Parental Experience of Services for Disabled Children

Qualitative Research

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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. 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 Social Research was commissioned to undertake customer insight research with parents of disabled children. The research study aimed to explore parents' experiences and views of the range of services they use and receive in relation to their disabled child, with a particular focus on understanding what factors underpin and influence experiences and ultimately affect satisfaction. The research was qualitative in nature and included a total of nine workshops (each comprising 12 parents), one in each of the nine government regions across England. 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 of parent, and ethnicity.

Details of services

When questioned about services used, parents generally required further explanation regarding what constituted a 'service'. Specialist healthcare services tended to be at the forefront of parents' minds when they considered the term 'service'. However, with probing, a wide range of health, social and education services were identified.

Experiences of accessing services focused on the initial point of contact, which tended to be either a teacher or GP. Experience of the initial contact varied and was generally influenced by a number of factors including: the knowledge and approach of the professional; the type of disability; and the age of the child. Following referral to relevant services by the initial contact, parents often described having to wait a long time for an appointment with a specialist and this was identified as being particularly problematic.

Once access was gained, services were generally viewed favourably and considered to be of a good standard. However, inconsistencies in service delivery were noted and these were felt to result from problems experienced either directly with the professionals providing the service, such as levels of knowledge, understanding and approachability, or with the service infrastructure more broadly, such as the speed and timeliness of receiving services.

Experiences of multi-agency working were limited. However where it had existed, effective joined-up working was said to be underpinned by good communication between practitioners, and practical considerations, such as services being located 'under one roof'.

'Core Offer' issues

Despite experiencing difficulties unpacking the specific terms, parents acknowledged the importance of all five elements of the 'Core Offer': information, transparency, assessment, participation and feedback.

- **Information** - parents' views about information related to two broad areas: their experiences of accessing information; and their views about the content of the information once received. Parents felt there was a lack of information provided to them at the initial stage of accessing services and this prompted them to adopt a pro-active approach to gathering information. Parents sought information on a range of issues, including their child's disability, the range of services available to them, and details of financial entitlements. Attitudes towards the information gathered tended to relate to how easy it was to understand and how tailored it was to an individual's needs. Information was often criticised for being too general and confusing in terms of the complexity of the language used and the format in which it was presented.

- **Transparency** - participants found 'transparency' a difficult concept to grasp. There was a sense that professionals were not always as forthcoming as they could be and this was based on parents' experiences of 'gaps in information' and remaining uncertainty in relation to specific issues such as the range of services and support available, expectations for service delivery, and the allocation of services.

- **Assessments** - the term 'assessment' was not universally understood by participants, with given examples of assessments ranging from specific assessments associated with identifying service needs, such as obtaining a Statement of Special Educational Needs, through to blood tests associated with making a diagnosis in health services. Perceptions of assessments were varied, with experiences affected by the time taken to conduct the assessment, the need for repeated assessments, and the quality of assessment. Discussions tended to focus on the importance of obtaining a Statement of Special Educational Needs, as this was felt to facilitate access to services and was viewed as the primary way to 'get the ball rolling'. It was felt that ease of access to Statements was affected by the age of the child, the type of disability involved, the attitude of initial points of contact, and local resource restrictions.

- **Participation** - parental involvement in decision-making about treatment, care and support varied considerably across the different sectors. In particular, parents described having minimal involvement in healthcare decisions and relatively more involvement in the education services. In order to ensure access to critical information and services, parents said they had to take a pro-active approach when dealing with services and this was said to add to the difficulties they faced. As might be expected, children's involvement in their treatment, care and support varied according to age. There was an overwhelming view that children and young people should be more actively engaged in decision-making across all services.

- **Feedback** - awareness of specific complaints procedures was generally limited across all service areas. However, parents were aware they could contact their teacher, GP or social worker to receive advice and information about making a complaint about other services. Mixed views were expressed about the complaints procedure by those who had experience of making a complaint. A verbal complaint was considered to be easier than completing a form, which was regarded as more time consuming and 'stressful'. A lack of communication during the complaint process was also felt to make the complaint procedure more problematic, requiring parents to 'chase up' progress. Parents expressed a tendency to avoid making complaints due to the associated stress and the potentially negative effect on current services.

Factors underpinning satisfaction

A wide range of factors were identified as driving satisfaction with services, and these primarily related to experiences of accessing services, service practitioners, and service delivery:

- Experiences of **accessing services** were affected by the knowledge of the initial point of contact, the information provided by professionals, the speed and timeliness of referrals, and perceived inconsistencies in service allocation.

- Parents' views of **service practitioners** were underpinned by practitioners' knowledge of specific disabilities and the full range of services available, and the way in which they interacted with parents and children. Favourable experiences included professionals adopting a friendly, open, non-judgemental style and communicating with both children and parents.

- Experiences of **service delivery** were affected by the degree of involvement parents felt they had in decision making, the extent to which services were responsive to the needs of their child, and the co-ordination of services.

Recommendations

Building on participants' views and experiences, a number of recommendations were identified with the aim of improving services. These could be grouped into three broad areas - practical issues, personal support, and professional support.

- **Practical issues** - broad areas of improvement were identified in relation to the consistency and speed of assessments and referrals; tailoring services to the needs of children and their families; and requiring practitioners to communicate effectively with families.

- **Personal Support** - parents' satisfaction with services was strongly associated with perceptions of feeling supported throughout the process. Suggestions aimed at improving personal support for parents included improving information provision; increasing practitioners' engagement with parents and children; and improving co-ordination between services.

- **Professional support** - recommendations were also proposed in relation to professional support provided by services and practitioners, including improving practitioners' awareness of children's disabilities; knowledge of procedures for accessing the full range of available services; and improving communication between practitioners and families.

1   Introduction

BMRB was commissioned by the Department for Children, Schools and Families to undertake qualitative customer insight research with parents of disabled children aged 0-19 years. This report outlines findings from an initial phase of the research exploring parents' experiences and views of the range of services they use in relation to their disabled child. Further research is planned to take place following a quantitative survey of parents, in order to explore and unpack survey findings.

1.1   Policy context

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. 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 to make up the Core Offer: information, transparency, assessment, participation and feedback.

1.2   Research objectives

Overall this research study aims to explore parents' experiences and views of the range of services they use in relation to their disabled child, with a particular focus on understanding what factors underpin and influence experiences and ultimately impact on satisfaction. Specifically, the research aimed to explore:

- Details of the services used and received, including services delivered in a multi-agency way;

- Experiences and views of the services used and received, including a consideration of what works well and any problems encountered;

- Factors underpinning experiences and views, considering what affects satisfaction and drives dissatisfaction;

- Impact of experiences on parents and families; and

- Recommendations for change and improvement.

