

Families living on a low income bringing up deaf children

Report to the National Deaf Children's Society

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Summary of the study

Chapter 1 is a review of literature relating to deaf young people living in low-income families. The aim of the review is to focus on research which increases fluency in language, and factors which improve language outcomes, even when socioeconomic circumstances are unfavourable. Deaf children growing up in low-income families currently have poorer language outcomes, and on average less successful academic outcomes from school. The review sets out the search strategy, which focuses largely on studies from higher income countries having similar health or education systems to the UK. The 59 sources are summarised and evaluated in nine themes. Finally, a synthesis examines the most important factors, discusses mediating variables where interventions may be possible to support low-income families, and summarises the most favourable strategies for interventions which could be more widely applied. One of the most promising results is the advantage with early identification and an early start in working with the family brings to language outcomes for deaf children from low-income backgrounds.

Chapter 2 aims to discover from parents living on a low income their experiences and views of bringing up a deaf child, the support available to them and challenges and supports they had in relation to their deaf child's language development. Questions were developed using the literature and focused on the idea of parent confidence and strategies, rather than seeing the families in a deficit light. Twenty-one families from all parts of the UK were interviewed, mostly face-to-face and two using phone interviews. The findings showed that for families living on a low income, new-born hearing screening and early intervention were not very effective. Many families, particularly those with weaker reading skills or those who did not use spoken English, wanted more information and discussion from professionals about language, communication choices and equipment. Families often had no way to report back to health and education professionals how they really felt, or found it hard to express their views. Parental confidence was related to having good information and an alternative source of information such as someone who knew about the education system. Many families did not have any alternative sources. Over half the parents in this study used British Sign Language (BSL) or more basic sign language at home. Professionals often discouraged them from using this approach, but parents found it useful. However, parents did not have many opportunities to learn sign language.

Chapter 3 discusses the findings of both parts of the study, relating the literature review to the findings from the analysis of interviews. Recommendations based on the findings are made in relation to National Deaf Children's Society (NDCS), teachers of deaf children and health professionals.

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Abbreviations

ACEs	Adverse Childhood Experiences
ADHD	Attention Deficit Hyperactivity Disorder
ASL	American Sign Language
AVT	Auditory Verbal Therapy
BATOD	British Association of Teachers of the Deaf
BSL	British Sign Language
CI	Cochlear Implant
CINAHL	Nursing and Allied Health research tool
CMV	Cytomegalovirus, a common virus which under some circumstances is associated with childhood deafness
dB	Decibel: a scale of sound intensity or loudness
DLA	Disabled Living Allowance
doi	Digital object identifier system, to identify academic articles on the internet
DWP	Department for Work and Pensions
EBSCO	a provider of research databases
Eds.	Editors of a book
EHDI	Early Hearing Detection and Intervention
ERIC	Education Resources Information Centre
et al.	and other authors: further details in the reference list
FSM	Free School Meals – associated with claiming means-tested benefits in the UK
GCSE	General Certificate of Secondary Education (UK exam, not Scotland)
IBSS	International Bibliography of Social Sciences
IEP	Individualized Educational Program (in USA context). In the UK Individual Educational Plan
IQ	Intelligence Quotient: a measure of general ability
JRF	Joseph Rowntree Foundation
LENA	Technology for monitoring family talk in the early years
LLBA	Linguistics and Language Behaviour Abstracts
LOCHI	Longitudinal Outcomes of Children with Hearing Impairment, an Australian research study
MEDLINE	a bibliographic database of the Life Sciences
MLU	Mean Length of Utterance, used in child language studies
N / n	Number of participants in a study / number in a sub-sample
NDCS	National Deaf Children's Society
NHS	National Health Service in the UK
ONS	Office for National Statistics
PhD	An advanced academic qualification called a Doctorate
prof.	Profoundly deaf
PycINFO	A resource database for Behaviour and Social Science research
SCOPUS	an abstract and citation database from publisher Elsevier
sev.	Severely deaf
SES	Socio-economic status
SSE	Sign Supported English
ToD	Teacher of deaf children
UNHS	Universal Newborn Hearing Screening

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Figures 1 and 2 are from Department for Work and Pensions (2019).

Figure 3 is from the Joseph Rowntree Foundation (2017).

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Chapter 1 Introduction

This study was commissioned by the National Deaf Children's Society as the organisation wanted to explore the experiences of families living on a low income bringing up deaf children. This group makes up from 16 – 37% of deaf children in the UK today. Eligibility for Free School Meals (FSM) serves as one indicator of the proportion of children in the UK who are living on a low income. To be eligible for FSM, families show that they are claiming means-tested benefits.

The proportion of children eligible for Free School Meals (FSM) varies across the UK. The countries report on FSM eligibility in slightly different ways; this summary is from 2017/18:

- In Wales, 16% of pupils were eligible (Welsh Government, 2018);
- In England 27% of pupils were eligible for pupil premium that is they were eligible for FSM then or over the previous 5 years (Department for Education, 2017, p.7);
- In Northern Ireland 30% were eligible (Northern Ireland Government, 2018);
- In Scotland 37% were eligible (Scottish Government, 2018).

NDCS was aware through casework that many families from a low-income background sometimes struggle to access the information and support they need to effectively support their deaf child's development in language and communication. The organisation wanted to improve their understanding of why this was and to begin to identify how the National Deaf Children's Society might be better able to support these families.

The study was conducted from the Scottish Sensory Centre, a research and practice centre which is part of the School of Education at the University of Edinburgh (www.ssc.education.ed.ac.uk). The study received ethical approval from the School of Education ethics committee (Ref. 1235, 13.2.18).

There are five research questions guiding this study. Chapter 2 looks at the first three, conducted through a review of the literature. Chapter 3 investigates the final two research questions, reporting on interviews conducted with 21 families living on a low income who have deaf children from across the UK.

Research Questions

- (a) What factors increase the prospects of fluency with language and communication skills and access to technology and services for deaf children from low-income families?
- (b) Can drivers be identified which may mediate these factors?
- (c) Which intervention strategies with families living on a low income have had the most success?
- (d) How do parents living on a low income view their access to information and support for their deaf child from family, community, third sector and statutory agencies?
- (e) What do these families see as the challenges and supports for themselves and their deaf children in relation to language and communication development?

Conceptualising poverty

Deaf children from the most deprived backgrounds, like their hearing peers, have the worst educational outcomes in the UK today (O'Neill, Arendt & Marschark, 2014). Poorer educational outcomes lead to fewer work opportunities, which has a continuing effect on lifetime earnings. These differences between children from families with a higher and lower income are evident in the very early years of life. Dickerson and Popli (2016) have shown that the cognitive effects of persistent poverty over the early years leads to a 20% cognitive gap by age seven, most of which is related to parental investment in the early years. So deaf children at the very start of school can be very much affected by their family's economic situation.

Families living in poverty often make decisions in very different ways to families with more economic and social resources (Sheehy-Skeffington & Rea, 2017); their rational choices may look irrational to professionals who often have no personal knowledge of living on a low income. Decisions effecting the early years are demanding for any family, but particularly for families living on a low income. Yet access to information and ability to make timely decisions are crucial in affecting outcomes in relation to the success of one or more languages (Ching et al., 2017). We hope that parents, teachers of deaf children, third sector organisations and policy makers find this report useful for exploring what is already known about the intersection of deafness and poverty internationally and in the lived experiences of a sample of UK families.

In this research we use a broad definition of the term *poverty*. The Department for Work and Pensions (DWP, 2018) describe people receiving below 60% of the median income as living in relative poverty. The median household income was £494 per week in 2016/17 before housing costs (see Figure 1); those living on a low income had a household income below £296 per week (or £15,392 per year). The DWP divide the whole population into 10% deciles with equal numbers of people based on income. Those living on a low income are in deciles 1 and 2.

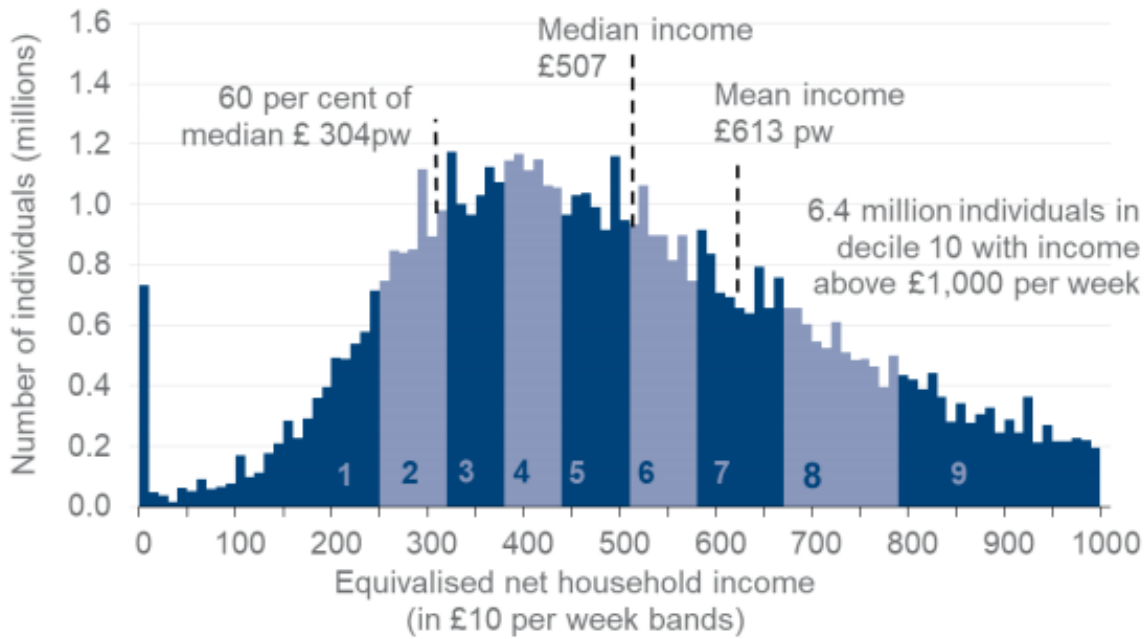


Figure 1 UK Income distribution before housing costs 2017/18

Source: Department for Work and Pensions, 2019, Households Below Average Income, p.3.

The proportion of children living in relative poverty was 30% in 2017/18 after housing costs, and has been at a similar level since the year 2002/3, see Figure 2.

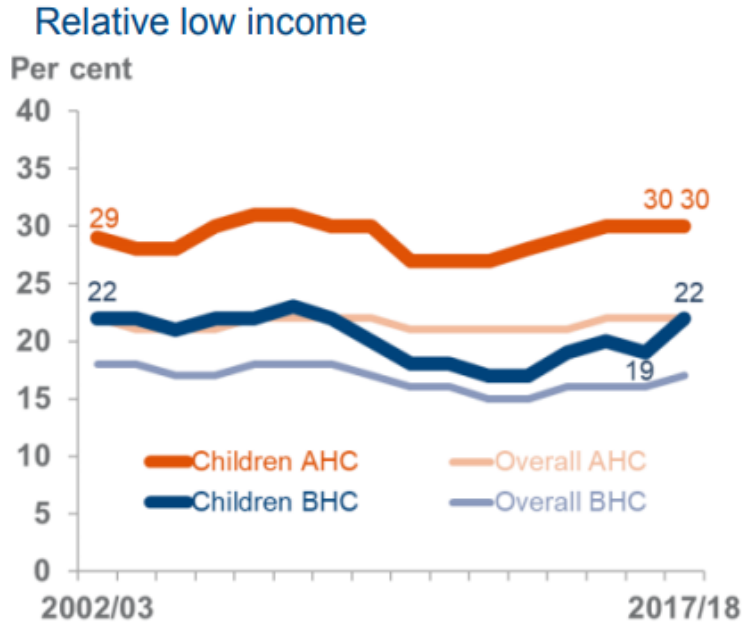


Figure 2 Percentage of children in relative low income 2002/3 - 2017/18

Source: DWP (2019) p.8. BHC = before housing costs; AHC = after housing costs.

Hirsch and Valadez-Martinez (2017) have shown that government estimates of poverty give more weight to workless households, whereas their calculations for the End Child Poverty Coalition have shown that 60% of children in poverty live in households where someone is working (see Figure 3).

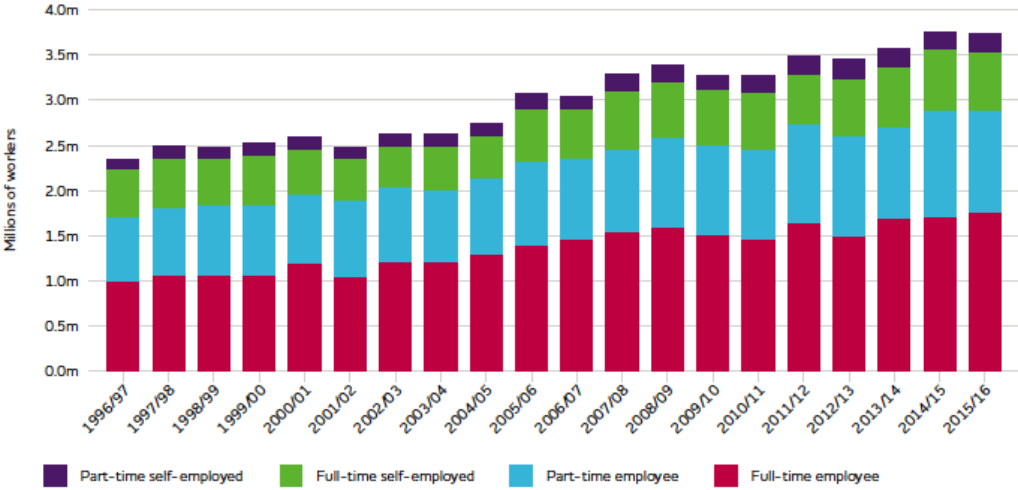


Figure 3 Number of workers in poverty by employment type

Source: UK Poverty 2017, JRF, p.36.

Families from ethnic minorities were more likely to have children living in poverty. There was still a 30% difference in the proportion of white families with children in poverty (19%) compared to Bangladeshi families with children (50%) in 2015/16, although this gap had narrowed from a 60% difference in 1997/98 (Joseph Rowntree Foundation [JRF], 2017, p. 27).

Similarly, disability is associated with poverty; the working age employment rate for non-disabled people was 80% in 2016 compared to 50% for disabled people (JRF, 2017, p.26). Disabled Living Allowance (DLA) and Personal Independence Payment add to income, but before taking that into account, the difference between poverty rates for working age adults with a disability compared to those without was 15% in 2016 (JRF, 2017, p.26).

Living on a low income has many economic, social and environmental costs (Netto, Sosenko & Bramley, 2011): *economic* in the lack of ability to afford meals, clothes, heating and services; *social* in the difficulty in taking part in activities and leisure pursuits; and *environmental* in the effects of having a poor infrastructure, poor services, more dangerous roads and more pollution and noise stress than more affluent neighbourhoods. This is a holistic way of approaching child poverty.

A different approach often driven by a policy agenda is Adverse Child Experiences (ACEs), i.e. counting negative child experiences such as living in a household with drug addiction or experiencing the death of a parent, also often associated with poverty (Health Scotland, 2018). Counting ACEs has become a common way to refer to the risks of living in poverty, even though they can be experienced by children living at all income levels. The advantage of counting ACEs is that it raises awareness of cumulative stress in some households. However, as Wickham et al. argue (2016), the specific ways in which poverty affects health and social outcomes need more investigation to find why they

happen. One example is poverty and neurocognitive function which Noble et al. (2015) investigated for hearing families. They found that the first signs of language and memory differences in babies occurred in the children of the lowest educated third of parents. Parental education is closely related to socioeconomic status. The differences appeared at 15 months and grew significantly worse to 21 months compared to expected development in the two-thirds of average or above averagely educated parents. Parental warmth was found in the same study to partially mediate the link between parental education and language development. Warmth is a factor in improving communication skills with infants; depressed mothers are likely to show less warmth.

Since 2006, universal newborn screening has been introduced across the UK but provision of early years services varies. Although most children attend follow up appointments, there is some evidence that families living in poverty have higher drop out from early years services, or through moving more frequently may miss appointments, or that mild deafness, not acted on by Universal Newborn Hearing Screening (UNHS) protocols in most cases, may affect poor children disproportionately (Watkin & Baldwin, 2010).

Thus, taking a holistic approach to child poverty is worthwhile, and looking for studies which explain the mediating factors between poverty and social outcomes such as cognitive and language skills. The studies reviewed in Chapter 2 examine the effects of living on a low income for families with a deaf child. Poverty and low socio-economic status (SES) are often controlled in studies about deaf children, but rarely focused on in their own right. Perhaps researchers feel this is a variable they can't influence, so it is controlled for in study designs. Poverty is less studied than other psychological characteristics of deaf children and their parents. The studies in this review are ones where SES is a central issue, or a variable which proved significant. The picture we will discover is far more interesting than a variable to be controlled: there is a higher proportion of deaf children from the poorest groups in society, and early interventions can have a significant effect on mediating the usual outcomes between poverty and educational achievement.

