

# Complex Needs, Complex Challenges

A report on research into the experiences of families with deaf children with additional complex needs

Research funded by the National Deaf Children's Society and undertaken by the University of Manchester.

The report was written by Wendy McCracken and Bridget Pettitt

The University of Manchester research team were:

Wendy McCracken  
Oliver Turner

Research Leader  
Research Assistant

**NDCS is the national charity dedicated to creating a world without barriers for deaf children and young people**

ISBN no. 978-1-907814-18-1

Published by the National Deaf Children's Society © February 2011

15 Dufferin Street, London EC1Y 8UR

Tel: 020 7490 8656 (voice and text) Fax: 020 7251 5020

NDCS is a registered charity in England and Wales no. 1016532 and in Scotland no. SC040779.

<b>Contents</b>	<b>Page</b>
Executive summary	3
1. <b>Introduction and methodology</b>	9
2. <b>About of the research and the respondents</b>	10
3. <b>Parents experiences of living with a deaf child with additional complex needs</b>	13
4. <b>Accessing services: problems relating to deafness</b>	16
4.1. Delays in assessing and diagnosing hearing problems	16
4.2. Lack of access to Teacher of the Deaf	18
4.3. Overshadowing	19
4.4. Reluctance to treat deafness due to additional complex needs	21
4.5. Lack of deaf awareness amongst professionals	22
4.6. Services unable to cope with additional complex needs	23
4.7. Summary and conclusions	23
5. <b>Accessing services: general problems</b>	24
5.1. Not being listened to	24
5.2. Lack of information	25
5.3. Poorly co-ordinated services	27
5.4. Lack of continuity	29
5.5. Lack of provision	30
5.6. Problems accessing support from social care	31
5.7. Poor equipment	33
5.8. Bureaucracy and inflexibility	34
5.9. Low expectations of outcomes for children	35
5.10. School transition	36
5.11. Fighting for services	36
5.12. Summary and conclusions	39
6. <b>What helped these parents</b>	40
6.1. Pro-active services	40
6.2. Being listened to and respected by professionals	41
6.3. Being kept informed	42
6.4. Inter agency communication/ co-ordination	43
6.5. Keyworker	43
6.6. Continuity	44
6.7. Reflective practice	44
6.8. Child and family centred approach	45
6.9. Positive perspective and focusing on the long term	45
6.10. Professionals with appropriate communication skills	46
6.11. Support and information from other parents	46
6.12. Direct payments	47
6.13. Respite	47
6.14. Summary and conclusions	47
7. <b>Parents' experiences of voluntary agencies</b>	48
8. <b>Summary and conclusions</b>	50
9. <b>Recommendations</b>	53
10. <b>References</b>	60
11. <b>Appendix 1: Background – literature on deaf children with additional complex needs</b>	63
12. <b>Appendix 2: Methodology and characteristics of the sample</b>	72

13. <b>Appendix 3: Additional complex needs of children reported by participating parents/ guardians</b>	80
14. <b>Appendix 4: Organisations and agencies</b>	86

## **Acronyms**

ABR:	Auditory brainstem response
ADHD:	Attention deficit hyperactivity disorder
CP:	Cerebral palsy
DLA:	Disability living allowance
DS:	Down's syndrome
ENT:	Ear Nose and Throat specialist
ERA:	Evoked response audiometry
FAS:	Foetal alcohol syndrome
KW:	Key worker
LD:	Learning difficulties
LEA:	Local education authority
NDCS:	National Deaf Children's Society
NICU:	Neonatal Intensive Care Unit
NGO:	Non-governmental organisation
OT:	Occupational therapy/therapist
RNID:	Royal National Institute for Deaf People
SaLT:	Speech and language therapy/therapist
ToD:	Teacher of the Deaf
VI:	Visual impairment

## Executive Summary

### Deaf Children with Additional Complex Needs: Parental experiences of service delivery

*"I am so pleased that this is being researched because it is quite a neglected area for children with deafness and other needs. I think very often if they have other needs the deafness gets very much neglected, and I don't think it should be. They need a better quality of life. [parent]"*

Fifty families from across the UK, each of whom have a deaf child with additional complex needs, have taken part in the largest ever study of parental experience of services. The interviews were carried out in 2009/10.

This study is important because there is a high incidence of additional complex needs amongst deaf children. Such needs may relate to a specific syndrome, a chromosome disorder, damage sustained during pregnancy, during delivery or following trauma in the early years of life. This heterogeneous group make up an estimated 40% of the total population of deaf children, [Holden-Pitt and Diaz, 1988; Stredler-Brown and Yoshinaga-Itano, 1994; Fortnum et al. 1996]. They are the group most frequently excluded from research studies. This group raise significant challenges for both families and services because of the complexity of needs. There is anecdotal evidence that such children are both less likely to receive appropriate services and where services are received they are less than optimal.

The research was funded by the National Deaf Children's Society at the University of Manchester and was approved by the University of Manchester Ethics committee. The research is qualitative in nature, where parents were invited to tell their own stories by telephone interview. The sample is not statistically representative, as people were encouraged to volunteer. The sample did include a wide geographical spread, across the UK, the majority of participants were White British (42) seven were cross cultural and one was Bangladeshi. The children discussed ranged in age from 0 to 18 and displayed a wide range of additional complex needs, and the majority had more than one additional need.

In listening to the stories of 50 families who had a deaf child with additional complex needs a rich, detailed and unique account of experience has been provided. The term deaf children with additional complex needs as defined by parents, includes a wide variety of cognitive, physical, medical and social needs.

Although the main theme of this research is parents' experiences and access to services, parents spoke movingly of the reality of their lives and the challenges they faced. This gives an important context to their experiences of services and the impact that good, and conversely poor, services have. Despite the considerable challenges faced by families physically, emotionally, personally, a common thread was of the joy of the children themselves.

*“Well he is a lovely kid and a joy and it is everything else, it is not the disability that gets you down it is everything else. The children themselves are never the problem; it’s everything else you have to contend with really.” [39]*

Parents described a desire to enjoy a ‘normal’ lifestyle for their disabled child, siblings and themselves. The everyday experiences taken for granted by the majority contrast markedly to the challenges each day presents. Exhaustion was both emotional and physical for many parents. The strain of coping with multiple needs can make considerable demands on individuals within the family. Stress was commonly reported by parents, especially relating to interacting with services. Many parents found that services were supportive and added significantly to their child’s life and as a result of this to the family’s life. Where gaining access to services and maintaining services was problematic, and where parents had to ‘fight for services’ this caused great stress and negatively affected their family lives. The parents also described the economic impact of having a deaf child with additional complex needs, as the multiple hospital appointments, complex daily routines and often the need to advocate for support meant that full time employment was not always possible.

### **Accessing services: problems relating to deafness**

Parents faced a range of barriers to accessing appropriate services for their children relating directly to their deafness.

#### *Problems and delays in assessing hearing problems*

Parents identified problems in assessing their child’s hearing problems, and thus delays in treatment. Indeed, fourteen parents identified significant delays in both achieving a detailed audiological assessment and in being fitted with personal amplification. In some cases, parent’s own concerns were not being taken into account. In others, it was a result of audiology departments not being able to assess audiological needs. Some examples revealed professionals struggling to cope with the challenge of assessing audiological needs in children who have a complexity of needs.

#### *Access to teachers of the deaf*

This research also found that access to teachers of the deaf was very variable for this group, and in some cases was withdrawn due to their additional disabilities. One in five did not have access to a teacher of the deaf.

#### *Overshadowing*

There also was evidence that complexity of needs was masking concerns regarding hearing status. Professionals missed hearing problems as they focused on learning disabilities and attributed many of a child’s problems to this rather than poor hearing. Some professionals seemed overwhelmed by the complexity of needs, and others inferred that deafness was a minor issue that could be left until later.

#### *Denying treatment on the basis of additional complex needs*

The research also showed examples of where some interventions (in particular cochlear implants) were refused on the grounds of the child’s additional complex needs. This suggests that some professionals are poorly informed about the

potential benefits of cochlear implantation for deaf children with additional complex needs, and may as a result be discriminating against these children.

#### *Lack of deaf awareness*

Some parents also identified a lack of deaf awareness amongst the many professionals that they inevitably came into contact with. This was seen across a range of professionals, including lack of signing in schools, and amongst health professionals. Some parents found that special schools for children with learning disabilities lacked skills and knowledge of deafness, which is contrary to the expectation that deaf children with additional complex needs can take advantage of all the specialisms within such schools.

#### **Accessing services: problems relating to additional complex needs**

There was a range of problems that these parents encountered relating to their access to other services for their children which were not specific to their deafness.

#### *Not being listened to... or being informed*

Parents found that their understanding and concerns about their child were not listened to by some professionals, often leading to lack of diagnosis and treatment. They also were not always kept informed of the services their child was entitled to, or actually receiving. Lack of coordination and communication between services were highlighted, meaning that services could be delayed, opportunities missed and that there was a need for parents to endlessly repeat their case history.

#### *Lack of provision*

One of the major issues that faces services with a limited resource in respect of personnel, equipment and expertise is how to best utilise the resource. A lack of provision meant that parents had to fight to get appropriate services. This was particularly the case for social care where parents were told they did not meet the referral level. There were examples of inappropriate, poorly fitted and delayed provision of equipment.

#### *Bureaucracy and inflexibility, and low expectations*

Accessing some services was bureaucratic and some had inflexible systems. Several parents expressed concern about services having low expectations of their child and also found some professionals unwilling to discuss possible futures for their child. Transition from pre-school to school, and again from primary to secondary, presented major challenges.

#### *Poor professional practice*

There were some examples of poor professional practice where serious conditions were left undiagnosed and often only picked up by a chance encounter by other professionals. For some this was attributed to individual mistakes. However, it seems that professionals had little critical mass of experience of a 'child like this'.

#### *Fighting for services*

Many of the issues enumerated above were compounded to mean that parents had to fight for services for their children. Parents often had to challenge resource

allocation and showed considerable tenacity in seeking to ensure a service that met their needs. This was often at a personal cost. Nearly a quarter of families looked for services outside the system including for assessments, placements, equipment and specific therapies. Often this set up an adversarial relationship with services and some participants reported that services sometimes left them feeling as if they were a problem. Parents described feelings of weariness and resignation.

### **What helped these parents**

Parents described good support which was pro-active, family centred and coordinated, that recognised a child as an individual rather than a 'case'. Individuals who were available and actively listened to parents, who made practical suggestions rather than 'completing tick boxes', who actively engaged with their child, were highly valued.

#### *Being listened to, respected and informed*

Parents found it important to be listened to and respected by professionals, have their concerns treated seriously and their expertise respected and acted upon. Parents also valued being kept informed about the services available and what they were actually receiving.

#### *Coordinated services*

Parents appreciated good coordination and communication between services, for example, that referrals were made across departments appropriately. Keyworkers, who took on a majority of the administration and coordination of services, were a very positive influence.

#### *Continuity*

Continuity and stability was prized by parents as it enabled children to build a good relationship with individuals that helped in development and assessment.

#### *Flexible, reflective practice*

Flexibility of roles and individuals was also greatly appreciated, for example, ToDs taking responsibility for a child's language development. Parents also rated professionals who had a positive attitude towards their children and would discuss the longer term future options.

#### *Support from other parents*

Parents found being in contact with other parents in similar situations very helpful in terms of learning about benefits, how to get the best out of the system and having someone who understands the nature of the experience. Respite care was also very important.

### **Parents' experiences of voluntary agencies**

Parents were in contact with a considerable range of national and local voluntary agencies. Parents rated two particular features of support from charities, (i) meeting with other parents who had 'lived the experience' and (ii) practical advice. Some also provided financial assistance and grants. The majority of parents interviewed had



had direct contact with NDCS. Parents were positive about weekend activities and valued the opportunities to meet other families. NDCS as a source of information was helpful and relevant for specific information about DLA or amplification, but some parents found little else of relevance and this serves to underline a feeling of not belonging to any group. Indeed many parents did feel a sense of isolation because of the 'lack of fit' with any group, none more so than where a child has a rare syndrome. Some parents expressed surprise and a degree of frustration that national charities did not link up better.

The stories that these parents told resonate with much of what is known in the literature about access to services for parents of disabled children. They face innumerable hurdles along the way so coordinated services with joint working are key. It is vital that even when economic considerations are at the fore of service provision, these very vulnerable children are provided with the services that they are entitled to.

Overall, parents had a range of different experiences of accessing services; some excellent and some poor. Some examples indicated that professionals lacked the experience of dealing with children with this level of complexity. This lack of experience, compounded by lack of training, meant that in some areas professionals appeared to be unable to offer appropriate baseline services to this group of deaf children.

## **Recommendations**

Full and detailed recommendations can be seen in the body of the report. The key recommendations from the report are summarised here.

### **Access to services**

Many of the issues identified by the parents of deaf children with additional complex needs in the current study are those that would be identified by many parents of children with additional complex needs but without the deaf dimension.

However, the issues are compounded in the current study because of the deafness. A deaf child with additional complex needs requires access to the full range of services available to children who have the disability of deafness alone, and also full access to the full range of services appropriate to their additional complex needs.

### ***Recommendation***

All specialist services for deaf children should be available to those deaf children with additional complex needs and no child should be denied access to a service for reason of his/her additional complex needs, whether this be, e.g. assessment by an audiology service; consideration of suitability for a cochlear implant or specific types of hearing aids.

### ***Recommendation***

All specialist services available to children with additional complex needs should be accessible to deaf children with additional complex needs and staff within these services should have deaf awareness training.

### ***Recommendation***

All children who are deaf, whether or not they have additional complex needs, should have a level of access to a qualified Teacher of the Deaf that is appropriate to their level of deafness and not determined by any other needs they may have, or by the educational establishment they attend.

## **Effective and timely assessments**

### ***Recommendation***

All deaf children with additional complex needs should have rigorous initial assessments

## **Effective and coordinated service provision**

Deaf children with additional complex needs require access to a range of professionals in a coordinated multi agency way, with a pro-active service and access to a keyworker.

## **Information to parents**

Parents of deaf children with additional complex needs require appropriate, timely and clear information about statutory and voluntary services, the services their child is receiving and their progress.

## **Education**

Deaf children with additional complex needs require access to appropriate, well-supported education placements with their hearing needs addressed, with a focus on improved outcomes and transitions.

## **Social care**

Deaf children with additional complex needs and their families require a range of support from social care, particularly respite. Parents should be informed about their entitlements and available provision.

## **Voluntary organisations**

Voluntary agencies can provide a vital support role to deaf children with additional complex needs and their families. There is an urgent need to coordinate responses between different disability organisations to recognise and address the needs for these children.

## 1. Introduction and methodology

This research arose directly from Family Weekends for families with deaf children with additional complex needs organised by the National Deaf Children's Society. It was the stories of these families that motivated research that would explore in detail their experience of services. To date, studies of deaf children with additional complex needs have tended to focus on either prevalence or aetiology with a much smaller number focusing on access to services. A detailed literature review is to be found in appendix 1.

Many different terms are used to define children with more than one disability – in this study we refer to deaf children with additional complex needs. Having additional complex needs is more than the sum of the parts of the various single disabilities, however, as there is a complex interrelationship between the different impairments, and their implications. Research suggests that up to 40% of deaf children have additional health, social or education needs (Holden-Pitt and Diaz, 1988; Stredler-Brown and Yoshinaga-Itano, 1994; Fortnum et al. 1996). Children with autistic spectrum disorder, and learning difficulties are more likely to have a hearing loss (for more details on the prevalence of additional complex needs, see appendix 1), and research suggests that this hearing loss is often not diagnosed. For individuals with learning disabilities, there is evidence of 'overshadowing' where more attention is placed on the learning disability and less on the child's hearing loss. Research from the USA also identified that professionals were unaware of the importance of hearing aids for children with additional complex needs compared with those for a child with deafness alone (Tharpe, 2000).

Research on accessing services for deaf children with additional complex needs, whilst limited, does describe a range of problems that parents and children have faced (see appendix 1 for a more detailed description of this research). Parents report the process of accessing and then dealing with services as being the most challenging aspect of having a disabled child. Parents described feeling isolated, noting a lack of planning among services for additional complex needs of children with disabilities, lack of adequate facilities, lack of professional training in learning disabilities, and the lack of co-ordination of appointments (Krauss, et al 2008, Middleton, (1998)). These experiences of parents of disabled children tend to be magnified due to the frequent hospital appointments they have to attend with their child (Wharton et al, 2005). Previous research by this author (McCracken, in Bamford et al, 2000) with parents of deaf children with additional complex needs identified a lack of satisfaction and confidence in the audiology assessments of their children and considered the testers inexperienced in additional complex needs. Research also suggests that ethnic minority parents are likely to encounter even more significant challenges when attempting to access services, facing questions about citizenship rights, an unwillingness of services to accommodate those not speaking English, stereotypes of 'caring extended families' (Ahman, 2000, Chamba, 1999).

In the UK developments and initiatives designed to improve the access of disabled people to services have been enacted, such as the Disability Discrimination Act of 1995 which made it unlawful for disabled people to be discriminated against by service providers on the grounds of their disability. The Every Child Matters agenda

in England and 'Getting it right for every child' in Scotland were government initiatives designed to ensure a national framework for cooperation across the spectrum of children's services (education, health, social care etc.). These programmes have a number of aims and intended outcomes and are designed around the ideal of increased inter-agency working. Within this initiative is the Aiming High for Disabled Children Programme, launched in May 2007, which has increased services for disabled children. Various initiatives and policies have emphasised the need for more co-ordinated approaches, with keyworkers, and increased parent voice (see appendix 1 for more details). It is hoped that the findings of this research can usefully inform the future developments of these or similar policies and initiatives.

## **2. About the research and the respondents**

This research project aimed to provide a voice for the parents of deaf children with additional complex needs who experience service delivery and can provide a unique and so far unheard perspective. The methodological approach was a qualitative one, based on narrative. Parents were invited to tell their own stories, in a telephone interview, in their own words within the broad framework of their experience of service delivery. Information packs were sent out to over 400 families throughout the UK using a variety of approaches (see appendix 2 for more information) to invite them to participate. The definition of additional complex needs was deliberately made as wide and inclusive as possible. The research was overseen by the University of Manchester Ethics Committee [Autumn 2008]. A total of 51 families were recruited, this included one family who contacted the study after the final data collection point.

The sample of parents was voluntary and therefore will not be statistically representative of all parents of deaf children with additional complex needs. The participants came from England, Scotland, Wales and Northern Ireland. Interviewees were offered to be interviewed face to face, but all opted to be interviewed by phone. Thirty-nine were with the mother alone, five with the father alone, and in one case both parents separately, one grandparent and where children were being adopted, the legal guardian was interviewed. In one case a mother who was interviewed had two deaf children with additional complex needs. For simplicity all parents and guardians will be called parents within this study, recognising that they are either biological parents, grandparents of adoptive parents. Forty-two families were white British, seven were cross cultural and one was Bangladeshi. All parents/caregivers were 'hearing'.

The socio-economic status of participants was also determined through their postcode. There were disproportionately high numbers of participants in the higher income bracket, however there is representation across the range of socio-economic groups. The majority of families had one family member in employment (20 full time, 7 part time), five had no employed members and just over ten had both parents working. There was a wide range of ages of the children, covering 0-18.

The children in the sample displayed a wide range of additional complex needs (see appendix 1 for details). The reported conditions have been grouped to illustrate the key areas of need – some children had multiple needs across all categories.

**Table 3: Additional complex needs reported as groups**

Cognitive	21
Physical	25
Sensory [other than deaf]	11
Specific Speech and Language needs	10
Behavioural/emotional	11
Medical	12
Named syndrome	14

The majority of children had two hearing aids: a few had one hearing aid; several had cochlear implants, some of whom had hearing aids and one child used a softband bone conduction aid. Five had no hearing aids. Just under half the sample (22) were in special schools for children with severe learning disabilities, 9 were in mainstream schools, 8 were in schools for the deaf or mainstream school with deaf resource base, 5 were in nursery, and 5 were pre-school age (at home). One was in a school for the blind, one was in a specialist MSI unit.

Each child and family have their individual strengths and needs making it important that services recognise this diversity and ensure approaches accommodate it. Understanding of the variety of needs and the heterogeneity encompassed by the term deaf with additional complex needs is illustrated by these two examples:

### **Child A**

A ten year old male was identified as having a severe hearing loss at 7 months and was fitted bilaterally with hearing aids. He has Down's syndrome and currently attends a special school for children with LD. He is visited by a teacher of the deaf (ToD) monthly and communicates through a combination of speech and Makaton.

### **Child B**

This four year old child spent the first 16 months of life in the Neonatal Intensive Care Unit and was identified as profoundly deaf at 7 months. This child was also identified as having CHARGE syndrome; and has cardiomyopathy, is registered blind, with optic nerve atrophy, has got a tracheotomy and a gastrostomy and has never fed orally. This child also has hypertonia, no semi-circular canals, facial palsy, dysphasia, sleep apnoea and an obstructive airway. After two years of investigation during assessment for a CI, with all the parental concern and expectation this brought with it, a CAT scan revealed this child had no auditory nerves. This child requires 24/7 care.

The following sections of the report describe from the parents' own perspectives the reality of living with a deaf child with additional complex needs; the issues about accessing services – especially the problems relating directly to deafness, other problems, and then what helped these parents. Their experiences of the voluntary services were explored and then recommendations were made drawing on the research. More detailed context to the report, description of the methodology and the sample can be found in the appendices.

### 3. Parents' experiences of living with a deaf child with additional complex needs

*"I am so pleased that this is being researched because it is quite a neglected area for children with deafness and other needs. I think very often if they have other needs the deafness gets very much neglected, and I don't think it should be. They need a better quality of life."*[19]

The sample of 50 parents represented a wide range of settings, family circumstances and child need. Parents' perspectives varied as did the importance of individual strands but key issues clearly arose that were common themes. The very large data set has meant that the themes are complex and elaborated. Parents were keen to identify good practice but also to highlight the challenges and complexities they had experienced in obtaining and working with a variety of service providers in Health, Education, Social Services and with the Voluntary sector.

Although the main theme of this research is parents' experiences and access to services, parents spoke movingly of the reality of their lives and the challenges they faced. This gives an important context to their experiences of services and the impact that good, and conversely, poor services have. Despite the considerable challenges faced by families physically, emotionally, personally, a common thread was of the joy of the children themselves.

