FINAL PLAN IN PLACE...**

**ASK: On a scale on 1-5 where 1 is v dissatisfied and 5 is very satisfied How satisfied are you with...**

	1 - Very Dis-satisfied	2 - Dis-satisfied	3 - Neither Satisfied nor	4 - Satisfied	5 - Very Satisfied
a) the school/college placement named					
b) the level of support detailed in the plan					
c) the education, health and care support meets your child's needs now					
d) the support will continue to meet your child's needs in the future					

**ASK: for reasons for overall satisfaction/dissatisfaction**

What needs to change? How? What more needs to be done?

**If dissatisfied**

**ASK: Have you had to take any further action? Such as going to tribunal/ dispute resolution/ mediation/lawyer?**

	1. V Dis-satisfied	2. Fairly Dis-satisfied	3. Neither Satisfied nor Dis-satisfied	4. Fairly Satisfied	5. Very Satisfied
<b>Dispute resolution / mediation / tribunal</b> (if you were unhappy with the support in the plan)					

What was good / needed to be better about this?

**ASK ONLY THOSE WHO PREVIOUSLY HAD A STATEMENT**

**ASK: What do you think of the EHC process compared to the previous statementing process?**

Is it better/worse? Why? In what ways?

What do you notice is different?

**Section 3: The EHC Process – How far does the EHC process adhere to the Principles of the new law and COP?**

AIM: To check whether and how the service delivered was in line with the COP

**Read ... There are some other things that are meant to happen during the EHC process that I'd now like to ask you some questions about**

**3.1 On a scale of 1-5 where 1 is not at all and 5 is extremely... How *informed* would you say you were about all of the EHC process?** (how long it would take, what it would involve, what would happen)

	1-Not at all	2 - Slightly	3 - Moderately	4 - Very	5 - Extremely
<b><i>Informed</i></b>					

**3.2 What made you satisfied/dissatisfied with it? What was good/bad?**

**3.3 What made it good / could have made it better?**

Were you given all the information you required? What was your experience?

**3.4 On the same scale of 1-5, how *involved* have you felt you've been in the process?**

	1-Not at all	2 - Slightly	3 - Moderately	4 - Very	5 - Extremely
<b><i>Involved</i></b>					

**3.5 What made you satisfied/dissatisfied with it? What was good/bad?**

**3.6 What could have made it better?**

Did you want to / like to feel involved?

What happened to ensure you were involved? OR What more should have been done to involve you?

**3.7 To what extent were your opinions considered and acted upon?**

	1-Not at all	2 - Slightly	3 - Moderately	4 - Very	5 - Extremely
<b><u>Your</u> opinions considered and acted upon?</b>					

**3.8 What happened to ensure your opinions were listened to? OR What more should have been done to act upon your opinions?**

**3.9 To what extent was your child involved in the process, with their opinions considered and wishes listened to?**

	1-Not at all	2 - Slightly	3 - Moderately	4 - Very	5 - Extremely
<b><u>Your child</u> involved in the process,</b>					

**3.10 What was good or bad?**

**3.11 How did they/should they have done this?**

What could have made it better?

**3.12 To what extent was your child at the heart of the process?**

	1-Not at all	2 - Slightly	3 - Moderately	4 - Very	5 - Extremely
<b>Your child at the heart of the process?</b>					

**3.13 What was good / bad?**

What happened to ensure your child was involved?

What difference did this make to you?

**3.14 What was / more should have been done to involve you and your child/family and to put your child at the heart of the process?**

**3.15 To what extent did all of the professionals work well together to support you?**

	1-Not at all	2 - Slightly	3 - Moderate ly	4 - Very	5 - Extremel y
<b>All of the professionals work well together to support you?</b>					

**3.16 What was good / bad?**

What happened to ensure that professionals worked together?

What difference did this make for you?