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

1.3 Research methodology

The research was wholly qualitative in nature and comprised a total of nine workshops with parents of disabled children aged 0-19. The workshops took place in each of the nine government regions and comprised approximately 12 parents in each group. Participants were selected using purposive sampling to reflect a range of characteristics, including:

- Age of the child (spread across early years, primary age, secondary age, post 16);

- Socio-economic grade of the parents (including ABC1 and C2DE);

- Nature of child's disability (including a range of disabilities)[2];

- Gender of parent (including male and female participants);

- Ethnicity (including a mix of ethnicity).

Eight of the workshops were organised according to the age of the child and the socio-economic grade of the parents, and included a mix of the remaining variables. In addition, one workshop was conducted with a sample of Black, Asian and Minority Ethnic participants, including a mix of all other variables (see group table below).

Group 1: North West	Group 2: South West	Group 3 : London
Early years	*Primary age*	*Secondary age*
ABC1	*ABC1*	*ABC1*
Mixed Gender	*Mixed Gender*	*Mixed Gender*
Mixed Ethnicity	*Mixed Ethnicity*	*Mixed Ethnicity*
Mix of Disability	*Mix of Disability*	*Mix of Disability*
Group 4: North East	**Group 5: Yorkshire**	**Group 6: East Midlands**
Post 16	*Early years*	*Primary age*
ABC1	*C2DE*	*C2DE*
Mixed Gender	*Mixed Gender*	*Mixed Gender*
Mixed Ethnicity	*Mixed Ethnicity*	*Mixed Ethnicity*
Mix of Disability	*Mix of Disability*	*Mix of Disability*
Group 7: East of England	**Group 8: South East**	**Group 9: West Midlands**
Secondary age	*Post 16*	*BME group*
C2DE	*C2DE*	*Mixed Age*
Mixed Gender	*Mixed Gender*	*Mixed SEG*
Mixed Ethnicity	*Mixed Ethnicity*	*Mixed Gender*
Mix of Disability	*Mix of Disability*	*Mix of Disability*

A breakdown of the quotas achieved across all workshops, as well as a description of the methods adopted for recruitment and analysis, can be found in appendix 1.
It is important to note the scope and limitations of this research study. Importantly, this workshop approach was designed to provide a broad understanding of parents' experiences

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[2] 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

of services, including parents of children with a range of disabilities and also considering issues across education, health care and social care services. The research is therefore broad in coverage and does not aim to draw out detailed insights in relation to individual stories; rather the study simply highlights variations noted by service area and personal characteristics where these occur. Furthermore, while the sample is recruited to reflect the quotas set (which means the sample would reflect a range of parents) it is unlikely to include the most disengaged parents, who would be unlikely to take part in research without being targeted specifically for this purpose.

1.4 Report outline

The next section of this report, **section two**, outlines the range of services used by participants and their experiences in terms of access, delivery and multi-agency working. **Section three** explores participants' experiences specifically in relation to the five elements of the AHDC 'Core Offer'. **Section four** focuses on the key drivers underpinning parents' satisfaction with services. Finally, **section five** reflects on the findings, considering the broader conclusions that can be drawn from the research and parents' recommendations for an ideal service.

2   Details of services

This section outlines details of the services used and received by participants in relation to their disabled child/ren. Specifically, it considers the range of services used and outlines experiences in relation to access, service delivery and multi-agency working.

2.1   Range of services identified

Parents identified a wide range of services that they had accessed in relation to their disabled children. Spontaneous responses tended to focus on specific healthcare services, such as, speech therapists, physiotherapists, and psychologists, with services relating to social care and education services being highlighted following probing. It should be noted that even after probing, the range of services mentioned within social care and education was considerably narrower than for healthcare services. The full range of services noted is outlined below in relation to each of the broad service areas - health, social care and education - and services that work across these areas (see table below).

- *Health services* - The range of health services identified by participants included both primary and secondary care services. Primary care services included GPs, pharmacists and opticians. Secondary care services were more wide ranging and included both broad services, such as health visitors, hospitals, and counsellors, as well as more specialist professionals, such as speech therapists, physiotherapists and psychiatrists.

- *Social care services* - Services associated with social care included a mix of local and centrally funded services, including social workers, respite care and home help, and financial support, such as Disability Living Allowance, Carer's Allowance, and government grants for equipment and home adjustments. Participants also identified a large number of voluntary organisations providing 'social' services. These ranged from local organisations offering support to parents of children with special needs and disabilities, to national support and campaigning organisations.

- *Education services* - Education services consisted of services provided both within and outside the school setting. Services provided in school included relatively generic support, such as teachers, school nurses, and classroom support, in addition to more specialised services, such as SENCOs, behavioural support and specialist schools. Out of school services consisted of portage, outreach teams, Connexions and child development centres.

- *Multi-agency services* - In addition to specific areas of support, participants identified a number of services providing multi-agency support. Specifically, participants mentioned initiatives such as Child Development Centres and Parent Partnership Officers, in addition to a number of local voluntary organisations, as examples of services that attempted to bridge traditional divisions of support, acting as a facilitator or go-between to ensure families received a broad range of required support. Notwithstanding this, experience of joined up services was limited.

Services highlighted are outlined fully in the table below:

Health care services	Social care services	Education services	Multi-agency services
• GP • Pharmacist • Optician • Health visitor • Community nurse • Speech therapist • Occupational therapist • Paediatrician • Dermatologist • Psychiatrist • Dietician • Physiotherapist • Surgeons • Consultants	• 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)	• School nurse • Head teacher • Classroom support • School behavioural classes • Special Educational Needs Co-ordinators (SENCO) • Connexions • Outreach team • Educational psychologists • Visual impairment teaching team	• Parent Partnership Officers • Child Development Centres • Children and Adolescent Mental Health Services (CAMHS)

2.2 Understanding of 'services'

Within the workshops, parents were asked to spontaneously outline the services they had used in relation to their child's disability. This approach allowed tentative insights to be drawn in relation to participants' understanding of what constitute a 'service'. Importantly, parents often found it difficult to identify 'services' used, and further clarification was often required in order to explain what was meant by the term 'service' before parents were able to list those received. This lack of spontaneous understanding in relation to the term has potential implications for how parents would answer more structured questions where this term was used.

