

Parental Experience of Services for Disabled Children

Qualitative Research (Phase 2)

Exploring the Findings from the
National Survey

Vicky Campbell-Hall, Alice Coulter and Lucy Joyce
BMRB Qualitative



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Table of Contents

- Executive Summary 1
- 1 Introduction..... 4
 - 1.1 Policy context..... 4
 - 1.2 Research objectives..... 4
 - 1.3 Research methodology 5
 - 1.4 Report outline..... 6
- 2 Range of services..... 7
 - 2.1 Wider services 7
 - 2.2 Integrated services..... 9
 - 2.3 Understanding of ‘services’ 10
 - 2.4 Summary of key findings..... 10
- 3 Accessing services 11
 - 3.1 Receiving a diagnosis 11
 - 3.2 Obtaining an assessment of need 11
 - 3.3 Experiences of accessing specific services 12
 - 3.4 Accessing services overall 14
 - 3.5 Variations 15
 - 3.6 Summary of key findings..... 16
- 4 Service availability 17
 - 4.1 Perceptions of service availability 17
 - 4.2 Knowledge and information 17
 - 4.3 Communication and understanding 18
 - 4.4 Variations 19
 - 4.5 Summary of key findings..... 19
- 5 What constitutes a ‘good service’? 21
- 6 Key Findings..... 22
 - 6.1 Summary of key findings..... 22
 - 6.2 Key policy implications and recommendations 23
- 7 Appendices..... 24
 - 7.1 Recruitment and research methodology 24
 - 7.2 Topic guide (depth interview)..... 27
 - 7.3 Topic guide (group discussion) 35

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Executive Summary

Aiming High for Disabled Children (AHDC) is the Government's transformation programme for disabled children's services in England.¹ The programme is jointly led by the Department for Children, Schools and Families (DCSF) and the Department of Health (DH), and aims to improve the services and support available to disabled children and their families.

BMRB was commissioned by the Department for Children, Schools and Families to undertake qualitative research with parents of disabled children aged 0-19 years. This research consisted of two phases exploring parents' experiences and views of the range of services they use in relation to their disabled child. This report outlines the findings from the second phase, which unpacked findings from a quantitative survey conducted with parents of disabled children in 30 pilot local authorities (DCSF's *Health and Wellbeing of Children* survey). Specifically, this research explored: service issues beyond the 'core offer'; parents' perceptions of difficulties accessing services; lack of service availability; poor communication and information about services; and, what constitutes a 'good service'.

The research was qualitative in nature and included twelve extended focus groups and six depth interviews, conducted across six Local Authority areas. Participants were selected using purposive sampling to reflect a range of characteristics, including: age of the child; socio-economic grade; nature of child's disability; gender; and, ethnicity of parent.

Wider services

Due to the focus on health, education, and care & family support services in the first phase of the research, this second stage explored parents' views about wider services, such as childcare, housing, transport and informal support organisations. Overall, the importance of wider services was highlighted, with parents depending on these to manage their day-to-day lives. In particular, the following wider services emerged as priorities:

- **Childcare** - parents' childcare needs ranged from a few hours every week through to daily help during school holidays. However, experiences of inadequate provision and limited access caused difficulties for many parents.
- **Housing** - perceived lack of 'appropriate' accommodation and difficulties accessing home adaptations resulted in frustration for some parents, particularly those living in social housing.
- **Transport** - A need for more specialised transport was highlighted, although experiences of support currently available were limited beyond services transporting children to special schools.
- **Support organisations** - Both formal and informal support organisations were generally viewed as invaluable sources of support and information for families.

In terms of **integrated** service delivery, parents had varied opinions of what they understood by integration and, for the most part, parents' appeared to be less focused on full integration of services, and more focused on having better links and communication between the services.

¹ DCSF (2008) *Aiming High for Disabled Children: Transforming services for disabled children and their families*, Nottingham: DCSF Publications

Accessing services

Issues regarding accessing services were explored, focusing on parents' experiences of diagnosis, assessment, accessing care and overall issues associated with accessing services.

As highlighted in the first report, receiving a **diagnosis** was viewed as a vital first step toward accessing services; however the ease of achieving a diagnosis was felt to vary depending on the level of disability and the age of the child. Following diagnosis, the next step was to get an **assessment** of the child's needs and identify which services were required. The most commonly cited example of assessments related to obtaining a Statement of Special Educational Needs, which many parents struggled to achieve.

With regard to **accessing care**, a range of issues were found to have an impact on parents' experiences. Most importantly, parents complained of having to be proactive and 'pushy' to access services. In addition, certain services were highlighted as being inflexible and unwilling to cater to the needs of individual families. There was also felt to be a lack of coordination between different service areas, or even within the same area. There was widely believed to be a degree of geographical variation in accessing certain services.

Specific examples of difficulties accessing services were raised in relation to each of the broad service areas - education, care & family support, and health. For example, particular difficulties accessing **care & family support services** were identified in relation to social workers and respite care. Accessing the best **education** for a disabled child was also said to be difficult as it depended on whether the child had obtained a Statement, and therefore access to a special school or additional support. In terms of **health care**, the ease of accessibility to services was again viewed as connected to the severity of the child's disability.

Service availability

It was apparent that parents' perceptions of a '**lack of services**' could refer to a variety of issues: the service not being available at all; being infrequent, inaccessible, or of insufficient quality; or parents simply not being aware of whether it was available.

It is important to note, that where parents were unaware of the availability of particular services, this was found to impact on their perception of services overall. Perceptions of a lack of knowledge and **information** about service entitlements and eligibility resulted in views of a lack of transparency about what services were available to parents of disabled children.

These complaints about a perceived lack of information were also related to problems of poorly coordinated services lacking sufficient communication processes. For parents, **communication** meant being involved throughout the process and having an open, honest, two way dialogue with professionals. Parents also described a need for communication to be tailored to the needs of the family and their unique journey.

What constitutes a 'good' service'?

A number of key aspects of what constitutes a 'good service' were outlined during discussions with parents, including:

- **Information / communication** - Parents being told upfront about all the services and support they could potentially access. Services communicating, both with other services and with families.

- **Accessibility** -Timely diagnosis in order to access services as soon as possible, followed up with access to the appropriate support.
- **Attitude of professionals** - A respectful, supportive and courteous attitude of all practitioners towards parents and children.
- **Co-ordination of services** - Services that are coordinated and offered joined-up working between professionals. A clear point of contact for advice and support, who worked 'on their side'.
- **Trust in system** - Parents wanted to be able to trust and have confidence in the system and in professionals.

Key policy implications and recommendations

The following key policy implications and recommendations have been drawn from the findings:

- **Increase ease of accessibility and flexibility** - Parents felt that having easy access to flexible services, including specialised and wider services such as childcare, would greatly improve their satisfaction with service provision.
- **Improve communication and coordination** - Parents expressed a need for better communication and more joined-up working between the different services and between the services and parents.
- **Tailored communication** - There was a perception that communication should be tailored to the child's particular disability and for the family's specific needs, as well as being communicated at the appropriate point of need.
- **Participation** - Parents felt they should be given more opportunity for involvement in the process and their opinions should be taken into account, especially when decisions are being made about their child's care.
- **Professionals** - Parents highlighted the central role that professionals play in service provision and the impact that they have on levels of satisfaction, therefore staff should be as consistent as possible and should have a respectful, supportive and inclusive attitude towards parents and children.
- **Charitable sector** - Parents were impressed by the support they received from charitable organisations.

1 Introduction

BMRB was commissioned by the Department for Children, Schools and Families to undertake qualitative research with parents of disabled children aged 0-19 years. This research consisted of two phases exploring parents' experiences and views of the range of services they use in relation to their disabled child. This report outlines the findings from the second phase, which explored and unpacked findings from a quantitative survey of parents conducted alongside the qualitative research.

1.1 Policy context

Aiming High for Disabled Children (AHDC) is the Government's transformation programme for disabled children's services in England.² The programme is jointly led by the Department for Children, Schools and Families (DCSF) and the Department of Health (DH), and aims to improve the services and support available to disabled children and their families. The programme supports the aims of *Every Child Matters* and the *Children's National Service Framework*, placing particular emphasis on the importance of joined up working and services focused around children and their families.

"The vision behind Aiming High for Disabled Children is for all families with disabled children to have the support they need to live ordinary family lives, as a matter of course."

One of the central measures outlined within the programme is a Core Offer to disabled children and families. The Core Offer is a statement of the standards which families with disabled children can expect from local services across the country. AHDC identified five elements which make up the Core Offer: information, transparency, assessment, participation and feedback.

1.2 Research objectives

The research consisted of two qualitative phases; the first phase involved an exploratory look at parents' broad views of using a range of services in relation to their disabled child, focusing specifically on the five elements of the core offer.³ The second phase, the focus of this report, explores and unpacks key findings from a quantitative survey with parents of disabled children in 30 pilot local authorities (DCSF's *Health and Wellbeing of Children* survey). It aims to better understand the implications of the findings for the Aiming High for Disabled Children programme more broadly and to allow space to explore issues beyond the Core Offer.