Chapter 2 Literature review

The aim of this chapter is to produce a purposive literature review of published studies in relation to families living in poverty with deaf children, including grey literature and unpublished theses.

The research questions for this part of the study are:

- (a) What factors increase the prospects of fluency with language and communication skills and access to technology and services for deaf children from low-income families?
- (b) Can drivers be identified which may mediate these factors?
- (c) Which intervention strategies with families living on a low income have had the most success?

Search Strategy

A search strategy of the literature between 1990 up to and including November 2018 was conducted using a wide range of electronic databases, covering the disciplines of education (ERIC: Educational Resources Information Centre); clinical psychology (PsycINFO: a resource base for behavioural and social science research); Ebsco (provider of research databases); social sciences (IBSS: International Bibliography of Social Sciences); linguistics (LLBA: Linguistics and Language Behavior Abstracts); and health (CINAHL: a Nursing and Allied Health Research tool). Search terms are given in Appendix 1. The large multidisciplinary database, SCOPUS, was used, which includes a search of MEDLINE, a bibliographic database of the life sciences. Individual journals that specifically publish research on deaf children were searched, including *The Journal of Deaf Studies and Deaf Education*, *American Annals of the Deaf*, and *Deafness & Education International*. Searches commenced from 1990, on the grounds that hearing aids and cochlear implants were much more effective from this date (Boothroyd, Geers & Moog, 1991; Levitt, 2007) and that evidence for bilingual education programmes were also more often researched seeing the Deaf community as a different culture, not deficient or disabled (Gregory, 1992). However, few studies came from the period before 2000.

Selection Criteria

We expected to find a range of approaches to research in the literature, so we should heed Suri (2011) in constructing a synthesis which is efficient, credible, sufficient and ethical. Rather than setting out key terms for databases and subsequently rejecting many studies as not being rigorous enough, we pursue a purposeful sample which will examine studies from several research traditions, particularly different theoretical approaches to the study of families living in poverty. In this way diverse methodological approaches will be accepted on their own terms. Connections between studies leads to synthesis (Cohen, Manion & Morrison, 2018), taking forward ideas to the co-researchers and the analysis of interviews.

In this review, first priority was given to peer-reviewed articles in English with child or parent participants. Abstracts and full texts were reviewed. Further searches of reference lists and citations of identified key articles were undertaken. Websites of third sector organisations concerned with poverty and disability were searched to identify studies closely related to the research aims or grey literature, focusing first on the UK, Europe, Australia, New Zealand and the USA. Key UK organisations (NDCS, British Deaf Association, Action on Hearing Loss, Sign Project, SENSE – a deafblind charity, Ear Foundation, Royal Association for Deaf People, Deaf Action, Auditory Verbal Therapy UK, and BID, a charity for deaf people based in Birmingham) were contacted to locate grey literature from 1990 onwards which may not be on websites.

Selection criteria were refined after reading the abstracts and full papers identified in the scoping search. The study did not exclude research about children with mild deafness, or deaf children with additional disabilities, or children with other impairments, as these are likely to interact with the main areas of poverty, communication and access to support. Inclusion criteria were then reviewed, prioritising peer-reviewed studies directly on the topic of family poverty, communication and language, and access to information and support for deaf children: participants who are parents living in poverty, longitudinal studies, and studies with qualitative, quantitative or mixed designs. Most of the sources found were in English but one in Portuguese was included as relevant. Studies were excluded if they did not report on deaf children and families in relation to socioeconomic status.

Countries chosen include the UK and other countries with similar health and education infrastructures, but also considered countries without these resources where poverty is more prevalent. Grey literature, i.e. informally published literature and literature in other languages, plays a role in this study because there have been some interesting unpublished projects from charities and self-help organisations. Scholars and non-governmental organisations from round the world have produced university-level theses and dissertations or qualitative evaluations that may help interpret from different perspectives how the factors leading to success with language and communication operate in other countries which could be useful for us to consider in the UK.

Analysis

There were 10,837 hits leading to 142 to pass to the next stage. Journals related to deaf education were searched, leading to 8 further studies. ProQuest Dissertations and Theses Global database led to 7 more being found. Google Scholar (17,500 hits since 2014) located 3 additional studies. Full texts were searched for from the University of Edinburgh and Interlibrary loans.

There were 160 screened sources and sorted. Fifty-nine were analysed for this review and 101 rejected after scrutiny; some were related but not directly e.g. about children in much poorer countries.

Nine themes emerged from the content analysis, shown below in the tables. In the right-hand column is a commentary on the importance or relevance of the work. The studies showing the strongest evidence are labelled * in the author column, and those focusing most directly on deaf children living in families on a low income with §.

The themes are presented below in nine tables:

1. The incidence of deafness and socio-economic factors
2. Outcomes for language and cognition are often weak for poorer children
3. Stress and adverse life events
4. Diagnosis and intervention pathways relating to SES
5. Having a deaf child has other associated costs
6. Knowledge of health and education system affects language acquisition
7. Home culture and language are important sources of strength
8. Professionals' attitudes are sometimes negative
9. Issues in research in this area

Themes from the studies

Table 1 The incidence of deafness and socio-economic factors

<i>Main issue</i>	<i>Authors</i>	<i>Country</i>	<i>Findings related to SES</i>	<i>Commentary</i>
Incidence of deafness in Hispanic communities	Lee et al. (1997)§	USA	The researchers take an epidemiological approach to examine the socioeconomic characteristics of the Cuban-American, Mexican-American and Puerto Rican children in the Southwest states of the USA. Using an existing multistage health survey of the whole population, they found that of 3,933 children aged 6 – 19 with audiological records, a larger proportion than expected in the wider USA, were deaf. Children who were not insured were nearly twice as likely to be deaf as those insured. The researchers suggest higher rates of crowded housing as a possible cause of middle ear deafness, otitis media.	The health insurance situation in the USA is very different from the UK context. However, these same issues of crowded housing cause temporary deafness around the world.
Incidence of deafness in a Scottish city	Kubba et al. (2004)§	UK	The study is based on births in Glasgow between 1985 and 1994. They found that level of deprivation had no effect on age of diagnosis, which was on average 18 months then, or on provision of hearing aids. But an increased chance of deafness was associated with poverty. The incidence of deafness (both ears, 40dB or more) per 1,000 live births was 0.47 for the most affluent Carstairs category compared to 1.72 for the least affluent with 105,517 children in the study. One reason suggested for the increased incidence was that families living in poverty are more likely to have a pre-term baby of low birth weight, both factors for a higher chance of deafness. The other reason given is that deaf families have lower educational qualifications, are more likely to be unemployed and often have several deaf children.	At this time the method of diagnosis was the Health Visitor distraction test often carried out at 7 - 18 months. It would be interesting to update it today.
Correlation of deafness and poverty	Boss et al. (2011)	USA	The researchers used a general population sample from the USA National Health Interview survey of families with 76,012 children, of whom 2.6% had some hearing loss and 0.43% had marked hearing loss. Families of hearing-impaired children were more likely to report poorer health status, have Medicaid, live in single-mother households, and live below the poverty level. Children with any degree of deafness were less likely to be able to afford prescription medications and less likely to have access to mental health services or dental services. The	The medical care context in the USA is clearly different from the UK, but incidence of deafness at different income levels is likely to be similar.

			survey showed that compared to families with hearing children, families with deaf children were more likely to live near the poverty line and use some health services less often, because they couldn't pay for them.	
Incidence and referral pathways after newborn screening	Watkin & Baldwin (2011)	UK	This study examines the prevalence of deafness to age 11 in Waltham Forest, London. The prevalence rate per thousand for bilateral deafness of 40dB or more was 1.01 from birth, 0.25 for children moving in to the area, and 0.25 for late onset, 54 children in all. At 1.51 per thousand this is higher than the UK average of 1.44. In this authority there were additional times when deafness might be reported: by parents, the health visitor distraction test and the school-entry hearing screen. Only 59% of deaf primary school children had been identified by the neonatal screen. In this part of East London, the incoming children come from many different countries and had usually not had a hearing assessment in their country of origin. The post-natal age of referral averaged 3;9 with the highest at 5;3.	The authors argue for the continuation of referral paths and later screens because newborn screening does not identify mild deafness, and because in areas of poverty and movement in and out of an area, many children are missed by the screen. This is more likely to affect migrants, who are more likely to be living on a low income.
Incidence in teenage years	Lin et al. (2011)§	USA	A sample of 3,143 young people aged 12 – 19 were audiological screened and recorded as deaf if their threshold was more than 25dB in both ears. From these results the incidence of deafness in the US population was calculated. For the 12 – 19 age group, the overall prevalence was 0.31%. However, this varied by gender (female 0.42, male 0.20) and race and ethnicity (White 0.26, Black 0.48, Hispanic 0.43).	The implications of these differences in incidence in teenaged deaf people are not discussed. The over-representation amongst Black and Hispanic young people in a USA context is highly related to SES. It would be interesting to find similar prevalence rates for a younger age group.
Socioeconomic factors relating to increased incidence of deafness	Kerschaver et al. (2012) *§	Belgium	Flanders in Belgium has had a newborn hearing screening programme since 1998. This paper uses data from 2003-4 to examine the usually known risks factors for deafness in newborn babies. The prevalence of deafness in one or more ear of 35dB or more was 0.15/1,000 babies. The researchers discovered a cluster of socioeconomic factors which raised this rate: gender (boys 1.78), birth order (e.g. 4 th child 2.38), baby length at birth, feeding type (bottle-fed 2.0), a lower level of education of the mother and origin of the mother, particularly Eastern Europe (3.82) and Africa (2.36). They conclude that health professionals should monitor babies who have these socioeconomic indicators carefully as they have a greater risk of deafness. Bottle-	As we have newborn screening in the UK, it may be thought this paper is not relevant. However, it contains significant findings. Not all families attend follow up appointments and some are lost to the system. The health service tries to follow up, but more effort could be made when these risk factors are present. National Health Service (NHS) Greater Glasgow (2015) is an example where difficult to engage families are visited at home or

			feeding a baby is clearly not a prenatal risk factor, but may be associated with poverty and less health information. They recommend that if newborn screening is not going to be used, as is the case in part of Belgium, then targeted screening of underprivileged babies can be highly effective. The team also recommend that if a pass or refer decision has not been taken within 20 minutes of a newborn screening test, they should be referred to audiology.	places easy for them to attend. Health and education staff would benefit from training on these socioeconomic risk factors.
Systematic review of paediatric risk factors for deafness	Vasconcellos et al. (2014)* §.	USA	This systematic review from 20 studies across the world (1966-2013) found that there was a significant association between child deafness and nutritional deficits and elevated blood lead levels and socioeconomic status. Babies more than two standard deviations below the mean for weight, body-mass index and length for age were at higher risk of deafness. Iodine deficiency may be associated, though more research is needed.	The authors carefully note that the association between deafness and these societal factors does not mean the societal factors are causal relationships.
Updating factors linked to deafness	Vos et al. (2015)*	Belgium	This second Belgian team wanted to update the old risk factors for deafness at birth because some, like rubella, are now treatable and very rare. They used a literature review of scientific studies and discussion between experts to decide on the new list of factors. A high level of evidence was found for Cytomegalovirus (CMV), toxoplasmosis and syphilis – all infections passed from mother to baby before birth. Also high was a family history of deafness, parents or grandparents being related, e.g. as cousins, malformation syndromes and foetal alcohol syndrome. There was a moderate level of evidence quality for risk from high levels of bilirubin, which can lead to jaundice. Other factors were previously high risk but are now much lower possibly, the authors argue, because of improved medical procedures: very low birth weight, low Apgar score and stay in intensive care baby unit for example. The panel of experts also noted that there is a cumulative effect for risk factors.	Some of these factors coincide and may be cumulative. For example, low birth weight, foetal alcohol syndrome and stay in intensive care are quite commonly found together, and are also risk factors for cognitive impairment. Many of these risk factors are associated with poverty.

Table 2 Outcomes for language and cognition are often weak for poorer children

<i>Main issue</i>	<i>Authors</i>	<i>Country</i>	<i>Findings related to SES</i>	<i>Commentary</i>
Parental involvement	Calderon (2000)	USA	Mothers who used additional services, such as speech therapy, sign language classes or other medical interventions, had children with poorer social and emotional adjustment. Maternal education was used as a proxy for SES, but in fact it did not predict positive language outcomes for the children; strong maternal communication skills did.	Teachers rated parents' involvement. Parents rated their use of additional services. Researchers rated parents' perceived involvement after a home visit. Researchers rated parental communication from videos of parent-child interaction.
Age of CI implantation	Holt & Svirsky (2008)	USA	The researchers wanted to determine if there were significant advantages of implanting before one year old. The 96 children in this study had no additional disabilities and were all implanted before age 4, with 6 being implanted before age 1. Their spoken language development was followed with standardised assessments for at least two years post implantation. Estimated family income was a variable. Findings were that the rate of progress with spoken language was not significantly faster for those implanted at under 12 months compared to the ones implanted between 1 and 2 years old. However, there was an effect of family income on the rate of language development: children from families with higher estimated incomes had faster receptive skills in spoken language, but slower expressive skills, and SES did not predict early word recognition in this study.	In this study the authors do not say how mean annual family income was estimated; presumably it was indirectly. A more robust measurement of SES would be more convincing. They suggest that the relationship between SES and language development is not likely to be direct, but mediated by maternal speech.
Spoken language and CIs	Geers et al. (2009)	USA	The study aimed to discover how far age appropriate spoken language skills could be expected for children implanted at a young age. The 153 deaf children were aged between 5;0 and 6;11, attended oral programmes in the USA and did not have any known additional disability. Using standardised language assessments results ranged from 50% who were within 1 standard deviation for receptive vocabulary to 39% for expressive language. That is, the children gained scores of 85 or better on a standardised test where the expected norm for that age is 100. The number of years of parental education was used as a proxy SES indicator. Years of parental education were significantly correlated with performance IQ, a non-verbal ability assessment. After controlling for the	The authors consider that teaching early vocabulary labelling may have influenced the expressive vocabulary results. This study uses regression in an interesting way to show that the best age for implantation varies depending on the type of language task being undertaken, with levels approaching average only being possible for receptive language skills if implantation is by one year old.

			effects of non-verbal intelligence and parental education, children who were implanted at younger ages had higher scores on all language tests. The age of implantation at which language scores were on average below 85 on a standardised test varied from 4 for expressive vocabulary to 1 for receptive language.	
Parental involvement	Sarant et al. (2009)	Australia	The 57 deaf children aged 6 or under were enrolled in oral programmes. The early years team rated parents' involvement. In the regression model, family participation explained 25% of Clinical Evaluation of Language Fundamentals Preschool scores, i.e. expressive and receptive spoken English. Years of maternal education were not significant, though the median was high in this study at 16 years. There was a positive correlation between years of maternal education and family participation, and family participation in the early years programme had a significant effect on spoken language outcomes.	The researchers suggest that above average parental involvement may be needed from families to achieve good spoken language outcomes.
Spoken language and CIs	Niparko et al. (2010)	USA	The research team aimed to investigate spoken language skill after CI implantation. The study potentially could have included all children implanted at 6 USA CI centres over a 3-year period. Criteria for inclusion were English is spoken at home, the children are enrolled at an English-speaking school and did not have significant learning difficulties. However, children with additional disabilities were not excluded. The group of 188 children was matched with 97 hearing children, although the parents of the hearing children tended to have higher incomes. Language skills were measured at 6-monthly intervals post implant for 3 years. Parent-child interactions were videoed and coded. Results showed that mean scores were not age appropriate after 3 years, but the means were better than would have been predicted from the baseline assessments. When the child had residual hearing before the CI operation, or there was more parent-child interaction or higher SES, then the rate of progression was faster in both comprehension and expressive skills.	This was a more inclusive sample than the Geers one. Results showed the positive effect of higher SES: higher family income was associated with more maternal involvement with communication and more years of parental education.