**3.17 What more should have been done to ensure professionals work jointly?**

**SECTION 4: Access to Wider Support Mechanisms and Awareness and Views of Other Elements of SEND Reforms**

AIM: To see what wider support families are aware of and are using

**Read ... There are different ways to get help for yourself and with your child and sorting out EHC Plans.**

**4.1 What other support do you know about/have you had?**

**4.2 There are different types of support that local services should provide can I check which of these you have heard of or used:**



	Not heard of;	Heard of but not used;	Heard of and USED
<b>Parent/Carer forums</b>			
<b>Independent Supporters (PROBE - were these private-e.g. Mencap? Barnardos?)</b>			
<b>Information, Advice and Support service (IAS)</b>			
<b>Key workers</b>			
<b>Dispute resolution/Mediation/Tribunal</b>			

ASK FOR ANY USED:

4.3 On a scale on 1-5 where 1 is v dissatisfied and 5 is very satisfied, How satisfied have you been with the wider support you have received from:

	V Dissatisfied	Dis-satisfied	Neither Satisfied nor Dis-satisfied	Satisfied	V Satisfied
<b>Parent/Carer forums</b>					
<b>Independent Supporters</b>					
<b>Information, Advice and Support service (IAS)</b>					
<b>Key workers</b>					
<b>Local Offer</b>					
<b>Personal Budgets</b>					
<b>Dispute resolution/Mediation/Tribunal</b>					

FOR ALL

4.4 Why is this?

What is good /bad about them?

What do/did they help with?

**4.5 What would make them even better?**

**4.6 How did you find out about them?**

**4.7 Have you heard of the Local Offer in your area?**

YES / NO (I'll send you information about it after we speak)

If YES

**4.8 Do you know what it is? How did you find out about it?**

**4.9 Have you used it? How?**

**4.10 How would you rate it out of 5?**

**4.11 What was good /bad about it?**

**4.12 What would make it better?**

**4.8 Have you heard of Personal Budgets?**

YES / NO (I'll send you information on it after we speak)

**4.8 Do you know what it is? How did you find out about it?**

**4.9 Have you used it? How?**

**4.10 How would you rate it out of 5?**

**4.11 What was good /bad about it?**

**4.12 What would make it better?**

## **SECTION 5: SUMMING UP**

**You have told me some really interesting things about the service you've received and how you'd like it to be.**

**5.3 We'd like to suggest ways for services to change in the future. What do you think should be improved with the EHC process and how should the services go about improving it?**

- What would have made it work better for you?
- If the services could change one thing, what should it be?

- Have you heard about anything happening in other areas that you'd like to see in your local services?

#### **5.4 What's the best way for services to get your feedback on how they're doing?**

- How would you like to be consulted?
- How would you be happy giving feedback?
- When in the process should this be?

#### **5.5 Is there anything else you'd like to tell me about the EHC process that we've not covered?**

### **STOP RECORDING**

Thank you so much for speaking to me today. As a way to thank you for your time we'd like to send you a £20 shopping voucher. These can be used in many shops including Boots, Argos, Debenhams, Toys R Us, Iceland, Matalan.

Can I just check your address to be able to send this to you. We will also send you information of where you can find out more about some of the issues we have discussed. Read out address.

Later in the year we will be telling the local service what families told us. Hopefully this will allow them to help more families like yours even better in the future so thank you.

Thanks and close

## Appendix E: Recruitment letters

Local Authority Parent recruitment letter

Local Authority Heading

Dear [Parent/Carer]

As you may know the law has changed so that all children and young people with Special Educational Needs and Disability (SEND) will now have their needs assessed and set out through the Education, Health and Care (EHC) Plan process.

[Our Local Authority] has decided to take part in a Department of Education project to find out how the new process is working, what's good about it and what could be improved. We are taking part as we want to get your opinions and provide the best possible support for families.

The aim of the project is to develop ways to help Education, Health and Social Care teams across England deliver the best support for families like yours.

To do this, independent researchers from ASK Research (who are carrying out the project) would like to speak to a range of families who are supported by our teams in this area.

**We would like to provide your contact details to ASK Research so that they can tell you more about the project and see if you would like to be involved.** Taking part is likely to include you talking to the research team by telephone about your experiences.