Specifically, the research aimed to:

- provide greater depth about parents' individual experiences of accessing and using services for disabled children
- explore key issues highlighted by the 'Health and Wellbeing of Children' survey, including parents' perceptions of:
 - difficulties accessing services;

² DCSF (2008) *Aiming High for Disabled Children: Transforming services for disabled children and their families*, Nottingham: DCSF Publications

³ BMRB report [forthcoming publication] *Parental experiences of services for disabled children – Qualitative research*

- lack of service availability;
- poor communication and information about services;
- what constitutes a ‘good service’.

1.3 Research methodology

Twelve extended focus groups were conducted across six Local Authority areas: Lewisham, York, Solihull, Oldham, Poole, Hertfordshire. Participants were selected using purposive sampling to reflect a range of characteristics, including area, age of the child, gender, ethnicity, socio-economic grade, and nature of child’s disability⁴. The sample breakdown of the twelve groups is outlined below:

Group 1: Lewisham Early years ABC1 Mixed Gender BME group Mixed disability	Group 2: Poole Primary age ABC1 Mixed Gender Mixed Ethnicity Mixed disability	Group 3 : York Secondary age ABC1 Mixed Gender Mixed Ethnicity Mixed disability	Group 4: Solihull Post 16 ABC1 Mixed Gender Mixed Ethnicity Mixed disability
Group 5: Hertfordshire Early years ABC1 Mixed Gender Mixed Ethnicity Mixed disability	Group 6: Oldham Secondary age ABC1 Mixed Gender BME group Mixed disability	Group 7: Lewisham Secondary age C2DE Mixed Gender Mixed Ethnicity Mixed disability	Group 8: Poole Post 16 C2DE Mixed Gender Mixed Ethnicity Mixed disability
Group 9: York Early years C2DE Mixed Gender Mixed Ethnicity Mixed disability	Group 10: Solihull Primary age C2DE Mixed Gender BME group Mixed disability	Group11: Hertfordshire Post 16 C2DE Mixed Gender Mixed Ethnicity Mixed disability	Group 12: Oldham Primary age C2DE Mixed Gender Mixed Ethnicity Mixed disability

In addition, 36 depth interviews were conducted with parents (six in each area) with the aim of exploring individual experiences in greater depth. In order to ensure that a range of opinions were gathered, the depth interviews included five parents who were identified as accessing a low range of services, either because of a perceived lack of need or dissatisfaction with services.⁵

Recruitment for this qualitative research incorporated a broad definition of disability, matching that used within the survey (see footnote 4). Sampling quotas were set to ensure a range of different types of disability were included, rather than levels of ‘severity’. As a result, a majority of the achieved sample covers children with less ‘severe’ disabilities, such as learning and behavioural problems, and fewer children with more serious or life impairing

⁴ Children’s disabilities were identified using the Disability Discrimination Act (DDA) definition, which defines a disabled person as someone ‘*who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities*’. Disability Discrimination Act 1995. Parents were screened to ensure a range of children’s disabilities in different categories of disability including: mobility; communication; and memory / concentration / learning.

⁵ Levels of engagement were assessed at the point of recruitment from responses to screening questions about parents’ use of services and support networks in helping to care for their disabled child. Parents who responded as having ‘never’ or ‘seldom’ made use of these services were classified as ‘less engaged’.

disabilities. While this approach has an impact on the findings, it also enables implications to be drawn across a wide range of experiences, including those who may have greater difficulty accessing services than parents of children with more severe disabilities.

1.4 Report outline

The next section of this report, **section two**, explores the range of services identified by parents in relation to caring for their disabled child. **Section three** considers parents' experiences and views of accessing these services. **Section four** explores parents' perceptions of service availability and how parents obtained information about these services. **Section five** unpacks parents' views about what constitutes a 'good service'. Finally, **section six** summarises the key findings and explores how these findings could be used to improve service provision.

2 Range of services

This section outlines the range of services accessed by participants for support in caring for their disabled child/ren. The table below reiterates the range of health, education, and care & family support services identified by parents during the first phase of research to provide context for subsequent discussions. The main focus of this section goes beyond these three formal service areas, considering the importance of wider services, such as childcare, housing, transport and informal support organisations. Further consideration is given to parents' experiences and views of integrated services. Finally, this section concludes by building on these findings and those of the first phase of research, to draw conclusions about parents' understanding of 'services'.

Table: Services identified by parents in relation to caring for their disabled child⁶

Health care services	Education services	Care & family support services	Multi-agency services
<ul style="list-style-type: none"> • GP • Pharmacist • Optician • Health visitor • Community nurse • Speech therapist • Occupational therapist • Paediatrician • Dermatologist • Psychiatrist • Dietician • Physiotherapist • Surgeons • Consultants 	<ul style="list-style-type: none"> • School nurse • Head teacher • Classroom support • School behavioural classes • Special Educational Needs Co-ordinators (SENCO) • Connexions • Outreach team • Educational psychologists • Visual impairment teaching team 	<ul style="list-style-type: none"> • Financial benefits (Disability Living Allowance; Carer's Allowance; grants) • Social workers • Counselling services • Local support groups - AMAZE, SNAPS, Sunshine group • National charities - ASBAH (Association for Spina Bifida and Hydrocephalus) 	<ul style="list-style-type: none"> • Parent Partnership Officers • Child Development Centres • Children and Adolescent Mental Health Services (CAMHS)

2.1 Wider services

As noted above, due to the focus on the 'big three' sectors of health, education, and care & family support services in the first phase of research, this second phase explored parents' views about the importance of wider services, such as childcare, housing, transport and informal support organisations.

When probed more closely around which wider services were important to parents, **childcare** emerged as a priority. Childcare needs applied to all parents participating in this research, ranging from a few hours every week to accommodate work or household management, through to daily help during the school holidays. However, experiences of inadequate provision and limited access to appropriate childcare for disabled children caused

⁶ BMRB report [forthcoming publication] Parental experiences of services for disabled children - Qualitative research

difficulties for many parents. Further issues relating to childcare are covered more fully in other areas of this report (see section 4.2).

Housing also emerged as a concern for parents, specifically relating to accommodation that was appropriate for the needs of the family and accessing home adaptations. Perceived lack of appropriate accommodation was particularly highlighted by parents living in social housing. Examples included homes that provided inadequate indoor or outdoor space for their child, or that were located in areas away from family and other support networks (see case study 1). Parents described difficulty addressing these issues, with experiences of being placed on waiting lists and informed that they were not a priority for relocation. Parents whose children had more serious needs for adapted accommodation, such as being wheelchair bound, were more likely to have accessed support with home adaptations, such as ramps or hoists. These tended to be accessed through social workers or occupational therapists. However, parents generally described a lack of clarity about eligibility to apply for additional funding for home adaptations.

Case study 1: Housing services

Kerry is a mother of two, currently going through a divorce which resulted from the stress of having an autistic child. She has always had to provide the care for the children and therefore does not have a job, although she would really like to start training as a carer. All three live in a 'tiny' flat in a social housing estate. She has asked to be moved closer to her aunt and have a place with a garden. This would give her some support with the children and allow them to play outside, which would enable her son to be more active. Currently, there is little opportunity to get out of the flat and she has to monitor her autistic son constantly to ensure he does not do things like write on the walls. She feels isolated and overwhelmed.

Parents generally described having minimal support available in terms of **transport**. For those parents who relied on public transport, travelling with their child could be difficult. Examples included difficulties controlling children with behavioural problems in busy public spaces, or complications negotiating public transport with a child with mobility and / or other impairments. These problems were compounded in situations where parents also had other children to look after. Even travelling by car could be difficult if they did not have essential car adaptations, such as a ramp for a wheelchair.

Transport was provided by most special schools for transporting children to school. Parents found this service to be extremely helpful, especially as some children had to travel quite far to attend their school, and this would have been impossible had transport not been provided. However, there was mention of its inflexibility, for example, one school bus would only drop the child at home rather than at an after-school care facility while parents were working. More generally, parents described difficulties accessing special transport services, specifically relating to uncertainty about provision.

"All the transport I've ever battled for has been decided more or less the week before she was due to go, so the pressure and the stress was just horrendous, not knowing whether she would be able to go or not". (Female participant)

Many of the parents were in contact with **support organisations** or belonged to support groups, such as the Parent Partnership, Befrienders mentoring programme, Contact a Family, as well as local support groups. These were generally viewed as invaluable sources of support and information, offering a variety of services including respite care, support groups, information and advocacy. Parents generally felt they had received more information about their child's disability and the services available to them from the charitable sector than from the formal sector.

Overall, the importance of wider services, such as childcare, housing, transport and informal support services was highlighted by parents. Parents depended on these services to manage their day-to-day lives. Having adequate service provision in these areas reduced the level of stress that parents experienced by giving them more free time to spend doing things other than caring for their child. Whether this time was spent doing chores, interacting with other family members, or simply relaxing, it was viewed as essential for their own well-being and that of their family. In contrast, where these services were inadequate or unavailable, parents described increased stress and frustration, compounding the perceived difficulties of accessing and using other services.