*"Well he is a lovely kid and a joy and it is everything else, it is not the disability that gets you down it is everything else. The children themselves are never the problem; it's everything else you have to contend with really."*[39]

Parents described the desire to enjoy a 'normal' lifestyle for their disabled child, their siblings and themselves. The everyday experiences taken for granted by the majority contrast markedly to the challenges each day presents. Simple activities of going to the shop, going for a coffee, meeting friends, were all potentially compromised.

*"Unfortunately, in certain environments, i.e. a restaurant or whatever, not many people really want him to go up to them and tug at their tail, or whatever, and ask 'What is your name? What number house do you live at?' I just want to walk around with a sign on my head saying, 'He really isn't being naughty, he has autism and he is deaf and he is curious.'"*[13]

Commenting on the experience of parenting one parent sums up the experience that many parents referred to, where the balance between providing appropriate input and parenting becomes blurred:

*"On the other hand, when I did finally get some appointments at one time I had five different programmes at home; with her physio, some occupational therapy, Teacher of the Deaf stuff, etc. but it's tough when you are a parent. It's hard to do the programme without being a parent as well... because you feel nothing is having fun together, there is always an ulterior motive, and all that is exhausting."*[23]

Exhaustion was both emotional and physical for many parents. The strain of coping with multiple needs can make considerable demands on individuals within the family:

*“My day normally starts at 4.30 and 5am every morning. Her medical needs, she needs lots of suction and drainage and different things, but the morning starts early then you have to get all the equipment ready and everything that needs to go with her oxygen and everything else...”[14]*

Such demanding routines not only influence the individual but also potentially affect the whole family. Parents were keen to try to protect the experience of the siblings. When multiple services are involved, children require medical intervention and a range of specialised equipment ‘normality’ can be difficult to achieve. Siblings may be keen to be involved in the daily care routines of their brother or sister but parents are concerned this may detract from their own childhood experiences. Parents actively sought as ‘normal’ experience of life as possible but also recognise this was not easy to achieve.

*“He loves going outside as well, there are quite a lot of children where we live and they come and say hello to him and whatever, but he can’t go out on his own. If he’s on his bike then I could push him around and be outside with him, you know a bike that has the callipers in to hold his legs because that is where he has low muscle tone.”[21]*

Parents were very aware that inclusive practice can be very beneficial, many actively sought such settings but were aware that this can raise significant challenges. For some families this offered a real opportunity for a child to be part of the local community. The benefits, both education and social, have to be weighed against the drawbacks.

*“He went to a mainstream nursery 2 days a week. He loved it because the kids were lovely with him but he was just the class mascot really, they didn’t do anything useful with him. He had a great time socially.”[39]*

This theme illustrates how the families of deaf children with additional complex needs seek a life which is similar to that of their peers and which is not shaped completely by the challenges presented by their child’s needs.

Stress was commonly reported by the parents. All parents recognise that children bring with them a range of positive emotions but that some events are stressful and drain emotional resources. Interestingly, such stress was described specifically as relating to accessing or interacting with services, rather than individual children.

Many parents found that services were supportive and added significantly to their child’s life and as a result to that of their family. Where gaining access to services and maintaining services was problematic, and where parents had to ‘fight for services’ this caused great stress and negatively affected the life of their family,



especially that of their siblings. This is expanded on in sections 4 and 5 below. One parent poignantly described her sense of sorrow that her own feelings regarding her deaf child negatively affected her other child's life:

*"He knows when I am stressed and I will end up shouting at him all the way home from school, and he said 'Mummy' very calmly – he was the adult because I would be in absolute tears, he said 'The reason you are shouting at me is because you are stressed about [child]' and he was quite right, and he was 11 years old and the adult and I was the child, and that isn't good to bring up your child like that."*[32]

The parents also described the economic impact of having a deaf child with additional complex needs. Multiple hospital appointments together with complex daily routines make significant demands on family members. This, coupled with the need in many cases to advocate for support, can mean that full time employment for both parents is not possible, with obvious financial implications.

*"There is no money coming in and we did have two salaries, full time salaries paying the mortgage, holidays and our lifestyle, now there is nothing. We are in the process of applying for some benefit help, which we have never done before, it is all a bit daunting."*[10]

Families with children who had severe physical needs were often faced with the prospect of raising the finances to purchase equipment that was identified as appropriate for their child. Parents fundraised to get a range of equipment, including a wheelchair, adapted bicycle, chair, orthopaedic bed and in this case for a chair to allow the mother to safely get the child in and out of the car.

*"I am having difficulty getting her into the car, because it is a bit of a step up and she is getting heavier and we went for an assessment at the driving place and they were suggesting a swivel seat for the car, but those seats are £4000 and again they are not provided so we either have to try and get a grant from somewhere or fund it ourselves."*[35]

As one parent who is currently unemployed and whose wife is training to be a midwife explained, the impact is more than simply financial;

*"Different people's opinions on how disability pays you well – it's quite insulting to hear this because first of all I would swap everything just to have a healthy child, and both [parents] have worked from leaving school to [child] coming along, so we have both worked for 25 years since I left school, so for 25 years I have never been out of work. [Spouse] has been the same, 20 years of working."*[14]

The following sections describe the experiences the parents had of accessing services. The first section describes some of the problems relating directly to the children's hearing, the second section describes problems relating to the children's other needs. These problems would be common to hearing children with additional complex needs and disabilities. The last section describes aspects of services that worked well for parents.

## 4. Accessing services: problems relating to deafness

*“You just think I didn’t know this world existed before I stepped into it, I feel like Alice in Wonderland sometimes fallen through some door, some weird door that you didn’t know was there.”[39]*

Parents were keen to highlight good practice with services, especially praising particular individual practitioners, and where services were well co-ordinated and pro-active. However, there were many examples where parents encountered significant problems with services which had huge impacts on the wellbeing of their children and their own experience. Parents’ comments and reflections on service provision can be categorised as either a system issue or an issue with an individual practitioner. One key issue was the very complex and, in some cases, confusing and contradictory, information which had massive implications for their child and their family.

### 4.1 Delays in assessing and diagnosing hearing problems

Parents described delays in assessing their child’s hearing problems. In fact, fourteen parents identified a significant delay in being identified. Although just under a third was diagnosed by 6 months, a similar number again were not diagnosed until they were at least a year old. These delays meant that time was wasted and opportunities that should have been available to their children were lost. Sometimes this delay was related to their additional disabilities.

#### **Example 1: Delays in assessing hearing problems**

A deafblind child who did not have a hearing loss identified until 18 months and despite the mother querying his vision before she left the maternity hospital and being told not to worry about it. It also includes two children who went through over 24 months of assessment for cochlear implantation and when finally agreed a CAT scan proved both had either no auditory nerve or the auditory nerve was too thin and was unsuitable.

One child had reached his third birthday when parents realised nothing was happening. Despite multiple assessments he failed to receive any therapeutic support. When the parents questioned this they were advised to wait until he was five to begin the statementing process. These parents reported discovering the extent of his disability when he consistently missed milestones. This increased their anxiety and sense of frustration.

One child aged four at the time of the research who was referred through the NHSP was still being assessed at the time of the research and as yet did not have hearing aids.

A further parent had their child diagnosed with a hearing problem, but this was then withdrawn, and then eventually was diagnosed as being severely deaf and issued with hearing aids.

Another child who had been referred by the NHSP to audiology services was not

identified as profoundly deaf until two years of age.

Parents acknowledged that the identification of need was not a simple task that could necessarily be easily achieved, and they recognised that complexity brings challenges. Several parents reported that audiology departments could not assess their child's hearing which was attributed to their additional disabilities. In some cases this was due to children's behaviour, in others it was because they did not have the motor skills to indicate if they had heard something. For example, in one case a family were sent home twice from tests where they were unable to get a result, which meant that the deafness was diagnosed late.

Despite concerns, and access to Health Visitor, Portage and hospital staff, a child born in 2004, when Newborn Hearing Screening was being introduced in England, had to wait two years to be identified as being profoundly deaf.

*"A lot of things that I was worried about – like she wasn't responding to her name, she wouldn't look when there was a noise, so I had concerns very early on. I had concerns when she was only 2 weeks old that there was something wrong with her hearing, but she passed her test at 3 weeks, although we have been told that there wasn't necessarily a problem. Because she passed that test we stopped worrying, but as she started getting older when she should have been starting to sit up and to speak she wasn't doing anything at all. At 15 months basically the hospital never picked up on it...Well, she was diagnosed just before she was 2, so there was a process of going for hearing tests and waiting, and obviously because she was so young as well, trying to get her to respond, and she did have glue ear as well so they needed to find out whether she was sensori-neural deaf or whether it was just the glue ear – that is when they did the test at the hospital and they found she was profoundly deaf."*[44]

One mother felt delays in diagnosis of hearing loss was a result of discrimination against her child because he had additional complex needs. Her child waited a year for a hearing assessment.

*"Yes, it is a long time and I feel very much as though a lot of it has to do with the fact that he had probably quite severe learning disabilities as well and I don't think it was a priority. That's how it felt to me at the time."*[20]

Parents described audiology departments not being able to cope with children's behaviour, or to adapt tests for children with additional complex needs. One parent described an audiologist getting frustrated with the child for not being able to focus on the task.[23] Where children presented challenges to audiologists it was often the child who was seen as problematic rather than the lack of flexibility in audiological practice.

*“Just as he has got older, because obviously he is physically disabled, the tests that they try and do to find out how much he can hear aren’t suitable for what he can do. I mean they ask him to try and knock blocks off a tray when he hears something. ...he is just not capable of doing that...it has been mentioned and they say that is the only test that they can do.”[45]*

*“I think they did try testing him, some doctors did manage to actually do a hearing test with him, but I think his behaviour was always the issue, and there have been times when the doctors haven’t been able to do a hearing test on him, because of his behaviour. [...] I think it was more about the services being there, but not being able to cope with his behaviour.”[22]*

Parents were clear that they did not want to be falsely reassured when information was lacking or inconclusive. For example:

*“The audiologist said she thought he might have glue ear and could we go back a few months later, so we went back a few months later and then she said he had atresia of his ear canals and she had suspected that before but because she wasn’t sure she thought she would leave it for a while, so then he was 2 and he was given his ordinary hearing aids.”[41]*

This child was taken to a private practitioner who suggested that a bone conduction aid would be appropriate and this was fitted successfully. Another family, who had a delayed referral, also found further delays in fitting hearing aids as they were moving away, so the audiology service decided not to proceed.

*“And then when we were referred to the audiology department at the hospital, at that point we were within months of coming up to Scotland so they were very much saying ‘Well, you are going back to Scotland so we won’t do anything.’ I think we said she will be getting better hearing aids, which she did there, so they wouldn’t bother giving her any here.”[1]*

## **4.2 Lack of access to Teacher of the Deaf (ToD)**

Many parents were concerned that having a deaf child with additional complex needs frequently meant the deafness was seen as a minor aspect of the child’s needs. Parents were clear that deafness had a ‘multiplier’ effect, and that children should have a right to regular access to a qualified Teacher of the Deaf. All the children in the study were by definition deaf. The majority of the children received support from ToD weekly or more often (27). However, twelve children (just over a fifth) had no contact with a Teacher of the Deaf (see appendix 2). Half of these were at special schools for people with learning difficulties, and one was in a school for the blind. This includes three children with a cochlear implant. Many parents were also unsure about what support was given, or were aware that the support was simply monitoring. For some it appears that their additional complex needs were the reason for losing this resource. One deaf child once identified as having learning disabilities

automatically lost access to a ToD. This loss of service was not reported to the family.

*"...it was learning difficulties, I only found this out recently that they removed our teacher of the deaf and he now falls into another category so now he is under the learning difficulties category. So we have lost our teacher of the deaf and I only found out by accident."*[38]

For example, parents of a severely deaf child who uses hearing aids on a daily basis noted:

*"I don't understand how they justify it. How they can say well you are deaf with no learning disabilities so you can have a qualified teacher of the deaf, but if you have learning disabilities which are quite severe you don't get a teacher of the deaf."*[20]

Another child with Down's syndrome is reported to have had no support from a ToD. He no longer wears his aids and his mother is concerned by his "mumbly indistinct speech"[19]. One parent felt that the child had access to the ToD denied because his/her child wouldn't wear his hearing aids.[30]

Some parents commented that access to ToD appeared to be poorer in schools for children with severe learning disabilities than in mainstream schools.

*"The children who don't have additional needs who will be in a school, maybe a mainstream school, seem to have so much more support from a teacher of the deaf while they are in school, than a child who is in an SLD school. It is still the same service. The teacher of the deaf just seems to be non-existent. It is as if it is not important – the fact that the child is deaf is just not important unless they are in a school, a mainstream school, where they don't have additional needs. They have better support regarding their hearing problems."*[29]

Some parents described having to 'fight' to get adequate ToD support for their child, even when it is in their statement. One parent felt that the age related cut off points for deaf children without learning disabilities did not take into account the slower learning of a child with special needs, who therefore needed some input for longer.[35]

For some parents, challenges in accessing services were very considerable. This was despite formal statements of educational need being in place.

*"We are waiting and his statement says that he is supposed to be seen by an advisory teacher of the deaf every 6 weeks. In fact, she has seen him once in the last 2 years, which is horrendous."*[20]

There were some concerns that teachers of the deaf would not have appropriate specialist training in the area of deaf children with additional complex needs.

### 4.3 Overshadowing

Overshadowing is a term that refers to situations where one need is seen as the major aspect of an individual whilst other equally important aspects of that individual are ignored. Complexity of needs was reported to mask concern regarding hearing status in many children. Parents were very keen to ensure that their child was seen as a whole rather than treated as a collection of special needs. Many parents felt that professionals were test focused rather than child focused and that this diminished the value of tests, thus a child may be asked to perform play audiometry using a physical response which is not possible because of motor difficulties. Parents were also keen that their child was not placed in a 'box' by professionals.

*"Yes, they don't look at a person with additional needs. They focus on his...what they see as a disability and focus on that."*[40]

Parents clearly identified instances where they felt that professionals missed hearing problems as they focused on learning disabilities and attributed many of the child's problems to this, rather than poor hearing.

*"I think the problem was, maybe because he had Down's syndrome with severe learning difficulties, a lot of the things that may have been picked up were missed because they were put down to his learning disability. I now feel that more could have been done to help him had his hearing been looked after properly."*[26]

This had meant for some that their hearing problems had not been diagnosed until late.

*"I think because she wasn't responding normally I just think they put it down [to the fact that] she had learning difficulties and so it wasn't really picked up until she was 2 and a half how bad it was."*[5]

For some families the opposite was true, deafness was seen as the focus of interest with other needs ignored.

*"B isn't a typical deaf child. He is a child with extra needs and he is probably the only deaf child within the school who has extra needs and I think for them it was a learning thing, and I think at the beginning I used to get quite angry that they used to think he is deaf and that is all the problem was and everything was based around his deafness."* [11]

Some schools whilst providing appropriate services for deaf children, failed to take on board additional learning needs.

*"Although they are used to providing a curriculum for deaf children, I think it was hard for them with his additional needs, and it just didn't work. They weren't very good with him."*[26]

Using labels worked in some cases to provide access to services but in other cases actively prevented children having easy access to services.

#### **4.4 Reluctance to treat deafness due to additional complex needs**

Parents identified that once deafness was diagnosed, some aspects of treatment were not being pursued due to their child's other needs. Examples were given of cochlear implants, other operations and some types of hearing aids.

Whilst some children with additional complex needs had access to cochlear implants, other parents reported that their children were refused access simply on the grounds they had additional complex needs.

*"Due to his other problems, (visual impairment, CP and LD)...and they didn't think a cochlear implant would help."*[11]

*"The audiologist had said that even if G was a child that could hear and speak she would still have problems with communication with her learning difficulties, so she didn't think that a cochlear implant would be an awful lot of help."*[33]

One parent described having to justify the merits of having a cochlear implant.

*"We were grilled, what is the point of it, she is not going to get much further, global developmental delay, how do you know it is going to work?"*[32]

*"I originally asked about cochlear implants at school, and it was actually 'no chance' and they said they can't do that because of his other needs. I pushed again not long ago and we actually went through the whole process going for a cochlear implant, and one of the first things she said to me is why didn't you come to see us years ago, he is perfect."*[40]

A parent seeking advice on cochlear implantation for her deafblind son was frustrated by the time wasted in attending assessments. He was successfully implanted at another centre, the fourth centre this parent had approached. She explains:

*"I went up there, did some tests and said they would have to do an MRI scan. We went up to that and I said look if you can't do it, because I really thought they couldn't do it due to the ossification, don't drag me all the way up here to just smile at me and say no thank you and go away. Tell me over the phone. No, I got the phone call, go up there for an appointment, and I thought God they are going to do it, and I sat there and, to put it in a nutshell, they said because of his severe learning disabilities they weren't prepared to do it. I came away so angry because that appointment lasted 10 minutes and we had spent all that time travelling."*[8]

One child was refused a bone anchored hearing aid because the parent could not guarantee their child would wear it 8 hours per day.

*“I thought they were discriminating against him because of his autism and not getting to the root of whether [the procedure] would be a problem for him, not just presuming it would be because he had autism.”[41]*

Another example was given of a child who kept taking his hearing aids out, but the audiologist was reluctant to fit in-the-ear hearing aids.

*“We listened to other parents about what sort of hearing aids they had, and they mentioned in-the-ear hearing aids, so we went back to [audiologist] and he put us off and said no that wouldn’t be suitable for him [...] So instead it was a constant battle with [audiologist]. We asked him again about the hearing aids and we think he was putting us off because of the price, and he reluctantly said he would make us one. [...] He has no problems wearing them.”[27]*

#### **4.5 Lack of deaf awareness amongst professionals**

Lack of deaf awareness amongst many professionals was a major concern for parents. Parents were surprised that many professionals had no deaf awareness and failed to demonstrate a commonsense approach of making communication clear, visual and accessible and using parent/carer skills to moderate their own.

Examples of this were identified across a wide range of professionals including in schools, health services and voluntary agencies, and even within specialist disability services. Some staff in schools were seen to be making basic mistakes relating to their children’s deafness:

*“I got very, very cross about it because I felt that the staff and the teaching staff in the school were making really, really basic mistakes like they would frequently sit [child] facing the window so, apart from the fact that because of his visual problems he is terribly drawn to light and he would gaze out of the window all the time, but on top of that even if someone was signing it is very difficult to see someone if you haven’t got good vision, it is hard to see someone signing if it is against his line of vision.”[20]*

Indeed even in special schools for children with learning disabilities, some parents expressed exasperation of the lack of deaf awareness.

*“[They] have very limited knowledge of deaf children...and even basic things like making sure that they always knew that he was looking at them when they were speaking. They had to be told all this, they didn’t know this automatically...and what sort of pitch to keep the hearing aids at and how the noise in the classroom would affect him when he was wearing hearing aids. There was just so much that the ordinary teacher in the classroom didn’t know.”[29]*

*“The school was asking my advice, they were asking about his communication and where did I suggest they start looking on websites and could I recommend any*



*books. Although parents are experts about their own children you are not really expected to be advising like that.”[41]*

Access to BSL was in some cases limited by staff training. Parents also identified a lack of signing and alternative communication skills amongst support staff working with their children, especially in schools. For example, one parent described that carers looking after his daughter could not communicate with her, as they only received basic signing classes once a month. Others described teachers not feeling confident to sign.

Children with additional complex needs often have considerable contact with health professionals. A clear issue for some medical staff, educational psychologists and a physiotherapist was that they had no deaf awareness and had no understanding of alternative communications. Examples were given of them shouting at children or relying on parents to communicate.

*“You think they are professionals, they have been in that job for 30 years, know he’s deaf, they have his records and they’re shouting at him from behind to turn around to try and get his attention. It is not very smart, is it?”[12]*

*“When he goes into hospital they don’t really know much about the deafness side, so they try and talk to him like a normal child. There is no signing or anything like that. They just take it that he is just a cerebral palsy child and not a deaf child as well.”[45]*

One parent was shocked that the speech and language therapist was not trained in working with deaf children.

#### **4.6 Services unable to cope with additional complex needs**

In section 2.1 above there were some examples where audiology departments struggled to diagnose hearing loss which was attributed to additional complex needs. There were additional examples of services for deaf children which were unable to accommodate additional complex needs. These included problems of physical access to their local audiology department which was not wheelchair accessible, and they had to get assistance to carry the wheelchair up the stairs.[34] Another parent described a hearing impairment unit in a school which refused to accept a child unless she was toilet trained.[36] This was also raised to some extent with the voluntary services (see section 5 below).

A number of parents were asked to explain medical interventions to their deaf child with additional complex needs. Even when this was well beyond the comprehension of the individual child hospital, staff were persistent.

#### **4.7 Summary and conclusions**

Parents faced a range of barriers to accessing appropriate services for their children relating directly to their deafness. Parents identified problems in assessing their

child's hearing problems, and thus delays in treatment. In some cases, parents' own concerns were being rejected, in others it was due to audiology departments not being able to make assessments due to additional disabilities. Some examples revealed an apparent lack of skills and knowledge of professionals in dealing with these problems, and to find alternative ways of diagnosis.

This research also found that access to teachers of the deaf was very variable for this group, and in some cases was withdrawn due to their additional disabilities. This implies that there is a lack of coherent policy regarding the rights of a deaf child with additional complex needs to have access to a ToD.

There also was evidence that complexity of needs was masking concerns regarding hearing status. Professionals missed hearing problems as they focused on learning disabilities and attributed many of a child's problems to this rather than poor hearing. Some parents identified that professionals seemed overwhelmed by the complexity of needs, and others inferred that deafness was a minor issue that could be left until later.

The research also showed examples of where some interventions (in particular cochlear implants) were refused on the grounds of the child's additional complex needs. This suggests that some professionals are poorly informed about the potential benefits of cochlear implantation for deaf children with additional complex needs, and may as a result be discriminating against these children. Some parents also identified a lack of deaf awareness amongst the many professionals that they inevitably came into contact with. This was seen across a range of professionals, including lack of signing in schools, and health professionals. Some parents found that special schools for children with additional complex needs also did not have good skills and knowledge of deafness, which is contrary to the expectation that deaf children with additional complex needs can take advantage of all the specialisms within such schools.