**Please let us know if you would not like your name and contact details passed on** by returning the form below or calling us on XXXX. We will not know who takes part in the research project, or what individual families say about our service. If you choose not to take part it will not affect the support you get from us.

If you do not return the form below by XXX then your contact details will be given to ASK Research who will be in touch with you soon. **If you are happy to be sent more details about the project then you do not have to return the form.** If you would like to know more about the research now or speak to the research team they can be contacted on Freephone XXX.

We will be able to update you on what the project finds towards the end of the year.

Yours sincerely

HEAD OF EDUCATION/ALL TEAMS

Dear [Parent/Carer]

### Education, Health and Care Plan Project

The Department of Education has asked us to find out how the new Education, Health and Care (EHC) Plan process is working for children and young people with Special Educational Needs and Disability (SEND) and their families in this area.

We are working with your local services to assess how they are supporting families like yours. We really want to hear the opinions of families and young people in the area. The aim of the project is to help Education, Health and Social Care teams across England deliver the best support for families like yours.

We will be speaking to a range of families in the area to see what's working well, what could be better and if there's anything you would suggest changing. **We would like to speak to you about your experiences of the new process.**

You are invited to speak to the Research Team about how the process has worked for you. We would like to talk to you by telephone for around 30 minutes. We will ask about your family, what you have done with services so far, what support and information you have had and how you feel about the service. You can tell us what has worked well, anything that has not been so good and the reasons for this. There are no wrong answers we just want to hear what you think!

Families who take part will receive a £20 shopping voucher to thank you for your time. Anything you tell us will be confidential. No-one outside of the Research Team will know which families take part and we will only tell your local services overall points that families in the area make, so they will not know who tells us what.

If you would like to take part or find out more about the research please

- Call us on Freephone XXXX
- Email us at [XXXX](#)

If we do not hear from you we may call you to see if you would like to take part. Not taking part will not affect the services you receive.

We hope you will be able to help us with this and look forward to speaking to you.

Yours sincerely

AMY SKIPP

## Appendix F: Online parent survey

### **ASK RESEARCH on behalf of the Department for Education Parent/Carer Satisfaction with the EHC Plan Process 2015**

#### INTRODUCTION

In September 2014 the Children and Families Act became law. This brought about changes to the way that children with complex special educational needs and disabilities (SEND) are assessed and supported.

The Department for Education has commissioned ASK Research to look at how EHC assessment and plans are being delivered.

The purpose of the research is to better understand the views and experiences of parents, young people and children in your Local Authority.

The survey should only take around 10 minutes to complete.

Your responses will be treated in confidence. We will not identify any individuals in our report and your individual responses to the survey will not be shared with the LA. However, we DO intend to share the overall findings from the survey with your Local Authority area and we will be using parents' comments anonymously on our website to inform professionals.

**Thank you very much for taking the time to contribute to this important work. We value your feedback.**

- 1. Unique Identifier (this can be found on the letter we sent you about this survey)**
- 2. What Type of Provision/School Does Your Child Attend?**

*(please tick one box)*

5a)	Mainstream		Special	
	Mainstream with provision / unit		Pupil referral unit (PRU) or Alternative provision (AP)	

**3. Did your child have any additional individual support, e.g. a Statement, before having their education health and care plan (EHCP)?**

*(please tick one box)*

Yes		No	
-----	--	----	--

**4. Where in the EHC Planning process are you up to?**

*(please tick one box)*

Process		Process	
Identification / Referral to service  (You have applied for an assessment or your child's school placement, doctor or others have suggested you need one)		Sign Off/ Final Plan  (You have received the final version with details of your child's school placement and type of support needs)	
Assessment  (Your child is being assessed by professionals, you are explaining what you want for your child,		Putting the Plan into Action  (The support set out in the plan is supposed to be starting or already taking place in nursery/school/college)	

reports are being written about your child's needs)			
Drafting the EHC Plan  (You have seen a first version of the Plan, you can comment on it or suggest changes but it is not yet the final version)		I don't know	

**Section One: General Levels of Satisfaction**

*We want to understand how satisfied you are with the overall EHC process.*

**5. Overall, how satisfied have you been with the EHC planning process (from when you first heard about getting a Plan for your child to now)?**

*(please tick one box)*

Very Satisfied	Fairly Satisfied	Neither Satisfied nor Dissatisfied	Fairly Dissatisfied	Very Dissatisfied

**OPEN:**

**Why?** What has been good?

What could have been better?