2.2 Integrated services

Upon probing, parents described limited experiences of 'integrated services' or 'joined up working' across service areas, and none of the parents involved in this research acknowledged having a 'key worker' with responsibility for co-ordinating services around the needs of their child. Those experiences that were mentioned included examples of services being provided through a single point of access, such as special schools providing a range of services under one roof, or where services had communicated with each other directly, such as practitioners making contact with other services on behalf of parents. Where parents had experienced more active links between services, this was viewed favourably.

Discussions also highlighted that parents had varying interpretations of what constitutes an 'integrated service', ranging from fully co-ordinated services provided through one access point, to communication between practitioners. While the former was appreciated by those who had experienced more fully integrated services, generally parents sought improvements in lower levels of integration, such as better communication between services so that parents did not have to take on the coordination role.

"I am the lynchpin - me and my husband - that co-ordinates all the services. I don't think there is one person who is thinking, because they think within their own little silo: in school they think of education; the paediatrician thinks about their medical health. I think, as a parent, you are the only one who thinks across the boundaries." [Female participant]

Examples of positive communication included those services that provided information and advice to parents about other relevant services, such as the Portage service. Portage was viewed very positively as the workers were perceived to be contactable, friendly, genuinely enthusiastic about working with children and able to put parents in contact with other services.

"I think the best service I've had anything to do with in the whole lot was the, I like the portage worker and the service they've offered and if she's not there the other team members always will help out and they like put on little picnics at the park and they do things off their own back and they genuinely seem to want to work with the children." [Female participant]

Parents also valued services that communicated directly with other services on their behalf. For example, one parent spoke of the 'excellent' service provided by his local community diabetes team, who visited his child's school on his behalf to explain how his child's diabetes could be managed at school.

"[A community diabetes officer] will talk to the schools and they will arrange things for you, so if you want them to be a link, you can do it yourself but if you are not confident enough to do it yourself, to go and speak to the head teachers, they will go and do it. So in that sector, yes it's good." [Male participant]

Communication and information provided by services is explored further in section four.

2.3 Understanding of 'services'

As in the first report, parents did not spontaneously identify a full range of services and it required prompting to outline all services accessed by parents in relation to their disabled child. Further exploration revealed that certain services and support were not initially viewed by parents as being a 'service' in this sense, primarily due to these being generic services that parents would have accessed regardless of their child being disabled, such as a GP or teacher. This lack of association between generic primary care services and specialist services for disabled children reflects findings from the first phase of research; that certain services are more likely to be at the forefront of parents' thoughts when assessing overall satisfaction with services in general.

Further to this point, it also became clear that parents had difficulty separating their views about different services according to broad service areas (health, education, care & family support, and wider services). Parents tended not to think in these distinct categories or with such clear separation between the different service areas.

2.4 Summary of key findings

This section provides a summary of the key findings relating to the range of services identified and accessed by parents. This summary of parents' viewpoints aims to highlight potential areas for further exploration in relation to policy or service development:

- Parents felt that improving access to and delivery of **wider services** beyond health, education, and care & family support, such as childcare, housing and transport, would provide more comprehensive support and lower the emotional impacts of caring for a disabled child.
- Parents emphasised the importance of **communication**, both between services and between practitioners and families. It was felt that having a single contact person who can facilitate the process of communication and coordination would provide an invaluable resource for parents.
- Parents valued the support they received from **charitable organisations**. For example, Portage workers were viewed as contactable, friendly, and genuinely enthusiastic about working with children. It was felt that lessons could be learnt from such experiences about how formal services could be delivered more effectively.
- In terms of what these findings mean for thinking about the **Core Offer**, although many issues raised in this section are included within the five areas, the importance parents placed on wider services, communication, and practitioner approach (from their experiences of charitable organisations) highlights the need for these issues to underpin effective delivery of the Core Offer.

3 Accessing services

One of the key issues highlighted by the quantitative survey was that of the difficulties parents faced when accessing services. This section unpacks these issues, exploring parents' experiences of diagnosis; assessment; accessing care; and overall issues associated with accessing services. It then explores variations between parents' experiences.

3.1 Receiving a diagnosis

As highlighted in the first report, receiving a diagnosis was viewed as a vital first step toward accessing services; however the ease of achieving a diagnosis was felt to vary depending on the level of disability and the age of the child. When the disability was diagnosed soon after birth or the condition was severe, health-related and 'straightforward', for example cerebral palsy or Down syndrome, accessing health services was felt to be relatively easy. For these parents, once services had been accessed, they were generally felt to be good.

"They got everything going as soon as they found out what was wrong. She was in hospital; she was having her treatment as a day care, you know, and coming home the same day. So that was very good." [Female participant]

If the disability was less clear cut or developmental and/or the child was older, then diagnosis and service access was perceived to be more difficult. This was felt to be a serious issue for parents, as delays in accessing the necessary support could have long term negative repercussions. For example, one parent described her concerns about delayed access to speech therapy for her son while waiting for a diagnosis, which she felt could lead to permanent speech problems.

"There's no support given to you in the meantime before you get to that point [achieving a diagnosis], you're just kind of left hanging, and in two years your child can go a long way downhill, can't they? And then it's getting back up from things going wrong, isn't it?" [Female participant]

3.2 Obtaining an assessment of need

After the child was diagnosed, the next step for many parents was to get an assessment of the child's needs and from that, identify which services the child and family should be able to access. Parents believed that sometimes assessments were not conducted on a child when they should have been. As a result of this, a number of parents felt that they had been 'forced' into having private assessments done; otherwise nothing would have happened for their child.

Assessments could be very stressful times for parents as so much was felt to depend on the outcome and parents wanted to ensure that their child could access the support they needed. Thus it was very important to parents that it was done properly, by a professional who understood the disability and their family situation.

"The community paediatrician was absolutely dreadful... I requested to be referred to the hospital paediatrician at the Child Development Centre... and had a completely opposite experience, somebody who sat on the floor with my child, that communicated with my child, that didn't talk over my child, that was very supportive, very friendly, very open and I thought she had a much better grasp of us as a family than this community paediatrician.." [Female participant]

The most commonly cited example of assessments related to obtaining a Statement of Special Educational Needs (also referred to as a 'Statement'), which would allow access to a broader range of services around the educational needs of the child. There were a number of issues related to obtaining a Statement. The ease with which one could be obtained was once again viewed as being dependent upon the type and severity of the child's disability. In particular, parents of autistic children spoke of their difficulties obtaining a Statement due to their child being assessed as 'coping' academically in a mainstream school. It was felt that unless the child had more obvious or extreme behavioural issues, their needs would not be seen as severe enough to warrant a Statement. Parents also believed that without a Statement their child would not receive extra support in a mainstream school and they would not be accepted to attend a special school.

Parents felt that some schools were less than cooperative when it came to applying for a Statement. It was thought that schools did not always know how to go about obtaining a Statement or did not feel that a particular child needed one, or were reluctant to go through such a time-consuming process. Parents did not always know that they could apply for a Statement on their own. A number of parents spoke about having to appeal their child's Statement as it was not adequate for their needs or lacked clarity about what support was due to the child.

3.3 Experiences of accessing specific services

Whether or not a child's needs had been assessed, parents described a range of issues to physically accessing care and support services for their disabled child. Specific examples of these issues were identified in relation to each of the broad service areas – education, care & family support, and health services – in addition to accessing more generic activities and financial support.

Particular difficulties accessing **care and family support services** were identified in relation to social workers and respite care. Social workers were said to be difficult to contact and access support, whilst respite care was generally found to be 'unreliable'. Many parents were struggling to manage caring for their child with other stresses and demands on their lives, yet felt they were not receiving sufficient support from social services. One parent described a general perception that the heavy workload that social workers must deal with means they do not have enough time to properly support parents; as a result, parents who needed help were being denied a key resource for support.

"There's not enough specialists in the field of disability. There's not time to talk... [Social workers] have maybe 12 cases in a day to see but there's only eight hours in a day, so rather than see those people it might be a telephone call for 10 minutes when actually that poor woman could be in her house in crisis point, but on the phone she's very brave and says, 'oh, everything's fine'... I think it fails because there isn't enough, what shall we say, valuable time?" [Female participant]

Accessing the best **education** for a disabled child was also said to be difficult as it depended on whether the child had a Statement, and therefore access to a special school or additional support. Further to this point, parents described difficulties in making the best decision for their child around education, specifically where parents had to decide between specialist or mainstream schooling. While special schools represented an 'all-in-one' package of services, concerns about children mixing only with other disabled children prompted concerns about academic progression and post-school transitions (see case study 2).

“The thing about when they go to a special school and you know, I mean, it’s fine when they adapt the education or the curriculum according to, you know, sort of, their abilities but they don’t really prepare them a lot for actually that transition to a college or to the next stage.” [Female participant]

Further to this, parents were concerned that many of the special schools ended when the child was sixteen and since, for many children, their Statement would finish when they left school, parents felt they would be left with few services aside from adult services, which were deemed to be inappropriate for a sixteen year old child, especially one with a disability.