As noted above, health services tended to be the first mentioned by participants. In particular, participants primarily referred to specialist healthcare services, such as speech therapists and psychologists, and required greater thought or prompting to identify services in other areas, such as education and social care. It can therefore be inferred that these specialist healthcare services tended to be at the forefront of parents' mind when they considered the term 'services'. There are a number of potential explanations for this, although we would need to consider this area more fully to draw more concrete conclusions. Possible explanations include:

- **Specialist healthcare services are viewed as a priority by parents of disabled children.** Ongoing dependence on specialist health professionals to manage or treat their child/ren's condition may push these services to the forefront of parents' minds, ahead of more mainstream or lower impact services.

- **Specialist healthcare services are more closely associated with parents'
  understanding of what a service entails compared to other support.** Perceptions of
  specialist health professionals as relatively exceptional or formal compared to other
  services, may lead parents to more easily associate this provision with the term
  'services', ahead of more mainstream or 'usual' services.

Moving beyond spontaneous thoughts, the ultimate list of services identified by participants
revealed a number of distinctions. These included not only different service areas, such as
health, education, social care and multi-agency services, but also a mix of service type.
Examples of different types of services included: local and national services; public, private
and voluntary services; physical, psychological and financial support; as well as generic and
specialist services. This mix reveals not only the wide range of services used by parents of
disabled children, but also the breadth of participants' interpretations of what constitutes a
'service'.

2.3   Accessing services

Parents described limited points of contact when initially accessing services. Doctors and
teachers were commonly cited as the main points of contact through which other services
were accessed and as a consequence these professionals were often said to be the first to
identify or diagnose a condition and were the main route through which other services were
accessed.

In addition to these official points of contact, parents also described accessing services
through word of mouth and informal contacts, such as family, friends and colleagues.
Informal networking with other parents of children with similar conditions was a valuable
source for finding out about available services. However, direct access to services via these
methods tended to involve informal support services, such as local support groups or
information and advice services, while more formal health, education and social services
required referral via the official contacts outlined above.

Parents' experiences of the initial contact varied and this was found to have been
underpinned by the knowledge of the professional, the type of disability, and the age of the
child. Details of this are outlined in the following sections.

Parents identified the **knowledge of the professional** as a key factor impacting on their
experiences of the initial stage of accessing services. Parents expected frontline
professionals to recognise and understand their child's disability sufficiently to be able to
identify and refer them onto relevant services. Experiences of delays in receiving diagnoses
or referrals, or parents identifying relevant services independent of this initial contact were
felt to be evidence of professionals having insufficient knowledge to adequately support
families in accessing services.

> *"It just seems that these people [doctors] haven't got the knowledge to do the job. You
> know, they're helpful, they really want to help, but they just don't seem to have the
> knowledge behind them to direct you to the next position."*
> [Male participant, East of England, C2DE, child 11-15]

The **type of disability** was said to be another factor affecting parents' experiences of
accessing services at this initial stage of contact. Parents were often of the view that certain
disabilities were easier to diagnose and this was felt to have impacted on how easy it had
been to gain access to services. There was evidence of parents 'struggling' to gain an
accurate diagnosis in the case of disabilities described as being less identifiable, for
example, non-physical disabilities such as psychological or mental health issues and this
was felt to have impinged on the ease with which parents were referred to relevant services.

"If somebody's disability is physical, you get a lot of empathy and a lot of understanding. If it's not and it consists of emotional, behavioural and other things, mental health things, you tend not to get the support or feel that you can even access the support." [Female participant, North East, ABC1, child 16-19]

The **age of the child** at the point of diagnosis was also seen to affect the ease with which services were accessed. Specifically, for children diagnosed with conditions at birth or in their early years, accessing additional services was felt to be relatively straightforward. In part this was due to perceptions of services operating as a 'conveyor belt', progressing from one stage to another. In contrast, for children diagnosed at later stages, it was often perceived as being more difficult to identify the appropriate level of support. In addition, parents expressed concerns about age restrictions placed on certain services and the impact this had on their child's ability to access them. Specifically, they highlighted the cut off of DLA aged 18, the end of support from certain special schools after age 16 and also age limits often put on local voluntary services.

Following referral to relevant services by the initial contact, parents often described having to wait a long time for an appointment with a specialist and this was identified as being particularly problematic within health services. Parents felt that they were initiated into the system by being referred to relevant services but then left for long periods of time before they were actually able to proceed, which was said to be frustrating.

"I think you can sometimes be put into a system and then get left for months."
[Female participant, London, ABC1, child 11-15]

2.4 Service delivery

Once access was gained, services were generally viewed favourably and considered to be of a good standard. Parents highlighted a number of support services they felt epitomised these favourable experiences and it was the advice and support received from these services that impacted on their opinion. The specific services mentioned included: Portage Workers supporting families with pre-school children and Connexions and mentoring schemes providing advice and support for older children.

However, inconsistencies in service delivery were noted and these were felt to result from problems experienced either directly with the professionals providing the service, or with the service infrastructure more broadly.

2.4.1 Approach of professional

In relation to professionals, parents identified weak areas of service delivery arising from **lack of knowledge and understanding** of children's disabilities. This was particularly evident within education services, where parents commented on a lack of understanding about disabilities in mainstream schools. Parents felt that teachers' lack of understanding of how to manage and support children with disabilities led to misunderstandings and inadequate services. For example, a parent described how her son, who suffered from cerebral palsy, had been repeatedly told off for fidgeting when he found it difficult to sit still due to his condition.

"When they were in Reception and Year one, a lot of the time they spent on the carpet with their legs crossed, well of course his muscles were obviously tighter than anybody else's so he used to fidget. And, you know, if I went to parents' evening it was, 'he's a lovely little boy but always fidgets'… They thought he was just a wriggler but it obviously wasn't." [Female participant, South West, ABC1, child 5-10]

Parents also identified varying experiences of professionals' knowledge and understanding in relation to social care services. In particular, high turnover of social workers was said to have resulted in parents experiencing a range of professionals of varying skills and competencies, which were often underpinned by how pro-active and willing they were to help. These experiences strengthened parents' views that it was simply 'down to luck' as to whether you were assigned to a professional who was helpful and knowledgeable.

> *"If [the social worker] is good she will make those calls for you, get you support, contact professionals, pass on your concerns, get them to ring you, but they don't all have the knowledge or experience."*
> [Female participant, West Midlands, mixed SEG, child mixed age][3]

Parents' experiences of service delivery were also strongly associated with the **'approachability' of the professionals** they encountered. Approachability was defined as comprising a passion for service delivery, demonstrating a genuine interest and desire to care for children, respecting parents and being open and non-judgemental. Professionals were felt to demonstrate respect for parents by listening to their views and acknowledging the efforts they made to care for and support their child. For example, one parent appreciated the comments of a physiotherapist who 'praised' her efforts of undertaking extensive exercises with her child.