**Section Two: Level of satisfaction with the different stages of the EHC process**

*We want to understand how satisfied you are with the different stages of the EHC process*

**6. How satisfied have you been with each stage of the EHC Planning Process that you have been through?**

*(please tick one box on each line)*

	Very Satisfied	Fairly Satisfied	Neither Satisfied nor Dissatisfied	Fairly Dissatisfied	Very Dissatisfied	Don't Know
<b>1. Identification/Referral – when you first got in touch with the SEN team or someone talked to you about EHC Plans</b>						
<p><b>Why?</b> What has been good?</p> <p>What could have been better?</p>						
<b>2. Assessment – when people were speaking to you and your child, maybe carrying out tests, to find out their/your needs and see if a Plan would help you</b>						
<p><b>Why?</b> What has been good?</p> <p>What could have been better?</p>						
<b>3. Drafting the EHC Plan – when you saw what the Plan</b>						

<p><b>had in it and could comment on anything you wanted changed</b></p>						
<p><b>Why?</b> What has been good? What could have been better?</p>						
<p><b>4. Final EHC plan – when you got the final version of the plan for your child, which included details of your child, the support they need and how that would be provided</b></p>						
<p><b>Why?</b> What has been good? What could have been better?</p>						
<p><b>5. Putting the Plan into Action – what happened after you got the final plan and how you and your child have been supported</b></p>						
<p><b>Why?</b> What has been good? What could have been better?</p>						
<p><b>6. Any conflict Resolution, Mediation or Tribunal – if you raised a disagreement with the Plan or the support you were getting</b></p>						
<p><b>Why?</b> What has been good?</p>						

What could have been better?

[Route for those who have final Plan]

**Section Three: your level of satisfaction with the outcome of the EHC process**

*We want to understand how satisfied you are with the outcome of the EHC process*

**7. How Satisfied Are You With The Following Key Outcomes Of the Plan?**

*(please tick all that apply)*

	Very Satisfied	Fairly Satisfied	Neither Satisfied nor Dissatisfied	Fairly Dissatisfied	Very Dissatisfied	Not Applicable
<b>1. Educational Provision Provided</b>						
<b>2. In-school Support Provided e.g. school support staff</b>						
<b>3. Health Provision/Support</b>						
<b>4. Social Care Provision/Support</b>						
<b>5. Other Local Offer Provision/Support</b>						

**Section Four: The extent to which you feel informed about the EHC process**

**8. We want to understand how much you feel/felt..**

	Extremely	Very	Moderately	Slightly	Not at all	Not Applicable
<b>1. Informed (about the process, decisions and provision)</b>						
<b>2. Involved in the process</b>						
<b>3. Your child's opinions and wishes were listened to</b>						
<b>4. Your opinions were valued and acted upon</b>						
<b>5. Your child was at the centre of the process</b>						
<b>6. All the professionals worked together</b>						
<b>7. You had to be proactive, make arrangements or organise the professionals</b>						

***Section Five: the extent to which you are aware of the different elements of the new way of supporting CYPF with SEND.***

*We want to understand whether you are aware of the other elements of the government's SEND reforms.*

**9. Please tell us which of the following you are aware of and which you have accessed?**

*(please tick all that apply)*

	<b>9 a) Heard of?</b>	<b>9 b) Used</b>	
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	<b>YES</b>	<b>NO</b>	<b>YES</b>	<b>NO</b>	<b>N/A</b>
Parent/carer network forum					
Independent Supporters					
IAS Service (Information, Advice and Support, formerly Parent Partnership)					
Local Offer					
Personal Budgets					
Dispute resolution (mediation) or tribunals					
Key workers					
Other.... Please State					