## **5. Accessing services: general problems**

Section 4 described problems parents faced in accessing services relating to their child's deafness. There was also a range of problems that these parents encountered relating to their access to other services for their children.

### **5.1 Not being listened to**

Many of the parents had developed considerable expertise not only in knowing their own child but in complex medical procedures, in working with the system of provision and benefits. Parents had often researched their child's needs as far as possible. Despite this some professionals were insensitive to the expertise available and failed to recognise or capitalise on this. Parents gave examples of where their insight, often of a serious issue, was ignored. Indeed, in this study separate parent reports included one child with hydrocephalus, one with a life threatening heart condition, one child who was deafblind, one child who was having multiple seizures and one

child who had a brain abscess, all of which were missed by experienced professionals significantly delaying appropriate service provision.

### **Example 2: Parental concerns being ignored**

One mother reported her concern that her son was having multiple seizures and was dismissed initially until a scan proved her to be correct. In another case, a family had to fight to get anyone to believe them when trying to secure medical treatment for their daughter. She was discharged three times and was at the point of slipping into a coma when she was admitted. She was self injuring, a sure sign to the parents that she was in severe distress; this was explained away by a doctor as “typical of children like this”. The parents in desperation retrieved photographs and video evidence of their daughter’s normal behaviour to show the doctor. It was only at this point that their daughter was referred for a scan that revealed a brain abscess.

Another parent describes how everyone reassured her she had a typically developing child and how, despite her serious misgivings, she was labelled as a neurotic mother. Her son was diagnosed later with a severe hearing loss, autism and LD.[41] Another mother, described as ‘over anxious’ when she queried her child’s sensory status, was told at 18 months old he was deafblind.[40]

Where a parent felt they were not being listened to or taken seriously it set up considerable animosity and a sense of isolation. Some parents described feeling guilty for not having insisted on following up their instincts, and in some described feeling humiliated and made to feel the centre of the problem.

*“When you first start off in it you just take their word for everything, you aren’t the expert, they are, so she was referred because her head was really large and she had really bad head lag, and he basically just measured our heads, mine and my husband’s, and he said your heads are larger than average so perhaps it is just a family of large heads – that is actually what he said to us. But once she was under the children’s hospital...the neurosurgeon...they were absolutely appalled that nothing had been done for that length of time.”[44]*

## **5.2 Lack of information**

Some parents also felt they were not being kept informed about what support their child received, especially when they were in school. Parents were unsure of both who was seeing their child and what programmes of support were being provided. Whilst recognising that needs change and that by school entry, their child may no longer need such intensive support, it was the lack of communication by services that concerned parents. As the vast majority of children in this study do not have well

established communication, parents found it particularly hard to know who they had seen during the course of the day or week.

Parents also described not being aware of available services, especially their entitlements to social care services (see in section 5.6 below). Parents described relying on other parents or voluntary organisations to find out about their entitlements.

Some parents were also frustrated about not being given information and the ability to make informed choices about different communication approaches. One felt that the approach of not using signing was political rather than taking their child's needs into account, and was not necessarily the right approach for a child with additional disabilities.

*Because of [child's] additional difficulties not just the hearing loss, the X services are all going for the aural approach [...] They really discouraged signing there and they were a little bit reluctant to advocate any signing whatsoever. but when you are talking about children with cerebral palsy or any other learning difficulties it is not as clear cut as that.[...] Because of his muscles and all the things that come with cerebral palsy it is much harder for him to learn to talk[...]and certainly after starting to do Makaton it helps both me and [child] to say what he wants.[...] I think there is perhaps more of a need to be a bit more open and not so almost political about it. they should listen to the parents a bit. It takes a bit to go out there with that sort of policy and say I want some signing, because it is completely not what they stand for.[17]*

In one family's case lack of information regarding their child's needs led to a mother actively learning sign language and trying to encourage her daughter to respond only to find out that this was inappropriate, she explains:

*"instead of me trying to learn sign language – because we didn't know she was blind, I should have been cuddling her instead of constantly stimulating her and having lots of people coming in, physios, OTs, teachers for the deaf, I was unwell and wasn't sleeping and actually maybe we should have held back a little bit. I think it got initiated too early. And when we started to learn the sign language, obviously we didn't get a response, we went to the doctors and the paediatrician at 9 months and said we are learning sign language and doing everything – in a way it was causing a bit of friction at home because I was trying to learn it and my husband said she is not responding, and I said well they say it takes a hundred times or a thousand million times before a child says mum, but never realised she was blind. In a way I wish I had maybe just cuddled her, we were just desperate to do everything correctly to maximise the child's potential." [49]*

Lack of sensitivity about how and where parents received information was reported by a number of families. This example illustrates how easily this can go wrong and the effects this has on the parent:

*"whoever had sent us a letter saying that they had taken his blood out of deep freeze and found out what was wrong with him had sent it to our old address and I hadn't got that letter, but it was just a relief to know what was wrong with him. It's just that I would have preferred not to have received that news without any warning when I*

*was in work with my colleagues, so we knew what was wrong with him when he was about 5.” [41]*

Parents, whilst recognising that their child individual needs were complex, wanted an honest and informed approach to identifying needs. Parents found false reassurances unhelpful, for example

*“It took a few months for the health advisor to be comfortable that there was an issue, then they referred us .....We were sent to a clinic and the doctor tested him and said there may be a problem. Like any mother you think ‘not my child!’ and the doctor backtracked from the diagnosis, so then we went back again and the doctor then said ‘oh there is probably no issue’ and this irritated me the most. People used to say he is a male and he has selective hearing, he has just learned to tune out women sooner!”[38]*

One parent was frustrated by the lack of contact with professionals once his child entered school. This parent felt even a simple book with stickers indicating who had visited or provided therapy would be helpful.

For many parents the timing of information was important. Where information regarding opportunities was mistimed it was both frustrating and unhelpful. Such information related not only to statutory provision but to voluntary services. One parent explained:

*“[child] wanted to join the Brownies but she found it very difficult to understand what was going on but she wouldn’t stay because she couldn’t understand. She couldn’t hear in a big hall, but there is somebody who would have gone with her, if I had known about this. They do that, but I didn’t realise there was anything like that”.[5]*

### **5.3 Poorly co-ordinated services**

Lack of co-ordination and communication between services was a major frustration to some parents. Where this was the case, parents felt that the services did not look at the whole child, but rather services who only deal with their own specialism.

*Obviously he was a very complex boy, but what I would say of the services they only tend to cater and deal with their own particular area. Perhaps they should look at them as a whole rather than individual. You get involved with the service and go down that particular line until you come to a cul-de-sac and then you have to come all the way back to start again.” [26]*

Parents gave some very clear examples of system failure with files going missing, files apparently unread or so cumbersome as to make it practically impossible for someone in a busy clinic to quickly appraise themselves of a child’s needs.

As many of the families who took part in this study had children with major health conditions they spent a great deal of time in hospitals both for routine checks and for emergency care. This is emotionally demanding but parental anxiety was compounded by the need to constantly repeat their stories.

*“It’s like when you go into hospital even though they have got the notes on your child, they want to go through everything again, so you have to start the old story again, and that in itself can be quite draining.” [14]*

One family, exasperated by having to repeat their stories took a very pragmatic approach.

*“we drafted up a letter, like a check list, and we used to take some of these with us to meetings, and then one of them would say what’s wrong with him we used to give him the sheet and say that’s what’s wrong with him. It’s an A4 size sheet. They are all the bullet points on what is actually physically wrong with him, diagnosed from you experts” [12]*

Lack of co-ordination also meant there were missed opportunities to co-ordinate treatment. For example one child, who had been diagnosed with a hearing impairment at birth, took over a year to get hearing aids, in spite of frequent stays in hospital. His parent pointed out that he could have been assessed and treated whilst on site [41].

For other families it was the poor inter-agency communication which resulted in frustration. One of many comments in this area illustrates the challenge faced.

*“the procedures and the channels of communication between all these agencies, whether it’s the paediatricians or the audiologists, social services, physiotherapists, speech and language therapists – the channel of communication between them all varies between very poor to non-existent, and people look at one specific area and don’t link the box up [...]. You wouldn’t criticise any individuals it’s just the structures that link them together – that’s the key thing. They do not talk to each other, and the paper chain must be hundreds of miles long. I am sure there must be a simpler way of people talking to each other ” [4]*

An example was given where professionals, rather than working together expressed fear of ‘treading on each other’s toes’ and overstepping the boundaries, at the risk of their own role.

*She has got to be careful, and the other thing is that the speech and language therapy won’t step on the teacher of the deaf therapist’s toes, nobody will step on anyone else’s toes for fear of going outside the boundary. The teacher of the deaf at the cochlear implant dept wouldn’t in the end write anything down for the appeal even though she said verbally this is what she needs, because she said I will be struck off and I would lose my job [33]*

A number of parents felt that current rules regarding confidentiality worked against appropriate inter-agency communication. They felt this meant people were unaware of information that was directly relevant to their service delivery, and went against their child’s interest. Parents felt that they should have the right to ensure open sharing of information between relevant professions.

*“recently my daughter had major spinal surgery, spinal rods inserted in November, and I said to school and to respite care and everyone I am happy for you, if I speak*

*to you or you phone home, to tell the others how she is. What I found out was that even in the school now they are not allowed to pass this on – if the teacher hears how P is she is not allowed to tell the others, she is not allowed to tell the boss.” [49]*

At a time of multi-agency working connected by digital communication systems it was interesting to note one parent’s comments that summed up the feelings of many:

*“ I very much felt like I am the glue joining all the bits together. [37]*

#### **5.4 Lack of continuity**

Lack of continuity was also a key concern for parents, both in terms of turnover of individuals, but also affected access to services. Continuity of individual members of staff is particularly important for many of these children and some examples were given of having overwhelming changes in their support.

*“- he ended up with 10 teachers and 20 support assistants in a week – this is for a child with autism. I don’t know if you are familiar with autism but they like regularity.” [41]*

*“there were other services such as social work where they have had 4 social workers in 4 years. Whilst we don’t see them a lot now, but you need them initially for referrals for things, we need them for funding for money matters. I just found building relationships up annually was stressful because you feel like you have got to tell them your whole life story again, so that has not been ideal” [10]*

Lack of continuity also meant the threat of losing access to services:

*“You are with one person and then they move department and the whole thing just grinds to a halt, it is very frustrating.”[26]*

*“Because they [Social Workers] move on, they don’t seem to stay around for whatever reason. I know people move on from jobs or cut backs, but trying to fill the relationship we have to keep starting from scratch.” [14]*

Similarly system changes left one parent unable to contact professionals.

*“I think there has been this breakdown of contact because at our local hospital where his services are all held they have had a big restructure there too, of departments. There have been lots and lots of staff leave in the National Health Service itself, so all the phone numbers have changed and we have tried to contact them and couldn’t get through to them” [3]*

#### **5.5 Lack of provision**

Parents frequently cited problems of a lack of provision – this ranged from BSL classes, specialist equipment and access to social care services. Lack of access to ToD and other hearing related services were highlighted in section 4 above. This problem was ascribed to shortage of funding and lack of staff. Parents were mindful of financial constraints on services and felt that individual practitioners brought significant skills and benefits to their child but that the service framework limited the scope of practice because of limited finances.

*“He had an occupational therapist going to school each week and then the lady went off sick for 3 months and they didn’t send any person to cover her so he lost out, and when I phoned up last week to find out what was happening she had started back that day....now she is on her annual leave and not back until September! ..... Speech and language he hasn’t had anybody since last November and when I rang them up they thought that somebody was going out and there wasn’t.... Apparently he is getting reintroduced to a teacher of the deaf, or a teacher of the deaf goes to the school, but only once every 3 months.” [3]*

This child is profoundly deaf and has a cochlear implant, is hemiplegic, has learning disabilities, epilepsy and behavioural problems. There has been no assessment of needs by Social Care services and only intermittent access to other support services, despite clearly identified physical, sensory and communication needs.

Despite a range of additional complex needs many parents were told that they did not meet the referral level to access Social Worker support.

Some parents had the energy and persistence to challenge resource allocation, taking the initiative and opening dialogue with managers. They recognised this was not something that all parents would want or be able to do.

*“I have found this piece of kit on the internet I want to trial this, but they say we haven’t got a budget, but I said I will phone the rep myself and get them to come out and have a look, and you have just got to be persistent really. I think a lot of families just haven’t got the energy to do it, or they are not articulate enough to do it, and they are really disadvantaged. If you can’t do that then you do just get fobbed off.” [39]*

In some situations, families resorted to looking outside standard NHS provision. For example in this case a family sought a basic audiological service independently, that should have been provided by the NHS.

*“when I realised that the NHS hadn’t even done a proper hearing assessment. In the private audiology clinic they spent 2 hours testing him compared to 10 minutes. That’s when I realised that things could probably have been better and the private audiologist said she was prepared to refer [child] to a specialist centre and to suggest that he had bone anchored hearing aid, bone conduction hearing aid. That’s when I realised we could by-pass them. When I got him to a specialist, and they said ‘gosh, of course he should have had bone conduction hearing aids, he has a conductive hearing loss’. I said yes I know.[20]*



The complexity of some children's needs means that family can face major challenges in seeking pre-school/nursery provision as in this case:

*There are no facilities for [child] for that, none whatsoever. We couldn't get anybody to take her from a care point of view. Some special needs children do go to nurseries where they have additional training, but there is nowhere in this area that would accept her. Even for the 6 week holidays, because I am a student midwife and I work shifts. My husband is left with 4 children and obviously [child] takes up all his time. We have tried the health authority and we have not been very successful at all. [10]*

In some cases deafness was identified and appropriate services were received but once other needs became apparent services to meet those needs were missing.

*"from my own kid's point of view and also from seeing other families of the children, not so much with a hearing impairment but with additional complex needs like autism, you know once they are diagnosed often there is actually very little in terms of services, so they are given a diagnosis and the parents are left. There is not very much support, but in terms of deaf children there is a lot of help." [1]*

Some families were forced to challenge and advocate for services that they had a right to expect would be readily available, and some went outside the NHS to get such provision (see section 5.12 below).

## **5.6 Problems accessing support from social care.**

Where children were identified with a complexity of needs some parents received support from a Social Worker and where this was the case levels of satisfaction were characteristically high (see section 4 below, especially 4.1 and 4.9). In our sample, 18 parents made no mention of support from a social worker. Of those who did report active involvement with Social Workers 15 reported a negative experience, 10 were positive and 7 were neutral. Of those who did not receive any support, this appeared to be unrelated to the degree of complexity of needs of individual children. Some examples where families have not had support from a Social worker are given below:

- a child who is deaf, autistic and hypotonic
- a profoundly deaf child with hemiplegia, severe intellectual disability and reported behavioural problems
- an adopted child with foetal alcohol syndrome, who had meningitis, is profoundly deaf with severe intellectual disabilities
- a child reported to have cerebral palsy, be blind, being peg fed, with severe intellectual disabilities, profoundly deaf and epileptic
- global developmental delay, tube fed, hypertonia and profoundly deaf

Some parents were simply unaware of which services were statutory.

*“We found out earlier this year that we should have had a social worker and that might have opened avenues for other forms of help really. We rang social services and they said ‘oh yes you should have been referred, but there is a 6 months waiting list to be assessed’”.*[4]

Some parents were frustrated by the perceived priorities regarding access.

*“We have had nothing. Nothing at all. We have a child with quite a lot of difficulties and the GP referred us about 3 years ago because she thought we needed some respite, and they came out did an assessment but said they couldn’t help, so we have had nothing..... They weren’t going to help us because we weren’t on drugs or alcohol and if we were still married, they just said we can’t help you. You are not a priority I am afraid, but she can’t walk, she can’t move by herself, she can’t go to the toilet, she can’t communicate, she can’t access extra-curricular activities.”* [23]

*“ I mean we rang the social services up because we were told he had to have a social worker and they just didn’t want to know. They said they were too busy. I am not making that up now, that is what they said to me on the phone.”* [12]

In some cases access to a Social Worker actually added to the parental stress, for example by offering inappropriate support or being ill informed or lacking skills.

An adoptive parent of a child described feeling her son was seriously let down by not placing him with a family until he was three years old; she felt that this child would have significantly benefitted from being within a caring family establishing relationships on a one to one basis much earlier. Another parent described a social worker mixing up her child’s details with another child and revealing personal information.

Parents found it particularly frustrating trying to access respite care. This was partly about lack of information about how to access it, but also due to a lack of availability. Some attributed the lack of available respite care to changes in child protection legislation which meant hospices and children’s charities no longer offered it.

*“ I think certainly accessing respite has been impossible through social services, it hadn’t been for the Hospice, because of the child protection issue. All the charities used to offer respite, like in children’s home, they can’t do it now because of this child protection issues, so we need the social worker as a gateway to help but again we haven’t got a social worker, and it is very frustrating. It drives you mad. There is a social worker for the deaf in this area but she couldn’t help us in any way.”*[23]

*“there is a man, whose name I was given who actually works at the school, a social worker, so I phoned him because they do respite holiday..... So I phoned him and he said, oh you need to ring somebody else and I phoned her and she hasn’t got back to me. We are talking six months ago.”* [21]

### **Example 3: Inappropriate services**

In several cases a referral to Social Services was made but failed to result in appropriate level of involvement for example, a parent whose child is severely deaf and has a rare syndrome that affects initial foetal growth, resulting in unusual facial appearance, short limbs, adrenal gland anomaly, reduced muscle tone, delayed puberty skeletal abnormalities. His mother was surprised to be referred to Social Care services and then be offered an alarm clock.

For another parent lack of sensitivity to family and child needs meant that direct payments were a more appropriate form of support.

*“I think going back to the social workers, I don’t think they have the right procedures in place. If you don’t get in touch with them, they won’t get in touch with you. They are not offering these things, you have to suggest things to them.”[51]*

Parents were sympathetic to rapid staff turnover and demands on staff time but where this meant their family received little or no support or that were treated unprofessionally they were naturally frustrated

## **5.7 Poor equipment**

Many of the children require a range of equipment ranging from earmoulds to orthopaedic beds. Parents identified equipment needs for daily management e.g. walking frames, feeding tubes, nappies and specialist formula and equipment to improve quality of life e.g. specially adapted bicycles. There were examples of inappropriate, poorly fitted and delayed provision, e.g. child sized wheelchairs only being available through adult services in a uniform grey with no headrest and long waiting lists; earmoulds that did not fit. As many children had such a range of special needs, some equipment that was recommended was expensive and beyond the reach of most families. This meant writing multiple letters requesting support and leading to some resentment with others feeling they were compromised in having to ask for help. Many delays and frustrations were reported.

*“[child] has no seating at the moment because she has outgrown her chair. We are unable to use it now and we have had to battle and battle and the only way that I have managed to get it is by I drove to the other side of town yesterday with my 3 children and put it in the boot of my car, and I have driven it back here. I couldn’t get it out of my car, I had to have help this morning but we still can’t use it because we now have to wait for the rep to come and actually fit [child] into it, but we have managed to get him to come next week but that wouldn’t have happened unless I thought I am going to ring to see what has happened with the chair. It was just sitting in the warehouse.” [34]*

Delays and inertia within the system not only mean children and families have to struggle without the appropriate equipment but also demonstrate the additional costs to the system. Failing to provide a fast response in paediatric services results in loss of revenue as equipment has to be reordered.

*“Well from June to October to get a headrest. Her shoes that are dealt with by physios. She has got clipper boots. Obviously if I take C to the shoe shop and if his feet have grown, you get him a new pair of shoes. Well I can understand with her boots, they are about £100 a pair, that it takes time to get the right shoes, but at one time I think I was waiting 3 or 4 months for a new pair of shoes and she was in the wrong size.” [31]*

*“He was measured for a standing frame and 6 months down the line we still haven’t had it made, because they are made for the size of the child, everyone is different, so I had to ring the superior over this physiotherapist to get him remeasured again, because obviously of the growth and to get one made. And I had to do that, to chase it up off my own back.” [21]*

## **5.8 Bureaucracy and inflexibility**

Parents found accessing some services bureaucratic and inflexible, and that services did not take account of the difficulties faced by parents with disabled children. Parents were frustrated by the red tape they faced in obtaining Disabled Living Allowance and Direct Payments. Some of this arose from simply not being aware of the allowances that were available.

*‘Did you know you can get disability living allowance’ and we said that he hasn’t got a diagnosis; we don’t know what is wrong with them. She said ‘you don’t need a diagnosis’ – so we had been going to this group and seeing people for a good while before this lady came to speak to us, and of course you don’t get it backdated. So as soon as you put your claim in it goes from the day you put your claim in, but nobody told us so we lost out there. ....Another thing with the Disability Living Allowance is [children’s] needs are never ever going to change, they are never going to better, what they have both got they have for life, but we have to fill these forms in every 3 years. [21]*

This parent also raises the need to repeat applications on the three yearly cycle when their child had profound and multiple needs that were not going to resolve. Others described the frustration when support was initially refused and then eventually awarded after re-application, meaning that significant time had been lost.

In other cases the system of support that was designed specifically to help families was administered in such a way that parents were left vulnerable. One example demonstrates the problems faced. This is a single parent who has two children, one of whom has PMLD. The mother has severe back problems resulting from having to lift her daughter and receives physiotherapy for this. She explained why she could not attend a meeting at the end of the term and asked for it to be moved to January.

*“She said because I had refused an appointment they are stopping the direct payment money. I said well that is for the tax and the two employees I have got in*

*January, if you stop the money I am not going to be able to pay the tax man, and who is going to pay the fine. I was sobbing down the phone and she said “stop crying”, but I said “you told me to stop crying but I am going to be short of money and I am going to have the tax man on my back and I haven’t refused an appointment, I can have one in January, and I am going to phone my MP.” [32]*

In some cases, systems which were implemented failed to respond to need and result in wasted client and GP time.

*“..even though you ring them and tell them that you are not able to go on that day and explain that you have two children with disabilities, you just can’t go on that day, and if that happens twice they just strike you off, and you are sent back to the GP. If you need to see them again you have to go through the whole system, go back to your GP and get a referral..... So [child] has actually been discharged even when he needed to be seen. It was discovered earlier when he had a hearing test ..... that his hearing was so poor that they sent a letter to the paediatrician asking her to ask for an urgent referral to ENT to get him seen. [29]*

In some cases it was clearly the system of provision is unable to ensure a rapid response to requests for equipment.