Professionals adopting an open and non-judgemental stance were highly valued by parents as supporting effective service delivery. In particular, parents highlighted examples of professionals acknowledging their lack of knowledge about specific issues rather than providing inaccurate or incomplete information. In contrast, where parents felt they were unable to trust professionals or felt they were being judged in some way, experiences of service delivery were felt to be less adequate. Importantly, where professionals were perceived as being judgemental, parents suggested they were less likely to turn to them for support.

> *"She [social worker] said to me quite honestly well I don't know, but I can find out for you and you don't mind if somebody tells you that, you know, if they get back to you it's amazing"* [Female participant, North East, ABC1, child 16-19]

2.4.2 Service infrastructure

In addition to parents' experiences of professionals, service delivery was also assessed according to basic **service delivery issues**, such as the speed and timeliness of receiving services, the availability of support and the openness with which this was communicated. Speed and timeliness of receiving services was an issue for parents across all services but especially in relation to healthcare services. Waiting lists to see consultants and specialists were felt to be long and parents expressed concerns at the implications of delays on their child/ren's development.

> *"I feel a lot of the services even if they do refer you, the waiting lists are very, very long. When they say the waiting list is three months it could be up to six to nine months, and then you don't get another one until a year later. If your child is 18 months and you get an appointment when they are 2, by that time you have dealt with it in your own way, you need the support when your child is 1 or 12 months, not when they are two and a half."* [Female participant, West Midlands, mixed SEG, child mixed age]

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[3] Mixed SEG refers to mixed social economic grade

More generally parents were concerned about the overall **availability of services**, and this specifically related to concerns about limited resources affecting waiting lists and appointment times. Once again, healthcare services were highlighted as having limited access to qualified and trained professionals, such as occupational and speech therapists. Resource limitations were felt to impact on the amount of time healthcare professionals could spend with children, therefore affecting the level of support they received.

Parents of secondary school age children and above were also concerned about the **availability of support** decreasing as children grew older. This group of parents were worried that their child would be 'forgotten' once they were no longer officially considered to be 'a child'.

> *"What worries me is I've only got 22 months and then my son is 16 and then no one will care about him at all will they."*
> [Female participant, East of England, C2DE, child 11-15]

These views were repeated by parents of older children for whom certain services had been withdrawn when the child reached 16 or 18 (as previously outlined in section 2.3). The withdrawal of services was often described as being emotional by parents, as described in the following example:

> *"My son goes to a summer play scheme and they run it at Easter. It's for kids with severe learning disabilities and he came back with a box of chocolates and card and I was saying it is not his birthday! You know, it was a goodbye card and I burst into tears… Nobody had warned us that was his last trip."*
> [Female participant, North East, ABC1, 16-19]

2.5   Multi-agency working

Parents outlined their experiences of using services in conjunction with other services, including examples of multi-agency working both across and within the broad service areas of health, education and social services. A variety of factors were seen to underpin parents' experiences of multi-agency working, including communication, practical considerations, and key worker involvement.

Communication was identified as a significant factor affecting parents' experiences, both in terms of communication between services and communication with parents. Where joined up working was felt to be effective, communication tended to be highlighted as a key reason underpinning its success. The connexions service was cited as a good example of a service that made links between different organisations and individuals and communicated with them effectively.

> *"[Connexions] are fantastic. They interact with the head of year and the head of year, they'll phone me. I found the communication was superb."*
> [Female participant, London, ABC1, child 11-15]

A perceived lack of communication between services resulted in parents having to act as a link between services, interacting with each service separately and passing on information between professionals. This was compounded in situations where professionals were seen to have a lack of knowledge and information about other services.

> *"It's exactly like this room. If you're a parent with your child on that table, your educational welfare officer, your psychologist, your paediatrician, they're all around the edge and you've got a parent in the middle and none of these people talk to each other and all you do is you ring each one up like that all the way around."*
> [Female participant, South West, ABC1, child 5-10]

Parents also described situations where they felt services were communicating with each other but not with them. As a result, parents felt removed from the 'information loop' and ultimately excluded from opportunities to participate in decision-making.

> *"They don't take any notice of what you're saying. It tends to be that, you know, we'll listen to the SENCO, we'll listen to the head, we'll listen to the speech therapist."*
> [Female participant, Yorkshire, C2DE, child 0-4]

On a practical level, having all services 'under one roof' was felt to improve the ease and efficiency of multi-agency working. Children's hospitals were felt to be good examples of parents being able to interact with a range of professionals in one site. In particular, Great Ormond Street Hospital was highlighted as an 'amazing' example of education and health services effectively working together, with teachers and doctors providing a combined service to children in one site.

> *"You've got the physio, the bone specialist and it's all referred on, it's all in one area, so basically everything feeds in and you don't need to move from that hospital."*
> [Female participant, Yorkshire, C2DE, child 0-4]

Participants had only limited experience of key workers. However, where they were used, parents found them useful in ensuring a co-ordinated service existed between professionals. For example, one parent highlighted the effectiveness of their key worker in organising education and social care professionals to come together for an annual review meeting. Yet parents felt this model was equally constrained by concerns raised in relation to individual services, specifically concerning the knowledge, attitude and continuity of practitioners involved in the process.

3 'Core Offer' issues

This section explores parents' experiences of services (as outlined in the previous chapter) in relation to the five elements of the Aiming High for Disabled Children 'Core Offer': information, transparency, assessment, participation and feedback.

3.1 Information

Disabled children and their families able to access appropriate information at every stage of their child's life.[4]

Overall, parents' views about information related to two broad areas: their experiences of accessing information; and their views about the content of the information once received. Each of these areas is explored below.

Accessing information

In general, parents felt there was a lack of information provided to them at the initial stage of accessing services. In particular, parents of children who had recently been diagnosed with a disability described concerns that they had not received adequate information about their child's specific disability and the services relevant to them. Information at this stage was felt to be particularly important in order to support parents to understand and come to terms with their child's disability. Parents of children with more long-standing diagnoses recalled difficulties processing information during these 'stressful' initial stages, highlighting the need for sensitive information provision.

This perceived lack of provision prompted parents to adopt pro-active approaches towards accessing information. A number of alternative methods were highlighted, including internet searches and library visits. Examples of useful information sources accessed in this way included local support groups, and websites and leaflets of relevant national charitable associations, such as the National Autistic Society.