**10. For each of the above which were used, please tell us how satisfied you were with the service provided?**

*(please tick one box)*

	Very Satisfied	Fairly Satisfied	Neither Satisfied nor Dissatisfied	Fairly Dissatisfied	Very Dissatisfied	<b>Not Applicable</b>
Parent/carer network forum						

	Very Satisfied	Fairly Satisfied	Neither Satisfied nor Dissatisfied	Fairly Dissatisfied	Very Dissatisfied	Not Applicable
Independent supporters						
IAS Service						
Local Offer						
Personal Budgets						
Dispute resolution (mediation) or tribunals						
Other, Please State						

***Section Seven: Learning Lessons - What Works Well? What Needs to be Improved?***

*We want to understand in more detail what we are doing well and where we need to improve*

**11. Thinking about your experience of the EHC Planning process: What worked well for you as a parent?**

*(Use Space provided to tell us)*

**12. Thinking about your experience of the EHC Planning process:  
What did not work well for you as a parent? (Use Space provided to tell us)**

**13. Would you make any specific changes to the way the EHC  
Planning process work in your area? What would you suggest services do  
differently? (Use Space provided to tell us)**

**14. Is there anything else you would like to tell us about SEND support in  
your area or the EHC planning process? (Use Space provided to tell us)**

**Thank you very much for taking the time to complete this survey**

## Appendix G: Examples of variation in service delivery

### Differences in delivery

Theme	Example
Referral approach	<p>Service 1 have regular multi-agency meetings to identify any children/YP who may need an EHC plan</p> <p>Service 3 encourage referrals through the schools route</p> <p>Service 3 has a Family Engagement Officer who goes to meet all families who apply for a referral. They can answer any questions and gather required evidence from the family</p>
Threshold levels	<p>Service 2 carries out a pre-assessment of the child/YP before agreeing to carry out full assessment</p> <p>Service 4 requires details from the placement about steps already taken to support the child/YP</p>
Decision-making processes	<p>Service 1 uses caseworkers to decide on whether families proceed to the next step and decisions in all but the most complex cases.</p> <p>Service 1 explains this as they have very experienced skilled caseworkers who feel confident in having this responsibility and making such decisions. In other services caseworkers have more of an administrative role (of pulling paperwork together)</p> <p>Services 2, 3 and 4 direct all decision-making to the 'panel' who come to a decision on the basis of evidence provided by the caseworkers.</p>
Signposting to Independent Support	<p>Service 4 clearly details their Independent Support service (independent of LA funding) on their Local Offer and in parent information</p> <p>Service 3 does not tell parents of the Independent Support (managed by CDC) and does not support the service to pass information out to parents</p>



## Appendix H: Examples of planned local authority actions based on feedback

### ISSUE: Getting a referral

#### What is the story?

Parents are not clear who to contact or what the process will involve

Parents are not clear they can self-refer

Professionals are confused about the process

#### What is the desired outcome?

By September 2016 at least 95% of professionals understand the process of Step 2 – My referral

By September 2016 at least 95% of parents understand the process of Step 2 – My referral

#### How will this look and feel?

Professionals will make appropriate referrals

They will have attended EHC training

They will know where information is

There will be less EHC referrals

There will be more SEN Support

There will be better universal and targeted series in Education, Health and Care

There will be good commissioning services

What steps need to be taken?	By whom? By when
<ul style="list-style-type: none"> <li>- Training for SEN governors and head teachers</li> <li>- Appoint SEN improvement partners / SEN advisors to work closely with schools</li> <li>- SEN Compliance post to ensure schools are compliant with law and local processes</li> <li>- Children and Families</li> </ul>	<p>Highlight to DCS</p> <p>Develop action plan</p> <p>By December 2015</p>

What steps need to be taken?	By whom? By when
Councillor will be a SEND champion <ul style="list-style-type: none"> <li>- Continue training, websites and information</li> <li>- Add more clear and easy to understand animations, film clips and social networking</li> <li>- Needs analysis for commissioning</li> <li>- Family commissioning events</li> <li>- Parent Newsletter (ENews) for all newly diagnosed children signposting to services/information</li> </ul>	

### **ISSUE : Schools unsure of EHC process**

#### **What is the story?**

The EHC process is seen as complicated (by those who do need deal with it everyday)

There is low professional knowledge across the board (for universal services)

It is a peripheral issues for mainstream teachers, Heads

SEN is a low priority (and low incidence) for most schools

Schools don't know local contacts

SENCOs change a lot (low consistency of staff leads to lack of strong professional relationships)

SEN/Early Help pathways are not clear

The process for Transfer of cases is unclear

Is this a priority issue for heads? Could it ever be?