In contrast, a mainstream school was felt to offer a better academic programme and social preparation, but adequate support was not always available. In addition, parents were concerned about their child being bullied due to their disability or lack of social skills. Parents believed that without a Statement, the school would not get extra funding to provide additional support and they were therefore concerned that their child would have to manage with whatever support was available and would be very unlikely to have any one-to-one support. Some parents felt strongly that educational decisions at local authority level were based on financial concerns rather than the needs of individual children.

Case study 2: Impact of decisions about education

Grace chose to send her son to a special school because of the wide range of specialist support available there. Her son has now finished school and has the opportunity to go on to college. Other learners from his school will be doing a very basic course at the same college as an introduction but he has been told he should be doing a more difficult course as he has the capability. However, he has not interacted with learners from mainstream schools before and is therefore too nervous to attend the more difficult course.

In terms of **health care**, the ease of accessibility to services was viewed as connected to the severity of the child’s disability. Parents felt it was far easier to access the requisite services when the child had an obvious, more severe disability, such as deafness. If a child was already receiving support from a hospital for a severe disability it was then felt to be easier to access follow-on care.

“So we really just depended on the Children’s Hospital really [to organise follow-on care]. They phone regularly and we phone them, they are fantastic.” [Female participant]

Waiting lists were another issue that arose in relation to health care services. In particular, specialised health services were said to be particularly difficult to access due to long waiting lists, especially if the child’s disability was not viewed as severe. In particular, there was perceived to be a major shortage of occupational therapists and speech and language therapists and parents described waiting months before they could get an appointment for their child with these services.

“We are on a long list for occupational therapy... It was closed down for a while because there was too many demands for people going there... She is right at the bottom of the list at the moment and it could be a very, very long time.” [Female participant]

Once accessed, these specialised services were viewed as very helpful, offering not only direct support for their child but providing parents with practical ways to support their child at home. For example, services such as speech and language, and occupational therapy could provide them with ways to work with their child at home doing special exercises.

As well as accessing the necessary formal services, parents also wanted their child to be able to participate in **activities** that any other child would be involved in such as sports, music, holidays and days out. Finding appropriate activities that could cater for a child with disabilities was viewed to be difficult due to perceived funding limitations.

“I’d like him to access the music therapy but when he was going to the Child Development Centre the funding just ran out and then when he left they still hadn’t got any more funding for it and to find a music therapist off your own back, they’re quite, I mean I haven’t been able to find anyone that wanted to work with special needs children.” [Female Participant]

Finally, accessing **financial support** was also described as an area of difficulty. Parents felt that they lacked sufficient knowledge about what benefits were available and what they were entitled to. Parents also described frustration with having to complete extensive and repetitive claim forms for financial support, particularly as these often had to be repeated at regular intervals.

3.4 Accessing services overall

Beyond the specific issues identified above, a range of issues were found to have an impact on parent’s experiences of accessing services. These included the perceived flexibility of the service, the need for parents to ‘fight’ to access services, the level of coordination between services, and key individuals involved in service delivery. Each of these issues is outlined in greater depth below.

Certain services were highlighted as being **inflexible** and unwilling to cater to the individual needs of a family, adding to the stress parents were experiencing. For example, some services were only available during school or work time, or there was no choice regarding appointment timings. One mother had been given a speech therapy appointment on Monday mornings when the child should be in nursery, which she found difficult to accommodate.

“[My son] only goes on Monday mornings and he goes for a block of 6 weeks but she [speech therapist] has no other time at all to see him apart from that Monday morning, you know. There’s no wriggle room at all.” [Female participant]

Parents repeatedly complained about having to be **proactive** and ‘pushy’ to access services and therefore expressed concern that those with less confidence or who were less proactive might never access services. The perception was that they were constantly being denied access or having to prove their child’s need rather than being supported. This caused a great deal of strain as parents were repeatedly having to plan and fight for what they felt their child needed, which added to the difficulty of having a disabled child and left parents feeling frustrated.

“You’ve got to open lots and lots of doors before you get to that door that says, oh yes, I can help.... [One time] over 4 days, I spent 6 hours on the phone, and when it got to this person, and she referred me back to this person I originally talked to, I just was furious.” [Female participant]

Parents described a **lack of coordination** between different service areas, or even within the same area. This resulted in a lack of direction and clarity and caused more difficulty for parents as often they were not referred on to additional services but had to find out about and access these separately. Parents were confused and angry about the way in which services were organised, and resented having a number of professionals dealing with various aspects of the child's disability but no one person acting as an overall coordinator.

"It's sort of stumbling and finding services, quite honestly, accessing them myself. And a lot of the services that I've come across are just by chance or perhaps talking to another agency and they said, 'why don't you access this service?' There's no one or person that actually linked all the services together." [Female participant]

Key **individuals** had a major impact on parents' experiences and it seemed that having a good quality of service depended on parents' views about key individuals rather than broader organisational standards. Having a professional who they felt was on their side and who was trying to make the process easier for them was very much appreciated by parents. Further to this, parents also appreciated having continuity of staff to avoid having to repeatedly explain their situation and the child's disability. The professional would learn from experience how to interact with their child and the child would have a familiar face.

"There's one doctor in particular that knows the family... She's not always there but I do ask to see her if I can because I think it's really important that they know your family situation." [Male participant]

A further barrier to accessing care was the **emotional difficulties** and mental health problems that many of the parents suffered either directly or indirectly linked to their child's disability. For these parents, such difficulties further complicated the process of accessing services, and in some more severe cases actually restricted the level of support they could access. For example, one depressed mother found communication by telephone to be stressful and therefore was unable to easily access the full range of services she and her child were entitled to.

3.5 Variations

A number of variations between experiences and opinions of parents with specific characteristics were noted from the discussions:

There was widely believed to be a degree of **geographical variation** in accessing certain services. For example, some areas were perceived to be more difficult to obtain a Statement due to financial constraints at local authority level.

"It is all money isn't it? That is what it is down to. But I suppose I feel quite bitter because... you know that the needs were there, and how he would have benefited from having one to one support, even if it was only a few hours a week." [Female participant]

Differences were also noted between parents of different **socio-economic** grades. Parents who were better off economically appeared to have better experiences of accessing a wide range of services, partly due to their ability to spend money on resources, such as private care and assessments, tutors and home or car adaptations.

Those parents who were actively choosing not to access the full range of services available to them either felt they did not need to access these services, or had decided not to because they were unsatisfied with the services they had received. It seemed that parents had little choice but to use some services, for example, the child has to go to school, but they felt they were getting little support from these services in relation to their child's disability. In general, these parents did have access to the other services but preferred not to use them due to these negative experiences.

3.6 Summary of key findings

This section provides a summary of the key findings relating to services access by parents. This summary of parents' viewpoints aims to highlight potential areas for further exploration in relation to policy or service development:

- **Ease of accessibility** to services, including specialised services, was viewed by parents as key to providing the necessary support for their child. As a first step towards access, it was felt that diagnosis should be prompt and followed up with a range of services catering for the child's particular needs.
- Parents highlighted the need for **assessments** to be conducted by a professional who understands the disability and the family's particular situation. In particular, parents felt the Statementing process should be clarified in relation to parents' rights in situations where they feel unsupported by their school.
- Parents expressed a desire for greater **flexibility** of services in order to cater more effectively to the needs of parents. Each family had a particular set of needs and a particular lifestyle and parents would like this to be taken into account when services are provided.
- Once again it was clear that parents wanted greater **coordination** between services and to have a key worker or central contact person. This person could provide much needed advice and support to parents, for example through the Statementing process and when choosing a school.
- Due to the important role that **professionals** played in service delivery and the impact they had on parents' level of satisfaction, parents felt that staff should be consistent throughout service delivery where possible and they should have a supportive and inclusive attitude towards parents.
- Parents highlighted a need for greater **emotional support** for parents suffering with depression and other mental health problems, and those struggling with feelings that they could not cope.
- Parents expressed concerns about a lack of **clarity** about what benefits and additional financial support are potentially available (this will be expanded on in the next section).
- The **Core Offer** covers issues outlined within this section, such as information, transparency and assessment; however, issues of accessibility and flexibility of services should once again underpin effective service delivery.

4 Service availability

A further two key issues highlighted by the survey were: a perceived lack of service availability and poor information/communication. During the qualitative research, these two issues were found to be closely related, such that assumptions about service availability appeared to be heavily dependent upon information and communication available to parents. Therefore, these issues have been collapsed into one overarching section, exploring: perceptions of service availability; knowledge and information; and communication and understanding.

4.1 Perceptions of service availability

When parents were asked about whether they felt there were sufficient services available, it was clear that the perceived availability of a service depended on parents' understanding of the term. Upon further probing a 'lack of services' could refer to a variety of issues: the service not being available at all; being infrequent, inaccessible, or of insufficient quality; or parents simply not being aware of whether it was available. For example, going back to parents' perception of a lack of availability of specialised health workers such as occupational therapists, further probing of this issue revealed a range of reasons highlighted by parents as to why they viewed this service as 'unavailable', including the range outlined above.