<i>Main issue</i>	<i>Authors</i>	<i>Country</i>	<i>Findings related to SES</i>	<i>Commentary</i>
Spoken language development after CI	Szagun & Sumper (2012)*	Germany	<p>This study had two aims: to investigate optimum age of implantation, and to find out if maternal education and maternal speech behaviour influenced spoken language outcomes. There was no overall effect of age of implantation, though there were differing patterns of spoken language growth by age. Faster linguistic progress was associated with higher levels of maternal education. Longer maternal mean length of utterance (MLU) was associated with higher maternal education, and also with children's progress. Expansions were also related to children's progress, but not so tied to maternal education. Expansions are a form of grammatical feedback; for example, if the child says 'two house' the parent may say 'yes, two houses'</p> <p>This study has a sophisticated approach to examining maternal language input for the child, considering the effect of child's language on the mother's input.</p>	<p>The article reveals, incidentally, that families with implanted children in Germany receive about 60 days per year at the CI centre with a parent over the first two or three years post implant. The likely economic effect on families is not discussed in this article.</p> <p>It could be that the extensive training all families receive from German CI centres may help with expansions, whereas MLU may be more strongly related to SES and less amenable to change.</p>
Spoken language in the home: early years	Van Dam et al. (2012)	USA	<p>Using the LENA recording device, this study aimed to discover if the families of 22 deaf children (mean age 30 months) had a similar adult word count and number of conversation turns with their child as in hearing families. Using the whole day recordings, they discovered that conversational turns were associated with the deaf child's receptive language skills, not the overall adult word count. The number of turns was associated with better hearing levels. The adult word count and conversational turn rates were better for both the deaf and hearing samples compared to the larger normative age matched group.</p>	<p>LENA has been widely used in the USA to monitor parental spoken language particularly in low-income families. Thus, the normative sample these researchers used was divided to find a subgroup matched to the deaf group by age of the child and maternal education level, i.e. attempting to match by SES. However, the matching was not very accurate and the deaf sample had higher levels of maternal education. We do not discover if the deaf toddlers had effective early intervention programmes.</p>

<i>Main issue</i>	<i>Authors</i>	<i>Country</i>	<i>Findings related to SES</i>	<i>Commentary</i>
Spoken language in the home: early years	Sacks et al. (2014)*§	USA	This study used the LENA recording device with 11 families of low socioeconomic status or where English is a second language with a deaf child. The mean age of the child was 33 months. Five of the children had CIs and the rest were aided. The researchers used LENA to provide data to parents as part of an early intervention programme. Families received an education session about child language development and strategies to enrich home spoken language. The deaf child used the recording device for 5 full days, with 4 feedback reviews between researcher and parent. Adult Word Count, Child Vocalisation Count, and Conversational Turns were counted per hour. Both turns and vocalisations increased significantly, suggesting that the intervention and feedback about the LENA results, or charts, were useful for parents.	Quantitative linguistic feedback is given to parents in this study as part of a behaviour change strategy. The researchers demonstrate that the approach works, although it seems at present the educational input is low and the cultural sensitivity of the intervention could be developed further.
Cognitive skills and SES	Macauley & Ford (2013)*§	UK	The researchers evaluated the cognitive development of 48 profoundly deaf children of average age 8 born from 1994 – 2002, looking at their family SES and how many siblings the deaf children had. They looked at verbal skills, and cognitive skills such as theory of mind and inhibition. The researchers matched the deaf children to a group of hearing younger children who shared many of the same verbal and cognitive skills. However, for deaf children with more siblings aged 12 and under, there were negative effects on memory span, inhibition, understanding others' beliefs, accuracy with sequencing pictures and mental state language, that is knowing how to talk about thinking and feelings. The researchers concluded that birth order is a serious issue for deaf children's language development, and that when time and resources are limited, deaf children were often not able to compete.	Inhibition means being able to focus on something and ignore a distraction, important for building concentration for school work. Theory of mind is the developing ability of a child to imagine or understand what other people are thinking. There is a relationship in the UK demographics between larger families and poverty (JRF, 2017)
Literacy outcomes and SES	Twitchell et al. (2015)*	US	The argument given for the success of deaf children who use speech and become literate is that the language of teaching is spoken English which matches the text in print. But many deaf bilingual children achieve literacy without necessarily developing spoken English. This study looked at the effect of SES and American Sign Language (ASL) proficiency on 135 deaf signing bilingual young people's reading skills. The age range of the deaf young people was 6 – 26 with mean of 15 years. The research team did not find a correlation between ASL and SES, but they did find that both factors predicted good reading, that is high SES and fluent ASL	Reasons are likely to be due to more knowledge of the reading process, more talk focused on the child in the early years, and more resources available to enrich vocabulary and support reading. We don't know from this study what access to learning ASL the hearing parents had (36% of the families), but the remainder were deaf families with fluent ASL. There

			both independently predicted better reading. The finding that high SES predicts better reading is true for all children, but in this study this result was confirmed for deaf children who are ASL users.	was no measure of spoken language in this study.
Spoken language in the home: early years	Suskind et al. (2016)*§	USA	The same research team as Sacks et al. tried a similar intervention with 32 families of low SES with children aged less than 4;6 and with deafness level of more than 30dB who had an aid or CI. The child wore the LENA device for a day. Parents were shown the LENA results as charts comparing their child to the normative sample. In addition, parents filmed themselves playing and analysed the video at the weekly visit. The researchers used before and after questionnaires with parents to establish if they knew more about child language development as a result of the 10-week home intervention. Results showed that the parents significantly increased their knowledge and maintained it. Adult Word Count and number of adult child conversational turns were measured. Although there were increases in the number of adult utterances, the variety of word type and length of utterance, these were not significant compared to the hearing control group.	The researchers recognise that parents living in poverty often have access to only low-quality childcare and can't afford educational interventions. The team aim to find a culturally appropriate parent curriculum for this group. <ul style="list-style-type: none"> • Also Theme 7: Knowledge of the health and education system
Spoken language	Cupples et al. (2018)*	Australia	This study of 339 deaf children is part of the Longitudinal Outcomes of Children with Hearing Impairment (LOCHI) study. The researchers compare factors influencing positive spoken language outcomes for deaf children with hearing aids and CIs. The range of maternal education in each group was similar. They found that maternal education (i.e. SES) was very significant for language outcomes for children with hearing aids, but not for CIs.	It is not clear from the authors why there is this difference. Possibly because children with CIs all receive more early intensive habilitation, whereas the amount may be more variable for aided children.

Table 3 Stress and adverse life events

<i>Main issue</i>	<i>Authors</i>	<i>Country</i>	<i>Findings related to SES</i>	<i>Commentary</i>
Father's presence and children's outcomes	Calderon & Low (1998)	USA	The researchers used validated questionnaires to establish information from parents and teachers about their involvement in their deaf child's development and early schooling. The sample of 22 is small, and the presence or absence of a father in these families was not related to SES. Results showed that the father's presence independently positively affected the deaf child's language and communication skills.	This is an old study now, from before newborn screening in the USA. In only 5 of the 22 families was the father absent. The researchers suggest that two parents provide more time available to interact with the deaf child, and that fathers' style of interaction through play may be facilitative.
Parental involvement in school	Kluwin & Corbett (1998)*§	USA	This study tackles the issue of under-achievement of black and Hispanic deaf children in the education system by interviewing 105 parents in USA cities whose deaf children were aged 2 – 14. Of this group, 41% were African American and 38% Hispanic. Results suggest that the parents need a great deal of support, as much as the children, and that different ways and persistence is needed to engage them.	It is not clear from this study how participants were identified. The analysis is largely quantitative and given the opportunity to gather parental views, strangely not listening to their perceptions. The authors realise that their findings are not causal, and conclude that the reasons for poverty being linked with under achievement are complex. <ul style="list-style-type: none"> • Also Theme 7: Knowledge of the health and education system
Maternal stress	Pipp-Siegel et al. (2002)	USA	The 184 mothers of deaf children in this study experienced significantly less stress than a normative sample. The families were from Colorado and New Mexico where early intervention programmes are well established. Using validated scales about parent child interactions, the researchers found that some factors led to higher stress levels: experiencing more everyday hassles, having less social support, and a lower annual family income. Many factors did not predict maternal stress including child's gender, ethnicity, age of identification of deafness, mode of communication, and maternal education	The early years intervention in Colorado in particular is very high quality, which could mean these results about maternal stress levels might not be replicated elsewhere. Despite the success of this programme, the negative effects of poverty are apparent in maternal stress levels.

<i>Main issue</i>	<i>Authors</i>	<i>Country</i>	<i>Findings related to SES</i>	<i>Commentary</i>
Emotional disturbance	Sinnot & Jones (2005)§	USA	The 115 deaf students in this 1994-1999 study had all received a diagnosis of emotional disturbance. They differed from other deaf young people in Illinois in being more likely to have had a premature birth and prenatal or perinatal trauma. They were more likely to have become deaf after birth but before the age of 3, live with a single parent, be from an ethnic minority and to live in an urban or suburban area than the whole deaf population. 15% of this group was in care and 50% was medicated. This group was more likely to use sign language than the other deaf group in the State.	This group had a multitude of issues which overlap with poverty. The authors conclude that they need highly skilled professionals to work with them and many are in residential care or medicated. SES was not a factor in this study but the focus of a descriptive survey.
Spoken language	Vohr et al. (2010)*	USA	This study collected SES information about the mothers, e.g. years of education, if they had health cover and language of the home to match to a group of hearing mothers. Maternal communicative behaviour, maternal stress, level of deafness in the child, and child stay in the intensive care unit were all associated with number of words the deaf children produced at 18–24 months. Higher SES was associated with more maternal structure and direction in play, which was associated with more words produced. When the mother had more resources, this was related to better overall enjoyment and availability of the mother in the play session, and more words produced.	The deaf children were all referred from newborn screening and 19/31 had been in intensive care. This research team is particularly interested in the cognitive effects of stay in intensive care, high for deaf children. They conclude that maternal stress is an important factor which reduces the quality of communication between mother and child.
Parental stress	Quittner et al. (2010)	USA	Although there is not strong evidence of increased parental stress when there is a deaf child in the family, this study attempts to find what the relationships are between the predictors of stress. Discrepancies in language levels and behaviour problems are the two factors investigated. The 181 children with CIs were matched with a hearing	The participants for this study were drawn from a CI programme. Matching between families of deaf and hearing children was not very effective. All children had CIs and used a spoken language approach.

			group of 92. However, the families with a deaf child were significantly more likely to be on a low income and be a member of an ethnic minority or speak Spanish at home. The team concluded that language delays affect parenting stress by way of behaviour problems.	The authors argue that better parent-child communication from early intervention programmes, may lead to less parental stress.
Social support and depression in mothers	Sipal & Sayin (2013)§	Turkey	The study investigated maternal depression finding a clear relationship in Turkey between having a deaf child and maternal depression, with social support mitigating this effect. A quarter of all the mothers were depressed, using validated scales. The results show a correlation between low SES and an authoritarian parenting style. The conclusion is that support to the whole family will help the mothers of deaf children.	This study used a simple 3-way classification of SES with 59% of the sample of 103 mothers being classified as low SES and 68% having had only primary education. This is a very different context from the UK, and support provided by the state for deaf children is likely to be much less than in the UK.
Social competence	Hoffman et al. (2015)	USA	Social competence is the ability to use social skills to get along with people. This study compared social competence between 74 deaf and 38 hearing children aged 2;5 - 5;3. The deaf children were all on spoken language programmes with CIs. The children's social skills were rated by both parents and teachers. The researchers controlled for SES (maternal education and income) and found that having hearing and having higher language skills predicted social competence. They argued that social skills are strongly mediated by language skills. They concluded that difficulty with language skills has a cascading effect on deaf children's social skills.	The research team found a large sample representative of different ethnic groups and SES groups in USA society, which had not been found before in CI studies.

<i>Main issue</i>	<i>Authors</i>	<i>Country</i>	<i>Findings related to SES</i>	<i>Commentary</i>
Low-income families with deaf children with CIs	Stanley (2018)§	USA	This recent PhD study looks at audiologists' views of the habilitation of 10 deaf implanted children from low-income families and compares this to themes found by interviewing the parents. The study provides evidence of socio-economic barriers, parents being disappointed with spoken language outcomes after the CI, and reports on parental health literacy. Audiologists were approving of parents who worked less so they had more time with their child.	<p>Questions to the audiologists suggested there may be difficulties related to poverty, not possible strengths. The study could have included children from a range of SES backgrounds and asked less biased questions.</p> <ul style="list-style-type: none"> • Also Theme 8: Professionals' attitudes are sometimes negative.

Table 4 Diagnosis and intervention pathways relating to SES

<i>Main issue</i>	<i>Authors</i>	<i>Country</i>	<i>Findings related to SES</i>	<i>Commentary</i>
Academic achievement	Reed et al. (2008)	USA	This study aimed to discover the supportive and detracting influences on school success for mainstreamed children at all levels of deafness. The 25 case study children aged 8 – 16 included interviews with the children, parents, class teachers and visiting specialist teachers. Focus is on the minority achieving above or below average. Despite the children performing at below average levels having considerable support from the school services and some interaction with home, the detractors outweigh them. Late diagnosis tends to lead to a cascade of other issues, including concentration and motivation.	<p>The focus is not directly on socio-economic status, but the findings show that distance to the school, knowledge of English and/or sign language, and contact with the school were all detractors. Noticeable is how many of the whole sample were achieving very well academically at school.</p> <p>Late diagnosis is listed as a child factor, when it is largely due to the organisation of health and education services. These children predated newborn screening.</p>
Spanish speaking families and language in the home	Aragon & Yoshinaga Itano (2012)*§	USA	The research team use a recording device, LENA, to investigate the spoken language environment in Spanish speaking households with a deaf child. Ten families took part, compared with English speaking families with a deaf child (24), and families with hearing children who spoke Spanish (10) and English (329). LENA does not examine what is said but counts the number of adult words, conversational turns, child vocalisations and silence / TV. The range of child vocalisations was smallest in the hearing parent and hearing child group, with the median similar to the families with a deaf child who speak English at home. The median level of vocalisation was lower both for Spanish families with and without a deaf child. Despite the lower SES, and as a result of the early intervention programme, the median adult word count was higher for Spanish speaking families with a deaf child than for English speaking ones with hearing children.	In the USA, speaking Spanish at home is highly related to SES and level of maternal education. The study was conducted in Colorado, a state with excellent early intervention services, so may not be possible to replicate elsewhere. In this study maternal education was highly linked to language spoken at home: the positive effect of early intervention programmes with families with deaf children, particularly those with Spanish at home, is a remarkable feature of the study. The conclusion is that the more conversational turns in the home, the better the deaf child's receptive and expressive vocabulary. This study shows how important high quality early intervention is, particularly for families living on a low income.

<i>Main issue</i>	<i>Authors</i>	<i>Country</i>	<i>Findings related to SES</i>	<i>Commentary</i>
Early intervention	Leigh et al. (2015)	Australia	As a study of 301 deaf 3-year olds from the LOCHI study, the research team investigated psychosocial and motor development. The presence of additional disabilities and low birth weight were significant predictors of poorer social skills and motor development, but SES and maternal education were not. The researchers found positive correlations between language ability, social and motor development, and the psychosocial performance of deaf children were within the range expected for hearing children. This was an unexpected finding given the history of previous research with deaf children, but this sample was identified at a very young age and experienced consistent early intervention services.	39% of the sample have a university degree, slightly above the Australian 2011 census rate of university attendance by 20-year olds of 37%. Maternal education and mean household income were used as SES indicators. Effective early intervention services may be one reason why SES did not correlate with social skills. Maternal education did not correlate with any of the psychosocial or motor outcomes.
Effectiveness of early intervention programmes for families living on a low income	Determan (2016)*§	USA	This PhD study is based on data from a newborn screening follow-up survey. Very large proportions of screened children are lost from the system in the USA: in 2011, 35% of babies who failed the screen and 26% of those confirmed deaf were lost to the system. Using an existing survey, all families with screened babies were asked about the level of early care and intervention received. The researcher investigated quality of early intervention with education level of parent, whether they were living in poverty, if the mother was a single parent and how many siblings the deaf child had, exploring relationships between Lost To System and these family contexts. Poor and less educated families living in states with less effective early intervention programmes were more likely to report they had not received any services, and if they did receive support, it was not well coordinated, as compared to similar families living in states with more effective programmes.	The variability of early years services between USA states has parallels with differences between local authorities in the UK. Having this follow up screening survey allows detailed and sociologically important work to be done to evaluate the effectiveness of programmes. The findings of this study are significant. The level of education of the mothers lost to system was less important than the quality of institutional support from health and education in the state. Audiological certainty about babies who failed the screen was reached for 97% of babies in one state (Massachusetts) compared to 17% in another (South Dakota).