Where is the best source of information for teachers? (Local/National)

#### **What is the desired outcome?**

Families of CYP with SEND are effectively supported to achieve

#### **How will this look and feel?**

Schools have better trained staff and are clear on contact points (in SEN team) for further help

There is clear information on the local process and local requirements and support

Better practice sharing between special and mainstream schools

More specialist provision (focusing on mainstream bases/inclusive provision)

Timely reminders are issued on PCRs, requirements and examples of good practice

Parents feel good quality appropriate support is available to them locally

What steps need to be taken?	By whom? By when?
<ul style="list-style-type: none"> <li>- Local authority has clear pathways, funding and policy on SEND with clearly allocated responsibilities at all levels</li> <li>- Mainstream training to raise awareness of SEND and EHC process (mandatory)</li> <li>- Children &amp; Families Act changes launched locally to raise awareness</li> <li>- SEND Reform Champion nominated locally, checks accountability</li> <li>- SEND and EHC covered in Teacher Training/ CPD</li> <li>- Better SEN communications with schools and relationship building</li> <li>- Advertise benefits of resources (e.g Wiki) to schools</li> <li>- Family support function in all schools</li> <li>- Teachers are informed</li> <li>- Funding/commissioning is centrally agreed (transparent data for all; 'lost/missing' children identified; one dataset used by all)</li> </ul>	<p>Head of SEN, DMO, (disability) social care head</p> <p>Head of Children's Service</p> <p>Head of Education, Health an Care services locally</p> <p>Head of Inclusion/Disabled children service</p> <p>DfE</p> <p>SEN team/practitioners, NOW</p> <p>SEN team/practitioners, NOW</p> <p>Headteachers</p> <p>Professional Bodies</p> <p>Local authority and CCG</p>

## **ISSUE: Lack of meaningful and timely health input into EHC planning process**

### **What is the story?**

Parents are not satisfied with the local input from health professionals into the EHC planning process

There has been increased incidence in children with autism

Many children have behaviour and learning difficulties, but with no underlying medical cause

CAMHS are not feeding into the process

### **What is the desired outcome?**

Appropriate support for all CYP so they are able to communicate independently, gain life skills and with effective plans informed by CAMHS professionals

### **How will this look and feel?**

Less children will reach crisis level

Parents will be more educated about SEND

Parents will receive appropriate diagnoses

Better joint working will exist locally, enabling all to meet statutory deadlines and timescales

<b>What steps need to be taken?</b>
<ul style="list-style-type: none"><li>- More joint working with CAMHS, set out at strategic level</li><li>- Discussions at strategic level to agree involvement of health professionals (and knowledge of joint inspections and statutory responsibilities)</li><li>- Better education of parents and professionals (about need for medical involvement)</li><li>- Hosting training locally for Health professionals</li><li>- Engaging schools to use top-up funding more effectively</li></ul>

## **ISSUE: Support not carried out as detailed in EHC plans**

### **What is the story?**

Plans and targets are not specific enough

Plans are not SMART, measurable or reaching

Need to realistically plan ahead (plan detail needs to be realistic) early enough

Not enough information about what is available

There are no consequences to not carrying out the plan and not always someone named to carry out aspects of the plan

Health not feeding into planning

### **What is the desired outcome?**

Support should be detailed in the plan, monitored and reviewed regularly to enable all children to get the required support and achieve their goals

Schools and colleges understand and get involved in the process

Funding is targeted at the appropriate planned provision and used appropriately

Able to locally plan and commission services which are needed and represent value for money