> *"You have to do research yourself. They don't say this is out there to help you... There are things you are entitled to but for some reason they don't actually put it to you on a plate do they."* [Female participant, Birmingham, mixed SEG, child mixed age]

Information sought by parents related to a number of issues, including:

- Information about their child/ren's disability;

- The range of services available to them; and

- Details of financial entitlements. In particular, parents described a lack of confidence about their entitlement to benefits, such as Disability Living Allowance (DLA) and Carer's Allowance.

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[4] HM Treasury & DES (2007) Aiming high for disabled children: better support for families, Norwich: HMSO

In some instances parents felt that services put up unnecessary barriers by not initially being forthcoming with information about the services available. Experiences of 'stumbling across' information from informal sources, such as other parents of disabled children or local support groups, prompted further dissatisfaction with service providers as it was thought to reveal the lack of information provided via formal routes. These experiences led parents to claim that in order to receive information about relevant services, they needed to know about them in advance and specifically request information on these.

> *"You find out by accident and then once you have found out about one thing, you meet a parent who's been really proactive and sharing information and they pass it on. Whereas when you go to the hospital you go home and then you are all on your own and nobody pretty much contacts you"* [Female participant, Yorkshire, C2DE, child 0-4]

> *"You have to know the questions to ask to get the service you need"*
> [Female participant, Bristol, ABC1, child 5-11]

Views about information received

Where parents had been able to access information, satisfaction levels varied in relation to the content of the information. Importance was attached to information that was easy to understand and tailored to individual needs. Experiences of information that was either too general, comprised complex language or presented in a confusing format prompted dissatisfaction. Specific examples included information provided by doctors about medical conditions that involved technical language or dense text.

In contrast, charities and local support groups were highlighted as providing relevant information specific to certain disabilities in the form of easy to follow newsletters, websites and discussion forums. These sources were felt to be particularly helpful during the initial stages following diagnosis, offering both emotional support for parents and providing information about the range of services available. Additionally, these sources of information were valued by parents as they offered the opportunity to engage with people in similar circumstances. In particular, parents of children who had recently been diagnosed with a disability found meeting other parents going through similar situations 'reassuring' and 'supportive'.

> *"Because [charities] are often founded by people who've got children with those problems, they know how to deal with it a lot better."*
> [Female participant, East England, C2DE, child 11-15]

> *"We've come to the conclusion that those organisations, those people who have a child with a disability in their family or their immediate family, they are more sensitive, they are more understanding."* [Female participant, South East, C2DE, child 16-19]

3.2 Transparency

Levels of support for disabled children and their parents determined on a fair, understandable and transparent basis.[5]

Participants found 'transparency' a difficult concept to grasp. With nothing to compare their experiences against, parents found it difficult to judge whether professionals had been open and transparent with them during the course of their contact. However, there was a sense that professionals were not always as forthcoming as they could be, and this was based on parents' experiences of 'gaps in their information' and remaining uncertainty on certain

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[5] HM Treasury & DES (2007) Aiming high for disabled children: better support for families, Norwich: HMSO

issues. In particular, parents highlighted a number of key areas where they felt professionals were not always forthcoming and this tended to focus on the range of services and support available, expectations for service delivery, and the allocation of services.

As previously noted, details about the **range of services and support available** were a key area where parents felt they were not provided with sufficient information by professionals. Relying on ad hoc information sources, such as other parents and support groups, or stumbling across information at later stages prompted complaints about professionals either withholding or not having the knowledge to provide important information.

> *"I happened to meet someone who told me that you can get extra money to help and when I enquired about it, it was a big rigmarole because they didn't want to give it to me."* [Female participant, East of England, C2DE, child 11-15]

Having accessed services, parents also described feeling 'uncertain' about **service delivery standards**. A lack of explanation about what they could expect from specific services, such as waiting times, eligibility criteria and frequency of provision, was said to undermine parents' trust in the information they were given by professionals and also meant professionals failed to manage parents expectations. Parents noted variation in the transparency of information they were given by professionals in relation to service delivery standards as a result of liaising with a range of different staff (often said to be caused by staff turnover). Lack of continuity was particularly highlighted in relation to social workers, where participants identified high turnover of staff as undermining their confidence in the service provided.

> *"They keep changing them [social workers] and that makes it really really difficult to trust somebody."* [Female participant, North East, ABC1, child 16-19]

Parents expressed concerns about a lack of openness in relation to the **allocation of services**. Clearly parents perceived there to be a 'postcode lottery' in relation to accessing services and this was underpinned by assumptions about local funding issues driving allocation decisions. These perceptions were widespread across all workshops, with participants providing anecdotal examples of service inconsistency both within and between local areas.

> *"If you live in this area we've got funding if you live in this area we can't help you."*
> [Female participant, West Midlands, mixed SEG, child mixed age]

Although parents had not been told this explicitly, experiences of difficulties achieving a diagnosis for their child or receiving information about available services were felt to signify that professionals were deliberately withholding services due to budget constraints. These restrictions were associated across all areas of service provision, although while social care services were felt to be limited to those most in need, access to health and education services were felt to be increasingly difficult to access for children with more severe and therefore more costly, disabilities.

> *"If your child has severe problems and you want an early diagnosis, it's very, very difficult to obtain them and the reason for that is money, it's funding. The earlier they diagnose a child, the earlier they have to start providing funds to support that child. Therefore, it's in their financial interest not to diagnose the child."*
> [Female participant, South West, ABC1, child 5-10]

In spite of these perceptions, personal experiences of services being restricted due to resource constraints were exceptional. One example involved a parent having to 'fight' with both her GP and local hospital to confirm who would fund her son's medical care.

"I had my child at the hospital recently and he was prescribed some medication and then because the letter doesn't necessarily get from the hospital to the GP, the GP doesn't know they are on medication so they won't prescribe it. So your child either goes without the medication for ages, and then they are both arguing whose budget it is going to come out of. And nobody really wants to take responsibility of paying."
[Female participant, East Midlands, C2DE, child 5-11]

3.3 Assessment

Disabled children and young people receive child-centred multi-agency co-ordinated services from the point of referral through identification and assessment to delivery.[6]

The term 'assessment' was not universally understood by participants and this was encapsulated by the variety of examples provided. These examples ranged from specific assessments associated with identifying service needs, such as obtaining a Statement of Special Educational Needs, through to blood tests associated with making a diagnosis in health services and eligibility assessments for receiving financial support, such as DLA.