*“ They were quite open about it, he said ‘I am sorry about this but I don’t touch that pile of paperwork on my desk, I give that paperwork one hour’s attention once a month’. So if we put the letter in on the 1<sup>st</sup> May he is not going to look at it until virtually the end of May, we have lost 4 weeks before anything remotely gets done about it.” [12]*

## **5.9 Low expectations of outcomes for children**

The lack of agreed outcomes for deaf children with additional complex needs make it difficult for parents to assess progress. The wide variation of needs does preclude any simplistic approach. The development sequence of learning does allow progress in all children to be monitored and supported. Parents did express concerns about children achieving meaningful levels of communication. Lack of clearly defined outcomes for this group of children may be contributing to the poor recognition of potential and low expectation.

Several parents expressed concern about services having low expectations of their child. For example, a grandmother whose daughter and grandson both have the same condition was able to compare their development. She identified that the grandson had a lower progression than his mother, and yet was not having reading lessons anymore. [7] A parent identified that their child with Autistic Spectrum Disorder was not allowed to join appropriate lessons because the teachers couldn’t understand him, and they doubted his ability to learn BSL although he learnt it with the mother at home. [13] This parent sums it up:

*“I feel frustrated at all levels really. I don’t think school understand where you are coming from, they just think she is doing fine, but fine to us is not fine, not in the*

*grand scheme of she has got to go through her life, however long that is going to be, and its got to be the best we can make it.”[11]*

Parents also found some professionals unwilling to discuss possible futures for their child. They did not appear to expect professionals to predict outcomes but rather to look at possibilities in an area where parents had no experience. Such questions were not necessarily answered or even considered worthy of a response.

*“I have asked in the past what will happen to [child] as an adult and they have just laughed at me, saying isn’t that a bit early. I said no, not really, I am a parent and I want to know.” [17]*

## **5.10 School transition**

For some parents transitions presented major challenges as hard won preferred primary placements did not necessarily translate to a preferred secondary placement. Parents repeatedly noted that the change from pre-school to school age provision often meant children received a similar or reduced level of service but that parents were seldom apprised of this. Parents were unsure of both who was seeing their child and what programmes of support were being provided.

## **5.11 Fighting for services and impact on parents**

Many of the issues enumerated above were compounded to mean that parents had to fight for services for their children. The very individual needs of this group of children clearly raised some significant challenges for parents who wanted a child focussed approach based on assessed needs. In trying to fit their child into local services many parents experienced significant challenges.

Parents showed frustration but also considerable tenacity in seeking to ensure their child received what they felt was a service that met their specific needs. Such services included access to a Sensory Integration therapist, access to specialist assessments, access to Conductive education (not available with the Children’s service), and access to a specialist assessment centre in Australia. Several parents had gone to a specialist centre for assessment of needs at their own cost, to try to ensure their case was taken seriously. Parents used their links with other parents, voluntary agencies and the internet to try to identify services that may improve their child’s quality of life. This was at personal cost both financial and psychological and had implications for other family members. In some cases parents recognised that specific needs and approaches may not be well established in the UK.

*“We have gone private and through a private OT, that we had for a year, we were introduced to sensory integration therapy, which I had read books about because it is big in the US, and he now goes to a private clinic once a week in London and it has made such a difference” [38]*

Parents solved these problems in a number of ways including moving house, paying privately for specialist assessments, taking the local service to tribunal –and when

turned down undertaking long and protracted fight to over turn the decision. Thirteen parents went outside the system and paid for other services: 3 for audiological assessment; 5 for educational placements, 2 for global assessment of need and one for medical, one for equipment and one for a specific therapy.

One parent borrowed in excess of 15K to take the local service tribunal to achieve the desired school placement for their child. She describes the process:

*“The expert witnesses that we were taking to tribunal, who assessed him and did reports, the psychologist spent half the day with him in his previous school and then he came to see us at home and she sat down in my dining room and cried, and she said I have been doing this job for 30 years and I have never seen a child in such an inappropriate placement. Now there were actually child protection issues that she put in the report, so I think that is why they didn’t want to go to tribunal as they would have to defend those reasons. So he has been there now for 18 months and his behaviour has just been great, our lives have just changed enormously but it cost us £15,000 for the solicitor but it was £15,000 well spent, but I am really annoyed that I had to spend that because I could afford it but a lot of people can’t. If you are on income support you can get legal aid but anybody who is not on income support on a very, very low wage they have got to pay for the solicitor. I did have to borrow money from my parents for it and that really annoyed me because I think he has got out of there because we had the money to do it and everybody is left there.”[41]*

In many cases parents actively sought access to other deaf children, and to provision where they felt their child’s learning needs would be more appropriately met.

#### **Example 4: Fighting for services**

This child has a rare syndrome, one effect of which is she has acid reflux which has badly affected her teeth making them highly sensitive. Dental advice was to have her teeth capped and other teeth filled but this raised considerable problems for the family.

*“they have refused to put her under a general anaesthetic on their own list to do any investigations because they said she is not at a stage where it is an emergency, but in the meantime obviously she has been deteriorating. I had this awful appointment where I took her down to the dental hospital and they were saying they can’t put her on the list....., so they would have to leave her in pain and not eating and they were even suggesting tube feeding for her if it got that bad, which was appalling and I was really shocked actually and angry coming away from that. I dug my heels in a bit and got the paediatrician on board and they have agreed to have her on the list.” [35]*

Participants sometimes showed that they had come to accept, or resigned themselves to, certain things when in contact with services. The demands of parenting a deaf child with additional complex needs, high levels of stress, frequently reported struggles to get information, access services, navigate bureaucracy, and

find appropriate sources of support lead many parents with a feeling of resignation that everything would be a struggle. When discussing the process of moving house, participant 23 spoke of her experiences with LEAs:

*“We had problems with the LEA, which we had anticipated... we thought, we accept that we are going to have to fight the statementing battle with the LEA when we get there.”*

Something as simple as arranging a hospital appointment was difficult for many parents as the system set up to provide a service failed to achieve this.

*“It is not difficult to get hold of them, you usually get hold of somebody but then you have to wait for somebody else to ring you back, and that is just how it is, you accept that but sometimes you get lost in the system a bit, you may well have to ring a few times and you do that but sometimes it means you have to remember things all the time. I rang and left a message and then they don’t ring you back”.[34]*

It is perhaps not surprising that parents reported feelings of weariness but they were also mindful of other families who they felt were at a disadvantage in dealing with such frustrations and delays.

*“A lot of families haven’t got the energy and aren’t articulate enough to do it (challenge services), and they are really disadvantaged.” [39]*

Some participants reported that services sometimes left them feeling as if they were a problem. This was a recurrent challenge faced by many of the parents in the study. Participant 35 described her experiences of being with medical professionals around the time when her child was undergoing medical procedures:

*“They were really terrible experiences because you feel like you are the problem, when actually you are just trying to do your best for your child.”*

In questioning provision one parent felt personally isolated by a service and as a result moved authority to seek a more family friendly service. Several families reported moving house to try to gain more appropriate services for their child.

*“My name is mud in X, Again I have not been rude to anybody or said anything derogatory.....Because I was saying , sort of questioning, well what provision can you give us then saying well that’s not good enough they... I don’t know where the animosity came from but its there...It became a personal thing.” [18]*

Many parents commented on the way in which the battles they had engaged in had changed them.

*“I wouldn’t have said boo to a goose 10 years ago, I would have just put my head down and carried on and had a chunter to myself but nobody else, but not any more. It does, it changes you as a person unfortunately, I would rather not be as hard as I am but I have to be now.” [31]*



A recurring theme reported by parents was an adversarial relationship with services where parents experienced considerable frustration and stress.

*“It was awful, we found them bullying and dogmatic, inflexible, and they treated us like a number. In fact in our[social work] case officer in X, when we rang up to query something, said I have got 320 children in my case book and I can’t be doing with that now, and that is exactly how you felt, that you were too much trouble”. [23]*

Where parents have an adversarial relationship with local services the effects can ripple out to the whole family as parents actively seek alternative provision.

*“In his previous school his behaviour was absolutely appalling...our lives were at rock bottom.” [44]*

Even when support is offered, this may be insensitive, or inappropriate and paradoxically a source of increased stress.

*“ My doctor said how about sending her for foster care because you are going to burn out you are absolutely exhausted, its partly mental as well, you know sorting out all the services, and I got back to her last time and said no she can’t go into care, she is part of the family. I just couldn’t do it even though she’s a complete burden she is such a sweet girl and she doesn’t deserve any of it. [32]*

## **5.12 Summary and conclusions**

There was a range of problems that these parents encountered relating to their access to other services for their children, which were not specific to their deafness. Parents found that their understanding and concerns about their child were not listened to by some professionals, often leading to lack of diagnosis and treatment. They also were not always kept informed of the services their child was entitled to, nor actually receiving. Lack of co-ordination, and communication between services were highlighted which meant services could be delayed, opportunities missed and a need for parents to endlessly repeat their case history.

One of the major issues facing services with a limited resource in respect of personnel, equipment and expertise is deciding how the resource is best utilised. A lack of provision meant that parents had to fight to get appropriate services. This was particularly the case for social care where parents were told they did not meet the referral level. There were examples of inappropriate, poorly fitted and delayed provision of equipment. Accessing some service was bureaucratic and had inflexible systems. Several parents expressed concern about services having low expectations of their child and also found some professionals unwilling to discuss possible futures for their child. Transition from pre-school to school, and again from primary to secondary presented major challenges.

Amongst the problems identified above, parents described examples of poor professional practice where serious conditions were left undiagnosed and often only picked up by a chance encounter by other professionals. For some this was attributed to individual mistakes. However, it seems that professionals had little

critical mass of experience of a 'child like this'. This lack of experience, compounded by lack of training in this area meant that professionals appear, in many cases, to be unable to offer appropriate baseline services to this group of deaf children.

Many of the issues enumerated above were compounded to mean that parents had to fight for services for their children. Parents often had to challenge resource allocation, and showed considerable tenacity in seeking to ensure a service that met their needs. This was often at a personal cost. Often this set up an adversarial relationship with services, and some participants reported that services sometimes left them feeling as if they were a problem. Parents described feelings of weariness and resignation.

## **6. What helped these parents**

Some parents were very satisfied with the level of support their child and family received. Such support was described as naturally falling into place and being characterised by family centred, co-ordinated, multiagency work that recognised the child as an individual rather than a 'case'. Excellence at an individual level was attributed across the range of professionals including consultants, audiologists, Teachers of the Deaf, Speech and Language Therapists, Social Workers, Occupational therapists, Physiotherapists, Keyworkers, Genetic Counsellor, Portage workers and Dieticians

*"I can honestly say that from the minute he was diagnosed with problems everybody has been on board and have been fantastic." [3]*

Individuals who were available and actively listened to parents, who made practical suggestions rather than 'completing tick boxes', who actively engaged with their child were highly valued. Many parents spoke of professionals who went 'beyond the remit', 'the extra mile', 'beyond the job description'.

The voluntary sector also offered a positive help to parents and this is described in section 7 below.

### **6.1 Pro-active services**

Parents praised services and individual professionals who were pro-active:

*'From 15 months she had a teacher of the deaf came to do home visits once a week, and we had regular audiology clinics. I was involved with a baby's group at that time. My overall experience of the services is that I have been very, very fortunate. Referrals came from within professions themselves. I didn't have to do anything" [*

*"Like I said speech and language have been excellent really. They have been very pro-active." [4].*

*“The social worker came every day, particularly involved with the deafness, rather than general social workers. They were fantastic in the support they gave, and we would go along and meet other deaf children. They were so helpful.....they [gave us information] about the schools in the area and what was available. My wife found them very helpful.” [19]*

Parents repeatedly praised professionals who invested time and interest in their child recognising this may involve considerable more investment and perseverance than would typically be expected. Parents often highlighted individual practitioners who they felt were exceptional.

*[audiologist] said “I am sure this child has a hearing problem, and I am going to keep going until I get it sorted out” She was absolutely determined to get it sorted, so we went either every week or every fortnight depending on her work and F got really used to the environment, and when the audiologist gently worked with her it was fine. [...] I think the great benefit was that she actually had some idea herself that F had additional problems and worked with her, so she didn’t just get frustrated with her when she didn’t touch and she kept going, familiarised her with the test and what was expected of her”.*

Parents were also keenly aware of provision of services available to them outside traditional school hours, for example praising a setting where weekend and holiday provision was the norm.

## **6.2 Being listened to and respected by professionals**

Parents found it important to be listened to and respected by professionals. This related to having their concerns and wishes about their child’s condition and treatment taken seriously. It also relates to being seen as an expert on their child, but also in some cases as researchers and experts in their child’s condition. Indeed, in section 5.1 there were several examples of parents describing the impact of not being listened to by professionals.

Many of the parents had developed considerable expertise not only in knowing their own child but in complex medical procedures. Parents had researched their child’s needs as far as possible. A number of children had rare syndromes or medical conditions that raised significant issues regarding staff knowledge and understanding eg IMAGE and Townes Brocks syndrome or VACTERL association. In other cases it was the multiplicity of needs that challenged service provision, for example severe deafness, cerebral palsy hyperthyroidism and autistic spectrum disorder. This made parents question whether the professionals were fully informed, and resulted in the parents actively researching their child’s conditions and acting as an informant to the medics. In one case the medic actively recognised the expertise of the parents and made positive use of their research for other cases.

*“.....there is a CHARGE support group, and we get a lot of ideas from different countries. One example was in America – they had a piece of equipment, .....the venting tube..... so when we suggested it to our consultant they said it was something they hadn’t heard of but would certainly look into it for us, and they did and we managed to get that piece of equipment put into E and it worked marvellous, and I saw the consultant about 6 months ago in ICU and he said, you know that piece of equipment you suggested I have used it on 2 other children, and it is absolutely fabulous, thank you for that. That consultant was prepared to listen to us and not just dismiss what we were saying.” [14]*

Rather than feeling challenged or threatened by such parents, there were examples of this expertise being respected and put to good use. For example one father is employed by a university to talk to trainee medical staff thus ensuring they are aware of the concerns of parents and the challenges they face not only in gaining access to medical services but only in the daily management of their child’s needs.

### **6.3 Being kept informed**

It was often the fact that professionals not only did their job well but also that they kept the parents fully informed by viewing them as part of the team.

*“I would say on the hearing side of both the children, the services are fantastic. L’s teacher of the deaf is seeing her today actually at school and she is lovely, she will ring me at home and just say she has seen L and ask how we are. She is lovely, she does more than her job’s worth.” [21]*

*Health service wise I found no problem, in fairness I found that people go out of their way to give you answers, especially in you have the questions,*

For many parents the timing of information was important. Parents recognised that they had, in many cases, received a range of information but that this in itself did not ensure parents could act upon it. Where professionals called to remind parents of a parent group meeting or similar activity the family valued this and was able to respond.

### **6.4 Interagency communication and co-ordination**

Some parents praised the pro-active nature of services (see above) and the fact that services would refer to each other so that appeared to ‘fall into place.’ This is often the result of well co-ordinated services. Some parents referred directly to the level of co-ordination. In one case a parent had moved, which allowed her to compare services in different locations, and to reflect on the importance of good co-ordination and communication between agencies.

*“They all work together so well, since we left the hospital and the education – because we had a teacher of the deaf at 7 weeks, and the teacher of the deaf we had was a specialist audiologist as well so it covered both things for us. [...] X was really, really good, they had a proactive head teacher of the deaf who basically made links between medical and education, so the children were completely covered. The teacher of the deaf had access to the Ear, Nose and Throat Specialist, so if anything needed to be arranged, it could be co-ordinated through the individual teacher of the deaf – which was fantastic, and I took that for granted when we moved here, but it doesn’t work the same.” [18]*

Another parent identified where services arranged to meet together to discuss issues to improve co-ordination.

*“so I had a visit from the social worker and I said it was worrying us, we all need to be doing the same thing and looking at a different route for communication, so she actually said we all need to get together, so that is how the last meeting came about” [44]*

Parents also recognised that where professionals were co-located this facilitated the sharing of expertise and ideas.

*“Early Years Centre, which is a multi-agency for early years deaf children, and they have a centre where you can go like a place where they can play and have coffee and meet the teachers of the deaf. They have deaf adults there, so they have plenty of role models, so that is quite good and so I go occasionally there with him, like a drop-in centre. They have been very supportive, they have given me information and they are very accommodating for his extra needs. so somebody phones you up and says just a reminder that we have a drop-in, or something will come through the post nearer the time just to let you know what is happening – they say you are very welcome to come, it will be lovely to see you, sometimes that is really nice because it just gives you a reminder, a prompt, that you are welcome, there is no pressure, and that has been really good.” [25]*

## **6.5 Keyworker**

For families with younger children a Keyworker was seen as a major positive influence that took much of the daily administrative load off parents and enabled them to focus on their child. This was described as *“one of the best things in our life”* [ 34].

In suggesting a way forward that would most support their family one parent actually described the part of the role a Keyworker would take:

*“We could do with someone who could look at the whole picture and that is very difficult, someone who is aware of all his difficulties. We only pursue something once we find out about it. If someone could co-ordinate it would make it a lot easier.” [26]*

Of the few who had an identified Keyworker parents reported a sense of hope and relief that the administrative and coordination load was removed allowing parents to

focus on their child and family. Parents also felt that where children had profound and multiple needs a Keyworker should be available throughout a child's education.

## 6.6 Continuity

Continuity and stability was prized by parents, and where this was achieved there were high levels of satisfaction. This was particularly important for children with Autistic Spectrum Disorder who find change disturbing.

*“Our teacher of the deaf certainly, she has been a saint, she has just guided us through everything. She knows B so well now, because he has been with her since 3 months old, so I think that consistency as well really helps to have somebody that really understands your child, especially when they have got other needs.” [50]*

Another described having the same teacher of the deaf for so long, which meant the child was familiar and confident with her. Not only did this provide a good learning environment but also helped with assessments, as when she met new people she felt intimidated and tended to regress into baby talk.

## 6.7 Reflective practice

One factor that recurred throughout the parent interviews was that of flexibility: professional willingness to think of options, to admit professional limitations and seek advice from other professionals. Parents did not expect a simple answer to be readily available in the face of very complex needs, rather they valued an open questioning mind that would pursue possibilities and seek options.

In some cases, where inter-agency working was not apparent, there was some evidence of role release, where professionals worked outside their usual role to provide services. For example, the knowledge understanding and skills were provided to a child and family by a professional but not necessarily by a Teacher of the Deaf but by a Speech and Language therapist. Where this was achieved parents felt a good quality of service was delivered. The importance of the service being available rather than a specific professional was evident in the parents' commentaries.

Flexibility of service was also appreciated, as in this example where lessons were either provided in a location with other parents or at home.

*you can either go in and have tuition in a group, if you find that works better for you, or you can have a tutor from home – that is what we had, we had that 3 times. In fact I texted the sign tutors, we have had 2 different ones because Fred had the cochlear implant, and one of them has text back and said that's great when do you want your next lot of lessons. It's fantastic really, so that's one thing. [43]*

Similarly having access to a drop-in service or having a home visit from a professional who can sort out problems with hearing aids to be posted back was appreciated :

*They have a drop-in clinic where you go when you are short of batteries or if the hearing aid doesn't work for any reason, you just drop in and you will be seen then,*

*or the teacher of the deaf will drop it in and it will be posted back to me. We have regular earmoulds taken so I can't fault them at all. We are very lucky actually. [47]*

## **6.8 Child and family centred approach**

Parents stressed that they wanted a service that was child, rather than service centred. This entailed respecting the individual differences of the child, and tailoring services according to their needs.

Parents also appreciated services that worked within the whole family, and supported the parents, in this case to bond with the baby.

*About a month later we got a peripatetic teacher for the deaf started coming to the house when he had his hearing aids. She was lovely. She didn't do a lot with him to start with but did a lot of work with me, particularly, because I was at home with him and a lot of work on living with a deaf baby, bonding with him. She was really useful and I didn't really see a lot of people at that time either because his chest was so bad I couldn't take him anywhere that was air conditioned because the risk of infections was really high, so I was quite isolated really and it was nice to have contact with her [39]*

Parents also valued practical support and advice. For example one family found the advice from a dietician that feeding could be carried out at night 'revolutionised' their care routine and family experience.

## **6.9 Positive perspective and focusing on the long term**

Where professionals offered a positive approach and options parents felt a sense of positive futures for their child, even in the face of major challenges. This child is blind, profoundly deaf a deaf and has CP. In reporting on the audiological assessment her mother reflecting on what she perceived to be a very positive and helpful approach

*"at the audiology clinic there was so much they could do now. 'We can't see her being deaf, not hearing anything, there is so much technology we will be able to do something', and it was quite early on really they referred us for the cochlear implant."* [42]

For parents who are faced with a situation that is completely outside their own experience, discussion of possible futures is an important area that they actively want to pursue. Parents reported that professionals were keen to focus on the short term and medium term whereas many parents had concerns about long terms options and opportunities. One parent was delighted that her ToD had talked to her about the future and possibilities despite the fact her daughter was only twelve. She found the conversation helpful and reassuring.

*“Apparently there is a place in Bath which is run by the RNID, it is for deaf adults with other needs so it is an ideal place for G obviously it will be good for her to go there – I think they have workshops and that type of thing, so hopefully that place is still up and running at the time G leaves school because that is one place that would be ideal for her [33]*

Where support is appropriately targeted parents felt secure in the future for their child and able to concentrate on the present, in the knowledge that a professional had anticipated needs and taken appropriate action.

*“As far as her social worker is concerned she is absolutely fantastic. She goes out of her way to help us if we have any kind of problems, and at the moment it is really just dealing with school and education and getting her on the job ladder, and we have found a lot of support there.” [17]*

### **6.10 Professionals with appropriate communication skills**

There were examples given of professionals being skilled in the relevant communication methods to work with the children. Having good communication techniques was important, but also being able to relate to children and to put them at their ease.