<i>Main issue</i>	<i>Authors</i>	<i>Country</i>	<i>Findings related to SES</i>	<i>Commentary</i>
Evaluating newborn screen policy guidance	Yoshinaga-Itano et al. (2017) *§	USA	The Early Hearing Detection and Intervention guidelines (EHDI, 2007) state that the hearing screen should be complete by 1 month, diagnosis of deafness by 3 months, and intervention to have started by 6 months. This study examines the impact of this policy on vocabulary outcomes for 448 deaf children of mean age 2 years from 12 USA states. Vocabulary quotients were significantly higher for the children who achieved the EHDI benchmarks. Other groups with higher vocabulary quotients tended to be younger, have no additional disability, have mild to moderate deafness, deaf parents, or mothers with higher levels of education.	The research concludes that a specific focus on assisting mothers with lower levels of education and incorporating adults who are deaf or hard of hearing into the early intervention programme would both likely support vocabulary development and prevent widening delays with chronological age. An implication of this study is that the EHDI guidelines seem particularly important for parents living on a low income. The guidelines put in place universal minimum standards which do not depend on parents being able to find out about language acquisition; knowledge of language acquisition is likely to be related to level of family education.
Vocabulary	De Diego-Lázaro et al. (2018)	USA	This study looked at expressive vocabulary in sign and speech for 53 young (8 – 34 months) deaf children from Spanish speaking families across 6 USA states, aiming to find if the factors which applied to English speaking deaf children's vocabulary levels would also occur in Spanish speaking children. These are maternal education, level of deafness of the child, age deafness identified and when amplification and intervention started. The team validated the assessment tool with a range of Spanish speakers. Results showed that 62% of the variance in deaf children's expressive vocabulary was predicted by their age, how deaf they were and age of intervention. Maternal education was not significantly correlated with vocabulary levels and neither was aided time per day.	This research group wanted to include maternal education as a proxy for SES because other studies had variable findings about the role of SES in relation to vocabulary outcomes. In this study the researchers coded maternal education into (1) less than a high school diploma and (2) high school and higher. In this sample there were only 5 parents with a degree. Possibly the distinction between college and degree level education is more significant for children's vocabulary levels.

<i>Main issue</i>	<i>Authors</i>	<i>Country</i>	<i>Findings related to SES</i>	<i>Commentary</i>
IQ and CIs	Cejas et al. 2018*	USA	The researchers tested non-verbal IQ of 147 deaf children before and after CI operations and into the school years with the Leiter International Performance Scale. Results showed that children with CIs and a group of 75 typically hearing children both had non-verbal IQs in the average range, although the CI group scored significantly less well. Deaf children with additional disabilities performed significantly less well, that is their processing speed or working memory was not so efficient, likely to affect English and Maths achievement. These delays did not show up before the CI operation, as additional disabilities were often diagnosed later. There were moderate to strong associations between maternal education and language scores in this study, as exist with hearing children.	<p>This study suggests that there may be a protective feature of early spoken language intervention services for children from lower SES families. The level of deafness and the SES proxy indicator years of maternal education were no longer predictors of IQ once spoken language performance was taken into account. The authors argue that non-verbal IQ is related to language through working memory.</p> <p>In this study early IQ measurements were not predictive of cognitive functioning for deaf children at school age. IQ measurements often relate to SES, suggesting that an effective early intervention programme can overcome some of the effects of poverty.</p>
Language and cognitive outcomes	Ching et al. (2018)	Australia	This article reports on the 5-year outcomes of the Longitudinal Outcomes of Children with Hearing Impairment (LOCHI) study of 470 children born in Australia between 2002 and 2007. When hearing aids and CIs were fitted earlier, better speech and language outcomes occurred. Better speech perception was linked to better language and higher cognitive scores. Higher maternal education was associated with better speech and cognitive outcomes.	This study advises improving the signal to noise ratio for young deaf children, i.e. using radio aid systems. These devices are often not available for free for preschool children (see Theme 5 below).

Table 5 Having a deaf child has other associated costs

<i>Main issue</i>	<i>Authors</i>	<i>Country</i>	<i>Findings related to SES</i>	<i>Commentary</i>
Costs of deafness in US	Leake et al. (2000) §	USA	This research is about the families of 50 of deaf child patients in Tennessee enrolled on an audiology programme because they did not have family health insurance cover. These patients were more at risk of loss to follow up because they would not automatically receive free hearing aids and in fact the researchers' clinic spent many hours helping patients apply for funding. Through phone interviews with the family and comparing results with audiological records they were able to show that most patients did find funding for hearing aids and used them. But they note the poorer group of children took 3 months to receive a hearing aid compared to 1 month with insured families.	The USA health economics context is very different from the UK; however, there may be parallels in the UK because of other barriers to starting aiding early, for example differences in early access to information and support.
Cost to families of a CI compared to a hearing aid	Barton et al. (2006)	UK	The researchers use a large database of deaf children to compare the additional costs to families of their deaf child receiving a cochlear implant compared with hearing aids. The costs to families with a child with a CI were considerably more in the two years after the operation; they were additional expenses and days off work. They conclude that these costs are not excessive compared to the cost of the CI to the health service.	Much of the early literature about CIs was considering issues of additional cost to the NHS and families, as well as benefits in terms of better quality of life.
Early intervention	Sorkin & Zwolan (2008)	USA	A survey was sent to a random stratified 300 parents whose children had received a CI to evaluate the early intervention service. Findings showed that families on a low income were more likely to have had a hearing aid bought for them, had sign language instruction and been exposed to deaf culture. Considering bias in advice received, 49% thought the advice was focused on one approach, and 18% that it was quite biased. The lowest income group were more likely to say they had received unbiased advice, and the opposite was true of parents with higher incomes.	The group surveyed had lower than expected proportions of black and Hispanic children and of lower SES families, i.e. there may be bias in which children received a CI. Auditory verbal therapy had only been received by 23% of families, yet this was a service in high demand from families. Many families reported they had paid for these services outside the early intervention programme. <ul style="list-style-type: none"> • Also Theme 6: knowledge of the health and education system

<i>Main issue</i>	<i>Authors</i>	<i>Country</i>	<i>Findings related to SES</i>	<i>Commentary</i>
Language outcomes for low income children in AV therapy	Hogan et al. (2010) §	UK	Auditory Verbal Therapy (AVT) is a paid for intervention in the UK, thus not usually available to families living on a low income. This study of 12 families where fees were paid shows similar child language outcomes to better off families using the service. The parent-focused therapy is described. In this study 9 of the 12 children had better than a year's progress per year by the end of their therapy period, similar to other studies the AV research group has conducted.	The additional transport and accommodation costs of attending the therapy are not discussed; fees are the only paid for element for this study and a family income of less than £30,000. In 2008 when the research took place the median household income was £31,250 (Statista, 2018) suggesting that this sample was in the lower half of the income range, but not necessarily living on a low income. Other interventions, e.g. from Local Authorities, continuing in parallel with the AVT intervention are not discussed.

Table 6 Knowledge of health and education system affects language acquisition

<i>Main issue</i>	<i>Authors</i>	<i>Country</i>	<i>Findings related to SES</i>	<i>Commentary</i>
Parental involvement in school	Wathum-Ocana & Rose (2002)§	USA	The researchers interviewed 7 Hmong parents, the teachers of their deaf children and some of the deaf young people from these families. This qualitative study showed that parents were highly interested in education, but did not understand the system. If letters home had been written in Hmong, or if the Individualized Education Program (IEP) process and their rights had been explained, the parents would have engaged more. The parents generally had low expectations for their deaf children.	This study finds themes, though does not explain how teachers were involved or whether the interviews were conducted in Hmong or via an interpreter. Practical implications for the education system are discussed well.
Parental involvement and support for language development	Freeman et al. (2002)§	USA	The researchers asked how urban parents facilitated their deaf children's language development. Interviews and observations were used. Nine parents, 2 grandparents and 6 staff took part. Findings showed that parents had many systemic barriers to participation, but did not view their position as urban parents as a barrier to supporting their children's language development. The education support system had not adequately supported parents through their feelings of grief at the diagnosis.	This study does not discuss 'urban' which seems to be a synonym for living on a low income. The detailed recommendations from this study seem to overreach the findings. <ul style="list-style-type: none"> • Also Theme 7: Home culture and language is an important source of strength.
Opportunities deaf school leavers	Fordyce et al. (2014)	UK	Interviews were conducted with 30 young deaf people aged 18-24 to ask them about their experiences at transition from school to further education or work. Results showed that parental intervention in education systems particularly was successful for families from better off households. However, one middle class participant with significant additional disabilities faced social isolation and lack of educational opportunities.	Of the deaf young people interviewed, 16 of the 30 were from the 20% most affluent household areas. The most affluent had generally had successful post-school transitions, while those from poorer backgrounds had many more hurdles, among them family lack of knowledge of the post-school education system.

<i>Main issue</i>	<i>Authors</i>	<i>Country</i>	<i>Findings related to SES</i>	<i>Commentary</i>
Family engagement in early years sign bilingual services	Batamula (2016)§	USA	This PhD dissertation uses interviews to establish views from 11 immigrant families living on a low income with deaf children aged 8 or under. Four of the parents were deaf, with interviews in spoken English, ASL, or via other language interpreters. The parents viewed conditions in their country of origin as worse for a deaf child. Their babies had mostly been identified at birth in the USA. Migrants who had arrived during their teens were more optimistic about having a deaf child and the available USA resources. In their first country they would have found it easier to ask for help from family and friends. All these parents had chosen a bilingual school where their child learned ASL but most saw their deaf children as multilingual and using speech as well as sign. Some parents had attended subsidised ASL classes at the deaf school; others could not fit the classes in their week. They were very pleased with the schools' support for parents, though they wanted to understand the school system more.	<p>Although not a theoretically strong study, the voices of these parents are powerful. A quarter of USA children under 5 are from migrant families, mostly living on a low income, so support for migrant families is an important area for the USA school system to consider. In England and Wales 28% of newborn babies had a migrant mother (Office for National Statistics, ONS, 2018).</p> <p>The implications suggested by the author of this study may apply to other settings for immigrant parents: school support with homework remotely or in school, more home visits and explanation of the education system.</p>
Science knowledge of parents of deaf children	Shauli & Baram-Tsabari (2018)	Israel	A questionnaire about science knowledge was generated from 6 interviews , with 115 parents responding. Better science knowledge was related to parents being able to advocate more on behalf of their deaf child. Science knowledge is an indirect predictor of advocacy.	This study looks at SES as a variable; 27% of the sample had finished junior high school compared to 35% in the Israel population, the rest being better educated. Only 19% of the sample had a lower than average income. But science knowledge only had a limited effect on advocacy skills and was related to years of education, not family income.

Table 7 Home culture and language are important sources of strength

<i>Main issue</i>	<i>Authors</i>	<i>Country</i>	<i>Findings related to SES</i>	<i>Commentary</i>
Early school learning for a high SES deaf child	McGill-Franzen (1997)	USA	One of the children in this qualitative study of four children's early literacy development is deaf. She is from an affluent background and is extremely well resourced at school with an ASL interpreter, highly skilled teachers of deaf children, and cued speech as a supplementary strategy. At home her hearing parents can use ASL, her older sister is deaf and fluent in ASL, and the family is intensely interested in Ani's views on the many stories she has access to. In contrast, the other three hearing children in the study live in poverty, have little time devoted to reading in school and despite early enthusiasm, all find reading boring by second grade.	This study is included in the review because it focuses on the types of advantage which high SES brings: more than actual capital. Knowledge about language and literacy development and time to devote to it in the home are significant for Ani's excellent literacy development in school. Ani achieves well above the other hearing children in this study. The study is dated, in that literacy teaching methods in USA schools have changed considerably since 1997. It illustrates using a case study approach the lack of time or interest from teachers in low SES schools in the language and literacy strengths children bring with them.
Parental resources and stress	Hintermair (2006)	Germany	Although this study did not focus directly on SES, it is relevant to this review. The researcher investigates the quality of life of the deaf child, regardless of communication mode, looking at resources the family brings, and rejecting a deficit approach to families with newly diagnosed deaf children. High parental stress levels are decisive factors in the socio-emotional outcomes of the children. Questionnaires from both mothers and fathers were returned from 35% of parents at a deaf school (N = 213 x 2). Knowing more about deafness did not make much difference to stress, but having an additional disability in the deaf child added significantly to stress. Deaf parents did not have less stress than hearing ones. There were fewer socio-emotional problems for parents of children with CIs. They conclude that parents need training in specific competences to support their deaf child. Strengthening and expanding networks of support is crucial.	Educational level of the parents was a variable in this study, but not focused on in the analysis because the path diagram model was drawn from previous literature. The researcher recognised that a wider range of social backgrounds would strengthen the research. The discussion shows that where children have strong communicative competence, parents experience less stress.

<i>Main issue</i>	<i>Authors</i>	<i>Country</i>	<i>Findings related to SES</i>	<i>Commentary</i>
Parental stress	Åsberg et al. (2008)	USA	The self-selecting sample of 35 parents tended to have more representation from better off families and those on middle incomes. Family income was a variable; the researchers found that receiving more support led parents to be more satisfied. Social support was often more important for these parents than material resources to support their child. The study has interesting reports on level of stress and different modes of communication, with using speech and sign being less stressful; however, these conclusions may not hold with a wider or more representative sample.	The article conducts statistical tests which may not be valid on such a small probably non-representative sample.
Parental expectations	Ingber & Dromi (2009)	Israel	This study of 50 Hebrew speaking mothers in Israel includes family income as a variable. The children were average age of 4 years and were all enrolled in deaf preschool, 60% using an oral approach. Validated questionnaires about stress were supplemented with interviews. Factor analysis was used convincingly to find subgroups of parents. The authors suggest different styles of communication from early intervention teams should be used to match their different needs.	SES is found by parental occupation, but not detailed in this article. The researchers found that both financial and social support were essential in coping with stress. One sub-group (A) had satisfactory social support in place, their children tended to start intervention later, they were more likely to use Total Communication and they seem to have lower SES.
Mothers' expectations for their deaf child	Freitas & Magalhães (2013)§	Brazil	Thirteen mothers of deaf children living in an urban area on a low income were interviewed. Mothers had other older children, their deaf child attended the deaf school in Belém, and the deaf child had no additional disability. The interview related to the mothers' expectations for the future for their deaf child. Six of the group had incomplete primary education, with the rest having less than this. The most important view from mothers related to their own efforts to support their child to an independent future, particularly valuing school completion.	The poverty these mothers experience is much more extreme than in the UK, particularly in relation to access to education. The fact that most of these mothers saw themselves as mainly responsible for their child's success may reflect the lack of state provided resources. This article is in Portuguese – the only non-English article accepted into the review.

<i>Main issue</i>	<i>Authors</i>	<i>Country</i>	<i>Findings related to SES</i>	<i>Commentary</i>
Parental views on school and school outcomes	O'Neill et al. (2014) [§]	UK	Part of this study is a questionnaire returned by 131 parents, representative of the wider sample of 557 children still at school from an earlier all Scotland deaf child study. Parents were asked to pass on advice to other parents of deaf children and the results showed some differences by SES: parents who suggested being an advocate and driver of change were less likely to come from the most deprived 40% of households, while those suggesting love, support, patience and non-interference for the deaf child were more likely to be from the most deprived 20% of households. A further part of the study looked at exam outcomes of 370 deaf children, showing that school achievement at age 16 was strongly related to level of deprivation for deaf and hearing children. Deaf children living in the most affluent 40% of households had better school achievement than all children in the 40% most deprived.	See also Theme 2: Outcomes for language and cognition In the UK school outcomes are highly related to SES. The achievement gap shown in this study between deaf and hearing children could be related to many factors, such as additional disability, late diagnosis, poor early intervention, noisy classrooms etc. The socio-economic differences in achievement from the education system are stark for deaf as for all children.
Family expectations for their deaf adolescent	Rinat et al. (2015)	Israel	The study was of 38 Israeli Hebrew-speaking families with deaf teenagers aged 16-17, 23 of them severely or profoundly deaf; 22 of them had a CI and 18 attended mainstream schools, the others being in classes for deaf students. Nine of the 38 parents were deaf. The parents mostly worked in white collar jobs (22/38; spouses 31/38). Using a series of validated questionnaires, the researchers examined parents' career and family expectations for their deaf teenager. Results showed that parents held lower expectations about jobs for their deaf child where communication was involved, but parents in more prestigious work had higher expectations for type of work their deaf child might do and they expected them to succeed in work requiring a high level of communication skill. There were no differences between deaf and hearing parents in these attitudes to future employment and work. Expectations of deaf children growing up were much higher for finding a partner than raising a child.	This study is about a relatively well-off sector of Israeli society, but suggests the possible influence from parents on career choices and life choices young deaf people may take.