Despite these wide-ranging examples, the Statement of Special Educational Needs emerged as a primary area of assessment that parents were familiar with and spontaneously focused on during discussions. The importance attached to obtaining a Statement was highlighted by parents' belief that things 'only start to happen' once a Statement has been issued. Once Statements had been obtained, access to services was felt to be more straightforward; effectively it was seen as the primary way to 'get the ball rolling'.

"Then everything happens [once you obtain a Statement], you get the help, you get the medication, proper diagnosis and putting into a specialist school."
[Female participant, East of England, C2DE, child 11-15]

Perceptions of assessments were varied, with experiences affected by three broad factors: the time taken to conduct the assessment; the need for repeated assessments; and the quality of assessments. The length of time it took for an assessment to be conducted and for results to be returned was a key factor affecting parents' views of the services. In particular, the process of obtaining a SEN Statement was felt to be time consuming, delaying access to relevant services. In instances where particular specialists were replaced by new staff, the need for repeated assessments was also described as 'frustrating', drawing out an already long process and affecting parents' views of service delivery more generally. The perceived quality of assessments was also seen to affect parents' views on procedures. In particular, parents of children with long-standing diagnoses felt that assessment procedures and understanding of certain disabilities had improved the effectiveness of tests since their children had been assessed.

"It's only in the last sort of seven or eight years that they've really come up with proper testing for [autism] where you get numbers for severity. I think nowadays they're so aware of it and how to assess autistic children."
[Male participant, London, ABC1, child 11-15]

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[6] National service framework for Children, Young People and Maternity Services: Disabled Children and Young people and those with Complex Health Needs (Standard 8): marker of good practise 2

Despite these positive experiences, participants identified perceived inequalities in the way that Statements were issued. Specifically, inequalities were felt to exist in relation to the type of disability involved, the age of the child, the attitude of initial contacts, and local resource restrictions. As noted in relation to access to services more generally, the type of disability was viewed by parents as affecting the ease of obtaining a Statement. In particular, parents felt that professionals were less likely to push for statementing of children with psychological disabilities as these could be confused with behavioural issues, in contrast to more clear-cut physical disabilities.

> *"If the illness is sort of psychological, mental and you can't see what's happening to that child, people just assume that they're okay or they're just a difficult child."*
> [Female participant, North East, ABC1, child 16-19]

The attitude of the initial contact was also felt to be an influential factor affecting the ease of obtaining a Statement. In particular, schools were viewed as key gatekeepers to the process, being either supportive or unsupportive of parents trying to obtain a Statement for their child. Exceptional experiences of parents making direct applications for a child to be assessed without the support of the school were unsuccessful, with the perception of these applications being 'just put on the shelf'.

Connected to this issue, age of child was also seen as having an effect on parents' experiences of obtaining a Statement. Parents felt that younger children were more likely to be put forward for assessment. Parents who went through the Statement process at a later stage in their child's life described finding the process more complicated, Parents felt that once children reached secondary school they were seen as 'one in a thousand' and the same level of support previously provided in primary school was no longer there. Parents felt that because children had reached this level of schooling without a Statement professionals assumed they did not need one.

> *"I've been really, really lucky because when my child was at nursery, even as young as two and a half, it was his, the head of the nursery that picked up that he was quite a lot behind everybody else and they actually started the procedure for statementing, you know, prior to infant school and he actually got a Statement within the infant school, which was great so and then when he went to the junior school it went with him"*
> [Female participant, South West, ABC1, child 5-10]

Finally, perceptions of local resource restrictions were also seen to affect the ease of obtaining a Statement. Parents described assumptions of a set target of children who could be assessed in any year, with the ease of acquiring a Statement being dependent on what point in the year the application was made.

3.4 Participation

Disabled children and their families have the option to be fully involved in the way services are planned, commissioned and delivered in their area, increasing their choice and control, which may include access to a supported parents' forum.[7]

Experiences of participation in service provision are explored in terms of parent participation and child participation.

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[7] HM Treasury & DES (2007) Aiming high for disabled children: better support for families, Norwich: HMSO

Parent participation

Parental involvement in decision-making about children's treatment, care and support varied considerably by the type of service participants came into contact with. Once accessed, parents described having a minimal role in how healthcare packages were decided and administered. In general, healthcare practitioners were considered to be 'professionals who knew best' and parents were deferential and tended not to question their views. As a consequence of this parents felt that practitioners would not listen to their views. In addition, perceived resource limitations in relation to health care services meant that parents felt they should 'take what they were given' and not question professionals for fear of losing current services.

Parents felt their input in education services was more influential, and that they were able to challenge points on Statement forms and feed into targets for their child if either of these were felt to be unrealistic or require modification. Reasons for this relative influence could be explained by parents' perception of schools as more familiar and approachable domains.

> *"I would say my child will leave school with qualifications because of what I've done, not because of the system."* [Female participant, South East, C2DE, child 16-19]

Engagement was initiated by both professionals and parents; however there was a general perception that parents had to be 'proactive' in order to engage. A main area where parents felt they had to take a proactive approach was in relation to obtaining a diagnosis of their child's disability. In some cases parents felt that professionals viewed parents as 'overdramatic' or 'neurotic' when trying to get their child assessed. One parent described having to film her son's behaviour in order to persuade a doctor to diagnose his ADHD following repeated refusals.

> *"You see it all the time, they just thought I was being dramatic, they wouldn't listen to me."* [Female participant, North West, ABC1, child 0-4]

There was a feeling amongst parents that they should not have to be pro active in order to receive information and, more importantly, the services their child needed. Parents highlighted that this level of involvement was stressful and time-consuming, and an added burden to managing their child's care at home. In addition, varying levels of confidence, energy and articulacy, were felt to result in unequal service provision. For example, ABC1 parents saw themselves as relatively 'articulate', which they felt enabled them to access services more effectively than parents less able to get their point across.

> *"If you bring it across eloquently and you sit there and state your case and you don't rant and rave they have to listen."* [Female participant, London, ABC1, child 11-15]

Child participation

As to be expected, children's involvement in their treatment, care and support varied according to age. Younger children tended to participate in decisions via their parents; whilst children over the age of 16 were more likely to engage in decision-making and access services independently from their parents.

Irrespective of age, however, parents described a general sense that practitioners did not seek to actively engage with children. Examples included children not being requested at meetings about care or, where in attendance, not spoken to directly by practitioners. In situations where children's views were sought, this tended to be limited to older children over the age of 16 or to responding to direct questions rather than more interactive engagement.