There is an appropriate strategic offer

### **How will this look and feel?**

Children and young people are making progress and achieving aspirational goals

Families are happy with their children's outcomes and the support they are given

Services are carrying out the responsibilities of their service area

Targets are based on the needs of the learner

The Local Offer is clear and understood

<b>What steps need to be taken?</b>	<b>By whom? By when?</b>
<ul style="list-style-type: none"><li>- Look at offer for post 16s</li><li>- Need commissioning mapping and gapping tool</li></ul>	LA and schools, ASAP LA

What steps need to be taken?	By whom? By when?
<ul style="list-style-type: none"> <li>- Professionals understand what evidence is required for local authority to complete a plan (training)</li> <li>- QA cycle of report writing</li> <li>- QA of EHC process</li> </ul>	<p>Inclusion Manager</p> <p>LA, ASAP</p> <p>LA, ASAP</p>

## **ISSUE: Little knowledge of Personal Budgets**

### **What is the story?**

A personal Budget is the amount of money set out by the LA to spend on families' needs

Knowing the details of these costs provides flexibility for families to decide how the needs are best met

It is parents' right to find out about the cost of provision

Parents think they have not been provided with sufficient information on Personal Budgets and how they can be managed.

Personal Budgets are quite abstract for parents and many confuse with Direct Pay (actually taking control of money)

Too much jargon exists around them

It has to be considered when is the right time to give parents information about Personal Budgets

### **What is the desired outcome?**

Every family receives consistent information, jargon free that they are able to understand

There is a consistent strategy for who gives out the information, how and when (suggested it is caseworkers)

There is transparency about Personal Budgets, how they are allocated and why decisions are made

### **How will this look and feel?**

More choices will open up to families and young people

Families will feel more informed and empowered about their child's care

SENDIASS will provide a strong role in supporting families with their understanding

What steps need to be taken?	By whom? By when
<ul style="list-style-type: none"> <li>- Training for all relevant professionals</li> <li>- Strategy developed about who, how and when information is disseminated</li> <li>- All professionals to check with families that they know about and understand Personal Budgets</li> </ul>	<p>Local Authority Leads</p> <p>SEN team</p> <p>All professionals</p>

### **ISSUE: Insufficient placements are available**

#### **What is the story?**

Parents may feel there are insufficient placements as:

Mainstream are not coping, so more need for SEN places

There is insufficient range available to meet differing needs and parental choice

Geographical location can put parents off appropriate schools for child's needs

Out of Borough placements are currently required where needs cannot be met locally – may need to map needs (e.g. very challenging behaviour)

#### **What is the desired outcome?**

Provision better responds to the needs of the service and individual families

#### **How will this look and feel?**

More preventative work will reduce need for specialist placement

Parents have their choice of school that meets their child's needs locally

Professionals feel confident offering suitable placements for child's needs

What steps need to be taken?	By whom? By when?
<ul style="list-style-type: none"> <li>- Better use of existing resources – some provisions are too narrow in who they will accept</li> <li>- Better presentation to families – schools need to be 'sold' and positive attitude from staff</li> </ul>	

What steps need to be taken?	By whom? By when?
<ul style="list-style-type: none"> <li>- Managing children who run away – local area need strategy to deal with this in schools and colleges</li> <li>- Increasing capacity – potentially through another specialist resource</li> <li>- Map and gap analysis</li> <li>- Strategic response to needs</li> <li>- Long-term matching of provision to future needs (eg Sherwood Park)</li> <li>- Skill up mainstream behavior bases, use more nurture groups</li> <li>- Developing post-16 provisions (eg Carew Academy)</li> <li>- Active management of current problem and future planning</li> </ul>	

**ISSUE: Panels overriding recommendations**

**What is the story?**

There is a lack of transparency around the panel processes, decision-making and outcomes

Professionals may not be making the right submissions to panels if there is felt to be a conflict between their opinion and the panel outcomes

**What is the desired outcome?**

Referrals to panel lead to decisions everyone is happy with

Decision making and the panel process is clear to all involved

Submissions are accurate allowing timely, accurate and consistent decision making