<i>Main issue</i>	<i>Authors</i>	<i>Country</i>	<i>Findings related to SES</i>	<i>Commentary</i>
K-12 Case study of a Latina student	Baker & Scott (2016)*§	USA	This in-depth case study on one Latina deaf multilingual learner charts her progress through different educational environments with varying specialist support in place. The participant, aged 19 at the time of the study, had no access to spoken Spanish. She arrived in the USA at 5, so did not experience any language in the early years. Her educational outcomes in English literacy were very poor, although she has low average skills in ASL. The case study focuses particularly on her family's legal rights to educational adjustments such as a language plan; the parents were unaware of the benefits of these plans because they were illiterate in Spanish and did not speak English.	<p>This case study raises many issues which migrants face: poverty and lack of information about rights and the education system being most prominent. The researchers note that the participant did not develop any fluent language early in life because of the poor quality of input. They focus on the lack of access the participant had to Latino and family culture.</p> <ul style="list-style-type: none"> • Also Theme 6: Knowledge of the health and education system

Table 8 Professionals' attitudes are sometimes negative

<i>Main issue</i>	<i>Authors</i>	<i>Country</i>	<i>Findings related to SES</i>	<i>Commentary</i>
Audiologists' views and SES	Kirkham et al. (2009)§	USA	The research aim was to investigate the views of paediatric audiologists working in CI centres: if they perceived poorer outcomes for children from lower SES backgrounds, what were their views on the reasons and how could these children's outcomes be improved. Of a verified list, 45%, or 103 paediatric CI audiologists returned questionnaires. Results showed that 78% perceived worse outcomes for low SES children, and in open-ended responses these were explained by two main factors: parent issues, such as low involvement, non-compliance, and external factors such as inadequate access to therapy. 87% wanted improvements in parent-directed interventions, while 15% suggested stricter CI candidacy requirements.	Paediatric audiologists in CI centres are in a powerful position in the implant process. Their views are significant, and from this survey it seems that a small proportion think it may not be worthwhile implanting children from low SES backgrounds. The authors note that other important health initiatives have had much better take-up from higher SES groups, such as anti-smoking messages. Conscious effort and directed focus are recommended by this team as ways to improve outcomes for children living in poverty.

Table 9 Issues in research in this area

<i>Main issue</i>	<i>Authors</i>	<i>Country</i>	<i>Findings related to SES</i>	<i>Commentary</i>
Incidence of deafness in UK	Fortnum et al. (2002)*	UK	The study examines children born 1985 – 1990 looking at the proportion of children in this group with deafness of more than 40dB. Set against the population of deaf children who had received implants, the researchers show that this first group were better off and more likely to not have an additional impairment, which was nearly 30% of the whole deaf group.	This was important research because it reminds us to guard against generalising from the first CI group – they may have done well because of other socioeconomic factors.
School achievement	Powers (2003)	UK	The study is based on two England-wide teacher completed surveys from 1995-6 about 16 year old deaf students, moderately deaf or more, and their General Certificate of Secondary Education (GCSE) achievement. SES is reported by eligibility for free school meals, which was 23% with 44% ineligible and 33% unknown for 617 children. SES emerges as a significant predictor of GCSE scores, but at not more than 5% of the variance. Degree of deafness makes little difference to educational attainment, as in other studies. The author speculates that there may be a school effect, but it remains unmeasured.	One possible reason for the small explanatory power of SES in this study is the large proportion of unknowns from the teachers completing the questionnaire. Parental occupation was collected but not coded. Also Theme 2. Outcomes for language and cognition are poor
Outcomes of early CIs	Belzner & Seal (2009)*§	International	This study is a review and synthesis of the literature. They conclude that early research from the USA using longitudinal studies of deaf children with CIs is biased towards the better off, towards children with fewer additional disabilities and white children. It also suggests that findings have been generalised too far from this group and that research in the UK and Australia is more cautious because it pays attention to SES and additional disability. They also suggest that some of the reviewed studies ignored findings such as the benefits of early Total Communication.	This is an important study because it looks at a wide range of CI studies and shows the influence of some USA ones which may have been researching with atypical samples. Influential research from the USA may lead teachers to have unrealistic expectations about the benefits of CIs.

<i>Main issue</i>	<i>Authors</i>	<i>Country</i>	<i>Findings related to SES</i>	<i>Commentary</i>
Vocabulary development	Coppens et al. (2012)	Netherlands	This study looked at the development of reading vocabulary in deaf children over primary years 4 – 7. The 74 children had to choose words rather than pseudo words, and also decide in which of 4 sentences they best fitted, i.e. they had to understand the word meaning. The starting point on the vocabulary assessment predicted their levels over time – there was little variation though there was progress. Results showed that school placement made a difference to vocabulary scores, with children in deaf schools performing worse. Not using a hearing device and using sign language at home were both negative factors in reading vocabulary in this study.	<p>Education level of parents was reported by the teacher, a question not well completed, so in fact the researchers could not use SES as a variable in the study. This shows the disadvantage of collecting data on SES via professionals who may not be able to or want to record details about families' personal circumstances.</p> <p>Educational placement of pupils is not necessarily causing this difference in score. Children who need more support, and have weaker reading vocabulary, are more likely to attend special schools.</p>

Discussion

Returning to the first three Research Questions, the themes will be used to support the synthesis of the evidence. This section will explore what the factors are which lead to success for communication with deaf children living on a low income, and what interventions might be put in place to counteract the effects of poverty in relation to deaf children's language development. It is important at the outset to note that few studies have focused specifically on deaf children in families living on a low income. References in the discussion will be drawn particularly from the studies showing the strongest evidence (*), based on the final column evaluation, and those studies focusing most centrally on deaf children living in low-income families (§).

(a) What factors increase the prospects of fluency with language and communication skills and access to technology and services for deaf children from low-income families?

The factor of *age of diagnosis* is crucial to deaf children's development of language and communication skills and to cognition (Reed et al., 2008). It also influences child mental health outcomes as a consequence of language delay, particularly to children in low-income families (Hoffman, 2015; Leigh et al., 2015). Although newborn hearing screening in the UK has been in place since 2005, the early years interventions which follow it are not uniformly developed. There are agreed pathways in NHS newborn hearing screening guidelines, but education does not uniformly link to them (NHS England, 2016). For this reason, the *age of starting educational provision* with the family in the early years is critical (Yoshinaga-Itano et al., 2017).

Understanding that the *risk factors for deafness* often relate to socioeconomic status would make UK early intervention services operate more effectively (Kerschaver et al., 2012; Lin et al., 2011; Vos et al., 2015; and Theme 1). Studies on the low-income children lost to the system have yielded important results (Determan, 2016) and similar analysis could occur in the UK. NHS guidelines (NHS England, 2016, p.16) show that children with risk factors who pass the screen or the audiological assessment should be followed up (UK Government, 2016). These risk factors are often related to being born into low-income families. It would be possible for organisations such as NDCS to register for reports from this system.

The effectiveness of diagnostic and intervention pathways (Theme 4) is an important factor for deaf children in low-income families. The USA health economy climate is harsher, but in the UK we have children lost to the system often living on a low income; we need to focus on how to re-engage with these families. This is a factor related to language fluency; some children will be systematically missed because the system is not closely attuned to people's real lives and cultures. There could also be issues relating to health professionals' training in anti-racism and equity awareness (Kirkham et al., 2009; Stanley, 2018).

Ethnic background of deaf children was a factor in many of the studies reviewed (Baker & Scott, 2016; Kluwin & Corbett, 1998; Lin et al., 2011; Quittner et al., 2010). As we have seen in Chapter 1, ethnicity is highly related to socioeconomic status as a result of international mobility, migration and the way richer countries recruit a younger workforce. The reasons why this is a factor are related to the following related issues:

Level of parental education has been used in many of these studies as a proxy indicator of socioeconomic status (e.g. Cejas et al., 2018). It is interesting to note the studies where positive language outcomes exist despite the level of maternal education, as this is an indication of successful support programmes for families living on a low income (Cupples et al., 2018; Aragon & Yoshinaga-Itano, 2012).

Related to level of education is *knowledge of the health and education system* (Theme 6 above) and understanding of language acquisition (Suskind et al., 2016) and science (Shauli & Baram-Tsabari, 2018). Not speaking English well in the UK, as in the US, is a barrier to understanding how the health and education system operate. This suggests that parents of deaf children may need more support in this area. In some low-income families, parents are not very literate. To succeed with early language development and schooling, literacy brings huge advantages of independence for parents. But other ways could be found to interact with families and bring them information, not always through reading.

Family attitudes towards deafness can mean the deaf child is integrated into her/his family or rejected (see Theme 7). Parents may have high or low expectations. In migrant cultures and communities in particular, the wider family is seen as the important point of reference. Health and education systems sometimes engage with the family, but usually expect the family to come to appointments in hospital and school, that is comply with their own way of organising.

Language behaviour of the caregiver with their deaf child is a factor much investigated (see Theme 2), often with a deficit viewpoint. Results for spoken language have been investigated far more than for a signed language. Many of the studies show that the way the family living in poverty interacts with their child is not as successful as middle class families where parents speak more, have less stress so interact more, engage in more structured play and use more expansions in their conversations with their deaf child. It is important to note in studies like this that there is always a range in the results, and the range is often larger in low-income families (Weisleder & Fernald, 2013).

Time and attention on the child are factors for successful outcomes, less likely to be achieved in families living on a low income without support, especially large families (Macauley & Ford, 2013) when economic survival has to be the first priority for the parents. Having a deaf child costs more (see Theme 5), the focus on time consuming therapy could be a risk to family income, and professionals are often unaware of these additional family stresses, e.g. transport costs (Hogan et al., 2010). Family stress (see Theme 3) reduces opportunities for conversational interactions (Vohr et al., 2010), and in addition child language delay can cause behavioural problems adding to parental stress (Quittner et al., 2010).

Additional disability is a factor for many more deaf children than in the whole child population (Ear Foundation, 2012), and the cognitive effect of additional disability is not distributed equally across socioeconomic groups, see Figure 4 (O'Neill, Arendt and Marschark, 2014).

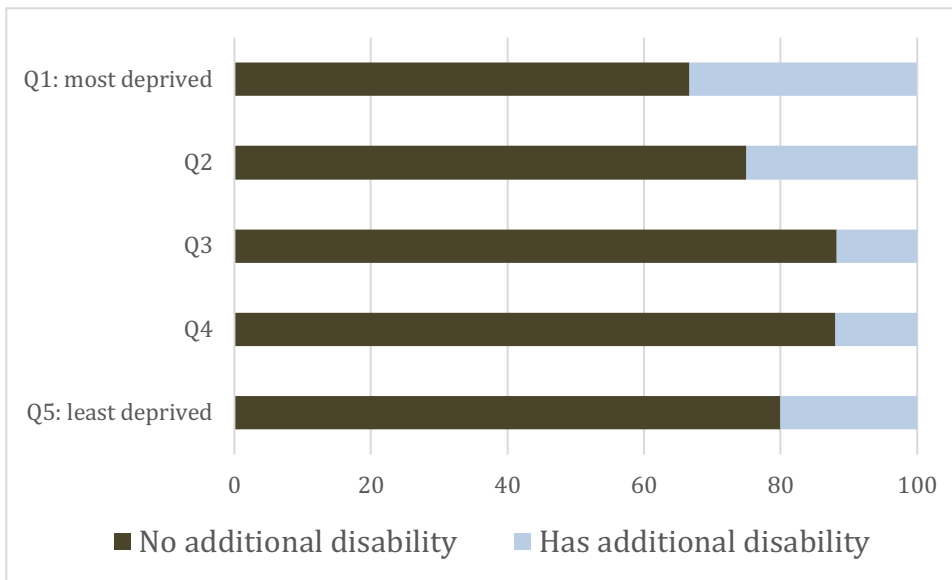


Figure 4 Proportion of deaf children with at least one additional disability

Source: O'Neill et al., 2014, p.22. N = 104 school aged deaf children.

Some disabilities are highly related to socio-economic status such as social, emotional and behavioural difficulties (Riddell & Weedon, 2016, p. 504). Studies reviewed here show negative effect on language and academic outcomes for deaf children in low-income families with additional disabilities (Leigh et al., 2015; Yoshinaga-Itano et al., 2017).

Professional attitudes towards low-income families (Theme 8). Two studies reviewed here show attitudes are sometimes negative (Kirkham et al., 2009; Stanley, 2018). The Stanley study reports parents' views about audiology and speech outcomes in low-income families, which would be useful to explore in the UK. Parents were disappointed about poor speech outcomes, but they had not been warned about them. This raises issues of bias within the research – it often has not been conducted with families from a wide range of socio-economic backgrounds (Belzner & Seal, 2009; Theme 9).

Level of deafness is often a factor in studies about deaf children, often significant to language and communication outcomes in families living on a low income (Hoffman et al., 2015; Van Dam et al., 2012). Cejas et al. (2018) for example, found that level of deafness was no longer significant once spoken language skills were taken into account. This suggests that a successful early intervention programme can reduce the differences between spoken language outcomes at different levels of deafness.

(b) Can drivers be identified which may mediate these factors?

Parents can be taught how to interact more effectively with their deaf child using speech, e.g. Szagun & Stumper (2012) who successfully supported families on a low income to use expansions more in interaction with their deaf children, even though their intervention did not have an effect on MLU. Culturally appropriate early interventions can support longer MLU (Cupples et al., 2018). The number of turns parents take in spoken conversations with parents can be raised, increasing receptive skills (Van Dam et al., 2012), though easier in speech with less deaf children.

Setting early years policy guidelines with clear targets will improve outcomes for all, but particularly for low-income families (Joint Committee on Infant Hearing, 2013; Yoshinaga-Itano et al., 2017). This includes identifying the socioeconomic risk factors and having an accountable procedure for following them up (Kerschaver et al., 2012; Vos et al., 2015).

Fluency in an accessible language from a young age is noted by Twitchell et al. (2015), who found a positive relationship between parents' fluent ASL skills and reading skills in their deaf children. This relationship was between fluent ASL and reading. If it is possible to establish fluent BSL in families, which implies free BSL classes continuing for years, then similar reading outcomes may be possible. No research was found from Ireland, but the system of home tuition in Irish Sign Language as a right from birth and through the school system is worth researching, particularly in how it works for families on a low income (Mathews, 2018).

Support from family and culture is crucial, but it will not be effective until the *school system works in more culturally sensitive ways*. Thus, the Hmong parents had low expectations, they very much valued education, but they did not understand the school system because nothing was translated for them (Wathum-Ocana & Rose, 2002). Teachers of deaf children have had their initial teacher education teaching children of school age and may have little idea about how to interact with families living on a low income or with parents who don't speak much English. Professionals and the way they interact are a mediating factor. Colorado once again provides the most positive examples (Aragon & Yoshinaga-Itano, 2012). The details of these culturally sensitive ways of working are not always found in research papers.

(c) Which intervention strategies with families living in poverty have had the most success?

The evidence from the literature shows clearly that *early intervention programmes* have the best chance of success with low-income families. The most convincing evidence comes from Aragon and Yoshinaga-Itano (2012), where the successful Colorado programme was so culturally specific and supportive that in the Spanish speaking households, which were most likely to be living in poverty, the median adult word count was above that in English speaking families with hearing children. Other studies corroborate this, showing that some early intervention programmes can to some extent mitigate the effects of poverty on deaf children's language outcomes (Cejas et al., 2018; Leigh et al., 2015; Sacks et al., 2013). Through a discussion with Yoshinaga-Itano (Workshop on reading, language and deafness conference, Spain, 18.10.18) details of the intervention programme became clearer: all families with deaf children of any degree of deafness aged 0 – 3 years have the right to 1.5 hours of home visits per week to focus on spoken language development, and 1.5 hours on ASL in addition if they choose. The practitioners come from a wide range of backgrounds and the ASL early intervenors are deaf fluent ASL users. This level of financial and linguistic support for families may explain how early communication is established so well in Colorado in spoken English, spoken Spanish and ASL, so that the linguistic effects of living on a low income seem to be overcome, although the stresses of poverty still remain (Pipp-Siegel et al., 2002). In addition, the Colorado early intervention programme addresses some other issues which have arisen from this review: ASL as a practical option, and the importance of support from home language and culture.

The second most outstanding success is the monitoring of early years services *using the easily understandable 1:3:6 month benchmarks* (Yoshinaga Itano et al., 2017). The larger the proportion of deaf babies that meet these targets, the more those from low-income families will benefit in terms of language outcomes. For example, UK health and education authorities could collaborate in each local authority area to report their achievement against these benchmarks each year. Parents and professionals would benefit from this very clear guide.

Suskind et al (2016) have had promising success with *LENA, and with knowledge of language acquisition process*. Their programme was a combination of information about language acquisition, video self-evaluation of parents in play with their deaf child, and feedback from LENA statistics. This could be a useful programme to trial, especially if it were delivered by professionals with cultural understanding, relevant life experience and knowledge of community languages. The LENA part would not be suitable for parents who are using only BSL, but similar day-long monitoring of BSL would be possible to develop.

Conclusion

This literature about deaf children living in low-income households has not previously been gathered together, yet it is clear much research has considered the issue. We can learn from the nine themes how to construct better interventions, how to train professionals and support staff in new ways, and above all how to work more effectively with families who often feel outsiders in relation to health and education systems.