"I have to ask and say, 'right, it's about him, he has got to come into this meeting. I want him here at some point so that he can tell you how he feels', but they don't like that, really they don't." [Female participant, North East, ABC1, child 16-19]

"It's talk, talk, talk to me and I say, 'he's there you know', and then they wonder why he's about to start peeling everything off the wall."
[Female participant, West Midlands, mixed SEG, child mixed age]

There was an overwhelming view across all parents that children and young people should be actively engaged in decisions about the services they use. Child participation was felt to improve quality of service provision by ensuring that services were tailored to the individual needs of the child. It also provided an indication of a 'good' practitioner, requiring a range of relevant qualities appreciated by parents. These qualities included a genuine regard for children and an ability to engage with children 'on their level', such as crouching down and looking them in the eye when they spoke to them.

3.5 Feedback

A clear and published complaints procedure for all families who are not happy with the services they are receiving[8]

Beyond participation, participants' understanding of 'feedback' was limited to formal complaints processes. There was evidence of complaints made across services and these tended to focus on the interaction between the professional and the child, specifically related to parents' perceptions of how professionals handled their child's care. For example, one parent complained to their social worker about the 'aggressive' way in which a nurse had undertaken a medical procedure on her child.

Awareness of specific complaints procedures across all service areas was generally limited. However, parents were aware they could contact their teacher, GP or social worker to receive advice and information about making a complaint about other services. In addition, parents identified a number of services that provided more specific advice about making a complaint, such as PALS (Patient Advice and Liaison Services) provided in hospitals.

For those who had made a complaint, there were mixed views about the complexity of the procedure. The actual method of making a complaint and the length of time each took was seen to affect parents' views of the procedure. A verbal complaint was considered to be easier than completing a form, which was regarded as more time consuming and 'stressful'. A lack of communication during the complaint process was also felt to make the complaint procedure more problematic, requiring parents to 'chase up' progress.

Despite these limited experiences, generally parents expressed a preference for avoiding making complaints. There were two broad reasons for this reticence: the stress associated with making a complaint; and the potentially negative effect on current services. The former point draws on parents' experiences of complaining, as noted above, which were felt to be stressful and time consuming. Parents felt they had 'struggled' to gain access to services and therefore did not have the energy to 'fight the system' any further. In addition, a feeling of vulnerability was associated with making complaints, whereby parents feared that if they did complain the level of service they received would decrease or the service would no longer be made available to them.

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[8] HM Treasury & DES (2007) Aiming high for disabled children: better support for families, Norwich: HMSO

4   Factors underpinning satisfaction

This section draws together the key factors underpinning participants' satisfaction with services. Following on from this, the impact of experiences on parents and their families is discussed.

4.1   Factors underpinning satisfaction

Parents were asked to identify factors that underpinned their satisfaction with services. A wide range of factors were identified as driving satisfaction and these could be broadly related to concerns about accessing services, practitioners, and service delivery. The importance of these drivers varied within and across workshops according to participants' individual experiences.

Accessing services: A number of factors underpinning satisfaction were identified in relation to accessing services.

- *Knowledge of initial contacts* - the knowledge of service 'gatekeepers', such as doctors and teachers, was felt to be crucial in order to efficiently identify and diagnose disabilities. Dissatisfaction arose in situations where access to services was felt to be delayed by practitioners' inadequate knowledge of disabilities and available services.

- *Information provision* - whether or not parents felt they received adequate information in the early stages of the referral process was felt to impact on their ability to access the full range of services. In general, parents were unsatisfied with information provided by official services, although appreciated information provided by support groups and charities.

- *Speed and timeliness of referrals* - the time taken for a child to be diagnosed or assessed was identified as a key factor impacting on views in relation to accessing to services. This was felt to be particularly important for younger children, where delays to accessing services were seen as having a significant impact on their development.

- *Inconsistencies in service allocation* - local service provision was identified by parents as affecting their ability to access services, in particular where resource constraints were felt to limit availability of services. Perceptions of a 'postcode lottery' on service allocation prompted dissatisfaction among parents, even where this was not based on personal experiences of services being withheld.

Service practitioners: The knowledge and approach of practitioners were identified by parents as affecting their level of satisfaction with services more generally.

- *Knowledge of practitioners* - practitioners' knowledge about specific disabilities and the full range of services available were felt to be crucial in ensuring children were able to access relevant services. This was particularly important during the early stages of the process, where parents relied upon practitioners as a main source of information.

- *Approach of practitioners* - the way in which practitioners interacted with parents and children affected the degree to which they felt supported throughout the process. Favourable experiences were underpinned by professionals adopting a friendly, open, non-judgemental style, and their ability to communicate with children and empathise with parents was seen as paramount in delivering a good service.

Service delivery: Factors affecting service delivery included parents' views about their level of involvement in decision-making, the extent to which services were responsive to the needs of their child and how services were co-ordinated.

- *Level of involvement* - the extent to which parents felt involved in decision-making around their child's care influenced their assessments of service delivery. Communication with practitioners and opportunities to provide input in meetings and reports about their child were crucial for parents to feel engaged in service delivery. The extent to which practitioners involved children in decision-making was also felt to reflect the quality of service provision.

- *Responsiveness* - the responsiveness of a service to the needs of parents and children impacted on perceptions of satisfaction, for example the degree of flexibility in selecting service options and appointment allocation. Engaging with parents and children was also felt to enhance perceptions of services being geared around the needs of the child and family, rather than treating them as 'just a name on a piece of paper'.

- *Co-ordination of services* - effective co-ordination of services was valued by parents who described experiences of having to act as the link between services or being kept 'out of the loop' altogether. Initiatives such as key workers or multi-practitioner review meetings improved parents' perceptions of joined-up service delivery.

4.2   Impact of experiences on families

The impact of experiences on parents their children and their families were widespread. In part, this reflected the different types of services they had come into contact with, such as variations between specialist healthcare provision and local support groups. However, it also reflected varying degrees of satisfaction with service delivery.

As mentioned previously, experiences of having to take a pro-active role and in some cases 'fight', to access services were felt to be time-consuming and 'stressful' for parents, which in certain cases was said to have led to health problems. This was particularly emphasised during the early stages of the process when parents were often struggling to come to terms with their child's disability. Local support groups and charities were felt to have an important impact during these early stages, providing information, support and sympathy for parents. Negotiating the diagnosis, assessment and referral process was generally felt to be demanding, but particularly in situations where parents felt unsupported or obstructed by practitioners, where they described feeling 'demoralised' and 'disempowered'.