*“He has a named one-to-one, who is a trained intervener, they are trained by SENSE.” [40].*

*she is the audiology consultant, and she is really really good. M has liked her right from him being 2½, he has always understood everything she was saying to him and he has been really content in letting her look at his ears and deal with his ears [10]*

### **6.11 Support and information from other parents**

Parents were very clear that a professional who had snapshot views of their child offered a less useful and realistic approach than parents who had a deaf child with additional complex needs and had lived the experience. Parents reported learning from other parents about benefits, how to get the best out of the system, how to access respite care, special charity funding, local services outside statutory provision and most importantly someone else who understood the nature of the experience.

*“it is sometimes word of mouth from other parents – that is very much the case, probably because of the parents you know from the school all their children are there because they have additional complex needs of various forms or another, and especially when their children are older they have had more experience so that happens quite a lot, we find out things to do and we help each other as well.” [44]*

Interestingly several parents noted the importance and relevance of attending pre-school groups for deaf children. These were not focussed on additional complex needs but rather on the needs of pre-school deaf children and their families. Where such groups were available, typically in urban centres, parents felt a sense of community and valued understanding more about deafness and Deaf culture.



*“They run a couple of groups a week for deaf children up to the age of 5, so we go to a couple of mums and tots groups there, and they do things like basic sign language classes, and they have themes – this week it is going to the park, to equip the parents to know when they go out on adventures they can give the children the BSL.” [18]*

Parents found that meeting other parents was particularly helpful in thinking about possible futures for their child.

## **6.12 Direct payments**

Direct payments were described as being much more flexible and offering the opportunity for family based decisions regarding best use of monies for their child. Parents, where they were aware of them, felt such payments made a significant and positive difference to their family. This flexibility was particularly appreciated by a family living in a rural area who needed respite care, but the only service available was 70 miles away.

*“If you want respite care I have to find out what to do but they are 70 miles away. That’s why I went on to direct payments because all they [Social Services] were offering was a service I didn’t want.” [50]*

## **6.13 Respite**

Several parents described the importance of respite. Some described the importance of it as being another part of their child’s world. Others emphasised the importance of places where the whole family was welcomed where appropriate.

*“we have had a lot more respite. We got to a low point where we just felt we couldn’t cope any more, and that has been a tremendous help”.[35]*

## **6.14 Summary and conclusions**

Parents described good support which was pro-active, family centred, co-ordinated that recognised a child as an individual rather than a ‘case’. Individuals who were available and actively listened to parents, who made practical suggestions rather than ‘completing tick boxes’, who actively engaged with their child were highly valued.

Parents found it important to be listened to and respected by professionals, and having their concerns treated seriously and their expertise respected, and acted upon. Parents also valued being kept informed about the services available and what they were actually receiving. Parents appreciated good co-ordination and communication between services, for example that referrals were made across departments appropriately.

Keyworkers, who took on a majority of the administration and co-ordination of services, were a very positive influence. Continuity and stability was prized by parents, as it enabled children to build a good relationship with individuals which helped in development and assessment. Flexibility of roles and individuals was also greatly appreciated.

Parents also appreciated professionals who had a positive attitude towards their children and would discuss the longer term future options. Parents found being in contact with other parents in similar situations very helpful in terms of learning about benefits, how to get the best out of the system and someone who understood the nature of the experience. Respite care was also very important.

## **7. Parents' experiences of voluntary agencies**

Parents were asked to think about voluntary agencies their relevance and the type of support. Given the very wide range of needs a considerable range of national and local voluntary agencies were mentioned.

Out of the 50 families interviewed for this project 36 had had direct contact with the NDCS. Parents had varied views of the services offered ranging from 'magnificent' [32] to 'very unhelpful'[6], interestingly both were mothers of profoundly deaf children, both children have a cochlear implant. Parents were realistic in their expectation that the main focus of NDCS would be on children who were 'just deaf' and felt that this was appropriate. Parents were particularly positive about NDCS weekend activities including 'Newly diagnosed weekends' and 'Additional needs weekends', those organised for families and those organised for the children themselves. Parents value the opportunity to meet other families. A typical comment sums up the families experience of NDCS activity weekends.

*"F has been on some activity weekends with them and they have been brilliant."* [23]

In using the NDCS as a source of information experiences were mixed. Where parents sought specific information relating to DLA or amplification they found the service helpful and relevant. For other parents they found little of relevance and this served to further underline a feeling of not belonging to any group.

*"even with the NDCS we don't feel that we don't fit in with the deafness, and though we sometimes fit in with the autism but if it is to do with a little more for deafness and the autism it is quite hard to find something."* [36]

*"I think that it never seems to have anything about deafness with additional needs. It appears to be about deaf children and people who write in just about deafness and nothing else. Because with all E's problems, even if it was just the deafness and cerebral palsy that is a big problem as well, so with the blindness on top of that it is even worse."*[42]

*“we always just seem to be on the fringe because we don’t quite know where we fit in, and that type of thing, so it is quite difficult” [37]*

Five parents were members of their local DCS which they found helpful and relevant providing opportunities to make links between families. Where parents received direct support in a tribunal or in applying for DLA parents were very satisfied with support they received from the NDCS.

The wide range of syndromes and needs amongst the children mean that families are in touch with both national and local charities. Parents expressed surprise and a degree of frustration that national charities did not appear to link up. Parents rated two particular features of support from charities, (i) meeting with other parents who had ‘lived the experience’ and (ii) practical advice. Many parents did however feel a sense of isolation because of the ‘lack of fit’ with any group but none more so than where a child has a rare syndrome. As one mother poignantly notes:

*“I just feel that there is just so little information out there how can I possibly expect anyone else to have any answers. It is quite isolating really.” [31]*

For many parents a combination of charitable organisations had been contacted with varying degrees of success. Parents experienced silo thinking where groups focussed on a specific aspect of a child. Whilst parents understood that this was reasonable and practical they also found it frustrating and unhelpful.

*“I think the overlap between them is not very good. I always find it very surprising that for example SENSE and RNID don’t host more joint ventures, they should have more collaboration between some of them because you think there is an overlap for a lot of these charities and there doesn’t seem to be the kind of niche where they focus, it is all the same. On the programme it will say it is running a day for children with learning disabilities and they don’t seem to invite a speaker along MENCAP or for autism, and I think why don’t they do it together, as there are a lot of children who overlap.” [20]*

SENSE was the second most mentioned charitable organisation. Families expressed a high level of satisfaction with the very practical approach that SENSE took in providing trained specialists who worked with families in a very practical way. In one case the importance of this to the Family’s sense of cohesion was considerable. Commenting on the family weekend organised by SENSE annually this mother noted:

*“I don’t know how they do it in such a way it works so well but it does work, and even as far as my oldest son now is 13 and he feels really part of it, and they have always just embraced everything that G does, and his deaf-blindness and they don’t feel weird about it, I think that is really special.” [20]*

Many parents sought out information about national, regional and local voluntary services. Families valued condition specific information that was seen within context of the whole child. In many cases the sense of ‘someone else who understands’ was of major importance. This was not restricted to parent to parent discussions but also

included a local group who provided access to a DVD that for the first time allowed a parent to understand that other parents were having similar experiences.

*“I must admit the ADHD Northwest have been brilliant. In the last month or so they have offered me courses..... and offered me support. They told me about a documentary which was on Channel 4 about ADHD .... I couldn’t believe that it was my son. **Everything what was on the documentary was my son.(parental emphasis).** [9]*

For some parents there were multiple contacts with charitable organisations, this was usually because parents were seeking support to provide equipment or access funds for holidays and seeking the ordinary life experience of families. Such parents were resourceful, determined and highly motivated but found the long and complicated routes they had to pursue exhausting. For one child, parents wanted to provide an adapted bicycle, an appropriate wheelchair, a wheelchair accessible family car, equipment to allow parents to care for their child at home, a specially adapted bed and funding to support the educational placement initially refused by the LEA. In order to do this the parents contacted seven national and two local charitable organisations. A full list of all the charitable organisations mentioned by the parents is included in appendix 2.

For all the families involved it became apparent that charitable organisations offer important and invaluable support to families that generally enrich the lives of the family and of the deaf child with additional complex needs.

## **8. Summary and conclusions**

In listening to the stories of 50 families who had a deaf child with additional complex needs a rich, detailed and unique account of experience has been provided. The term deaf children with additional complex needs as defined by parents, includes a wide variety of cognitive, physical, medical and social needs. The majority of children have a number of needs in addition to being deaf.

Although the main theme of this research is parents’ experiences and access to services, parents spoke movingly of the reality of their lives and the challenges they faced. This gives an important context to their experiences of services and the impact that good, and conversely poor services have. Despite the considerable challenges faced by families physically, emotionally, personally, a common thread was of the joy of the children themselves.

*“Well he is a lovely kid and a joy and it is everything else, it is not the disability that gets you down it is everything else. The children themselves are never the problem; it’s everything else you have to contend with really.” [39]*

Parents described a desire to enjoy a ‘normal’ lifestyle for their disabled child, siblings and themselves. The everyday experiences taken for granted by the majority contrast markedly to the challenges each day presents. Exhaustion was both emotional and physical for many parents. The strain of coping with multiple needs

can make considerable demands on individuals within the family. Stress was commonly reported by parents, especially relating to interacting with services rather than individual children.

Many parents found that services were supportive and added significantly to their child's life and as a result of this to the family's life. Where gaining access to services and maintaining services was problematic, and where parents had to 'fight for services' this caused great stress and negatively affected their family lives, especially their siblings. The parents also described the economic impact of having a deaf child with additional complex needs. Multiple hospital appointments together with complex daily routines make significant demands on family members. This coupled with the need, in many cases, to advocate for support can mean that full time employment for both parents is not possible, with obvious financial implications.

### **Accessing services: problems relating to deafness**

Parents faced a range of barriers to accessing appropriate services for their children relating directly to their deafness. Parents identified problems in assessing their child's hearing problems, and thus delays in treatment. In some cases parent's own concerns were being rejected, in others it was due to audiology departments not being able to make assessments due to additional disabilities. Sometimes the examples revealed an apparent lack of skills and knowledge of professionals in dealing with these problems, and to find alternative ways of diagnosis. This research also found that access to teachers of the deaf was very variable for this group, and in some cases was withdrawn due to their additional disabilities. This implies that there is a lack of coherent policy regarding the rights of a deaf child with additional complex needs to have access to a ToD. There also was evidence that complexity of needs was masking concerns regarding hearing status. Professionals missed hearing problems as they focused on learning disabilities and attributing many of a child's problems to this rather than poor hearing. Some professionals seemed overwhelmed by the complexity of needs, and others inferred that deafness was a minor issue that could be left until later. The research also showed examples of where some interventions (in particular cochlear implants) were refused on the grounds of the child's additional complex needs. This suggests that some professionals are poorly informed about the potential benefits of cochlear implantation for deaf children with additional complex needs, and may as a result be discriminating against these children. Some parents also identified a lack of deaf awareness amongst the many professionals that they inevitably came into contact with. This was seen across a range of professionals including lack of signing in schools, and amongst health professionals. Some parents found that special schools for children with additional complex needs also did not have good skills and knowledge of deafness, which is contrary to the expectation that deaf children with additional complex needs can take advantage of all the specialisms within such schools.

### **Problems relating to additional complex needs**

There was a range of problem that these parents encountered relating to their access to other services for their children, not specific to their deafness. Parents found that their understanding and concerns about their child were not listened to by some professionals, often leading to lack of diagnosis and treatment. They also were

not always kept informed of the services their child was entitled to, nor actually receiving. Lack of co-ordination, and communication between services were highlighted which meant services could be delayed, opportunities missed and a need for parents to endlessly repeat their case history.

One of the major issues that face services with a limited resource in respect of personnel, equipment and expertise is how to best utilise the resource. A lack of provision meant that parents had to fight to get appropriate services. This was particularly the case for social care where parents were told they did not meet the referral level. There were examples of inappropriate, poorly fitted and delayed provision of equipment. Accessing some service was bureaucratic and had inflexible systems. Several parents expressed concern about services having low expectations of their child and also found some professionals unwilling to discuss possible futures for their child. Transition from pre-school to school, and again from primary to secondary presented major challenges. There were some examples of very poor professional practice where serious conditions were left undiagnosed and often only picked up by a chance encounter by other professionals. For some this was attributed to individual mistakes. However, it seems that professionals had little critical mass of experience of a 'child like this'. This lack of experience, compounded by lack of training in this area meant that professionals appear, in many cases, to be unable to offer appropriate baseline services to this group of deaf children.

Many of the issues enumerated above were compounded to mean that parents had to fight for services for their children. Parents often had to challenge resource allocation, and showed considerable tenacity in seeking to ensure a service that met their needs. This was often at a personal cost. Frequently, this set up an adversarial relationship with services, and some participants reported that services sometimes left them feeling as if they were a problem. Parents described feelings of weariness and resignation.

### **What helped these parents**

Parents described good support which was pro-active, family centred, co-ordinated that recognised a child as an individual rather than a 'case'. Individuals who were available and actively listened to parents, who made practical suggestions rather than 'completing tick boxes', who actively engaged with their child were highly valued. Parents found it important to be listened to and respected by professionals, and having their concerns treated seriously and their expertise respected, and acted upon. Parents also valued being kept informed about the services available and what they were actually receiving. Parents appreciated good co-ordination and communication between services, for example that referrals were made across departments appropriately. Keyworkers, who took on a majority of the administration and co-ordination of services, were a very positive influence. Continuity and stability was prized by parents, as it enabled children to build a good relationship with individuals that helped in development and assessment. Flexibility of roles and individuals was also greatly appreciated. Parents also rated professionals who had a positive attitude towards their children and would discuss the longer term future options. Parents found being in contact with other parents in similar situations very helpful in terms of learning about benefits, how to get the best out of the system and

someone who understood the nature of the experience. Respite care was also very important.

### **Parents' experiences of voluntary agencies**

Parents were in contact with a considerable range of national and local voluntary agencies. Parents rated highly two particular features of support from charities: (i) meeting with other parents who had 'lived the experience' and (ii) practical advice. Some also provided financial assistance and grants. The majority of parents interviewed had had direct contact with the NDCS. Parents were positive about weekend activities, and valued the opportunities to meet other families. The NDCS as a source of information was helpful and relevant for specific information about DLA, SEN Tribunals or amplification, but some parents found little of relevance and this service to underline a feeling of not belonging to any group. Indeed many parents did feel a sense of isolation because of the 'lack of fit' with any group, none more so than where a child has a rare syndrome. Some parents expressed surprise and a degree of frustration that national charities did not link up better.

## **9. Recommendations**

Drawing on parental experience of both statutory and voluntary services a number of recommendations can be made that would help to ensure a more coherent and positive approach to meeting needs of deaf children with additional complex needs.

### **Access to services**

Many of the issues identified by the parents of deaf children with additional complex needs in the current study are those that would be identified by many parents of children with additional complex needs but without the deaf dimension.

However, the issues are compounded in the current study because of the deafness. The deaf child with additional complex needs requires access to the full range of services available to children who have the disability of deafness alone and also full access to the full range of services appropriate to their additional complex needs.

### **Access to specialist services**

*All specialist services for deaf children should be available to those deaf children with additional complex needs and no child should be denied access to a service for reason of his / her additional complex needs, whether this be, e.g. assessment by an audiology service; consideration of suitability for a cochlear implant or specific types of hearing aids. Professionals should work in partnership with parents, and children.*

### **Audiology Services**

- Positive consideration of all the amplification options including soft band bone conduction aids, bone anchored hearing aids, and cochlear implants should be made according to audiological need.
- Where a cochlear implant is considered it should be based on a medical and audiological assessment of need alone.
- Research on the advantages of cochlear implants for children with additional complex needs should be made available to audiologists (and parents).
- When a Cochlear implant is being considered early consideration of cochlear and auditory nerve viability should be made.
- Fast track paediatric earmould provision, and drop-in facilities for hearing aid repairs should be standard practice.
- There should be a formal mechanism which allows families to share information that can inform clinical practice [Mccracken, Ravichandran and Laoide-Kemp, 2009]

### ***Deaf awareness***

*All specialist services available to children with additional complex needs should be accessible to deaf children with additional complex needs and staff within these services should have deaf awareness training.*

- Training should be provided for all professionals in the area of deafness and additional complex needs.
- Approaches to adapting hearing screening tests for children with additional complex needs should be developed and be made available to practitioners to ensure best use of resource.
- All medical staff should have experience of deaf children with additional complex needs as part of their initial training or on going CPD. Parents of deaf children with additional complex needs should take an active part in any such training.

### ***Access to qualified Teachers of the Deaf***

*All children who are deaf, whether or not they have additional complex needs, should have a level of access to a qualified Teacher of the Deaf that is appropriate to their level of deafness and not determined by any other needs they may have, or by the educational establishment they attend.*

A fifth of the children in this study had no access to a teacher of the deaf, and some had the support withdrawn on the basis of learning disabilities.



- Children with learning disabilities should have input from teachers of the deaf. This could be through joint working with learning disability specialist, INSET training on deaf awareness to staff, assessment of the acoustic environment, assessment of communication and listening skills that can act as a basis for developing a programme of work or direct teaching.
- Teachers of the deaf should assess the potential value of FM amplification on a case by case basis.
- Amplification should be checked daily by a trained support assistant.

### **Effective and timely assessments**

All deaf children with additional complex needs should have rigorous initial assessments

*Children with additional complex needs were facing delays in diagnosis of hearing problems and identification of need, causing unnecessary delays in treatment and services, and stress to parents. Most screening processes are designed for the majority population and may not be appropriate for children with additional complex needs.*

- Diagnosis of hearing loss should be prioritised with other needs.
- Practitioners need to be rigorous and determined to establish the audiological status of a child. This may need repeat appointments, and may need to allocate more time to identify hearing loss with these children, by developing relationships with the child
- Practitioners should have access to support and training in working with and communicating with children with additional complex needs including sensory impairments, learning disabilities and behavioural issues.
- Parents should be kept aware of the purpose and findings of any assessments, even when they are inconclusive, and not to be falsely reassured.
- A partnership approach between parents and professionals can help professionals build up a picture of needs by actively including and supporting parents
- Offer a flexible approach to assessment, allowing self referral when parents considered there was change, rather than routinely testing on a regular basis.
- Parents should always be viewed as positive informants regarding their own child's. Examples of where parents recognised needs that were missed by professionals underline the importance of recognising parent expertise.

- All assessments should result in confirmation of the current approach or a change in approach.

## **Effective and co-ordinated service provision**

*Deaf children with additional complex needs require access to a range of professionals in a co-ordinated multi agency way, with a pro-active service and access to a keyworker.*

### *Co-ordinated approach*

- For deaf children with additional complex needs, who need access to a range of professionals, a co-ordinated multi-agency approach is essential. Services should see the child holistically rather than a set of discrete conditions. Multi-agency meetings should be timetabled, and result a clear action plan, with a realistic time line that is made available to parents.
- Families should be provided with a dedicated Keyworker who co-ordinates visits and meetings, chases referrals and keeps families informed of progress and activities. For those families where children have profound and multiple needs access to a Keyworker should be extended to cover the child until they leave full time education.

### *Pro-active service*

- Professionals should make referrals to other services on behalf of the parents, so that parents do not have to chase services.

### *Flexibility*

- Services should attempt to provide as flexible a service as possible. Consideration for example should be made for home visits, role release where services can be provided by different professionals, and being flexible about appointment times.

## **Information to parents**

*Parents of deaf children with additional complex needs require appropriate, timely and clear information.*

- Health care professionals should provide a brief summary of key medical findings to share at review meetings with family and medical staff, to ensure a shared understanding of needs is held by all.
- Parents should receive information about statutory and voluntary services. This should be updated and families should receive simple reminders of activities and services as they become relevant to individual children. A simple individualised time event line that identifies local events and includes child specific information, could be used for each family to act as a prompt for busy professionals and to ensure information is timely .

- Links to information and to parent networks are valued, and should be made available including NDCS, local Deaf Children's Society activities.
- Information about entitlements to service and benefits, and available services should be given to parents immediately, and to re-inforced by keyworkers, or other regular visitors.
- Parents should be given ongoing information about the services their children are receiving, including specialist input, and progress made
- For those parents where children are identified with a rare syndrome or condition it is essential that they are provided with sources of further information, particularly contact with similar families, even if this means contact via the internet because of the rarity of the diagnosis.
- Contact details for services should be given out immediately following diagnosis, and should be updated when circumstances change.
- Parents should be actively informed about the whole range of different communication choices [BLS, MAKATON, PECS, objects of reference], and training to be offered at a time when parents can attend.
- Where medical/genetic investigation is on-going files, both paper and electronic, should be clearly tagged so that all staff are aware of whether information has been given to parents. The date of disclosure and professional responsible should also be tagged clearly.

## **Education**

*Deaf children with additional complex needs need access to appropriate well supported education placements, with a focus on improved outcomes and transitions.*

- Schools, teachers and learning support assistants should be well supported, advised and trained in room acoustics, best use of amplification, establishing communication and developing listening/ looking behaviours.
- For parents of school age children, clear communication from the school should be made to ensure that parents understand the type, level and regularity of input from specialists. This could be in the form of regular phone discussions with specialists, simple sticker system in the home school book to say which therapist had worked with their child
- Teachers and other professionals should willing and able to discuss possible future options for individual children.

- Greater emphasis and knowledge about the potential outcomes for deaf children with additional complex needs should be made.
- Placement options should be discussed in an open way that recognises the individual needs of children. Parents should be linked with other families and the NDCS to discuss possible options for their child.
- The current adversarial system that sets families and local services on opposite sides is both stressful and unhelpful. For those children most in need local authorities are likely to find it hardest to provide appropriate provision. Funds that support the tribunal system would be better used to provide services that met needs, locally wherever possible.

## **Social care**

*Deaf children with additional complex needs, and their families require a range of support from social care, particularly respite. Parents should be informed about their entitlements and available provision.*

- Parents should be informed clearly of their entitlements for support and benefits such as DLA and direct payments, and other local provision and services.
- Where support is not available directly, suggestions for alternative contacts and provision should be offered.
- Information about respite care possibilities should be made available to families including funding streams, direct payments, facilities and services. This should be in a readily accessible format.