Discussions also revealed a link between service availability and how this was communicated to parents. Where parents were unaware of the availability of particular services, this was found to impact on their perception of services overall. This issue is explored in greater depth in the following sections.

4.2 Knowledge and information

Perceptions of a lack of knowledge and information about service entitlements and eligibility prompted perceptions of a lack of transparency about what services were available to parents of disabled children. In particular, two areas were highlighted where parents felt a lack of information and knowledge were particularly problematic – specifically, financial support and childcare.

Lack of information about **financial support**, such as benefits and funding for additional support, caused substantial frustration for parents. Complexities of accessing benefits added to parents' stress and strengthened perceptions that barriers were deliberately placed in parents' way to accessing financial support. Additional support, such as funding for respite care, house adaptations or holidays was acknowledged as available but parents described experiences of 'discovering' such support only through independent research or word of mouth from support organisations and other parents. Having to obtain information in this manner prompted cynicism about resources being 'withheld' from parents and caused a great deal of frustration.

"No one said to me you're entitled to this or that, so I've never had a clue about what's available there." [Male participant]

"I think there are good services available... I think there are a lot of services out there but it's knowing about them and knowing what they do." [Female participant]

As noted above, parents emphasised the importance of **childcare** to their ability to manage family life. Yet parents described feeling unconfident about what support they could access for their disabled child, particularly during school holidays. This meant parents felt they were potentially missing out on vital respite opportunities for themselves and their families.

“I found them [childcare support services] when [my daughter] was about 13 and they provide respite and summer activities and all sorts of things, but I didn’t find them until she was 13... To be honest it was too late by then....And I’ve got two older boys, so they were just pushed to one side and a day out then would have been absolutely a breath of fresh air.” [Female participant]

4.3 Communication and understanding

Parents’ complaints about a perceived lack of information were also related to problems of poorly coordinated services lacking sufficient communication processes. Firstly, parents felt they had to find information about services on their own because they did not have an expert central contact point; and secondly, they wanted professionals to be communicating both with them and with the other services.

“Even the ENT people, the consultant and the hearing clinic... I was having to tell the consultant what his doctor had been doing with him in the hearing clinic.” [Female participant]

For parents, communication meant more than just professionals sharing information with parents or other services. It was about parents being **involved** throughout the process and having an open, honest dialogue with professionals with opportunities to provide their opinions. Parents who currently felt they did not have a ‘voice’ in their child’s care wanted to feel included, and be consulted in the decision making process.

“[The health visitor] said, ‘you are going through all the right channels’. But I can go through all the right channels but I haven’t got a voice in school like a health visitor has got a voice in school and a doctor has got a voice in school.” [Female participant]

In addition, parents spoke of a lack of opportunity for them to give formal **feedback** or make complaints about the services. Those parents who had made formal complaints felt that this was not taken seriously and no action was taken in response.

“I’m still waiting 18 months after the carers withdrew to find out why the carers withdrew, why they decided they couldn’t look after [my child] any more. We still don’t know, despite having been through the complaints procedure, despite having gone as far as the local government ombudsman. The local authority threw their hands up and went, ‘yes we stuffed up’, so the local government ombudsmen went, ‘yes okay that’s fine’, and has done nothing.” [Female participant]

Parents also described a need for communication to be **tailored** to the needs of the family. Experiences of receiving a bulk of written information at the point of diagnosis was felt to be overburdening some parents at a sensitive time (see case study 3). Rather, some parents described a preference for having access to a friendly, informed person to talk through the information with them and answer their questions, someone who was on their side.

“You could do with some sort of key worker that knew the system, that was there, you could go to once you’d got a diagnosis and that you could keep going back. ‘Okay what should I do now?’ so they were actually clear about what you were doing, because it is confusing enough.” [Female participant]

Case study 3: Importance of communication

Fiona was given a folder full of information by the assessment centre when her son was diagnosed as having a disability. Fiona works fulltime and has four children so she found it very difficult to wade through all of this information to find what she needed, especially since it had been a 'devastating' experience finding out about his disability. She felt that if someone had been available to work through the information with her, it would have made the process much easier. She has now joined a support group and has gained a great deal of support and advice from this forum.

At the time of diagnosis and throughout the child's life, the **timing** of communication was found to be important for parents to process key information at different points. A number of key transitional points requiring specific communication efforts were identified by parents:

- Diagnosis - information about the condition; how parents can support the child; the range of services and support that is available to the family
- Obtaining a statement - information about the process; how to complete necessary forms; what to ask for
- Starting school - information about choosing between mainstream school and special school; what support is available
- Move from primary to secondary school - information about how to help child cope with the change / more challenging environment
- Post 16 years - information about services available for 16-19 year olds, not just the adult services

4.4 Variations

From the discussion regarding service availability and information / communication, the only significant variations between experiences and opinions of parents with specific characteristics related to parents with children of different **ages** requiring different information about service availability at the key transition points outlined above.

4.5 Summary of key findings

This section provides a summary of the key findings relating to service availability. This summary of parents' viewpoints aims to highlight potential areas for further exploration in relation to policy or service development:

- Parents' views about service availability highlighted a range of issues bound up within perceptions of a '**lack of services**'. Where parents were unaware that a particular service was available, this impacted on their perception of services overall.
- Parents expressed a need for **comprehensive information** about services and support potentially available. This would improve perceptions of transparency and service availability.

- It was felt that **tailoring** communication around the child's particular disability and the family's specific needs would improve parents' perceptions of service provision. One practical way in which communication could be improved is by having a communication and information strategy which connects to the journey of a family and their changing needs throughout the child's life.
- Having a **central contact** person to provide support and advice was perceived as key to ensure that parents know who to contact to obtain information and advice. This would help with minimising any perception that resources are being withheld from parents.
- Parents highlighted concerns about a lack of opportunity given to them by professionals for **involvement** in the process, and felt that their opinions should be taken into account when decisions are being made. They would like feedback and complaints to be taken seriously and acted upon in a timely manner.
- In terms of the **Core Offer**, the areas of information, transparency, participation and feedback cover all key points in this section apart from the issue of parents wanting a central contact person, which is more about a need for greater co-ordination.

5 What constitutes a 'good service'?

The final key finding from the survey was that parents had clear conceptions of certain services either being 'good' or 'bad'. To avoid repetition from the previous phase of qualitative research, which included an exploration of factors underpinning parents' satisfaction with services for their disabled child, this section aims to draw out some key summary findings related to service delivery as discussed in other areas of the report. A number of key aspects of what constitutes a 'good service' are therefore outlined below:

Information/communication - Parents being told upfront about all the services and support they could potentially access. Services communicating, both with other services and with families. Services offering opportunities for parents to provide feedback and have their opinions taken into account when decisions were being made.

Accessibility - Timely diagnosis in order to access services as soon as possible, followed up with access to the appropriate support from all relevant service areas, including the wider services outlined above.

Attitude of professional - A respectful, supportive and courteous attitude of all practitioners towards parents and children. Professionals who understood the child's condition and the impact it had on the family, and played a more supportive role to help take some of the burden off of the parents. Professionals who exhibited a positive attitude towards the disability and focused on what can be achieved rather than what will never be achieved.

Coordination of services - Services that were coordinated and offered joined-up working between professionals. A clear point of contact for advice and support, who worked 'on their side'.

Trust in system - Parents really wanted to be able to trust and have confidence in the system and in professionals as it would lesson their stress levels. They wanted to be able to trust that things would progress without requiring much input from parents.

6 Key Findings

This section summarises the key findings of the research and explores how these can be used to improve the services available for disabled children and their families.

6.1 Summary of key findings

With regard to the **range** of services, although it was viewed as essential to have health, education and care & family support services in place, access to wider services was also seen as important, especially access to childcare. Parents did not always have a good understanding of what was meant by the term 'services', and tended to focus on specialist services rather than more everyday, generic services. Parents wanted more 'joined-up' working, but rather than referring to complete integration, this focused more on having good communication and coordination between services. Support organisations provided an essential service and were viewed very positively by parents.

In terms of **access** to services, parents highlighted a number of issues which they had come across when attempting to access services. Diagnosis was viewed as key to accessing services but ease of obtaining a diagnosis was felt to vary depending on the level of disability and the age of the child. For many parents, these difficulties persisted when seeking an assessment of needs. Ease of access to assessments was again viewed as dependent on the nature and severity of the child's disability. Parents wanted to feel more empowered in the assessment process, through being kept more informed about the process itself and what the child should get out of it.

Parents felt they had to be very proactive and pushy to access services because of problems related to: inflexibility of services, a lack of coordination between services and a lack of service availability. Key professionals had a major impact on their experience. Parents were concerned about their ability to access the best education for their disabled child in order to allow them to reach their potential. A number of parents were suffering emotional difficulties and mental health problems that were exacerbated by, or even the result of, stresses related to their child's disability.