The process of accessing services was identified as having an impact on disabled children. Experiences of delays in diagnosing conditions and accessing services were felt to be detrimental in terms of their health and educational progress and their emotional wellbeing. Less positive experiences of accessing services were also felt to place stress on family relationships, limiting the time and effort parents could give to partners and their other children. Examples provided included couples requiring counselling sessions to after finding their relationship had come under serious strain as a result of continued stress.

Once accessed, services were generally felt to have a beneficial impact on parents and their children, although this varied in situations where services were felt to be unsatisfactory. Where parents were satisfied with the services provided, associated benefits included both practical and emotional support for parents and children. In practical terms, experiences of effective care and treatment supported parents in their ability to manage their child's disability and were generally felt to improve their child's situation by ensuring they were not left behind other children. Examples of services providing practical support for both parents and children included Individual Education Programmes and various healthcare specialists.

Positive experiences of services were also felt to provide emotional support for parents and children. Parents highlighted the importance of services that supported children's social development and wellbeing. In particular, services such as, Connexions and mentoring support were viewed as providing both practical and emotional support. Also important for parents was the impact of services on their family as a whole. Short breaks and care schemes not only supported disabled children's independence, but also provided families with opportunities to rest and engage with other members of the family rather than focusing their attention on their disabled child.

5   Conclusions

Participants identified a wide range of services they had used in relation to their child's disability, revealing a number of underlying priorities and assumptions about what constitutes a 'service'. Parents' views of services focused on three broad areas: accessing services; service delivery; and multi-agency working. Experiences of accessing services varied according to practitioner knowledge, type of disability and age of child, and revealed parents' difficulties in negotiating this early stage of the process. Once accessed, services were generally viewed favourably, although inconsistencies in service delivery were noted and felt to result from problems either with the professionals providing the service or the service infrastructure more broadly. A variety of factors were seen to underpin parents' experiences of multi-agency working, including communication, the involvement of key workers, and practical considerations, such as locating related services within a single site.

Parents acknowledged the importance of all five elements of the 'Core Offer' - information, transparency, assessment, participation, and feedback - although described difficulties unpacking the specific terms. Experiences of each element were mixed, revealing both positive experiences and the need for further improvements. Perceived areas of concern included: a lack of information provided by practitioners in the early stages of the process; transparency issues relating to allocation of services and service delivery standards; inequalities in how assessments were obtained; a lack of meaningful participation between children and practitioners; and an aversion to complaining about service provision. Overall, a wide range of factors were identified as impacting on parents' satisfaction with services, including the knowledge and approach of practitioners, speed and timeliness of accessing services, the level of parental involvement in decision-making, and flexibility and co-ordination of services. In addition to impacts on satisfaction, experiences also had practical and emotional impacts on parents, their children and their families. Positive and negative impacts were identified, reflecting different types of services they had come into contact with and also varying degrees of satisfaction with service delivery.

5.1   Recommendations for change and improvement

Building on participants' views and experiences, it was possible to identify key elements underpinning their perceptions of an ideal service. These are outlined below in relation to three broad areas: practical issues; personal support; and professional support.

Practical issues

Practical issues relating to how services were accessed and delivered were highlighted as a key area for potential improvement. Broad areas of improvement were identified in relation to consistency, speed, flexibility, participation and co-ordination. Specific suggestions included:

- Ensuring approaches to assessments and diagnoses are consistent across service areas and geographical boundaries;

- Reducing the length of time between referral and receiving services, and more generally ensuring a continuous flow of appointments across multiple service areas;

- Tailoring services to the needs of children and their families by ensuring that they are involved in all stages of the process and services are delivered in a flexible way; and

- Requiring services and practitioners to communicate effectively with each other and families to ensure the package of services are co-ordinated around the needs to the child.

Personal support

Parents' satisfaction with services was strongly associated with perceptions of feeling supported throughout the process. Suggestions aimed at improving personal support for parents included:

- Improving information provision to parents about their child's disability and the services and entitlements available to them, particularly in the early stages of the process;

- Requiring practitioners to engage with parents and children by listening and responding to their views and keeping them informed at every stage of the process; and

- Improving co-ordination between services to ensure that parents were able to access relevant support, for example by assigning key workers or single points of contact who could negotiate services on parents' behalf. Moreover, parents suggested they would also benefit from support from informal sources, such as a voluntary worker, as parents suggested they would find it useful simply to have someone else there to help them negotiate the system.

Professional support

Recommendations were also proposed in relation to professional support provided by services and practitioners. These included:

- Ensuring that key points of initial contact, such as GPs and teachers, are aware of children's disabilities and procedures for accessing services;

- Requiring practitioners to be aware of the full range of associated services available to families in order to better co-ordinate service delivery;

- Improving communication between practitioners and families to ensure services are co-ordinated; and

- Requiring practitioners to be accomplished in interacting with children and parents.

Appendix

Recruitment and research methodology

The recruitment was managed by our internal field team who used 9 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 this research

Group 1: North West	Group 2: South West	Group 3 : London
Early years	*Primary age*	*Secondary age*
ABC1	*ABC1*	*ABC1*
Mixed Gender	*Mixed Gender*	*Mixed Gender*
Mixed Ethnicity	*Mixed Ethnicity*	*Mixed Ethnicity*
Mix of Disability	*Mix of Disability*	*Mix of Disability*
10 participants	12 participants	10 participants
Group 4: North East	**Group 5: Yorkshire**	**Group 6: East Midlands**
Post 16	*Early years*	*Primary age*
ABC1	*C2DE*	*C2DE*
Mixed Gender	*Mixed Gender*	*Mixed Gender*
Mixed Ethnicity	*Mixed Ethnicity*	*Mixed Ethnicity*
Mix of Disability	*Mix of Disability*	*Mix of Disability*
11 participants	11 participants	11 participants
Group 7: East of England	**Group 8: South East**	**Group 9: West Midlands**
Secondary age	*Post 16*	*BME group*
C2DE	*C2DE*	*Mixed Age*
Mixed Gender	*Mixed Gender*	*Mixed SEG*
Mixed Ethnicity	*Mixed Ethnicity*	*Mixed Gender*
Mix of Disability	*Mix of Disability*	*Mix of Disability*
9 participants	11 participants	12 participants

Achieved results for recruitment across the sample were:

- Total respondents - 97

- Males - 20; females - 77

- ABC1 - 48; C2DE - 49

- BME - 23; white - 74

Group discussions were carried out by five experienced qualitative researchers, trained in the techniques of non-directive interviewing.

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.