Themes from this review and connections between studies were used with the co-researchers to discuss concepts about support for families living on a low income and to inform the analysis of the interviews to help answer the final two Research Questions, introduced in the next chapter.

Chapter 3 Interviews with families

Introduction

The purpose of the second part of the study is to explore the views of a sample of families from across the UK to discover their perspectives on bringing up a deaf child or children in these circumstances.

The research questions guiding this part of the study are:

(d) How do parents living on a low income view their access to information and support for their deaf child from family, community, third sector and statutory agencies?

(e) What do these families see as the challenges and supports for themselves and their deaf children in relation to language and communication development?

The construct of *confidence* in bringing up a deaf child / children was important in the way we framed questions to the parents. We share the view of Vance and Brandon (2017, p. E35) in relation to their definition of parental confidence:

“Parenting confidence is an essential component for parents to function successfully in their role. Confidence helps buffer and support parents in their ability to care for not only healthy infants but also those with complex health care needs. Parents who are challenged with developing health care-related confidence and caregiving behaviors to their parenting repertoire, often do so in the hospital setting. This requires parents to adjust and develop new skills and strategies for balancing life with a child who has a chronic condition.”

Vance and Brandon conclude that parental self-efficacy is highly related to parental confidence. We used this concept to support the development of questions for the interviews with parents.

Methodology and participants

Approach to research

This research is trying to find out about the ideas of parents, but sees the material context the parents live in as very important in understanding their realities. The title of the project ‘Telling it like it is’ was designed to encourage parents to speak out about possibly hard times, but in a context of peer-to-peer exchange of views. The discussions we had with parents aimed to explore issues from several points of view: experiences of the education system, support available and confidence in raising a deaf child. We started not from a deficit viewpoint of families living in poverty, but looking for features which could be useful for other families and communities, where their actions and ideas had improved their lives. As such, the enquiry can be seen as a participatory action research approach informed by feminist theory (Giacomini, 2010).

Ethics

The proposal was approved by the School of Education ethics committee at the University of Edinburgh (13.2.18, Ref. 1235). Level 3 ethics was granted, which applies to novel procedures, sensitive personal data, or the use of atypical participant groups and projects in which ethical issues might require more detailed consideration but are unlikely to prove problematic. The ethical guidelines used for this study are from the British Educational Research Association (2011), now updated (2018).

Research team

The study was carried out during 2018 with a team of seven (see Table 1). Interview questions were developed by this group in a team meeting, drawing on key literature findings (See Appendix 1). We aimed to work in as transparent a way as possible, sharing documents on the university secure drive and passing voice files on to the transcriber. The team discussed working with vulnerable families, egalitarian and solidarity approaches to interviewing, and reasons why families living on a low income may sometimes experience poor services from health and education. In these discussions we were drawing on ideas about feminist research, which examines power relations between interviewer and interviewee (Gilbert, 1994). It also builds on ethnographic interviewing which sees the encounter as possibly useful to both sides (Grote et al., 2007) and entering the participants' world in a short time-frame (Hockey & Forsey, 2012). We were hoping that all the interviewers would have personal experience of bringing up a deaf child while living on a low income. The main interviewer for this project, Jo Bowie who conducted sixteen of the interviews, had this experience. The other four interviewers, conducting five, did not. We wanted the interviews to be face to face, but two in the end were conducted by phone because this suited the participants best.

Table 10 Research team

Name	Role	Attributes useful to this study
Rachel O'Neill	Principal investigator, literature review, one interview, analysis	Previous research experience with parents of deaf children and deaf young people
Jo Bowie	Interviewer (16 interviews) and analysis	MSc Deaf Studies, lived experience of bringing up a deaf child on a low income
Helen Foulkes	Interviewer (2)	Deaf teacher and registered BSL/English translator
Dr Audrey Cameron	Interviewer (1)	Deaf researcher, including child protection experience
Dr Rhian Meara	Interviewer (1)	Researcher with strong interest in minority languages
Dr Dona Camedda	Analysis	Researcher in inclusive education
Caroline Maloney	Transcription	Extensive academic transcription experience

The advantages of interviews are that they are efficient, and give participants the opportunity to take the lead and shape the shared discussion, summing up ideas about someone's life in a short time. They are a subjective, relativist account where the interviewer takes on the world view of the interviewee. Related to this strength there are also weaknesses: facts cannot easily be checked. In these interviews we did not verify deafness levels or additional disability reported in the participants' children. We took on trust their report of benefit status or claiming of free school meals or means related tax

credits, established prior to the interview. By talking in depth to each family, we had no reason to doubt that they were living on a low income. Each family received a £30 voucher for their time.

The proposal included focus groups as well as interviews. Participants were offered both, but only one participant wanted to be in a focus group. This is likely to be due to the stigma of discussing income in public. Several participants were worried about anonymity in the study and discussing issues about benefits and income.

Finding participants

The ethics committee had asked us to approach heads of school services through Directors of Children's Services. This proved challenging and time consuming, though many UK local authorities were very co-operative. Other methods of distribution through NDCS, BATOD and the Heads of Services Forum meant that professionals responsible for deaf education often found out about the study through several methods.

Inclusion criteria for the study were:

- The deaf child should be aged 12 or under so that if deaf from birth and born in the UK they would have gone through the newborn hearing screen. This group should have received quicker diagnosis and intervention pathways, so their outcomes should be optimal compared to older children. Families also would not find the memory of the important pre-school years too distant. We also wanted to confine it to primary aged children because it would mean practices discussed would still be fairly current.
- The family should be living on a low income, that is on a means tested benefit which includes tax credits, or for asylum seekers, vouchers, or eligible to claim Free School Meals.
- Any level of deafness, including being deaf in one ear
- Any part of the UK

The project website (www.ssc.education.ed.ac.uk/research/tellingit/) and a linked Facebook site were set up so that potential participants could read more about the project and download consent forms and information sheets. Translations on the website were in Arabic (text), Bengali (text and audio), BSL video, Polish (text), Punjabi (text and audio), Romanian (text and audio), Somali (text and audio), and Welsh (text). The decision to include audio files was made from evidence that migrants from Bangladesh, Pakistan, Romania and Somalia are less likely to be literate in their home language (Strand et al., 2010). We made a commitment to translate into other languages if asked. People from most ethnic minority backgrounds are more likely to be in households living in poverty, coping with deprivation and social exclusion (Bradshaw, 2016), and there are higher odds for deaf children to come from households living in poverty (Vasconcellos et al., 2014).

Other methods were used to publicise the research: BBC Radio Scotland, the University of Edinburgh website, emails to deaf organisations such as the British Deaf Association, Action on Hearing Loss, SENSE – a deafblind charity, BID – a deaf organization based in Birmingham, the Royal Association for Deaf People, Cued Speech, British Association of Teachers Of the Deaf (BATOD) and Auditory Verbal Therapy UK, emails and posters to deaf centres, emails to the network of teachers of deaf children within cochlear implant centres, and contacts in networks of specialist social workers with deaf people. These provided additional publicity for the study which may have contributed towards the participants coming forward. Posts on the Facebook site encouraged members to post links on other

deaf related sites. Food banks were approached, Women's Aid across the UK, the charity Shelter, Sure Start Centres, and housing associations offering support to low-income families. Most participants came because a teacher of deaf children had distributed the project website or a leaflet, through the Facebook site or through personal contacts. Participants came from England, Scotland, Wales and Northern Ireland. The interviews had a mean length of 50 minutes ranging from 24 to 100 minutes.

There were limitations to our recruitment approach. Initial publicity focused on parents being on means tested benefits, whether they were in work or not, with a confidential conversation with a researcher. Later publicity mentioned Free School Meals entitlement as an easier way to discuss low income. A BATOD colleague with experience of educational research suggested another approach of running an electronic survey for all parents and asking for free school meal entitlement and postcode (e.g. Welsh Index of Multiple Deprivation, 2014), to locate families living on a low income, asking for agreement for follow-up interviews. This approach might have been more successful and should be considered in future work with hard to reach groups. However, 40% of people living on a low income live outside the most deprived postcode areas (Clelland & Hill, 2019).

Gaining agreement

Parents all read, listened to or watched a participant information sheet before agreeing to take part in the study (the project website still shows this information: <http://www.ssc.education.ed.ac.uk/research/tellingit>). We discussed the parents' eligibility to take part in the study face to face, on Skype or in a phone call, or in two cases via an interpreter. Their written consent was obtained in a form produced in a language they could understand. At the start of the interview verbal consent was obtained again so there could be clarification about the study. We discussed anonymisation with participants, explaining that we would not mention any local authority or part of the UK in the results.

Describing the sample

In a qualitative study using a constructivist framework (Rodwell, 2015) we do not need to insist on a completely representative sample because we are not seeking to generalise these parents' views to all parents living on a low income bringing up a deaf child. Rather, we want to explore the range of their views, attitudes and opinions, which are often highly specific and personal.

Nevertheless, the sample did show a wide cross-section of characteristics of deaf children compared to the Consortium for Research In Deaf Education (CRIDE, 2017) UK survey. Table 12 shows the demographic characteristics of the 21 families. There is an over-representation of deaf children at deaf schools in the sample. Severely and profoundly deaf children are represented more in this sample than in the CRIDE survey (see Table 11). The proportion of children with an additional disability is slightly higher in our sample, and the proportion of children who use other languages at home is much higher.

Table 11 Demographic data from CRIDE compared to this sample

<i>Deafness category</i>	<i>CRIDE %</i>	<i>Telling It sample %</i>		<i>Additional disability</i>	<i>CRIDE %</i>	<i>Telling It sample of 21 families %</i>
Unilateral	20	0		UK	23	29
Mild	26	6				
Moderate	32	32		<i>Use of other languages</i>		
Severe	10	21		Use other spoken languages at home	13	29
Profound	12	41		Use BSL / SSE or some sign at home	Not collected	76

However, the CRIDE survey is data created and collected by school services; they are not always aware of the languages used at home. In these interviews we were able to explore multiple languages used at home including spoken community languages used by parents or grandparents, and forms of sign language, including very basic sign in some cases, used by a wide range of families. The proportion using BSL or more basic sign needs to be interpreted with caution; the sample was not a representative one and is small. It raises questions for further research because the proportion of families using BSL or some form of sign at home could be much larger than CRIDE reports at school.

The proportion of deaf parents in the 21 households is 13% in our sample, compared to the USA average, which is 4% (Mitchell & Karchmer, 2002), likely to be similar in the UK. Our recruitment strategy may have led to more representation from families who sent their child to a deaf school. From previous research (O'Neill, Arendt & Marschark, 2014), it has proved difficult to attract mildly and unilaterally deaf young people to a research study with 'deaf' in the title. The identity of parents of unilaterally and mildly deaf young people may be similar, that is they don't necessarily see their child as deaf.

Table 12 Demographic characteristics of the 21 families in the study

Name parent	Family structure	Age child	No. children	No. deaf children	Location type	Level deafness	Additional disability	Ethnicity	Languages used at home	Deaf parents	school type
Ahmed	2 parents	8	2	1	city	severe	possible	Bangladeshi	English, Bengali, BSL/SSE	0	deaf (2)
Amanda	2 parents	5 to 13	over 5	3	rural	moderate, mild, mild	yes (1)	White British	English, some sign	0	local (3)
Amy & Tony	2 parents	5	1	1	city	profound	Yes	Other White	English, BSL Spanish	0	deaf – nursery
Carri	2 parents	5	2	1	city	moderate	No	White British	English	0	Local
Cristina	single parent	5 to 14	3	3	city	mod, mod, profound	no, yes, yes	Other White	BSL English, Romanian	1	local, local, deaf deaf (3)
Danielle	single parent	3 to 9	4	4	town	prof. (4)	No	White British	BSL	1	deaf nursery (1)
Diane & Stuart	2 parents	5	3	1	town	moderate	Yes	White British	English	0	local
Eilidh	single parent	4	1	1	town	moderate	No	White British	English	0	local nursery
Firas	2 parents	6 to 18	4	3	city	mod (2), Prof (1)	No	Arab	Arabic, BSL	0	college, resource, local
Kayley	single parent	6	1	1	town	profound	Yes	White British	BSL	0	resourced
Leah	2 parents	10 to 16	4	3	city	Sev (1) prof. (2)	No	Pakistani	Punjabi BSL	1	resourced (3)
Leanne	single parent	2	2	1	village	severe	No	White British	English BSL	0	PT playgroup
Letitia	single parent	3, 7	2	2	city	moderate, profound	yes (1)	Black British Caribbean	BSL	1	deaf (2)
Louise	single parent	6	1	1	town	profound	No	White British	English BSL	0	resourced
Mariam	2 parents	7	4	1	city	severe	No	Black African	Arabic, English, BSL	0	local
Natalie	single parent	7	5	1	city	moderate	Yes	White British	English	0	local
Nicole	single parent	9	1	1	town	moderate	Yes	White British	English, BSL	0	resourced
Rose & Dave	2 parents	3, 8	over 5	2	town	severe profound	No	White British	English, some sign	0	local (school) 1 at home
Sara	single parent	5	3	1	town	severe	Yes	White British	English, some sign	0	local
Sue	single parent	8	2	1	town	profound	No	White British	English	0	local
Tina	single parent	8	2	1	city	profound	No	White British	English BSL	0	deaf / local
	30 parents in 21 households			34			10/34		6/21 other spoken 16/21 sign / BSL	4/30	

Analysis

The data were analysed by Dona Camedda and Rachel O'Neill with Jo Bowie as the main interviewer who also had personal experience of the focus of enquiry. First the interviews were listened to or watched many times from the sound and BSL files. The process of listening with the transcript helped correct minor errors in the transcription or translations. It also gave a sense of the feelings and urgency of some of the views expressed.

Summaries (see Appendix 4) were constructed using the interview transcripts. This was the first stage in understanding the person's world-view and what was important to this particular family. We used the NVivo (QSR International, Version 11, 2017), a program for sorting and coding sections of qualitative data. The interviews were coded by two researchers working independently at first using the first eight themes from the literature review. Sub-themes which emerged were discussed and used by both analysts. New themes developed from this stage, which led to further iterations of coding. The two researchers and main interviewer discussed the definition of parent confidence in relation to these themes.

The final part of the analysis was checking with the participants that they agreed with the anonymous summary about their family (see Appendix 4). We asked parents to check the details about their family in Table 12, and to confirm they were happy that the information given about their family would mean they were anonymous. Thus, the interview was the first part of an ongoing dialogue with the families.

Qualitative research, according to Polit and Beck (2016) should be *transparent*, showing how information was collected and documented, who reviewed it and how themes were formulated; researchers should show *diligence* in reading and rechecking the interpretation using several sources where possible to corroborate evidence; there should be *verification* of the study to make sure it is methodologically coherent, carried out in this study by the research team agreeing the principles and values of the research from the start; there needs to be self-reflection and scrutiny, for example in considering how the researchers' own backgrounds or relationship with participants may shape the analysis; this sort of research *involves the participants*, so they have some control over the enquiry and people with similar experience are crucial to the study; finally, the research should link the data and new knowledge to the literature with *insightful interpretation*. This section has aimed to support the inquiry as a piece of trustworthy and reliable research.

Findings

We examined the interviews in the light of the two research questions d and e. In Table 12 below these research questions are listed with the associated themes found.

Table 13 Summary of Findings

(d) How do parents living on a low income view their access to information and support for their deaf child from family, community, third sector and statutory agencies?

1. The impact of living on a low income
2. Knowledge of the Health and Education system
3. Experience of Early Years intervention services
 - Parents' experiences of informed choice
 - The role of the nursery
4. Attitudes to and from professionals
5. The education system: listening to parents?
6. The role of voluntary organisations

(e) What do the families see as the challenges and supports for themselves and their deaf children in relation to language and communication development?

7. Acquiring language and literacy
8. Parents' and services' expectations for their children
9. Advice to other parents

Research Question d: How do parents living on a low income view their access to information and support for their deaf child from family, community, third sector and statutory agencies?

1. The impact of living on a low income

All the parents taking part in these interviews were aware of the subject of the research; however, direct discussion of living on a low income was not often raised by parents. Rather, the effects arose indirectly, such as a Family Fund grant enabling a family to go on holiday for the first time (see Natalie's summary in Appendix 4 below). Parents were more likely to discuss the effect of their deaf child not being able to join in activities such as after school clubs. Lack of confidence meant that parents did not always ask for additional funding to be spent on their children.

Interviewer: And did she have someone that could sign on the summer play scheme?

Sara: No. They didn't have anybody like that on the play scheme side of things but obviously they were coming out through the holidays. Like obviously I was up at the hospital and that quite a few times through the holidays for testing and that as well and (name of ToD) was like, 'is there anything that you need, do you want me to do anything?' I was like, 'nah', been quite [laughs] just getting on with it really. I think the holidays are stressful for every parent not just someone that's got a deaf child so [laughs].