**How will this look and feel?**

Parents expectations are in line with the local process and the type of decisions taken

Parents are informed of the process and involved in it

Decisions are clear and transparent

Caseworkers and other staff have close links with families so submissions are accurate



What steps need to be taken?	By whom? By when?
<ul style="list-style-type: none"> <li>- Parents have a clear understanding of local processes, when decisions are made and what is available</li> <li>- Leaflets are produced to explain the panel process clearly</li> <li>- Telephone updates at set times of process with key professional</li> <li>- Role of SEN caseworker/named professional is developed for closer links with family</li> <li>- Reasons for decisions made are produced in clear detail and shared with families and team</li> <li>- Assess summary sheets and supporting schools' preparation for submissions</li> <li>- Panel procedures to be reviewed (and revised). Need to consider: <ul style="list-style-type: none"> <li>o What panels are for</li> <li>o Checking decisions with parents (maybe rep on panel)</li> <li>o Staff availability to attend</li> <li>o Supporting submissions</li> <li>o Role of caseworker</li> </ul> </li> </ul>	<p>IASS</p> <p>SEN team</p> <p>SEN team and key professionals</p> <p>Head of Service</p> <p>Head of Service</p> <p>SEN team and SENDCos</p> <p>Head of Service</p>

### **ISSUE: Poor post-16 options**

#### **What is the story?**

The 18-25 year olds offer is unclear

There are a lack of full-time post-16 placements, also issues around support during college holiday times

Lack of post-16 funding

Tension between focus on academic progress versus life skills development

### What is the desired outcome?

The 18-25 offer will match the 16-18 offer

There will be an increase in full-time provision for SEND young people

Meeting needs will take priority over funding

There will be a holistic approach to young people's development

### How will this look and feel?

Young people will experience a variety of challenging and stretching educational experiences

There will be better transition to adult services and adulthood as health and education practitioners link up

Services will provide a 'one stop hop' of SEN services for parents and young people to access

What steps need to be taken?	By whom? By when?
<ul style="list-style-type: none"><li>- Look at continuity of services, eg CAMHS transfer to adult services at 16. Assess how these can all be joined up and involved in EHC process</li><li>- Local Offer is updated with all post 16 services</li><li>- Consistency of communication from practitioner to strategic level</li></ul>	SEN team /LA/Health  Local Offer lead  Heads of teams / DMO

### ISSUE: Little knowledge of the Local Offer

#### What is the story?

Parents feel they have no knowledge of the Local Offer and what it does

Its name doesn't help

It is not being promoted

Professionals are unsure whose role it is to inform parents of the Local Offer

It cannot be accessed on a phone device

Professionals are unsure of the process to add new information

**What is the desired outcome?**

Parents are aware that it is there and can use it as a supportive tool

It is user-friendly, visually attractive and full of relevant up-to-date information

Professionals are confident in promoting it and aware of how to add information

The content is regularly updated in a timely manner

**How will this look and feel?**

The Local Offer will be well-known as it is routinely and positively marketed

Families and young people will be able to easily find all the information and access support they need

What steps need to be taken?	By whom? By when?
<ul style="list-style-type: none"> <li>- Content checked (updated, no dead links), made visually more appealing</li> <li>- Lead person as point of contact for enquiries about content (such as how to add)</li> <li>- Lead person attends community and professional events to promote Local Offer</li> <li>- Marketing strategy is developed (display in supermarkets, leisure centres etc) with link added to all leaflets, team info etc</li> <li>- Get advice from Local Offer guidance on how to effectively produce and promote content</li> <li>- Increase professional awareness</li> <li>- Regularly monitored at professional meetings</li> <li>- Assess neighbouring Local Offers</li> </ul>	<p>Local Offer lead</p> <p>SEN team/IASS</p> <p>Local Offer lead</p> <p>SEN team / Local Offer lead</p> <p>Local Offer lead / team members</p> <p>All practitioners / training</p> <p>All practitioners</p> <p>Early Support team</p>



Department  
for Education

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**Reference: DFE-RR523**

**ISBN: 978-1-78105-576-2**

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

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