## **Voluntary organisations**

*Voluntary agencies can provide a vital support role to deaf children with complex additional complex needs and their families. There is an urgent need co-ordinate responses between different disability organisations to recognise and address the needs for these children.*

- Voluntary agencies should recognise that a high percentage of their target population will have additional complex needs. This should be recognised and the implications understood at all levels of the organisation, and actively demonstrated in the materials provided for parents and in staff training. This would need to include consideration of joint training and increased joined up working.
- By having up to date information on their websites and in their literature for families, voluntary agencies can ensure parents do not fall between the gaps.

Such data should signpost parents to information and other voluntary agencies.

- Voluntary agencies should run joint training for staff, pooling information and up-skilling the workforce.
  
- Information for families should where appropriate be jointly written/prepared and contain information that looks at the whole child rather than focussing on a specific disability. In this way parents would gain a more holistic approach where the synergies between conditions had been considered. Such information might include:
  - Pre-school services
  - Additional sources of support DLA, Direct payments etc..
  - Aids and adaptations to support learning
  - Communication approaches
  - Behaviour management
  - School age support
  - Activity weekends for children
  - Family weekends
  - Post school provision
  - On going support

## 10. References

- Ahmad, W.I.U. (1999) *Ethnicity, Disability and Chronic Illness*. Buckingham: Open University Press.
- Bamford, J., Davis, A., Hind, S., McCracken, W., and Reeve, K. (2000) Evidence on very early service delivery: What parents want and don't always get. In R.C. Seewald (ed.), *A sound foundation through early amplification. Proceedings of an international conference*. 151–157. Stäfa, Switzerland: Phonak AG.
- Beresford, B.A. (1994) Resources and Strategies: How Parents Cope with the Care of a Disabled Child. *The Journal of Child Psychology and Psychiatry*, 35(1), pp.171-209.
- Cass, H. Price, K. Reilly, S. Wisbeach, A. and McConachie, H. (1999) A Model for the Assessment and Management of Children with Multiple Disabilities. *Child: Care, Health and Development*, 25, pp.191-211.
- Chamba, R. (1999) *On the Edge: Minority Ethnic Families Caring for a Severely Disabled Child*. Bristol: The Policy Press.
- Davis, A., Bamford, J., Wilson, I., Ramkalawan, T., Forshaw, M., and Wright, S. 1997. A Critical Review of the Role of Neonatal Hearing Screening in the Detection of Congenital Hearing Impairment. *Health Technology Assessment*, 1(10), pp. 1-177.
- Department for Education and Skills(2004) Every Child Matters: Change for Children. London: Stationery Office
- Department of Health (2001) Valuing People: 21<sup>st</sup> century strategy for people with learning disabilities. London:HMSO
- Fisher, K. (2004) Health Disparities and Mental Retardation. *Journal of Nursing Scholarship*, 36(1), 48-53.
- Fortnum, H., Davis, A., Butler, A and Stevens, J.. (1996)Health Service Implications of Changes in Aetiology and Referral Patterns of Hearing Impaired Children in Trent Region, 1985-1993. *Report to the Trent Health, Nottingham and Sheffield. MRC Institute of Hearing Research and Trent Health*
- Hess, C., Rosanowski, F. Eysholdt, U. and Schuster, M. (2006) Hearing impairment in children and adolescents with Down's syndrome, *HNO* 54 (2006), pp. 227–232.
- Hind, S., and Davis, A. (2000) Outcomes for Children with Permanent Hearing Impairment. In: Seewald, R.C. (ed.) *A sound foundation through early amplification: Proceedings of an international conference*. Switzerland: Phonak AG.
- Holden-Pitt, L. and Diaz, J. (1998) Thirty years of the Annual Survey of Deaf and Hard of Hearing Children and Youth: A glance over the decades. *American Annals of the Deaf* , 143(2):72-76

Kerr, A.M. McCulloch D., Oliver, K., McLean, B., Coleman, E., Law, T., Beaton, S., Newell, T., Eccles, T. M., Prescott, R.J. (2003) Medical needs of clients with intellectual disabilities require regular reassessment and the provision of client held reports. *Journal of Intellectual Disability Research*. 47:134-145

Kiely, M. (1987) Epidemiology of mental retardation. *Epidemiology Review*, 9,194-218

Knoors, H. and Vervloed, M.P.J. Educational Programming for Deaf Children with Multiple Disabilities. (2003) In: Marshark, M. & Spencer P.E. (Eds.) *Oxford handbook of deaf studies, language and education*. Oxford: Oxford University Press.

Krahn, G.L, Hammond, L. and Turner, A. (2006) A Cascade of Disparities: Health and Health Care Access for People with Intellectual Disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 12, p.70-82.

Krauss, M.W., Gulley, S., Sciegaj, M. and Wells, N. (2003) Access to Specialty Medical Care for Children with Mental Retardation, Autism, and Other Special Health Care Needs. *Mental Retardation*, 41(5), pp.329-339.

Mazzoni, D.S., Ackley, R.S., Nasjh D.J..(1998) Abnormal pinna type and hearing loss correlations in Down's syndrome. *J Int Dis Res* Vol 38 (6) 549-560

McCracken, W., Ravichandran, A. and Laoide-Kemp, S. (2009) Audiological certainty in deaf children with learning disabilities: An imperative for Inter-agency working. *Deafness and Education International*. Vol.10(1):4-21

Meyer, G. (1997) Syndromes and inborn errors of metabolism. In Batshaw, M.L. (ed). *Children with Disabilities* (4<sup>th</sup> Edition). Baltimore: Brookes, pp.813-834

Middleton, L. (1998) Services for disabled children: integrating the perspective of social workers. *Child and Family Social Work*, 3(4), pp.239-246.

Perrin, J.M. (2002) Health Services Research for Children with Disabilities. *The Milbank Quarterly*, 80(2), pp.303-324.

Robinson, R. O.(1983) The frequency of other handicaps in children with cerebral palsy. *Developmental Medicine and Child Neurology*. 15; 305-312.

Roizen, N.J., Wolters, C., Nicol, T. and Blondis, T.A. (1993) Presbycusis and early onset hearing loss in Downs syndrome. *Scandinavian Audiology*, 19, pp.103-110

Rosenhall, U., Nordin, V., Sandstrom, M, Ahlsen G, Gillberg, C. (1999) Autism and Deafness. *Journal of Autism and Developmental Disorders*, 29(5), pp. 349-357

Silverman, D. (2000) *Doing qualitative research: a practical handbook*. London: Sage

Stredler-Brown A. and Yoshinaga-Itano, C. (1994) F.A.M.I.L.Y. assessment: a multi-disciplinary evaluation tool. In J. Roush and N. Matkin (eds). *Infants and Toddlers with Hearing Impairment*. Baltimore;York Press

Stromland, K., Sjogreen, L., Johansson, M., Ekman Joelsson, B.M., Miller, M., Danielsson, S., Billstedt, E., Gillberg, C., Jacobsson, C., Norinder, J.A. and Granstrom, G. (2005) CHARGE association in Sweden: malformations and functional deficits. *American Journal of Medical Genetics*, 133A, pp. 331–339

Tharpe, A.M. (2000). Service Delivery for Children with Multiple Impairments: How Are We Doing? In R.C. Seewald (ed.), *A sound foundation through early amplification. Proceedings of an international conference* pp. 151–157. Stäfa, Switzerland: Phonak AG.

Vernon, M (1960) Multiply handicapped deaf children: Medical, educational and psychological considerations. CEC Research Monograph. Washington: The Council for Exceptional Children

Wong, V. (2004) Cerebral Palsy: Correlation of Risk Factors and Functional Performance Using the Functional Independence Measure for Children (WeeFIM) *Journal of Child Neurology*, Vol. 19, No. 11, 887-893

Wharton, S. Hames, A. and Milner, H. (2005) [The accessibility of general NHS services for children with disabilities.](#) *Child Care, Health and Development*, 31(3), pp.275 – 282.

WHO (1980) International classification of Impairments, Disabilities and Handicaps. Geneva: world Health Organisation

WHO (2002) Towards a common language for functioning, disability and handicap. ICF Geneva, World Health Organisation

#### Websites

[www.cafamily.org.uk](http://www.cafamily.org.uk)

[www.library.nhs.uk](http://www.library.nhs.uk)

[www.chargesyndrome.org](http://www.chargesyndrome.org)

[www.ninds.nih.gov/disorders/hypertonia/hypertonia.htm](http://www.ninds.nih.gov/disorders/hypertonia/hypertonia.htm)

[www.nlm.nih.gov/medlineplus/ency/article/003204.htm](http://www.nlm.nih.gov/medlineplus/ency/article/003204.htm)

[www.nlm.nih.gov/medlineplus/ency/article/000343.htm](http://www.nlm.nih.gov/medlineplus/ency/article/000343.htm)

[www.pmlnetwork.org/](http://www.pmlnetwork.org/)

[www.vacterl-association.org.uk/index.php](http://www.vacterl-association.org.uk/index.php)



## **11. Appendix 1**

### **Background – literature on deaf children with additional complex needs**

It has long been recognised that a percentage of deaf children have additional or complex disabilities (Vernon, 1960). Studies of deaf children with additional complex needs has however, had a strong focus on prevalence (Karchmer, 1985; Holden-Pitt and Diaz, 1998) or aetiology (Fortnum et al., 1996). Study of this heterogeneous group of children is limited. The World Health Organisation moved on from a largely medical model of disability (WHO, 1980) to produce a more complex framework incorporating biological and psycho-social influences on health and disability (WHO, 2002). Inconsistency of use, poor definitions, and changing terminology create significant challenges in interpreting research data. Learning disability (LD) is defined as: “including the presence of a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning) which started before adulthood, with lasting effect on development” (DH, 2001, Valuing People, p.24). For individuals with LD there is evidence of diagnostic overshadowing, where ‘behaviour stemming from a mental health or physical disorder is erroneously attributed to intellectual disability’ (Krahn, Hammond and Turner, 2006, p.74). This is illustrated in a study by Kerr, McCulloch, Oliver, et al. (2003) who undertook audiological assessment of a population of adults with LD and identified that 89% had hearing outside normal limits, 13% were profoundly deaf. The majority of nursing staff (74%) judged the same group of individuals with LD to have hearing within normal limits. This definition of LD however fails to include the significant medical needs that many deaf children with additional complex needs have.

Within the field of deaf education there is very limited evidence base on which to draw. The current research arose directly from Weekend Workshops for Families with a deaf child with additional complex needs organised by the National Deaf Children’s Society. It was the stories of these families that motivated research that would explore in detail the experience of services. In particular one parent explained how she had requested digital aids and although her son now had them there was little progress. When this was discussed it became clear the audiologist had simply posted the aids out to the family. There had been no attempt to fit them to the child’s specific audiological needs. The parents had no knowledge of paediatric fitting protocols and real ear measures and were in no position to question the professional’s action. This led us to research whether such unprofessional practice was a common experience amongst parents of children with complex need, and to give an opportunity for parents of deaf children with additional complex needs to tell their own stories of working with service providers. This unique insider voice is important in moving beyond simple descriptions of services and numbers of children. Rather it looks in detail at the lived experience of parents and provides a rich multi-layered description of the impact of services on individual children and their families. Complexity of needs brings with it a range of professionals and services. This study therefore includes consideration of Health, Education and Social Services and the role of voluntary agencies.

## **Background**

According to Fortnum et al (1996), one child in every thousand in the UK is born deaf, with up to 40% of deaf children displaying additional health, social or educational needs ranging from asthma or dyslexia to more severe disabilities like cerebral palsy, autism and Down's syndrome. Holden-Pitt and Diaz (1998) reinforce this with a study showing that 20-40% of deaf and hard of hearing children present additional disabilities. It is clear from this snapshot of research of some aetiologies that the incidence of deafness is considerably higher in some groups than in the general population. Whilst in a typically developing population the incidence of deafness is 1.3 per thousand for example: in the case of Autistic Spectrum Disorder it is thought to be 9 per 1000, in the case of learning disabilities 4.2 children per 1000 are thought to have a hearing loss. To understand the complexity and diversity of needs with this group it is useful to consider some of the prevalence data, summarised in table 1.

Table 1 below shows the co-occurrence of deafness and a range of additional disabilities and conditions.

Group	Prevalence	Prevalence of deafness within group	Study	Author
Learning disabilities	4.2 /1000	Paucity of studies looking as LD in isolation but figure of 50%	Abnormal pinna and h.loss correlates in DS	Mazzoni et al., 1998 J Int Dis Res Vol 38 (6) 549-560
Individuals with Downs syndrome	0.92/1000	60-80%  90% of DS compared to 50% with LD non DS and 0% in controls  50%(inc 8.6 sn loss; 82% conductive; 6.9 % mixed)	H. Loss in children with DS Abnormal pinna and h.loss correlates in DS  H impairment in children and adolescents with DS	Roizen et al. 1993 Journal of Pediatrics Mazzoni et al., 1998 J Int Dis Res Vol 38 (6) 549-560  Hess et al (2006). HNO vol. 54(3) 227-232
Cerebral palsy	1.4-2.4/1000	Quadriplegia 22% Hemiplegia 8% Diplegia 17% Dyskinetic 17% Mixed 21% 4.5% h.loss	The frequency of other handicaps with cerebral palsy  High risk factors of CP	Robinson, 1983 Developmental Medicine and Clinical Neurology  Wong et al., 2004
Profound and multiple learning disabilities		55% extensive support* 24% intermittent support*	The prevalence of mental retardation	Kiely M. 1987 Epidemiology Review
CHARGE syndrome	Unknown	<b>E</b> =ear anomaly with or without hearing loss  74%	Syndromes and inborn errors of metabolism  CHARGE assoc in Sweden	Meyer, 1997 in Batshaw Children with disabilities  Stromland et al., 2005 Am J Med Genetics
Autism spectrum disorder	9/1000	7.9% mild mod: unilat 1.6% profound 3.5%	Autism and H Loss	Rosenhall et al., 1999 J of Aut and dev dis

**Table 1. Prevalence of additional disabilities and conditions and prevalence of deafness within those population groups**

### ***Definition of terms***

Individuals with more than one disability have been referred to in the literature by a variety of terms. McCracken (2001) reminds us that deafness co-occurs with a range of disabilities and some deaf children may be referred to as having 'multiple', 'additional' or 'complex needs' or as 'handicapped' or, as is sometimes the case in the US, 'mentally retarded'. The varying use of these terms has presented a confusing picture and made interpreting the literature problematic. For this study, we refer to 'deaf children with additional complex needs' to describe the population of interest.

### ***Children with additional complex needs***

Knoors and Vervloed (2003) ask whether children with multiple disabilities should be inevitably considered multiply disabled. "Multiply disabled", they explain, "does not mean the simple existence of multiple disabilities, but instead denotes a combination of two or more disabilities with an onset early in life for which, given help, education or intervention developed and suitable for children with one disability is not applicable." The idea that a deaf child with multiple disabilities is more than the sum of the parts of various single disabilities is explored by various authors (e.g. Krahn et al, 2006; Fisher, 2004) who refer to the concept of 'overshadowing' where one condition or disability can overwhelm another or others. In the case of a deaf child this may be the case if more attention is placed on, for example, a learning disability and less on the child's hearing loss. The child, in other words, is considered in parts rather than as a whole person.

According to Cass et al (1999), the advent in the 1970s of Problem Oriented Medical Records meant that a previous 'single disease' emphasis on patient management was replaced by a more holistic approach which incorporated other health, family and social issues. In children with 'multiple, severe' disabilities however this approach becomes more limited because "it does not address the complex interrelationships between each area of functioning", resulting in the identification of a child's problems not producing priorities and a lack of a clear plan of management. Tharpe (2000) furthers this discussion by referring to the individual needs of deaf children with complex disabilities, using the example of hearing aids: "hearing aid selection and fitting should be different for the child with multiple impairments than for the otherwise normally developing child with hearing loss." The reason for this, Tharpe (2000) explains, is that such children have different functional needs and 'the goal of education' therefore for a child with both visual and hearing problems, for example, is maximum independence.

### ***Policy context***

In the UK recent developments and initiatives designed to improve the access of disabled people to services have been enacted, such as the Disability Discrimination Act of 1995 which made it unlawful for disabled people to be discriminated against by service providers on the grounds of their disability. In the UK the main health service provider is the NHS and Wharton et al (2005) describe an apparent paradox: "...disabled children and adults have greater health needs than the general population. However, disabled people often face difficulties when they try to use general NHS services."

In England The National Service Framework for Children emphasizes the need to provide appropriate support to children and young people and their families at a local level, and it addresses the provision of care for children with additional complex needs as well as setting standards regarding delivery of care. The Children's Plan is a 10 year strategy published in 2007 in which there is a further commitment to strengthening intensive support to the neediest families by piloting a keyworker approach. In 2009 the Healthy Child Programme was extended to cover up to 19 year olds and contains guidance on children with additional complex needs, and specifies that children with complex health needs should have an individual health plan put in place by 2010.<sup>i</sup>

Every Child Matters is an initiative designed to ensure a national framework for cooperation across the spectrum of children's services (education, health, social care etc.) in England. Launched on the back of a 2003 green paper<sup>ii</sup> the programme has a number of aims and intended outcomes and is designed around the ideal of increased inter-agency working. Within this initiative is the Aiming High for Disabled Children Programme, launched in May 2007. It aims to deliver: 1. Access and empowerment for disabled children and families. 2. Responsive services and timely support. 3. Improved service quality and capacity. The Early Support Programme is a co-ordinated support for the under 5s in England which brings together all the services and support available from different agencies. Some families will be allocated a key worker who provides advice and support and can help negotiate the system, and it is being extended to Wales.

"Getting it right for every child" is Scotland's national approach to supporting and working with all children and young people in Scotland. Although Aiming High for Disabled Children does not relate directly to Scotland, under the Barnett Formula allocation, increased funding was made available for disabled children. In a review of the specialist services in Scotland by the National Steering Group for Specialist Services in 2007/8 a recommendation was made to strengthen and invest in specialist services for children with additional complex needs. As part of the National Development Plan for Children's Services, funding was developed to set up the NMCN CEN to ensure that each child is fully and appropriately assessed, and has access to a full range of specialist care underpinned by evidence base.<sup>iii</sup>

The National Service Framework for Children, Young People and Maternity Services in Wales was launched in 2005. Chapter five outlines the standards and key actions for services for disabled children and their families. This includes the development of hand held records, children with additional complex needs should have a multi-agency care plan and that service providers should jointly agree and provide a keyworker service.<sup>iv</sup>

In Northern Ireland, the 10 year Strategy for Children and Young People emphasizes that actions must be taken to improve the lives of children, young people and their families who need help most. Several policies and research papers have focused on services for children with additional complex needs for example an inspection of services for disabled children in hospital (2005) and a research report into nursing for children with complex physical health care needs in 2007. In response to this in 2009, the Northern Ireland Executive announced a £9 million investment in providing care packages including nursing support, equipment, training and respite care.<sup>v</sup>

Since March 2006 the full roll out of the NHSP means all parents are offered the opportunity to have their baby's hearing screened. For many children with additional complex needs the first hours, weeks and in some cases months of life may be spent in the Special Intensive Baby Care Unit [SCIBU] receiving a range of interventions. This may make early hearing screening impractical, because of high levels of ambient noise or because the infant is too medically fragile.

Since May 2010 there has been a new Coalition Government, and it is as yet unclear what changes this may make to services for disabled children with additional complex needs. The spending review announced in Autumn 2010 proposed a 12% reduction in the Department of Education's non-schools budget and 28% decrease in local council allocations over the next four years. In England, after April 2011 funding for local areas will no longer be ring fenced, which includes funding for Aiming High for Disabled Children. However, the government has indicated they do not envisage this resulting in fewer services for disabled children. It also stated that the Government will be extending the use of personal budgets.<sup>vi</sup>

### **Access to services**

From the literature it is clear that while the parents and families of children with disabilities are generally able to access services, they face innumerable hurdles along the way. Beresford (1994) tells us that parents report the process of accessing and then dealing with services the most challenging aspect of having a disabled child. Beresford suggests what compounds the problem is the fact that overall responsibility may not be held by any of the variety of services (health, social, educational) parents come into contact with and thus they are in danger of 'slipping through the net.' Middleton (1998), remarks that "Research focusing on those caring for disabled children, usually mothers, consistently documents the isolation such parents feel, and the lack of support available to them...The underlying picture of parents (is that they receive) too little support from either statutory or voluntary services."

Perrin (2002) outlines some of the issues surrounding the process of researching access to services for children with disabilities. These children, he tells us, are frequently excluded from research into health services and the disabled because of concerns about risks and special problems in studying that particular population. As a result, he explains, "we have little information about the epidemiology and characteristics of children and adolescents; the use, organisation and financing of services for them; the best practises; methods of assessing and improving care; ways of keeping them safe and protecting them from medical errors; and basic issues of long-term clinical management." In reflection of this, the literature concerning access for children with disabilities to services is disappointingly sparse; Wharton et al (2005), when reviewing the literature on access to services for children with learning disabilities, located only a single article (from the US). Most often, we find that attention has previously been focussed on services and deaf or disabled *people* (as distinct from children) more generally, as Perrin (2002) above confirms. This literature can be utilised however, along with the small amount of previous research specifically focussing on access to services for deaf children and those with additional complex needs. The establishment of Children's trusts following the

Children Act 2004 sought to ensure services were focussed on child need rather than on services. Children's Trusts are required to actively promote the five outcomes described in Every Child Matters. Guidance issued in November 2008 provides an imperative for all those involved in Children's trusts to actively work co-operatively. Joint working across agencies with the child at the centre was a key feature of the last government agenda. It is recognised that a move to such services will be step wise over time.

### ***Disabled children***

Wharton et al (2005) interviewed 25 parents of children with disabilities (including learning disabilities, Asperger's Syndrome, Autism and Cerebral Palsy) to gather information on perceived positive and negative aspects of the health care they received. The questionnaires used in the study were designed around 8 themes (such as 'preparation', 'waiting' and 'overseeing care'). The authors found that, among other things, parents noted a 'lack of planning' among services for the additional complex needs of children with disabilities; the potential for improvements in the flexibility of scheduled appointments; difficulties with on-site parking; difficulties for wheelchair users (such as a lack of automatic doors, which were welcomed where present); poor waiting areas; a lack of professional training in learning disabilities (though some were pleased when staff involved their child in the consultation); the need for private and improved ward facilities; the desired support of a staff member to oversee and coordinate appointments. Of course, a number of these issues, if not all, might be considered representative of those faced by the parents of children not disabled, but as Wharton et al point out: "the experiences of parents of children with disabilities are often magnified, as they are likely to have to attend hospitals more often. It seems that there is a case for certain problems to be prioritised for children with additional complex needs."