A perceived lack of **service availability** combined a number of different assumptions, including: services not being provided; inappropriate or inadequate services; or parents lacking knowledge about service availability. Closely connected to this issue, a key barrier to accessing available services was due to a lack of **information and communication** and therefore a lack of awareness. Better information would improve perceived transparency about what services were available, as well as improved communication with and between services. Opportunities for participation and feedback were considered important aspects of communication.

Finally, elements of what makes a 'good service' include good information and communication, easy accessibility, positive and approachable attitude of professionals, coordination of services, and being able to trust that the services will work to support families.

6.2 Key policy implications and recommendations

The following key policy implications and recommendations can be made across all areas of the research:

- **Increase ease of accessibility and flexibility** - Having easy access to flexible services, including specialised services, would greatly improve parents' satisfaction with service provision. In order to improve support and lower parents' stress levels, access to wider services beyond those of health, education and care & family support services, such as childcare, housing and transport should be considered. When services are accessed, as far as possible they should be flexible and cater to the particular needs of each child and their family.
- **Improve communication and co-ordination** - Having better communication and more joined-up working between the different services and between the services and parents would ensure that the process of service provision runs smoothly. One means of achieving this is by having a single contact person who can play the coordination role, as well as providing much needed information, support and advice to parents would provide an invaluable resource. This would also help ensure that there is more transparency about what services and support are available to parents by keeping them well informed.
- **Tailored communication** - Communication should be tailored to the child's particular disability and for the family's specific needs. Timing of the communication is important, with parents requiring specific information at particular transition points. The task of tailoring communication could be the responsibility of the central contact person discussed above.
- **Participation** - parents felt they should be given more opportunity for involvement in the process and their opinions should be taken into account, especially when decisions are being made about their child's care. In addition, any feedback or complaints they have made should be taken seriously and acted upon in a timely manner.
- **Professionals** - Due to the central role that professionals play in service provision and the impact that they have on parents' levels of satisfaction, staff should be as consistent as possible and should have a respectful, supportive and inclusive attitude towards parents and children.
- **Understanding of services** - As discussed, it was difficult to get a sense of parents' opinions about broad service areas. This was most likely due to the fact that they make use of a number of different facets of each sector, for example they may consult with an educational psychologist separately from the school. If they have had varying degrees of good service within a sector, this could make it difficult to make an overall judgement.
- **Charitable sector** - Parents were impressed by the support they received from charitable organisations and it is therefore important to explore what lessons can be learnt from the services provided by the charitable sector and implemented in the formal sector.

7 Appendices

7.1 Recruitment and research methodology

Participants

Participants were recruited in two ways: some participants were taken from the survey sample; others were recruited through free-find methods such as through support groups and organisations. Therefore the sample included a mix of those who took part in the survey and those who did not.

Including a 'fresh' sample of parents further widened the reach of the research by exploring the views of a new group of parents; and secondly, allowed for the inclusion of a small sample of 'disengaged' parents who are by their nature are less likely to have taken part in the survey.

The sample design

In order to both gain an in-depth understanding of parents' experiences and motivations as well as explore the degree of agreement on key issues, we conducted both face to face depth interviews and groups discussions.

Six Local Authority areas were selected: Hertfordshire, Poole, Solihull, York (North Yorkshire Authority), Lewisham and Oldham. The six areas were selected to provide a spread of characteristics, such as geographical location and overall satisfaction score in the survey.

The sample included a range of characteristics most likely to impact on parents' experiences of services:

- Geographical area;
- Age of child 0-19 (early years, primary age, secondary age, post 16);
- Socio-economic grade (ABC1, C2DE);
- Gender of parent (to include male and female respondents);
- Ethnicity (to include a mix of ethnicity, including White, Black and Asian).
- Disability (a mix of disabilities to ensure a spread across the sample as a whole. The range of disabilities would include: mobility, visual or hearing impairments, memory/ability to concentrate or understand)

Recruitment

The recruitment was managed by our internal field team who used experienced recruiters. The field managers were fully briefed on the project and provided with detailed recruitment instructions and a screening questionnaire in order for recruiters to assess respondents' eligibility to participate in research. All recruiters are members of the IQCS (Interviews Quality Control Scheme).

All respondents were recruited using free find, snowballing or community recruitment. With the free-find method a recruiter approaches individuals either in the street or by door-knocking. Having introduced themselves and confirming their identity as a BMRB recruiter,

the individual is then given a brief overview of the research, the client, and asked whether they would be interested in participating. Where interest is shown, the recruiter then asks a series of questions to determine their eligibility and ensure that the designated quotas are accurately filled. With snowballing once an eligible respondent has been recruited the researcher will ask whether they know of anyone else who is also eligible to take part. Community recruitment comprised the recruiter going to local help groups and charities to try and identify eligible respondents.

Individuals agreeing to participate in the study would be given a confirmation letter, which would further describe the nature of the study, the voluntary nature of their participation, the appointment date and time for the group discussion and the confidentiality of their answers. Individuals are re-reminded at least once before the day of the group discussion.

The following table outlines the recruitment quotas achieved for the groups:

Group 1: Lewisham Early years ABC1 Mixed Gender BME group Mixed disability 5 participants	Group 2: Poole Primary age ABC1 Mixed Gender Mixed Ethnicity Mixed disability 6 participants	Group 3 : York Secondary age ABC1 Mixed Gender Mixed Ethnicity Mixed disability 9 participants	Group 4: Solihull Post 16 ABC1 Mixed Gender Mixed Ethnicity Mixed disability 5 participants
Group5: Hertfordshire Early years ABC1 Mixed Gender Mixed Ethnicity Mixed disability 7 participants	Group 6: Oldham Secondary age ABC1 Mixed Gender BME group Mixed disability 5 participants	Group 7: Lewisham Secondary age C2DE Mixed Gender Mixed Ethnicity Mixed disability 7 participants	Group 8: Poole Post 16 C2DE Mixed Gender Mixed Ethnicity Mixed disability 7 participants
Group 9: York Early years C2DE Mixed Gender Mixed Ethnicity Mixed disability 6 participants	Group 10: Solihull Primary age C2DE Mixed Gender BME group Mixed disability 8 participants	Group11: Hertfordshire Post 16 C2DE Mixed Gender Mixed Ethnicity Mixed disability 5 participants	Group 12: Oldham Primary age C2DE Mixed Gender Mixed Ethnicity Mixed disability 8 participants

Achieved results for recruitment across the depth interview sample were:

- Total respondents - 36
- Males - 10; females - 26
- Early years (0-4years) - 8; Primary age (5-10 years) - 8; Secondary age (11-15 years) - 11; Post 16 (16-19 years) - 9
- Engaged - 31; Disengaged - 5
- BME - 3; White - 33

Fieldwork was carried out by five experienced qualitative researchers, trained in the techniques of non-directive interviewing.

Analysis

Material collected through qualitative methods is invariably unstructured and unwieldy. Much of it is text based, consisting of verbatim transcriptions of interviews and discussions. Moreover, the internal content of the material is usually in detailed and micro-form (for example, accounts of experiences, inarticulate explanations, etc.). The primary aim of any analytical method is to provide a means of exploring coherence and structure within a cumbersome data set whilst retaining a hold on the original accounts and observations from which it is derived.

Qualitative analysis is essentially about detection and exploration of the data, making sense' of the data by looking for coherence and structure within the data. **Matrix Mapping** works from verbatim transcripts and involves a systematic process of sifting, summarising and sorting the material according to key issues and themes. The process begins with a **familiarisation stage** and would include a researcher's review of the audio tapes and / or transcripts. Based on the coverage of the topic guide, the researchers' experiences of conducting the fieldwork and their preliminary review of the data, a **thematic framework is constructed**. The analysis then proceeds by **summarising and synthesising the data** according to this thematic framework using a range of techniques such as cognitive mapping and data matrices. When all the data have been sifted according to the core themes the analyst begins to **map the data and identify features within the data**: defining concepts, mapping the range and nature of phenomenon, creating typologies, finding associations, and providing explanations.

The mapping process is similar for both individual interviews and group discussions. The analyst reviews the summarised data; compares and contrasts the perceptions, accounts, or experiences; searches for patterns or connections within the data and seeks explanations internally within the data set. Piecing together the overall picture is not simply aggregating patterns, but it involves a process of weighing up the salience and dynamics of issues, and searching for structures within the data that have explanatory power, rather than simply seeking a multiplicity of evidence.

7.2 Topic guide (depth interview)

Aim: To explore and build on findings from the 'Health and well-being of children and young people' survey about parents' experiences of using health, education and care and family support services for disabled children.