Disabled Living Allowance (DLA) was asked about in interviews or in a follow-up questionnaire and 18 families reported their deaf child had it. Ten of these families referred to help in getting DLA, because the forms are difficult. NDCS or another local Deaf Children's Society helped in eight of

these cases, with one family receiving help from a Health Visitor and another from a refugee case worker. Diane and Stuart (see family summary Appendix 4), were annoyed that they had to go through such a difficult process to receive funding which their child so obviously needed.

Table 124 Age of deaf child when DLA received

	Age 1 or less	2 - 4	5+	Did not respond to this question
Deafness diagnosed at birth	9	2		2
Deafness diagnosed after birth		4	3	1

Responses from 18 families in relation to their oldest DLA-eligible deaf child

Table 13 shows that 2 children identified deaf at birth took a long time to receive DLA. This was due to issues such as homelessness, an additional disability or having no English reading skills. Late diagnosis did not necessarily mean the deafness started after birth; reasons for late diagnosis were having an additional disability which took precedence, being a refugee, and not being picked up by audiological tests in the early years. These factors led to late DLA claims, which meant lost income to these families.

Of the sixteen families using BSL or some sort of basic sign with their children, three of these had deaf BSL-using parents. Of the other 13 families, six had been to BSL courses, and four families had some opportunities to learn through school, though not getting as much tuition as they wanted. Four of these six had some financial help or a free course. Amy discussed how she found funding for learning BSL:

But...so we were given all the right information but then how do you go about learning it? ... I was really lucky, I got funded for my level one. I had a really good key worker in (name of Housing Association). And he worked with a bunch of charities and got me funding for level one.

But that was for me, Tony's not, not been able to do it. And that was it. I mean level one is, I mean... a lot of it isn't really relevant. I mean I learnt how to give directions and.....I need it for my child, you know what I mean?

Amy

The limited length of BSL courses was as much of an issue as the cost. Leanne had a free course because it was provided by the local college, i.e. it was free for people on benefits. This raises the issue about BSL very often being only available through a company or charity; these providers do not have subsidies for people on benefits.

Radio aids or FM systems are useful both at school and home to focus mainly on the teacher or parent's voice, reducing emphasis on environmental noise or other speech. FM systems can be bought by families to use at home, but they are expensive: £1,800 is typical (Connevans, 2019). Seventeen families were asked about FM systems at school or at home, that is 25 deaf children; of these, only 8 children had one at school and only one had one for home use. Thirteen of the families had not been told by the school service about borrowing an FM system for home use. FM systems are increasingly being offered to deaf children of nursery age and for home use (Allen et al., 2017), but they would not usually be offered to very young children or those mostly using BSL at school.

Mildly deaf children are also not usually offered them. From Table 12 we would expect 17 of the 24 deaf children whose parents were asked about FM to be eligible to use the system at school, yet only 8 received one. There is a great deal of variation across the UK between local authorities in the allocation of FM systems both at school and at home. Many authorities do have arrangements to lend systems for home, but some insist on families paying high insurance, noted by Amanda. She reported that she could only borrow one for home use if she paid for very expensive insurance.

Firas, a refugee who had been in the UK for three years, knew the benefit of FM for his children at school and wanted one at home to help his son, but lacked information about how to get one and how much it cost:

We can have one at home, we can use it to communicate with him. If I'm sitting here and he would be in the other rooms, so he can maybe hear me. Is it possible to arrange for one? When we are using the radio it would be clear and he can hear it better clearly. ...Do you have any rough idea how much it would cost?

Firas

Five families mentioned transport costs as a barrier; for three this was not just about the cost but also because the mother was not able to manage the behaviour, or having a large number of children made transport very difficult, restricting them to local activities. Kayley discusses an alternative she would like which would help her get to NDCS events:

Or people on low income that cannae get, don't have money for a bus so I'd be.....putting a small bus...ten minutes or something away that they can walk to.....or something like that.

Kayley

For several families persistent poverty over several generations was evident, often accompanied by social isolation. Kayley's mother had had nothing to do with her daughter or deaf grandchild since the diagnosis. Her mother had not been able to accept the diagnosis, adding to Kayley's wider sense of isolation and feeling of difference in having no money.

Although all the 21 families were eligible for means tested benefits, they varied in how much access they had to actual capital. In interviews with three families, it was clear from the discussion that money had been available either from a previous job which paid reasonably, or relatives, or a grant from an employer. See the family summaries for Amanda, Sue and Tina in Appendix 4. In these families the parents also had very good access to information about deafness and early development, which meant they sometimes questioned the views of professionals and were able to fund an alternative approach they believed would be more effective.

2. Knowledge of the Health and Education system

The parents' knowledge of audiology varied a great deal. Usually parents knew about issues affecting their own child, for example deteriorating deafness, or the advantages and disadvantages of CIs if their child was eligible, or why their child may not be eligible. Deaf parents were just as well informed as other parents about hearing technology:

It's not something that I have to force upon them. They choose to have them on. It's an automatic reaction now that if they can't find them, they're asking, "Where are my hearing aids?" ... They don't have a radio aid. I'm not sure if they have a radio aid at school or if they

put the connection on the back of the hearing aid, is like a shoe it's called, called it in school, 'cause they often come home and they've left that part on their hearing aid and they go, "Oh, I should have left that at school." ... With those devices they're able to access the teacher speaking a lot clearer because it goes directly into the hearing aids and that leaves them to have that bilingualism where they have sign language and they have access to the spoken language.

Letitia

Some parents had developed expert knowledge in the whole area:

Well I, I went in and I've always been quite open wi' (name of audiologist) and that and asking questions. And like I can read the charts now, like it says it's like Sandra's like 80% whereas she should be at 20 for a normal hearing child and she's hanging at 80, well between 80 and 90. And with her hearing aid she hears probably, she hears just within the speech bubble. So... I sorta like clued myself up and I was always asking questions, asking about the cochlear implant and things like that to see if that would be more beneficial for her.... But aye, I've always like been open and asked loads a' questions.

Sara

A minority of parents had very poor understanding of audiology. Their children had moderate deafness, or English was not their home language:

*Natalie: I did see a lot of wax, but because every time we were going for different hearing things it just, her hearing wasn't getting any better. Her hearing was just right down.
Interviewer: Has anyone explained it all out to you, what's the difference between wax and glue and all of that stuff?
Natalie: No, do you know something, I don't know much myself about, like, deaf children, to be honest with you. Literally, do not know.*

In relation to knowledge of language development there was more of a contrast between parents who knew a lot and not very much. Parents with a sophisticated understanding of speech and / or BSL development had often had a great deal of contact with teachers, for example some of those whose children attended a deaf school, or were deaf themselves, or they were a teacher or training to be one:

But I think as well whilst I've tried my very best and between you and I, don't tell anyone I am a primary school teacher! [interviewer laughs] So I've tried my very, very best. He just don't wanna do it, he just doesn't want (to read). I think part, partly it's a boy thing. So I do what I call incidental learning. So I go, 'oh love I can't quite read that sign, what does it say?'

Nicole

The advantages Nicole had in having been a teacher gave her great confidence in dealing with the education system; though financially now she was not well off, through working as a support worker she was often able to ask the teachers of deaf children extra questions about her son. She saw time with them as very valuable.

A similar number of parents, though, had very little knowledge of language development. One deaf parent, Cristina, who learnt BSL as her main language very late, confused baby signs with sexual signs and punished her son. A hearing parent with very little English, turned to her doctor for advice on literacy because he explained in Punjabi:

the doctors said to us that if we maybe place two fingers on his neck...or on his throat he will try to make a noise. So we do try that now and then when he's reading. We put that there and he's trying to read it out loud. ... And you know this, it does help now and then.

Leah

Confusion about different methods and approaches to language development coming from different professionals was common:

It makes us feel a bit bad for signing with her and not, you know, just the trying to make her talk and maybe making her lazy by signing and not talking. I think that is hard you know.

Dave

Those parents who had decided to learn BSL, over half of the hearing parents, had found it useful at home, though the sign language classes were usually not aimed at parents. Most of these parents could not understand why there was such a stark contrast in approaches advocated by different professionals they came across, as they saw the benefits of both:

So when he got the implants then it was like, 'oh don't sign like because it'll stop his speech.' And then actually what I found was when I signed it encouraged. It was as if he had a lack a' confidence tae speak.

Louise

One parent had investigated early intervention thoroughly and decided on auditory verbal therapy when her daughter was a few months old. She was aware of the importance of speed in making an early start on highly structured spoken language therapy:

I had researched online and, you know, discovered that with cochlear implants there was a good chance that she could be completely spoken... And, as I say, with all the research we've done, we discovered, I'd spoken to AV Therapy about two months after she was diagnosed.

Sue

This service was not available locally. Through the internet, Sue found out that in countries like Australia it is commonly available as an option for all parents of deaf children.

In general, the differences between parents in relation to knowledge of audiology, language development and the education system seemed to be related to confident literacy skills in English and using the internet.

3. Experience of early intervention services

Thirteen of the families had experience of deafness being diagnosed following newborn screening. Their experiences of Early Intervention from statutory agencies such as Health and Education were mixed, half being fairly happy and the other half feeling unsure what was going on or getting no or very little information.

The reasons for six families generally feeling satisfied with Early Intervention were:

- Two families had very high quality information from close work between the ToD and the audiologist (Sara, Rose and Dave). However in both cases they did not have such good support with learning BSL, which both families wanted.

- Two families, both living in cities, had high quality and prompt information and advice (Ahmed). and some exceptional professionals who followed them through a period when they were homeless (Amy and Tony).
- One family had early support, excellent SLT support for four years, although experiencing a poor transition to primary school because of ToD absence (Carri).
- One mother had multiple tests for her deaf child and aiding at 11 months, but very happy with the continuity of ToD support and the transition to the local school (Eilidh).

Well I had Jenny. She was appointed to Joe and she was amazing. Like she was very helpful so she was. So she'd come in and like speak through anything, any a' my concerns. Like speak, have a wee bit a' speech and stuff wi' Joe and she was brilliant. So... She's visited him like since he's been born through here and all in school and stuff.

Eilidh

The reasons for seven families feeling unsatisfied with Early Intervention were:

- Two were deaf single mothers one of whom had post-natal depression which made the early years very complicated and took a long time to resolve with wider health and social services. However, it is interesting how these two fluent BSL-using families reported so little in the way of Early Intervention. One had rejected hearing aids, the other embraced them. Early pre-literacy advice would have been useful (Danielle and Letitia).
- One mother had very little English and did not understand the system, had inconsistent support and little interpretation was available into Punjabi (Leah).
- Four had prescriptive professionals or ones who the parents felt held low expectations. These families did not take the choices that they felt were being recommended to them (Tina, Sue, Louise and Leanne).

I think that they (the nursery) are taking a lead from the teacher of the deaf from what they say and from what they would like to do with Katie. But again for me it's very good that they say one thing, but in reality it's completely different. Like telling them, 'oh you need to keep the hearing aids in more' but I think they need to... I don't want to give them more work but it would be nice if they had better knowledge and they used some signs as well.

Leanne

Eight of the families found out their children were deaf after birth and in four cases this was probably due to deafness starting after birth. Three of these families with late diagnosed deafness (Nicole, Diane and Stuart, and Natalie) were happy with their early years support, which was mainly from the ToD and Speech and Language Therapy. Diane and Stuart experienced late diagnosis of their deaf child because of other very serious health issues their child had from birth, which had to be attended to first.

It was more just, it was audiology just going up, getting regular kinda hearing tests and things. And then once he got his hearing aids, he was then under the teacher of the deaf. She would come out to the house and kinda...just kinda do fun things wi' him, just to get him used to things....But regular visits and then they started nursery cause we ended up having Jake. So wi' the three a' them and additional needs and things we managed to get him into nursery. So she would go into visit there as well and just kinda building up the support with nursery and things. So that, that was kinda good that they were willing to come in and give support to nursery as well.

Diane

A further parent, Kayley, was not happy because it took her a long time for her to accept the deafness. When she found suitable provision outside her home local authority, which was difficult to navigate because of her weaker literacy skills, she was upset at the lack of responsibility her home authority took. For all these families with late diagnosed deaf children, transitions to nursery and primary school were particularly important.

The four where deafness probably started at or soon after birth but Early Intervention services were not available all had other issues which delayed diagnosis or take-up of services. None of these parents was happy.

- The family did not speak good English and the child passed repeated hearing tests but had extremely delayed speech, later confirmed as severe deafness (Mariam).
- There was deafness in the family, but the family are refugees so there was no early medical support as they were not in the UK (Firas).
- Deaf parents – hearing professionals probably had great communication difficulties with the mother who started using BSL as a teenager, i.e. not standard BSL (Cristina).
- The first two children were mildly deaf so this was not picked up by the screening test. The third child was moderately deaf, which would usually be diagnosed after a refer at the screening stage. This family also experienced delays in provision of services because they lived on the boundary of several local council and health authorities:

So he (the youngest child) failed, but they just kept going until they got the result they wanted....At the time, we did question it, and we didn't get an awful lot of response. So, basically it was that he's passed now, it's fine, so we sort of left it cause we didn't really know. And it wasn't until my daughter was showing, her behaviour was becoming quite erratic, so we went to our health visitor and said maybe she has ADHD like my eldest son, and they went, well we can't do anything at this stage, we'll send her for a hearing test to rule it out, and it came back that she was deaf. So because she came back as deaf, they then checked everybody else in the house, and it came back that three out of four were deaf.

Amanda

Parents' experiences of informed choice

We asked the families specifically about their experiences of informed choice in the early years. Seven of the twenty families which reported on their experience of informed choice felt they had received balanced or fairly balanced views on options from statutory agencies. This parent was treated with respect and given choices based on evidence in a fair way:

Well they've, like I feel like the, like audiology side of it, yeah, they've really been spot on. Like I've always felt like I've never sorta been in the position where I've like, they've not like taken me seriously or....., they've, they've been like, 'if you want us to go ahead with trying to see about getting the cochlear implant we can, but I have seen things like in the past where children in her position with her age, her level of hearing and her responses to the testing at this stage have been denied getting the cochlear implant put in'. He's like, 'but if you want me to go ahead with it I will definitely do that for you'.

Sara

Several of these families felt that although they had the information, they didn't have the actual services because BSL was not available for them to learn.

I think you're given the information but you're not given the tools. So you're told a lot about sign language but then you're not really put in a position where you can learn...so you're told a

lot about British sign language, how it benefits children, how, you know, an even approach is the best, how it won't delay her..... But...so we were given all the right information but then how do you go about learning it? Amy

Six families reported they received biased views about BSL: three had received anti BSL messages, two did not have any information about it provided, although they wanted this, and one found the information provided was too strongly pro BSL.

Interviewer: from what you're saying it sounds like it was the cochlear implants that were presented to you. But was there anyone presenting sign language?

Parent: No I was, it was the opposite. I was getting told, 'no don't sign'. Don't use sign, it will prevent him fae speaking blah, blah, blah, all this stuff. And obviously just be, you just, these are professionals, I was just believing what they were saying. But I quickly realised no we need some form a' sign.

Louise

(The speech and language therapist's) expectations for Martha were very low, as was the teacher of the deaf at the time, she's now retired. Again she'd said that it would be good for Martha to be signing and that NDCS were supportive of that as well, of learning, teaching Martha to sign. I felt that they were really...pro signing, everyone that was with us. And again I understand that but what I felt was that was the kinda really only option that was put forward....everything that we did we did on our own without any local services support.

Sue

Two families reported they had very strongly pro-CI information from the statutory agencies.

The audiologist recommended her to have a cochlear implant. That was straight away. I said no and he tried to pressurise me. I kept saying no, until one day, I became very angry because they kept going on and on. They kept asking a lot of times. I was very angry and told them to write a note on her records to stop asking me and she will not have a CI. They had asked me a lot of times and I wanted to be clear that I'm saying no. I wanted it on the records. No. If they were to ask me again, we won't be coming back - that would be it! They were wary and agreed to make a note not to ask me again.

Danielle

Six families did not have early years services, in some cases because their children were not diagnosed deaf in the early years or were not in the UK. This parent had information from audiology and tried hearing aids and then CIs for her daughter, but neither was successful.

Interviewer: What was your experience of the early years team? Did you get any support?

Kayley: None.

Interviewer: Did you have a peripatetic teacher of the deaf come out to your house?

Kayley: No. Not until she was two and a half. And that was somebody from the National Deaf Society...that has a deaf child of their own.

It is interesting that all three deaf BSL-using families are in this group (Letitia, Cristina and Danielle), and the issue seems to have been that professionals could not communicate with the parents. One of these families had rejected the early years services on offer because it was not accessible to her.