The sample in the above study is small, an issue recognised by the authors as they describe it merely as 'preliminary and small-scale'. They also concede that a follow-up study with a more specific focus would build on their initial findings.

Krauss et al (2003) reported the findings of a 1998/1999 survey conducted in the United States of 2,220 families of children with special health care needs. Children in the sample were described as falling into three categories: those with Autism, 'mental retardation' and those with special health care needs and other conditions. The study found that the families of children with autism most frequently reported problems in accessing services (37%), followed by those of children with 'mental retardation' (23%) and then those of children with other conditions (21%). The study was conducted in the United States but a number of issues raised by the questionnaire (and thus the data collected) are transferable to the UK, such as 'getting referrals for services', 'getting appointments' and 'finding skilled and experienced speciality doctors.' In every 'access problem domain', the families of children with autism most frequently reported that they had encountered difficulties. The authors suggest that this may be due to the complexity of the condition and the range of specialists typically required. Krauss et al conclude by explaining that: "Access to...care is not a binary outcome whereby children with special health care needs simply receive or do not receive the care they need. Instead, there appears to be a variety of potential hurdles for families that are associated with the process of accessing this care even when it is received."

## ***Deaf children***

Tharpe (2000) surveyed audiologists across the United States (N=6000) responsible for fitting children between the ages of 0 and 12 with hearing aids. 425 were eligible to complete the questionnaire. The average age at which respondents indicated they fitted children with hearing aids was 13 months. It was also found that children with autism were fitted later than children with any other additional impairment. The questionnaires used in the survey also asked audiologists which children (i.e. those children with various additional impairments or disabilities) would most benefit from the use of a hearing aid, compared to children with hearing impairments alone. 57% of respondents felt that deaf children with an additional visual impairment would benefit more from a hearing aid than a child with a hearing impairment alone. This figure was highest among the other presented options: 'mental retardation'; 'physical and autism'. Finally, Tharpe (2000) notes that around half of respondents did not know how a deaf child with autism would benefit from a hearing aid compared to a child with deafness alone. This, the author argues, "is consistent with the dearth of information on children with autism present in the audiological literature."

## ***Deaf children with additional complex needs***

McCracken conducted an interview study with the parents of deaf children with complex disabilities, (Bamford et al, 2000). The study showed firstly that 57% of respondents were not satisfied with the manner in which audiological tests on their children were carried out. In addition, 43% were not satisfied with the explanation of the tests and the results that followed. Thirty-six percent said that they had little confidence in the results of the assessments and half of the parents claimed that their own observations were not sought. Sixty-four percent of parents considered the testers inexperienced around children with additional complex needs. All the parents interviewed however regarded hearing status as particularly important for their child's development and well-being.

Some authors suggest that ethnic minority parents are likely to encounter even more significant challenges when attempting to access services. Minority ethnic disabled people and carers, Ahmad (2000) suggests, face questions about citizenship rights, an unwillingness of services to accommodate those who do not speak English, stereotypes of 'caring extended families', arguments about 'low numbers' to marginalise needs and methods of keeping users and carers ignorant of their rights. Chamba (1999) conducted a national UK study of the experiences of parents of ethnic minorities accessing services for their disabled children. All participants in the study reported having encountered at least one problem, with those Black African/Caribbean and Indian ethnicity reporting problems most frequently. The most frequently reported problems were cited as: time taken for services to become organised; having to fight for services; lack of knowledge about available services; a lack of professional understanding about the challenges of raising a disabled child. In addition, parents reported insensitivity towards their cultures and religions as well as communication problems. The study also found, however, that two thirds of parents were generally satisfied with the services they encountered and satisfaction levels were highest among the parents of younger children. There is evidence that the incidence of deafness is higher in some ethnic minority groups and that within this



group the incidence of additional complex needs is significantly higher than in the rest of the population.

## **12. Appendix 2**

### **Methodology and characteristics of the sample**

This research project aimed to provide a voice for the parents of deaf children with additional complex needs who experience service delivery and can provide unique and so far unheard perspective. The methodological approach was a qualitative one, based on narrative. Parents were invited to tell their own stories, in their own words within the broad framework of their experience of service delivery. The interviewer's job was to clarify points in the narrative as it progresses to ensure information is collected about comparable events across all interviews undertaken; to support the narrative telling through empathic engagement with the teller; to record the interview for later analysis. In this way, parents did not respond to a set of predefined questions in which to fit their experience, but rather are given the scope to make decisions themselves about what is meaningful and important in their experiences, and to set the criteria by which they would want their experience to be understood and evaluated.

The sample was a purposive one, because only those parents whose children fulfilled the definition of deaf with additional complex needs were invited to participate. The lack of agreed definition of deaf with additional complex needs raised questions regarding the focus of this research. It was important to ensure that parents did not see this as a simple audit of service provision or as being focussed specifically on a specific group of service providers. The information leaflet for parents was thus designed to ensure that parents had a shared understanding of what was being defined as complex. In addition information was provided for parents regarding the considerable and varied range of potential service providers that may be involved with any specific family.

The definition of additional complex needs was deliberately made as wide and inclusive as possible. A range of syndromes and conditions were included on the information sheet. This included major identified syndromes that are known to have a high incidence of deafness, for example Down, CHARGE and Fragile X syndrome as well as Autistic Spectrum Disorder [ASD], Meningitis and Profound and Multiple Learning Disability (PMLD) Judgements regarding complexity was made by the families themselves.

#### ***Recruitment***

Recruitment aimed to ensure that all the families who wanted to be involved were offered that opportunity. This was a UK wide study so Information packs went to Heads of Schools and Services for Deaf Children, the Heads of Schools and Services Annual conference and electronic forum. Packs were available at NDCS Additional Needs weekends and were sent to parents who had previously attended such weekend via the NDCS. Additionally information about the study with an invitation to join in was published in the NDCS magazine and in Information Exchange magazine. Information packs were available at a national conference 'Deaf Education Fit for the Future' organised by the University of Manchester in partnership with the Newborn Hearing Screening Programme. In addition professionals working with this group of children were specifically targeted. In total in

excess of 400 packs were sent out. As part of this recruitment process families received information sheets and consent forms in accordance with an ethical protocol agreed by the University of Manchester Ethics Committee [Autumn 2008]. A total of 51 families were recruited, this included one family who contacted the study after the final data collection point.

### ***Characteristics of the sample***

A voluntary sample of 50 participants took part in the study. Participants were UK residents geographically distributed as follows: thirty eight from England; five from Scotland; two from Wales; five from Northern Ireland. Participant numbers from each were intended to loosely represent the proportional population demographics of the UK.

Respondents were encouraged to choose who should be interviewed and whether that interview should be at home, in a place of the parent/guardian's choosing or by telephone. All opted for an interview by phone. Of the 50 interviews undertaken, 39 interviews involved the mother alone, 5 the father alone, in one case both the mother and father requested that they were interviewed separately. In one interview a grandmother was the respondent and in three cases where children were in the process of being adopted, the legal guardian was interviewed. In one case a mother who was interviewed had two deaf children with additional complex needs. For simplicity all parents and guardians will be called parents within this study, recognising that they are either biological parents, grandparents of adoptive parents. Forty two families were white British, seven were cross cultural and one was Bangladeshi. All parents/caregivers were "hearing".

The socio-economic status of participants was determined via their postcode. Participants gave their address details during interview and these were entered into an internet search tool available through [www.upmystreet.com](http://www.upmystreet.com), an independent property information website. Each postcode entry would provide a number between 1 and 56 which could then be cross-referenced with ACORN (A Classification Of Residential Neighbourhoods; [www.caci.co.uk/acorn-classification.aspx](http://www.caci.co.uk/acorn-classification.aspx)), a scale which categorises the residential areas of the UK. ACORN divides all areas of the UK into five broad groups: wealthy achievers (1-12); urban prosperity (13-23); comfortably off (24-36); moderate means (37-43); hard pressed (44-56). In such a way, the socio-economic status of each participant in the study was roughly determined (except for those in Northern Ireland as postcodes there were not searchable on the website used).

Parents completed a narrative-based interview lasting on average of 45 minutes. Parents chose to be interviewed by phone at a time that best suited them, this included evenings where children were asleep or a partner was at home. In addition parents completed a simple questionnaire to collect sociodemographic information.

The families who opted into the study all judged their children to be deaf with additional complex needs. The diversity of need was expected, it demonstrates some of the challenges in defining such a group. Any simple definition of needs fails to capture the heterogeneity of this group of children. Simple labels may hide a degree of complexity.

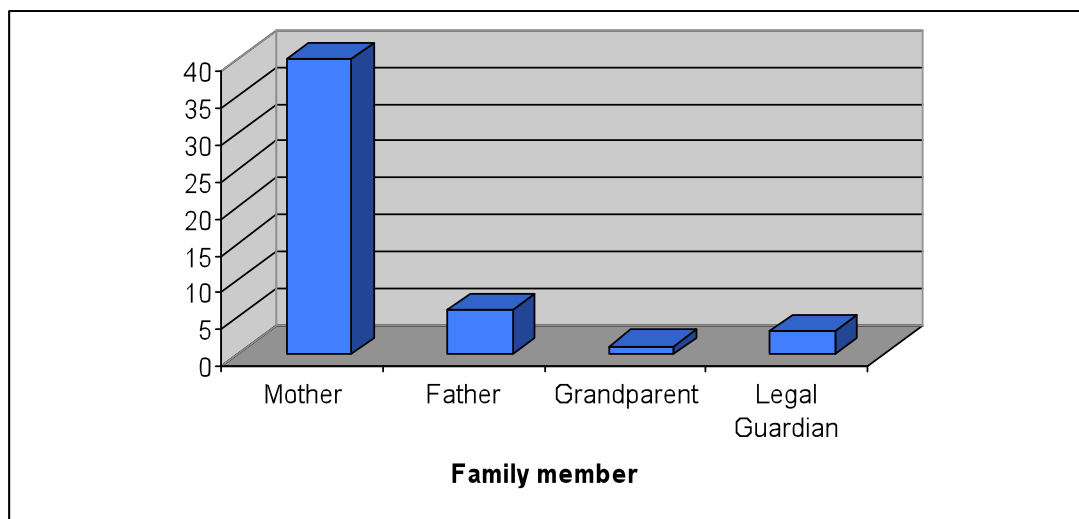
## **Analysis**

Data were audio recorded and transcribed in full. A thematic content analysis was carried out. Codes were generated independently by the authors then compared for consistency or deviance. When there were disagreements further discussion with reference to the transcripts lead to the final coding framework. As the analysis progressed some codes were collapsed into others as it became apparent they were capturing the same/overlapping experiences. The analysis used cross-sectional techniques from both within case and cross-case perspectives (Silverman, 2000). A “case” is regarded as an interview (i.e., there were 50). Within case perspectives pay attention to similarity/difference of response between participants within the same interview. Cross-case analysis considers shared and disputed perspectives between the experiences contained within the 50 interviews. The following treats each of the 50 interviews as its own “case.”

## **About the sample of children and their families**

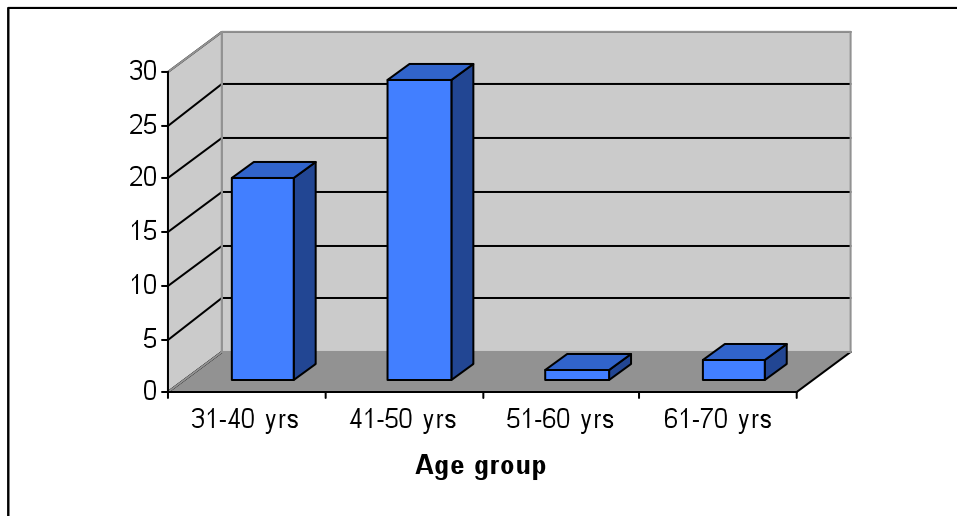
Participants in the study were the parents of deaf children with additional complex needs, their grandparents or legal guardians, illustrated in the figure below:

**Figure 2: Relationship of participating family member to the child**



Participants were asked to report the age group to which they belonged. These results are shown below:

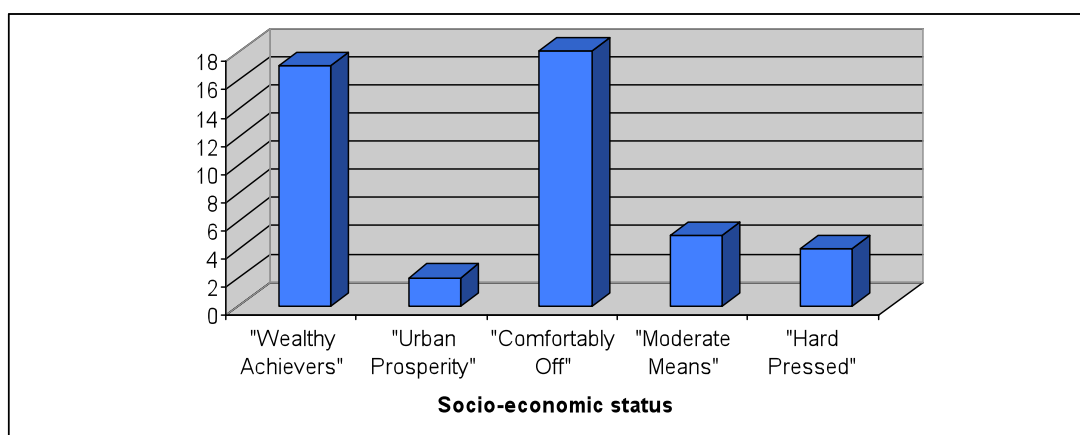
**Figure 3: Age of participating family members**



Participants in the study were asked to report their own ethnicity and that of their partner (if applicable). That participants themselves volunteered to be involved meant that a sample truly representative of the UK population was unlikely, but a mix of ethnicities was achieved: Forty-two families were white British, seven were cross cultural and one was Bangladeshi.

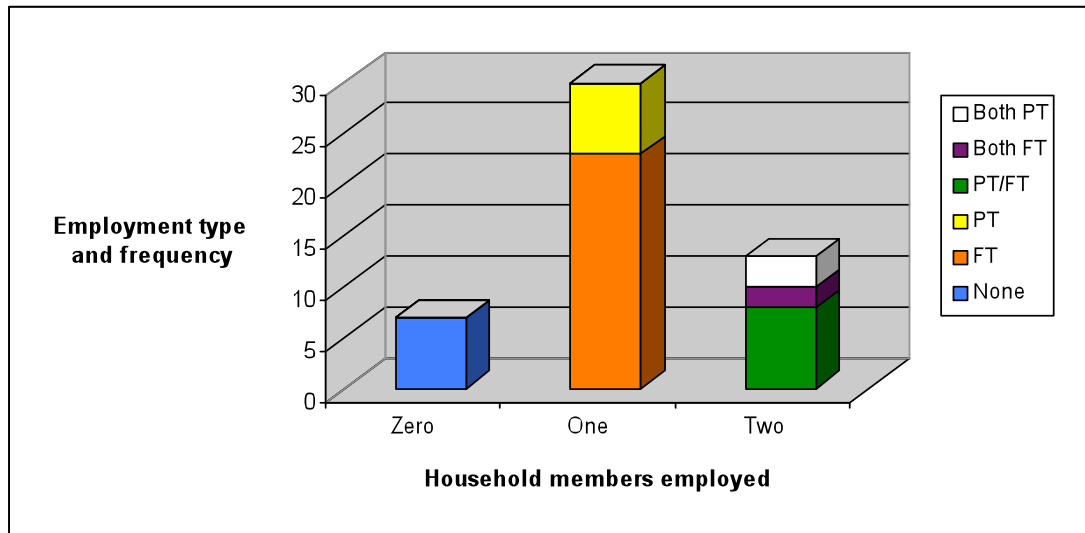
The socio-economic status of participants was also roughly determined. The graph below shows the dispersion of participants across groups. Again, a voluntary sample meant that the 'spread' of participants is biased to those parents who opted to join in this study the majority of families were in the higher income bracket. However there is representation across the range of socio-economic groups.

**Figure 4: Socio-economic status of participants**



Participants were asked whether or not they or their partners (if applicable) were in paid employment. They were then asked whether this work was full time or part time. The results are shown below:

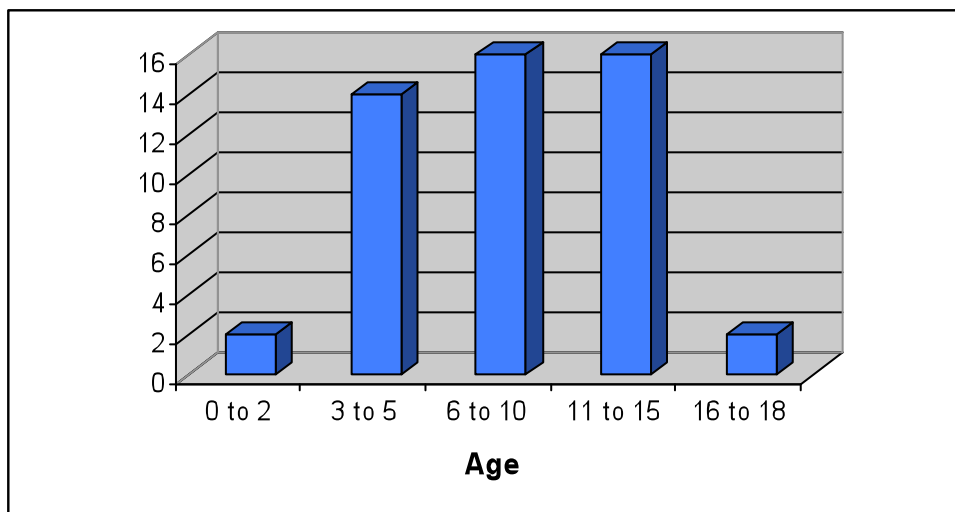
**Figure 5: Number of household members employed**



*Child characteristics*

To be eligible for the study, the children of participants had to be aged 18 years or under. The age ranges of children whose parents or guardians were interviewed were as follows:

**Figure 6: Age distribution of children**



The 51 children of participating parents and guardians displayed a wide range of additional complex needs. The frequency each occurred across the children can be seen below. The majority of children had more than one reported additional need (see table 2 below).

**Table 2: Frequency of each additional need across children as reported by parents**

<b>Additional need</b>	<b>Frequency</b>
Learning difficulties	13
Cerebral Palsy	12
Blindness/Visually impaired	11
Epilepsy	11
Developmental delay	8
Speech/language difficulties	7
Autism	6
Muscular Hypertonia	5
Down's syndrome	5
Physical disabilities	5
CHARGE	3
Heart problems	3
Hypertonia	2
Behavioural problems	2
Kidney problems	2
Asthma	2
ADHD	2
Cardiomyopathy	2
Lung disease	2
Very complex – no diagnosis	2
Cleft palate	1
Eczema	1
Enuresis	1
Vocal chord palsy	1
VACTERL syndrome	1
IMAGe syndrome	1
Cornelia de Lange syndrome	1
Townes Brock syndrome	1
1p36 Deletion Syndrome	1
Foetal alcohol syndrome	1
Motor skills problems	1
Emotional problems	1
Dyspraxia	1
Congenital hypothyroidism	1
Hypopituitary	1
Hydrocephalus	1
Scoliosis	1

This range of definitions illustrates the challenge faced by parents and professionals in both understanding the complexity of need and in ensuring such needs are met. Reported conditions have been grouped to illustrate the key areas of need. It should

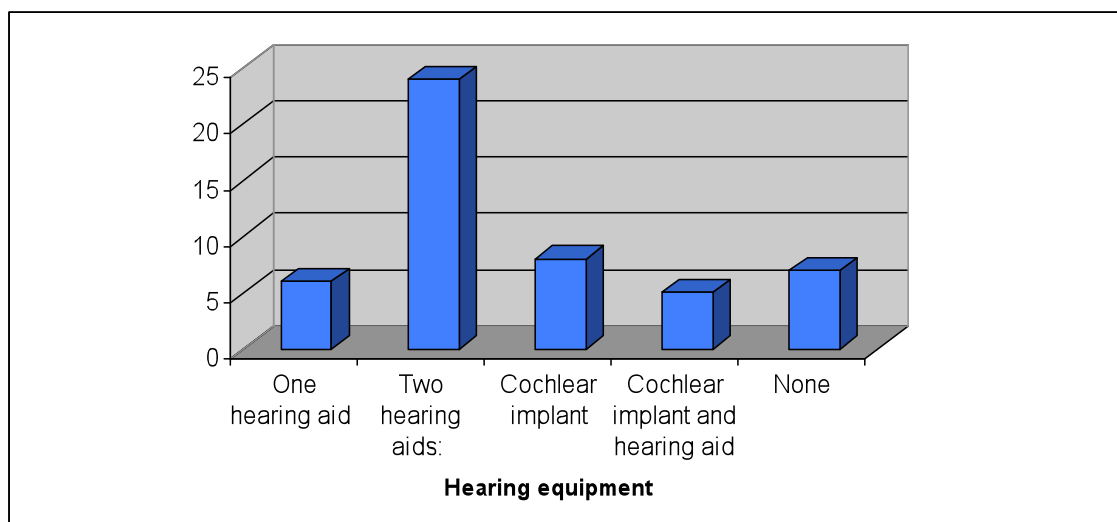
be noted that in the case of syndromes children had multiple needs across all categories.