Specifically, this research will:

- provide greater depth about parents' individual experiences of accessing and using services for disabled children
- explore key issues highlighted by the 'Health and well-being' survey, including:
 - Difficulties accessing services
 - Poor communication and information
 - Lack of services available
 - Factors underpinning satisfaction with services

Introduction

- About the project: Follow up research to unpack findings from a survey about parents' experiences of using health, education and care and family support services for disabled children.
- BMRB independent research agency; working on behalf of the Department for Children, Schools and Families
- Purpose of the interview (see box above)
- Recording interviews; explain recordings are only available to the research team
- Confidential - their views will be used, but not identifiable
- Duration of interview (1 hour)

Background

- Explore personal circumstances
 - household composition
 - number of children, age (s)
 - employment / hobbies
- Briefly explore nature of child's disability
 - how impacts on day to day life and needs
- Briefly outline range of services parents have used for help with caring for their child with a disability

[Note to researcher: Initially, the range of services should be explored spontaneously, to be followed up with prompts where necessary - see **Box A**]

BOX A: Services for families with disabled children

Health care services: GP / Practice nurse (at the GP surgery), Health visitor, district nurse, other community nurse, Paediatrician / other specialists, Psychologist, Physiotherapist, Speech therapist, Occupational therapist, Podiatrist/chiropracist (foot specialists), Optician or eye specialist, Dentist, Dietician or nutritionist, Emergency health care, Complementary or alternative medicine practitioner

Education/early year services: Pre-school or nursery, children's centre, home teaching, portage, private tutor, mainstream school, special school, special education unit, hospital education service, support from special needs teacher, dedicated teaching assistant/learning support assistant, educational psychologist, further education college, connexions

Care and family support services: home adaptations (ramps, lifts), respite, foster care, short breaks, help at home with care for child, social worker services, help within the home from an outside provider, home start or sure start, emotional support of counselling.

Other services: anything not included in the above such as services from other departments: transport; housing; youth etc.

Integrated services: key workers co-ordinating services within and across service areas; information sharing between practitioners; other examples of multi-agency working co-ordinating services around the needs of the family

Mapping the customer journey

NOTE TO RESEARCHER: Walk parents through distinct stages in their 'journey' of accessing and using services linked to caring for their disabled child. Researcher to plot parents' journey on the 'journey map', noting where experiences fall above and below the 'neutral' line and probing for reasons throughout. The aim of this section is to establish customers' individual experiences of services, elements of which will be explored further in later sections.

EXPERIENCE VARIATIONS: Parents are likely to have widely differing experiences, driven by a range of factors, including the nature of their child's disability. Therefore the probes included in this section should be used flexibly - i.e. repeated use of 'what happened next?' Aim to identify and probe fully on ALL relevant services - including health, education and care and family support services, in addition to examples of integrated services.

ACCESSING SERVICES

- Explore experience of **accessing services** to help care for their disabled child
 - Outline description of experiences; plot specific elements of accessing services on 'map'
 - Explore general views - what aspects of accessing services were positive / negative experiences; outline reasons; as necessary, probe on the following:
 - Initial point of contact (e.g. teacher, GP, other) - knowledge; expertise; understanding; attitude
 - Other practitioners (aiding or blocking access) - knowledge; expertise; understanding; attitude
 - Information received about disability / accessing services / entitlements - accessible; sufficient; appropriate; understandable
 - Information provided by parents - whether parents had to provide information about child's history / condition to different practitioners
 - Identifying relevant services - route to accessing further services; information received; discussions with practitioners
 - Assessment - whether undertaken; process of obtaining an assessment; transparency of assessment allocation / outcome; impact of completing an assessment
 - Referral - information provided about subsequent referrals; participation in decision-making; speed / timeliness of referral process
 - Speed / timeliness of accessing services - whether services can be accessed efficiently / in a timely manner
 - Transparency - whether parents are confident about how services are accessed
 - Proactive approach towards accessing services - whether parents are required to 'push' to access services
 - Views about overall process of accessing services - what went well; any problems encountered; key aspects affecting their experiences

USING SERVICES

- Explore experience of **using services** to help care for their disabled child
 - Outline description of experiences; plot specific elements of using services on 'map' [*where necessary identify specific services*]
 - Explore general views - what aspects of using services were positive / negative experiences; outline reasons; as necessary, probe on the following:
 - Practitioners - knowledge; expertise; understanding; attitude
 - Appointments - speed / timeliness of accessing services; waiting times
 - Participation - parents' / child's involvement in decision-making; sufficient; appropriate
 - Range of services available - sufficient; appropriate; access to specialist services
 - Quality of services - whether met expectations; why / why not
 - Flexibility of services - whether able to meet families' individual needs
 - Co-ordination of services - joined up working between services; information sharing; single point of contact; management of co-ordination
 - Accessibility - location of services; transport issues; timing of appointments
 - Feedback - opportunities to provide their views / opinions about services
 - Views about experiences overall - what went well; any problems encountered; key aspects affecting their experiences

Unpacking survey findings

NOTE TO RESEARCHER: This section aims to explore specific findings from the 'health and well-being of children and young people' survey. Participants may have taken part in this survey. Regardless, explain that this recent survey identified a number of issues affecting parents' satisfaction with services for disabled children. This section aims to probe about these specific issues in greater depth. Note, this may involve some repetition from previous sections.

ACCESSING SERVICES

- Explore views about **accessing services** providing support to parents in caring for their disabled child
 - Probe on:
 - Practitioners - supporting / blocking access
 - Information - about child's condition; entitlements; services available; accessing services
 - Assessment - transparency; support from practitioners
 - Referral - information, participation
 - Speed / timeliness of accessing services
 - Transparency - confidence about entitlements / process
 - Proactive approach - whether parents required to 'push' to access services
 - Variations between service areas – health, education, care and family support services
 - Views about accessing services overall – what do they feel are key drivers of satisfaction in relation to accessing services
 - Would these drivers of satisfaction be applicable to other parents; who; outline views

INFORMATION AND COMMUNICATION

- Explore views about **information** and **communication** in relation to services to help care for their disabled child
 - Information
 - What does 'information' mean to parents - information about their child's condition; entitlements; how to access services
 - What information do parents need / want / expect; outline reasons

- Whether information needs currently being met
 - If not, why do parents feel they are not getting the information they need / want; outline views
 - If so, when do parents feel they are getting the information they need; probe for examples
- Communication
 - What does 'communication' mean to parents - communication with whom, about what; with parents; between professionals
 - Feedback opportunities - what do parents understand by feedback; do they get opportunities for feedback; would they like more opportunity to give / receive feedback
 - What level of communication do parents need / want / expect; outline reasons
 - Whether communication needs currently being met
 - If not, why do parents feel they are not getting the communication they need / want; outline views
 - If so, when do parents feel they are getting the communication they need; probe for examples
- Variations between service areas - health, education, care and family support services
- Views about information and communication overall - what do they feel are key drivers of satisfaction in relation to information and communication
 - Would these drivers of satisfaction be applicable to other parents; who; outline views

SERVICES AVAILABLE

- Explore views about the **availability of services** providing support to parents in caring for their disabled child
 - Probe on:
 - What services do parents need / want / expect
 - Awareness of range of services available; are parents uncertain about what's available / entitlements
 - Perceptions of service availability
 - lack of available services / support; reasons - funding, local authority variations
 - sufficient availability of services / support; outline views

- Variations between service areas - health, education, care and family support services
- Views about service availability overall - what do they feel are key drivers of satisfaction in relation to service availability
 - o Would these drivers of satisfaction be applicable to other parents; who; outline views

Overall views / factors underpinning satisfaction
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NOTE TO RESEARCHER: Use the 'journey map' from Section 3 as a visual aid for this section and a means of identifying key factors affecting satisfaction.

- Explore parents' **overall views** about their experiences of accessing and using services for disabled children
 - Thinking about what has been discussed, explore overall views about services
 - o Aspects of provision that parents particularly liked / valued / worked well; provide examples / outline reasons
 - o Aspects of provision that worked less well; any problems encountered; provide examples / outline reasons
 - Explore specific aspects of services affecting parents' satisfaction with their experiences; probe for elements marked above / below the 'neutral' line on the journey map (from section 3)
 - o Initial point of contact
 - o Practitioners
 - o Information
 - o Assessment
 - o Transparency
 - o Referral process
 - o Participation in decision-making
 - o Range of services available
 - o Co-ordination between services / integrated services
 - o Opportunities to feedback
 - o Other issues - accessibility; location of services; other

- Explore parents' views specific to **health, education, care and family and other support, and integrated services**
 - How do parents' views outlined above differ in relation to individual service areas - health; education; care and family support; integrated services; provide examples
 - Factors underpinning differences between service areas
 - Health services - e.g. practitioners, availability
 - Education services - e.g. relationship with school / teacher
 - Care and family support services - e.g. understanding of what constitutes 'care and family support services'; perception vs experience
 - Other - e.g. transport; housing; youth
 - Integrated services - e.g. single point of contact, information sharing, co-ordination of services
 - Explore parents' views about the availability of **specialist services** specific to health, education, care and family, and other support. Probe issues around signposting/ comprehension of what these services encompass, low levels of provision, access barriers in the following services
 - Health services - e.g. physiotherapist
 - Education services - e.g. speech and language therapy
 - Care and family support services - e.g. psychiatrist
 - Other - e.g. adapted transport; adapted housing

Closing

- Thank you very much for your time
- Incentive - As a thank you for taking part in this research, we are offering all participants a gift of £25. This will not affect any benefits they are claiming and they do not need to declare it as earnings.