**Table 3: Additional complex needs reported as groups**

Cognitive	21
Physical	25
Sensory [other than deaf]	11
Specific Speech and Language needs	10
Behavioural/emotional	11
Medical	12
Named syndrome	14

Participants were asked what type of amplification, if any, was used by their child. The results are shown in the figure below:

**Figure 7: Amplification worn by the children of participating family members**



N.B: One child used softband bone conduction aid and was included in the 'One hearing aid' category. Participants were also asked about the type of school their child attended, as shown below:



**Table 4: Type of school environment attended**

Mainstream school	9
Special school for children with severe learning disabilities	22
School for the deaf/Mainstream school with deaf resource base	8
Nursery	5
Pre-school support at home	5
School for the blind	1
MSI unit	1

Support from ToDs ranged from daily, in schools for the deaf or deaf resource bases to biennially, see figure 9. Where support was outside specialist deaf provision in two cases parents reported individualised support from a ToD. In all other cases the support was either monitoring or unknown in that parents neither knew the frequency of contact or content of their child's support packages.

**Table 5: Frequency of ToD contact**

Frequency of ToD contact	number of children
Daily	6
Twice a week	2
Weekly	20
Fortnightly	3
Monthly	5
Every half term	1
Less than annually	1
Don't know*	3
No contact	10
Total**	51

\*Of the three who didn't know, one had just moved and was uncertain about what provision would be happening, and two had access but didn't mention how often.

\*\*The total number of children comes to 51, as one family has two children.

Of the fifty families involved in this study, 18 made no mention of having contact with Social Care services. As with ToDs many families were unsure of the role and responsibilities of Social Care workers.

## **13. Appendix 3**

### **Additional complex needs of children reported by participating parents/guardians**

#### **1p36 Deletion Syndrome**

1p36 Deletion Syndrome is a chromosome disorder characterized by moderate to severe intellectual disability, delayed growth, limited speech ability and distinct facial features.

1p36 Deletion Syndrome occurs in around one in every 5,000 to 10,000 births and is the most common chromosome deletion.

Resources: [www.1p36dsa.org](http://www.1p36dsa.org)  
[www.rarechromo.org](http://www.rarechromo.org)

#### **Attention Deficit Hyperactivity Disorder (ADHD)**

ADHD is an impairment of either activity or attention control or both. Children with ADHD usually appear as 'always on the go', unable to settle, exhibits poor concentration, poor ability to organise activities or to engage in tedious activities or tasks requiring sustained mental effort.

ADHD affects around 4% of school-age children.

Resources: [www.adhd.org.uk](http://www.adhd.org.uk)  
[www.addiss.co.uk](http://www.addiss.co.uk)  
[www.adhd.com](http://www.adhd.com)

#### **Autistic spectrum disorder (ASD)**

ASD is a group of developmental disorders. They are characterised by abnormalities in social interaction and communication and by restricted and repetitive behaviours and interests.

The prevalence of ASD is around 6 to 10 in every 1000 in younger children. Boys are more commonly affected than girls.

Resources: [www.autism.org.uk](http://www.autism.org.uk)  
[www.nhs.uk/conditions/autism-aspergers](http://www.nhs.uk/conditions/autism-aspergers)  
[www.cafamily.org.uk/Direct/a84.html](http://www.cafamily.org.uk/Direct/a84.html)

#### **Cerebral Palsy**

Cerebral palsy is a general term that indicates brain injury suffered either before or during birth. Individuals with CP may have problems controlling movement and other symptoms vary from mild learning difficulties, with or without signs of muscle weakness, to severe impairment.

Around 3 in every 1000 children show some degree of CP.

Resources: [www.scope.org.uk](http://www.scope.org.uk)  
[www.nhs.uk/conditions/cerebral-palsy](http://www.nhs.uk/conditions/cerebral-palsy)

### **CHARGE syndrome**

CHARGE is an acronym for: Coloboma; Heart defects; Atresia choanae; (blockage of the nasal passages); Restricted growth and development; Genital hypoplasia; Ear anomalies.

CHARGE syndrome is a genetic pattern of birth defects. It is an extremely complex syndrome and manifests in extensive medical and physical difficulties that differ from child to child. Babies with CHARGE syndrome are often born with life-threatening defects, such as in the heart. Swallowing and breathing problems can occur along with hearing and vision loss and balance problems which delay their development and communication.

The prevalence rate of CHARGE is around one in every 9 -10000 births.

Resources: [www.chargesyndrome.org](http://www.chargesyndrome.org)  
[www.chargesyndrome.org.uk](http://www.chargesyndrome.org.uk)  
[www.cafamily.org.uk/Direct/c12.html](http://www.cafamily.org.uk/Direct/c12.html)

### **Chronic lung disease (CLD)**

There are a variety of conditions that can affect the lungs in children. For advice on such condition and on use of oxygen, medication and allowances more information can be gained from the groups listed.

Resources:

British Lung Foundation

Tel: 0845 850 5020 Helpline (Mon-Fri, 10am-6pm)

Tel: 020 7688 5555

Fax: 020 77688 5556

e-mail: [enquiries@blf-uk.org](mailto:enquiries@blf-uk.org)

Web: <http://www.lunguk.org>

[www.lunguk.org/you-and-your-lungs/conditions-and-diseases/childrens-lung-disease](http://www.lunguk.org/you-and-your-lungs/conditions-and-diseases/childrens-lung-disease)

### **Cornelia de Lange syndrome (CdLS)**

Children with CdLS will have slow or very slow development, usually associated with significant learning problems of varying severity. Some children have psychological and behavioural problems including autistic-like features and self injury. Most children have some form of limb abnormality.

CdLS is rare, affecting between 1 in 15,000 and 1 in 50,000 babies born.

Resources: [www.cdls.org.uk](http://www.cdls.org.uk)  
[www.cdlsusa.org](http://www.cdlsusa.org)  
[www.cdlsworld.org](http://www.cdlsworld.org)

### **Down's syndrome**

Down's syndrome is a chromosomal disorder caused by an extra 21st chromosome. Typically, individuals experience learning difficulties, short stature, and recognisable physical features. Down's syndrome is the commonest identifiable cause of learning disability.

The current incidence in the UK is around 1/1100 live births.

Resources: [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)  
[www.nhs.uk/conditions/Downs-syndrome](http://www.nhs.uk/conditions/Downs-syndrome)  
[www.cafamily.org.uk/Direct/d30.html](http://www.cafamily.org.uk/Direct/d30.html)

### **Dyspraxia**

Dyspraxia is a developmental disorder of organisation and planning of physical movement. The essential feature is the impairment of motor function that significantly interferes with academic achievement or activities of daily living. Dyspraxia sometimes runs in families.

Dyspraxia affects up to 10% of the UK population and boys are four times more likely to develop it than girls. Up to one in 30 children are affected by it.

Resources: [www.dyspraxiafoundation.org.uk](http://www.dyspraxiafoundation.org.uk)  
[www.nhs.uk/conditions/Dyspraxia%28childhood%29/Pages/Introduction.aspx](http://www.nhs.uk/conditions/Dyspraxia%28childhood%29/Pages/Introduction.aspx)  
[www.dyspraxia.org.uk](http://www.dyspraxia.org.uk)

### **Dysarthria**

People suffering dysarthria have difficulty expressing certain sounds or words. They have poorly pronounced speech (such as slurring) and the rhythm or speed of speech is changed. Usually, a nerve or brain disorder has made it difficult to control the larynx and vocal cords, which make speech. Dysarthria, which is a difficulty pronouncing words, is sometimes confused with aphasia, which is a difficulty producing language. They have different causes. People with dysarthria may also have problems swallowing.

Resources: <http://www.mult-sclerosis.org/dysarthria.html>  
<http://www.library.nhs.uk/stroke/ViewResource.aspx?resID=237642>

### **Foetal Alcohol syndrome (FAS)**

FAS is not a diagnosis, it describes a range of features which may include post-natal growth retardation, smaller than normal opening to the eye or moderate-to-severe learning difficulties. It occurs when babies are exposed to heavy maternal drinking during pregnancy.

Between one in two and one in three pregnant women with alcohol problems give birth to babies with FAS.

Resources: [www.fasaware.co.uk](http://www.fasaware.co.uk)

[www.nofas-uk.org](http://www.nofas-uk.org)  
[www.cafamily.org.uk/Direct/f27.html](http://www.cafamily.org.uk/Direct/f27.html)

### **Hypopituitarism**

Hypopituitarism is a condition in which the pituitary gland does not produce normal amounts of some or all of the hormones it should. Hypopituitarism may be caused by brain surgery, brain tumours or a head trauma or immune system or metabolic diseases. Symptoms are varied and can include Short stature (less than 5 feet) if onset is during a growth period, facial swelling, slowed growth and sexual development (in children), fatigue and headaches.

Resources: [www.pituitary.org.uk](http://www.pituitary.org.uk)  
[www.nlm.nih.gov/medlineplus/ency/article/000343.htm](http://www.nlm.nih.gov/medlineplus/ency/article/000343.htm)

### **Hydrocephalus**

Hydrocephalus describes a condition where the flow of brain fluid is obstructed. It accumulates in the ventricles which then enlarge and compress surrounding brain tissue, interfering with the blood supply to the brain. In babies (but not older children or adults) the head will enlarge.

Hydrocephalus is estimated to affect approximately 1 in every 500 children.

Resources: [www.hydroassoc.org](http://www.hydroassoc.org)  
<http://nhfonline.org>  
[www.ninds.nih.gov/disorders/hydrocephalus/  
detail\\_hydrocephalus.htm](http://www.ninds.nih.gov/disorders/hydrocephalus/detail_hydrocephalus.htm)

### **Hypotonia/Hypertonia**

Hypotonia literally means low muscle tone. It is caused by injury to motor pathways in the central nervous system, which carry information from the central nervous system to the muscles and control posture, muscle tone, and reflexes. When the injury occurs in children under the age of 2, the term cerebral palsy is often used. Hypertonia is where there is increase muscle tone this can be so severe that joint movement is not possible.

Resources: [www.ninds.nih.gov/disorders/hypertonia/hypertonia.htm](http://www.ninds.nih.gov/disorders/hypertonia/hypertonia.htm)  
[www.dystonia-foundation.org](http://www.dystonia-foundation.org)  
<http://www.livingwithcerebralpalsy.com/hypertonia-cerebral.php>

### **IMAGe syndrome**

IMAGe syndrome is a rare syndrome characterised by retarded foetal growth, abnormal bone development, underdeveloped adrenal glands and genital abnormalities. The only site located was aimed at medical professionals. This lists symptoms, diagnosis, misdiagnosis, causes, treatments and provides a list of references. No parent focussed web based resource was located.  
[http://www.wrongdiagnosis.com/i/image\\_syndrome/intro.htm](http://www.wrongdiagnosis.com/i/image_syndrome/intro.htm)

### **Learning Disabilities (LD)**

Learning disabilities are sometimes referred to as learning disorders or learning difficulties and the classification actually includes several disorders in which a person

has difficulty learning, usually as a result of unknown factors. Problems with the brain's ability to receive and process information can make it problematic for a person to learn as quickly or in the same way as someone not affected.

Individuals with LD account for around 1-2% of the UK population, between 602,000 and 1,204,000 million. People with moderate to profound learning disabilities represent 0.35% of the UK population, or about 210,700 people.

Resources: [www.mencap.org.uk](http://www.mencap.org.uk)  
[www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)  
[www.bild.org.uk](http://www.bild.org.uk)  
[www.learningdisability.co.uk](http://www.learningdisability.co.uk)

### **Mitochondrial cytopathy**

Mitochondrial Cytopathies are a group of disorders which may present at any age and are extremely variable in presentation and outlook. Mitochondrial cytopathies can involve either one tissue alone, such as muscle, or several different tissues.

Recourses: [www.cafamily.org.uk/Direct/m33.html](http://www.cafamily.org.uk/Direct/m33.html)  
[www.climb.org.uk](http://www.climb.org.uk)

### **Profound and multiple learning disabilities (PMLD)**

Children and adults with PMLD have more than one disability, the most significant of which is a profound learning disability. Every individual with PMLD will have difficulty communicating and many will have additional sensory or physical disabilities, complex health needs or mental health difficulties. Behaviour may also be affected and some people, such as those with autism and Down's syndrome, may also have PMLD. Both children and adults with PMLD will require high levels of support with most aspects of daily life.

There is very little data on the prevalence of PMLD, however a report by the Centre for Disability Research (CeDR) at Lancaster University on behalf of the Department of Health estimated that, in an 'average' area in England with a population of 250,000 the number of young people with PMLD becoming adults in any given year will rise from 3 in 2009 to 5 in 2026 ([www.mencap.org.uk/document.asp?id=14824](http://www.mencap.org.uk/document.asp?id=14824)).

Resources: [www.pmlidnetwork.org](http://www.pmlidnetwork.org)  
[www.dundee.ac.uk/pamis](http://www.dundee.ac.uk/pamis)  
[www.library.nhs.uk/learningdisabilities/ViewResource.aspx?resID=283450](http://www.library.nhs.uk/learningdisabilities/ViewResource.aspx?resID=283450)

### **Townes Brocks Syndrome (TBS)**

TBS is a genetic condition which affects several parts of the body. The most common features are an obstruction of the anal opening, abnormally shaped ears, and hand malformations that most often affect the thumb. Most people with this condition exhibit at least two of these three features.

The prevalence of TBS is unknown, although it has been estimated that it affects 1 in 250,000 people.

Resources: <http://ghr.nlm.nih.gov/condition/townes-brocks-syndrome>

**VACTERL Association (VA)**

VACTERL is an acronym for Vertebral anomalies; Anal anomalies; Cardiac anomalies; Fistula +/- esophageal atresia anomalies; Renal or Radius anomalies; Limb anomalies. VACTERL is manifest in a variety of ways so that the exact prevalence is unknown. Babies diagnosed as having VACTERL association usually have at least three or more of these individual anomalies.

Resources: [www.vacterl-association.org.uk](http://www.vacterl-association.org.uk)  
[www.cafamily.org.uk/Direct/v12.html](http://www.cafamily.org.uk/Direct/v12.html)  
[www.vacterlnetwork.org](http://www.vacterlnetwork.org)

## 14. Appendix 4: Organisations and agencies

During interviews participants spoke highly of organisations or agencies (some perhaps lesser-known) which have helped them in different ways with the challenges they face in raising their children. These organisations are both local and national and their focus of concern varies from deafness to other additional complex needs. The two most commonly named national charities were NDCS and SENSE.

[www.ndcs.org.uk](http://www.ndcs.org.uk)  
info@sense.org.uk

Below is a list of other organisations mentioned, in alphabetical order, which families may find useful:

### **Brainwaves**

Brainwaves seeks to help children between the ages of six month and 12 years old who have developmental delay, a brain injury or genetic condition. Brainwaves assess children and design child-centred therapy programmes for parents

Website: [www.brainwave.org.uk](http://www.brainwave.org.uk)  
Email: [enquiries@brainwave.org.uk](mailto:enquiries@brainwave.org.uk)  
Tel: 01278 429089

### **Cerebra**

Cerebra seeks to help improve the lives of children with brain related conditions. It conducts research, educates and directly supports children and their carers. Cerebra offers financial assistance as well as practical and emotional support to families.

Website: [www.cerebra.org.uk](http://www.cerebra.org.uk)  
Email: [info@cerebra.org.uk](mailto:info@cerebra.org.uk)  
Tel: 01267 244201

### **Children's Hearing Evaluation and Amplification Resource (CHEARs)**

Hearing assessment, fitting and evaluation of amplification is free via the NHS. CHEARs offers the only independent specialised paediatric audiology facility for hearing assessment from birth to adulthood. For more information go to:

CHEARs.co.uk Tel:01763 263333

### **Child Growth Foundation**

The Child Growth Foundation, among other things, aims to: Support and encourage children and adults (and their families) with growth disorders; Promote and fund research into the causes and cure of growth disorders in children; Educate the public in general and workers in the medical profession in particular, in the problems and difficulties encountered by those with growth disorders.



Website: [www.childgrowthfoundation.org](http://www.childgrowthfoundation.org)  
Email: [info@childgrowthfoundation.org](mailto:info@childgrowthfoundation.org)  
Tel: 0208 995 0257

### **Caudwell Children**

The goals of Caudwell Children are: to make donations to specific child cases of sickness, specialised medical requirements and dying wish holidays; To buy or build a property to aid children/children's charities; To continue to fulfil its half a million pound pledge to the NSPCC Full Stop Campaign.

The charity has made over 2000 donations to families with disabled children, donated almost £1million to help children with wheelchair needs, been independently acknowledged as the second largest voluntary provider of specialist equipment in the UK, supported children with over 300 different conditions and spent over £1.2 million on treatments and therapies for autistic children.

Website: <http://www.caudwellchildren.com>  
Email: [charity@caudwellchildren.com](mailto:charity@caudwellchildren.com)  
Tel: 0845 300 1348

### **Connect (St.Helens)**

Connect are a local voluntary organisation supporting families of children with disabilities in St Helens.

Website: [www.connectparents.org.uk](http://www.connectparents.org.uk)  
Address: Connect  
c/o Rosetree Cottage  
Portico Lane  
Prescot  
L35 7JW

### **Crossroads Care**

Crossroads Care offers a variety of support services for carers. Services include a trained carer support worker who comes into the home to take over the caring responsibilities, enabling the primary carer to take a break.

Website: [www.crossroads.org.uk](http://www.crossroads.org.uk)  
Email: Email via website  
Tel: 0845 450 0350

### **DASH (Hillingdon, London)**

DASH aims to provide advice, support and information that will enable disabled people to make choices about how they live their lives.

Their mission statement is: "To promote and enable equality of opportunity for all disabled people who reside, work or are undertaking educational or vocational training within the London Borough of Hillingdon and to ensure that all services are conducted in an holistic and inclusive manner".

Website: [www.dash.org.uk](http://www.dash.org.uk)

Email: [Info@dash.org.uk](mailto:Info@dash.org.uk)  
Tel: 0208 848 8324

### **Deaf Connections (West Scotland)**

Deaf Connections delivers specialist services to deaf adults in the West of Scotland. It works with health professionals and members of the Deaf community to improve Deaf people's access to health services. Deaf Connections provides a range of advice and information on health issues to the Deaf community and runs a wide variety of clubs and societies for Deaf and Hard of Hearing people from its base at the Glasgow Centre for the Deaf.

Website: [www.deafconnections.co.uk](http://www.deafconnections.co.uk)  
Email: [enquiries@deafconnections.co.uk](mailto:enquiries@deafconnections.co.uk)  
Tel: 0141 420 1759

### **Evening Chronicle Sunshine Fund (ECSF) (North East England)**

The ECSF endeavours to enhance the lives of disabled children in the north east of England region and help everyone associated with the child. The fund provides equipment to the families of disabled children.

Website: [www.eveningchroniclesunshinefund.org.uk](http://www.eveningchroniclesunshinefund.org.uk)  
Email: [general@communityfoundation.org.uk](mailto:general@communityfoundation.org.uk)  
Tel: 0191 230 0689

### **Hamlet Centre Trust (Norfolk)**

The Hamlet Centre Trust seeks to provide high quality services for the relief of children and young adults with special needs in Norfolk. At its headquarters in Norwich the Trust provides a wide range of activities for children with special needs and support and respite for families.

Website: [www.hamletcentre.org.uk](http://www.hamletcentre.org.uk)  
Email: [admin@hamletcentre.org.uk](mailto:admin@hamletcentre.org.uk)  
Tel: 01603 616094

### **I Can**

I CAN works to support the development of speech, language and communication skills in all children with a special focus on children with speech, language and communication needs.

Among other things, I Can seeks to: Increase public awareness of the problems children face; give expert advice to parents and families; provide assessments for children.

Website: [www.ican.org.uk](http://www.ican.org.uk)  
Email: [info@ican.org.uk](mailto:info@ican.org.uk)  
Tel: 0845 225 4071/0207 843 2510

### **Meningitis Trust**

The Meningitis Trust provides services to anyone who has been affected by meningitis, including [counselling](#), [art therapy](#), [one-to-one contacts](#), [home/hospital visits](#) and [family days](#).

Website: [www.meningitis-trust.org](http://www.meningitis-trust.org)  
Email: [info@meningitis-trust.org](mailto:info@meningitis-trust.org)  
Tel: 01453 768001

### **Motability**

Motability raises funds to provide financial help to Motability Scheme customers who would otherwise be unable to afford the type of car and any adaptations that they need. It administers the Government's Specialised Vehicles Fund which provides financial assistance for customers who need to travel in their wheelchairs. It provides technical support to customers and the adaptation and conversion industry.

Website: [www.motability.co.uk](http://www.motability.co.uk)  
Email: Email via website  
Tel: 0845 456 4566

### **Newlife Foundation**

The Newlife Foundation helps disabled and terminally ill children in the UK. It provides nurse services, equipment grants and links to medical research. They also conduct awareness campaigns.

Website: [www.newlifecharity.co.uk](http://www.newlifecharity.co.uk)  
Email: [info@newlifecharity.co.uk](mailto:info@newlifecharity.co.uk)  
Tel: 01543 462 777

### **Northern Counties Children's Benevolent Society (NCCBS) (North of England)**

The NCCBS provides grants for children to continue or commence independent education, grants for clothing (usually for disabled applicants) and grants for computers (usually for disabled applicants).

Website: [www.northtyneside.gov.uk/serviceitem.shtml?p\\_ID=376](http://www.northtyneside.gov.uk/serviceitem.shtml?p_ID=376)  
Email: [info@gmmlegal.co.uk](mailto:info@gmmlegal.co.uk)  
Tel: 0191 236 5308

### **Partners in Policymaking (England and Wales)**

Partners in Policymaking is a leadership training course for disabled adults and parents of disabled children. It shows people how to ask the right questions and how to present their questions to people who work in services.

Website: [www.partnersinpolicymaking.co.uk](http://www.partnersinpolicymaking.co.uk)  
Email/Tel: See website for region-specific contact details

### **Royal Association for Deaf People (RAD)**

RAD is a deaf-led organisation which promotes the welfare and interests of Deaf people. It provides a wide range of services for deaf people including translation services, social care, advice and support groups.