7.3 Topic guide (group discussion)

Aim: To explore and build on findings from the 'Health and well-being of children and young people' survey about parents' experiences of using health, education and care and family support services for disabled children.

Specifically, this research will explore key issues highlighted by the 'Health and well-being' survey, including:

- difficulties accessing services
- poor communication and information
- lack of services available
- factors underpinning satisfaction with services

Introduction

- About the project: Follow up research to unpack findings from a survey about parents' experiences of using health, education and care and family support services for disabled children.
- BMRB independent research agency; working on behalf of the Department for Children, Schools and Families
- Purpose of the discussion (see box above)
- Recording interviews; explain recordings are only available to the research team
- Confidential - their views will be used, but not identifiable
- Duration of discussion (2 hour)

Background

- Group participants to BRIEFLY introduce themselves, including:
 - Name
 - Household composition, including number / age of children
 - Employment / hobbies
- BRIEFLY explore nature of child's disability

[Note to researcher: reiterate that discussion focuses on the experiences of parents with disabled children]

- Details of disabled child - age, type school attends
- Nature of disability; how impacts on day to day life and needs

- Briefly explore the broad range of services parents have used for help with caring for their child with a disability

[Note to researcher: Explore range of services very briefly to gain overview. Please note on flipchart and compile list with parents. The services noted will be explored in more detail in subsequent sections]

- Explore **spontaneous** details of the services parents use and receive; ask parents to ‘shout out’ range of services and note on flipchart
- **Probe on:** healthcare services, education services, care and family support services, other services, integrated services. See Box A

Box A: Services for families with disabled children

Health care services: GP/Practice nurse (at the GP surgery), Health visitor, district nurse, other community nurse, Paediatrician/other specialists, Psychologist, Physiotherapist, Speech therapist, Occupational therapist, Podiatrist/chiropract (foot specialists), Optician or eye specialist, Dentist, Dietician or nutritionist, Emergency health care, Complementary or alternative medicine practitioner

Education/early year services: Pre-school or nursery, children’s centre, home teaching, portage, private tutor, mainstream school, special school, special education unit, hospital education service, support from special needs teacher, dedicated teaching assistant/learning support assistant, educational psychologist, further education college, connexions

Care and family support services: home adaptations (ramps, lifts), respite, foster care, short breaks, help at home with care for child, care and family worker services, help within the home from an outside provider, home start or sure start, emotional support of counselling.

Other services: anything not included in the above such as services from other departments: transport; housing; youth etc.

Integrated services: key workers co-ordinating services within and across service areas; information sharing between practitioners; other examples of multi-agency working co-ordinating services around the needs of the family.

Note to researcher: Reiterate aims of research - to explore and unpack key findings from a survey conducted earlier in the year with parents of disabled children. The following issues were highlighted by parents within the survey and therefore we shall be discussing these issues today:

- Difficulties accessing services
- Poor communication and information
- Lack of services available
- Factors underpinning satisfaction with services

Accessing Services

- Explore views about **accessing services** to help care for their child with disabilities
 - Explore general views - what aspects of accessing services were positive / negative experiences; outline reasons; as necessary, probe on the following:
 - Initial point of contact (e.g. teacher, GP, other) - knowledge; expertise; understanding; attitude
 - Other practitioners (aiding or blocking access) - knowledge; expertise; understanding; attitude
 - Information received about disability / accessing services / entitlements - accessible; sufficient; appropriate; understandable
 - Information provided by parents - whether parents had to provide information about child's history / condition to different practitioners
 - Identifying relevant services - route to accessing further services; information received; discussions with practitioners
 - Assessment - whether undertaken; process of obtaining an assessment; transparency of assessment allocation / outcome; impact of completing an assessment
 - Referral - information provided about subsequent referrals; participation in decision-making; speed / timeliness of referral process
 - Speed / timeliness of accessing services - whether services can be accessed efficiently / in a timely manner
 - Transparency - whether parents are confident about how services are accessed
 - Proactive approach towards accessing services - whether parents are required to 'push' to access services
 - Views about process overall - what are the key issues (supports / difficulties) affecting experiences of accessing services
- Explore parents' views about accessing services specific to **health, education, care and family and other support and integrated services**
 - How do parents' views outlined above differ in relation to individual service areas - health; education; care and family support; integrated services; provide examples
 - Factors underpinning differences between service areas
 - Health services - e.g. support from practitioners; understanding of referral process; information provided in relation to accessing services
 - Education services - e.g. relationship with school / teacher; whether school is supportive; whether school is proactive or parents required to 'push' to access services; speed and timeliness of assessment process

- Care and family support services - e.g. understanding of what constitutes 'care and family support services'; perception vs experience; speed and timeliness of obtaining assistance
- Other services - disconnection from primary support services (health, education and care and family)
- Integrated services - e.g. single point of contact, information sharing, co-ordination of services

Information and communication

- Explore views about **information** and **communication** in relation to services to help care for their disabled child
 - Information
 - What does 'information' mean to parents - information about their child's condition; entitlements; how to access services
 - What information do parents need / want / expect; outline reasons
 - Whether information needs currently being met
 - If not, why do parents feel they are not getting the information they need / want; outline views
 - If so, when do parents feel they are getting the information they need; probe for examples
 - Communication
 - What does 'communication' mean to parents - communication with whom, about what; with parents; between professionals
 - Feedback opportunities - what do parents understand by feedback; do they get opportunities for feedback; would they like more opportunity to give/receive feedback
 - What level of communication do parents need / want / expect; outline reasons
 - Whether communication needs currently being met
 - If not, why do parents feel they are not getting the communication they need / want; outline views
 - If so, when do parents feel they are getting the communication they need; probe for examples
 - Views about information and communication overall - what do they feel are key drivers of satisfaction in relation to information and communication
 - Would these drivers of satisfaction be applicable to other parents; who; outline views

- Explore parents' views about information and communication specific to **health, education, care and family and other support and integrated services**
 - How do parents' views outlined above differ in relation to individual service areas - health; education; care and family support; integrated services; provide examples
 - Factors underpinning differences between service areas
 - Health services - e.g. information about entitlements; information about child's condition; practitioners attitude / listening to parents; inconsistent communication from different healthcare practitioners
 - Education services - e.g. information about entitlements; communication within school about child's needs; communication between school and parents about child's progress
 - Care and family support services - e.g. understanding of what constitutes 'care and family support services'; perception vs experience; information about entitlements (e.g. benefits, counselling etc); opportunities to review / feedback; communication with other practitioners
 - Other services - e.g. information about other areas of support available such as transport; youth; housing
 - Integrated services - e.g. single point of contact, information sharing, co-ordination of services

Services Available

- Explore views about the **availability of services** providing support to parents in caring for their disabled child
 - Probe on:
 - What services do parents need / want / expect
 - Awareness of range of services available; transparency of service availability; are parents uncertain about what's available / entitlements;
 - Perceptions of current service availability
 - i. lack of available services / support; reasons - funding, local authority variations
 - ii. sufficient availability of services / support; outline views
 - Views about service availability overall - what do they feel are key drivers of satisfaction in relation to service availability
 - Would these drivers of satisfaction be applicable to other parents; who; outline views

- Explore parents' views about service availability specific to **health, education, care and family and other support, and integrated services**
 - How do parents' views outlined above differ in relation to individual service areas - health; education; care and family support; integrated services; provide examples
 - Factors underpinning differences between service areas
 - Health services - e.g. any specific services that are not available; areas where parents resorted to private care; perceptions of variations to healthcare services provision
 - Education services - e.g. areas where children require more support than is currently available; where children's needs are not being met; role of schools in accessing services
 - Care and family support services - e.g. understanding of what constitutes 'care and family support services'; perception vs experience; areas where children require more support than is currently available; where children's needs are not being met
 - Other services - regularly used services not forming part of primary service provision for disabled children (Health, education and care and family);
 - Integrated services - e.g. single point of contact, information sharing, co-ordination of services

Overall views / factors underpinning satisfaction
--

- Explore parents' **overall views** about their experiences of accessing and using services for disabled children
 - Thinking about what has been discussed, explore overall views about services
 - Aspects of provision that parents particularly liked / valued / worked well; provide examples / outline reasons
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 - Initial point of contact
 - Practitioners
 - Information
 - Assessment
 - Transparency

- Referral process
- Participation in decision-making
- Range of services available
- Co-ordination between services / integrated services
- Opportunities to feedback
- Other issues - accessibility; location of services; other
- Explore parents' views specific to **health, education, care and family and other support, and integrated services**
 - How do parents' views outlined above differ in relation to individual service areas - health; education; care and family support; integrated services; provide examples
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 - Health services - e.g. physiotherapist
 - Education services - e.g. speech and language therapy
 - Care and family support services - e.g. psychiatrist
 - Other - e.g. adapted transport; adapted housing

Closing

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