The role of the nursery

Fourteen families discussed the role of the nursery in providing early years support. There was strong support for the nursery services experienced from nine of these families, whether it was from the nursery staff themselves, or the visiting Speech and Language Therapist, or more often the visiting teacher of deaf children. A common theme amongst this group was the feeling of success in securing a place for their child into a nursery at a younger age than usual, and seeing the positive effect on their communication skills. This parent was very pleased at the level of support from the teacher of deaf children and continuity in the local nursery and into the first year of primary school:

His teacher a' the deaf goes out three times a week and his school teacher has the FM radio system there as well. So they use that. He got that when he was in nursery, I think just to kinda build it up for when he did start, just so he was used to it... (His speech) is coming on to start with. ... are still now certain things he kinda tries to say. It's, unless you kinda know how his speech is you wouldn't understand him. But it's, it's definitely kinda coming on.

Diane

Five families were not so happy with the nursery services for their deaf child. In some cases this was because the parent had not yet come to terms with the deafness, or the nursery did not notice that the child was deaf, i.e. it was pre-diagnosis. Some parents felt their child's language was very delayed by this time and they didn't receive enough services in the nursery years, but they found it hard to criticise services:

So they'll be like, 'Joanne do you know where the piggy is?' And then, 'like can you do piggy?' and she'll be like, 'piggy'. So yeah she does, she is picking it up slowly but ...they feel she shoulda been further on than she is at this stage but like she did get kept back a year at nursery and obviously the...the teacher a' the deaf, they were involved but they weren't there like all the time. I think it was like once a week and then they upped that to like three times a week and now it's like every day for a few hours every day. So it's helping a lot.

Sara

4. Attitudes to and from professionals

All the parents discussed attitudes to and from professionals in health and education. Most parents had mixed views, often finding one particular professional easy to communicate with while others were less committed, less available or patronising and negative. Parents often showed independence when challenging professionals, although often not expressing this face to face, but in the interview using humour:

Interviewer: So you felt blamed by the, the fact that he wasn't progressing the way they wanted him to?

Louise: Yip as, as if I wasn't doing enough in the house. ..as if I wasn't. And I'm like you don't teach anybody tae speak by showing them loads a' flash cards do you [laughs]. It's no how I learned tae speak [laughs].

Tina experienced threatening messages from the teacher of the deaf team in her county, so she moved twice to find the right provision for her daughter.

We were living in (name of County) at the time, which is very oral, so the teacher of the deaf came around and told us to not sign at all with her, and that we should do a running commentary as we were walking round the house. If I'm walking into the lounge and I'm

turning on the light, and I was going, she can't hear any sound at all, even with hearing aids, like [laughs]...yeah, they were crazy, so we asked for a different teacher of the deaf, cause she refused to help us to learn to sign and suggested, when I was saying I was really desperate, she suggested we went to a group for children with additional needs....So, so we got a different teacher of the deaf and she was just as bad, but less vocal. But eventually, she said the same things as, you know, if you learn to sign, if you sign with your deaf child, she'll never learn to read and write, and we'll never pay for her to go to a deaf school, you won't get a statement in (name of County).

Tina

Families often mentioned home-school communication as being particularly important to them and were disappointed when home-school books stopped early at primary. They also very much valued being able to ring or text the ToD, and they wanted more information to help them understand review meetings in advance. Firas did not feel he fully understood the planning meetings at his daughter's resourced school:

So, to be quite honest, I don't want to be unfair with them, they would send us a paper to say there is a meeting and, but we do not really comprehend all the contents of the letter, so maybe they are sending something, but we are not understanding it. Yes, but of course when we go there we know that they will show us our daughter's achievements, what she is studying, and all of this stuff.

Firas

Danielle, a very confident deaf parent, felt in her case the health authority was easier to get on with than the deaf school and for her communication is key:

At the moment I feel that we're waiting on a lot of questions being answered that I've asked them, and so waiting on that information coming in. So, communication with the school isn't the best. I tend to get a lot of information from the school, either from other parents or directly from the children themselves. Communication with the school is not great. Communication with other professionals, so for example audiology, we email each other back and forth, and that works really well. That's within my local area. And we can email each other with simple things like, if the children lose their hearing aids, I just send a quick email.

Danielle

If we had interviewed a wider range of families including those from families with a higher income, we may have found a similar range of views about different professionals. However, many of the families we interviewed did not feel confident about challenging negative views or low expectations from professionals.

5. The education system: listening to parents?

Twenty families commented on the questions in the interview which were about how the education system listens to parents.

Generally communication channels were good between the parents and the schools. Those parents who had their children in a deaf school would have liked easier contact as they could not drop in, and the cost of transport to school was often a factor. One school had made provision for deaf parents to ring using BSL, which was highly appreciated:

This school, if there's any issues you can get the visual aid service so you can sign back and forth to the school. The last school it would be sending texts and they would be misconstrued or they wouldn't be replied to. I didn't feel there the access was as good, but here the access is absolutely fantastic. And of course it's perfect. The teachers are deaf. What more could you want? It's easy access, full communication. Yeah, here it's much, much better.

Letitia

When it came to more formal reviews of provision, the teacher of deaf children often acted as an advocate and was able to push for better provision for deaf children very effectively, as they are part of the education system.

Like I mean I was in there... and they didn't wanna do much really. And then when the teacher of the deaf stepped in, they sorted it straightaway so... they weren't listening to me, school weren't listening to me. They kept saying, 'oh she's not presenting like that in school, she's always smiling'. Cause my daughter's always, like all my kids are always smiling. She was coming home and saying, 'it's a bit too much, I'm struggling. I need a...' But they weren't, they weren't registering. They were saying, 'we're not seeing that in school'. So... I had to get on and get on and then the teacher of deaf phoned me and said, 'would you like me to come and speak to them? And I said, 'yeah that'd be great'. So she arranged a meeting. As soon as we done that... they sorted it yeah

Dave

However, this was a double-edged sword for some families; they liked the advocate and friend approach but it was difficult then to raise concerns about the service for deaf children itself.

And they just stopped it. And I find everything chopped and changed all the time, you know. Like my daughter, she's at school and she's had her teacher of the deaf and she's got a really close bond with her and now just before the summer holidays she's stopped. And now she's got another one and she's got to get a new rapport with her.

Dave

Parents received information in advance for review meetings and interpreters were booked if English was not the home language. But they were not prepared for the review meetings and they generally expected their role to be a listening one. Two parents, however, saw their role more assertively, setting targets for the school to implement and one reported support from an independent voluntary group in the multi-professional review meeting, even though it was a group which didn't know about deafness:

Well we have a review for, in fact it's coming up in two weeks' time. So, we do it every six months, all agencies all sit in a room and we discuss what's, what, what the next stages are and where we are with her and stuff like that. I say my piece and its very much they write it down and it goes into the minutes. But it just seems to be the same, like we just keep ticking over rather than them, they note that I have concerns but no, I'm doing the right job and ... I'm keeping the hearing aids in and it's very much, yeah like, ... We're actually, the (name of voluntary group), they came out to the house not that long ago and they were going to attend this meeting and they were going to bring everything up because I've obviously mentioned that to them as well. ...they're going to try and do and say, 'well you're not listening. You're doing, you are doing your job but you need to listen just that little bit more'.

Leanne

Parents were well aware that specialist tuition and equipment for their deaf children was highly rationed. Some teachers of deaf children reinforced this approach by saying particular children didn't need any more.

Interviewer: So, do they have review meetings at the school for the children?

Amanda: No. No.Yeah, if you talk to the teachers they go, 'well, you know, she's got this'. And you go, 'well, that's great', and the teacher for the deaf will come in and go, 'well, you know, she has a Soundfield system, she's fine'.... Oh, and you're being over-dramatic, or you know, well, your children aren't that bad. ... We've had all of it, you know, well they're not that deaf. Okay, thanks for that.

One parent had difficulty with her home local authority which denied additional services because her child was at a resource base school in a different authority. Parents often felt powerless in these situations and didn't know how to challenge the system.

I mean the school is the only people that help me. I get no help what, fae ma own authority whatsoever. ... So it's disgusting! ... And because she's went outwith the authority I'm entitled tae nothing. ... It's, it's horrible. They treat people wi' no respect whatsoever. What about the people that's got kids wi' disabilities? It doesnae mean you have tae shunt them somewhere else or ...but it doesnae mean just because they've been put somewhere else, they get no help fae their own.... But I used tae have speech and language, I get no help fae them. .. I honestly feel as if sometimes I'm talking tae a brick wall because people don't understand what it's like. You know, put yourself in my shoes or somebody else's shoes, just for five minutes and see how you would cope.

Kayley

6. The role of voluntary organisations

There were 57 comments made from 20 of the families about the role of voluntary organisations, both for the parents and their deaf children. However, questions were not asked about awareness of all the possible options. The interviewers did explicitly ask about the awareness of NDCS activities and services. The balance of comments is summarised in Table 12 below.

Table 15 Involvement of families with voluntary sector organisations

	NDCS help for parents with applications e.g. DLA, applications, education advice	NDCS courses, activities and events for parents and/or children	Local deaf children society events	Local Deaf centre including youth club and BSL courses	Other Voluntary sector about deaf children	Voluntary sector advocacy and support organisation for parents	Local voluntary sector Provision e.g. cubs, swimming, football, disabled gym
Positive	7	1	7	5	3	2	7
Aware but doesn't use	1	5	5				1
Not aware	2	3			1		
Negative	1	4					2
	17 of 20 families commented on NDCS and local DCS activities.						

n = 57 comments from 20 families

Many parents were very enthusiastic about the role of NDCS, particularly local Deaf Children's Societies' events.

I wish I'd known about the local groups of the NDCS earlier, I really do. I sort of stumbled across them. My daughter went for swimming lessons at the local pool and the pool was packed with about 150 kids, and all you could hear was my daughter's swimming teacher going, 'Annie, Annie, Annie!'. 150 kids, all you can hear is my daughter's name being shouted [laughs]. And we went for months, and months, and months and she never progressed, she never did anything because, of course, she couldn't hear with them standing on the sides and her in the water. And then one of the swimming teachers came up to me and went, 'you do know we do deaf lessons here on a Friday?' And I went, 'I beg your pardon?' She said, 'we do deaf lessons here on a Friday'. And I went, 'do you?' She went, 'yes, it's run by the DCS'. So she gave me the number of the lady that organised it, and I rang her up and she went, 'oh, yeah, yeah, we're the local deaf organisation', she said, 'we do loads of things, come along'. So we went along to that first lesson and, of course, the instructors were in the water, and it was remarkable, cause my daughter was engaged, she didn't drift off. And I have to say, it was absolutely remarkable, I remember crying my eyes out because they came out, the teacher came out and went, 'oh, she's done amazingly', and it's just like, wow, you know, wow. And I just wish I'd known about them earlier. And, you know, it sort of opened up a bit of a world, my daughter got to meet other people with hearing aids.

Amanda

The reasons for not being involved, though they were aware of local DCS and NDCS activities, were issues such as the events being too far away, not being able to travel with so many children in the family, and the expense of getting there. The negative comments in relation to NDCS courses and activities were being too expensive, being too pro-speech or being too pro-BSL; one mother attending a weekend for the families of newly diagnosed deaf babies was 19 at the time, felt different from the older, married couples there:

I went tae a family weekend wi' the NDCS in (name of city). I went there one time but...I felt awkward in the place cause everybody was .. They were like...I say big mums [laughs], and they were married and they, oh and I dinnae feel like I could really speak about, like I dunno, I just...
Louise

Travel to NDCS events was a problem for eight families; parents mentioned the cost or difficulty of travelling such a long way, especially with large families. Two single parents had deaf children who were not able to use public transport because of communication and behaviour difficulties, effectively confining them to the local area.

Interviewer: Have you been on the train with her?

Kayley: Oh aye.

Interviewer: Is she better on the train than on the bus?

Kayley: No, no, no. ..We tried that when we went tae (CI centre – 30 miles away) and it was a nightmare. Cause I don't know if she could feel people staring at her. ..And she would just erupt.

Interviewer: So if you had someone along with you, would it make it easier?

Kayley: Somebody that... understands, yeah.

The families that didn't know of NDCS at all either had a language other than English at home, were new arrivals or because their children were preschool age were focusing on local activities. Sometimes families knew of one aspect of NDCS but not the wide range of possibilities; for example, one family knew about support with DLA forms but didn't know that BSL classes were sometimes available through NDCS.

Like Amanda with the deaf swimming class, the way parents found out about the existence of NDCS was often through word of mouth and from friends:

How did I actually find out about NDCS? I found out about that because a girl I knew, she does hair, and her, she came up to do my hair one day, and I met through my pal actually, and she was telling me about her son, he's got the... implants. So, it was actually her that made me realise about Melanie as well, cause when she was up doing my hair she said, 'is she deaf?' She says, 'no'. She said, 'are you sure, have you had her tested?' I'm like, 'aye, when she was a baby, but everything was fine'. She says, 'no, get her tested'. It was her that put it in to my mind, cause it all started to click. She says, 'that telly's up pure loud'. I was like, 'I know, she turns it away up so she can hear'. She said, 'I think she could be deaf in some way'.. And it was her that says to me herself about the National Deaf Children's Society, and also the (local DCS group), she says to me, 'contact them and get, obviously, somebody close, from in your area, like, works there, see if they can come out to you'. She says, 'and apply for DLA.'

Natalie

A broad range of other voluntary organisations was used by these 21 families: deaf centres where there was sometimes a youth club and often BSL courses, an Asian deaf network, local youth club or organisation such as the scouts, an Arabic school for learning to be literate in the home language, sports clubs, dance clubs and a free week-long Cued Speech camp.

Cause they just offered to teach us for free, visit our house .. taught us in a weekend, gave us a free five-day camp intensive learning, had a creche for the children. It was like a holiday. It was amazing. So, they were really supportive. And almost all of them really are fluent, beautiful signers as well..... and the creche was run by deaf adults. You know, it was like, I was like wow, this is good, there's all these deaf kids here in a creche, run by deaf adults, and we're getting put up somewhere for free, and taught this funny cueing thing, and yeah, it was really lucky.
Tina

Not surprisingly, the feature parents commented on most often were value for money and finding free sports and clubs for their children to join:

Natalie: She goes to dancing. ... On a Thursday. She's doing it in that wee club down there. So we take her down to that from six o'clock till half seven.... She loves dancing, so that's why I put her in. It's a free dancing as well.

Interviewer: Do you not have to spend a fortune on costumes?

Natalie: No, it's a free dancing. They had a...no that Thursday there, but the Thursday before, they were doing, it's like for a competition, they got filmed wearing summer clothes and doing a summer song, so it'll go on Facebook.

The general impression from these parents is that voluntary sector organisations were very important to them, supplementing what was available through statutory services such as Health and Education. However, they didn't have such good access to the whole range of services available: lack of full information, and financial and practical issues often prevented them from joining in.

Research Question e. What do the families see as the challenges and supports for themselves and their deaf children in relation to language and communication development?

As early language development is such an important issue for deaf children, parts of the interview focused on their language and literacy, parents' expectations in relation to language, and the advice parents would give to others. We refused to position parents as inadequate in this area, though sometimes parents living on a low income are viewed in this way by professionals. We started from the assumption that the parents would develop their deaf children's language development using strategies which could be shared with others. Though we found plenty of positive strategies, there were many challenges and little support for parents in relation to language and communication development.

7. Acquiring language and literacy: challenges and supports

Challenges to language development

Challenges related to having limited access to resources, and encountering professionals who made unnecessary barriers. Parents who were young, single parents found it challenging when professionals said negative comments in their own homes. The arena for language development is the home; feeling threatened in that space, and not having the right tools for language development in the home were very frustrating for parents.

Several families commented on the challenge of not being able to learn BSL to communicate with their children: the expense, the lack of classes and the very limited learning resources available.

but it's like I want more you know? I'm not greedy, I just want there to be... I, I just want... I There's nothing wrong wi' that [laughs], you know. You know I just, I just want more. Like we could have conversations and we could think but as she gets older, you know, we need more, you know.

Dave

And one came as a sign language teacher for children. One sign language, one for playing my son, and one for me interpreter. .. Yeah she's give me the one book, she's give me the book and I'm following the sign like Saturday, Sunday, Monday, that is a sign. Or though some words like bread, milk and colour yellow, like they're different, different. She's given me the one book, I remember sign. But I'm not more, learning no more.

Leah

Parents were not always aware of the advantages of equipment like FM systems, but when they were, it was often not available, not allocated by the local authority and too expensive to buy:

I did toy, my husband and I did toy with trying [a radio aid] from the NDCS, cause you can trial stuff, but to be perfectly honest, they [education]'re not gonna give us one, and I didn't want to try it, give it to him, for him to go oh, that's amazing mum, and then have to take it off him...But, cause there's no way we can afford one. As I say, I'm currently working all the hours I can, my husband's unemployed, and I've got mouths to feed and roof to keep over their heads, so there's no way that we could afford one ever in a million years, so....

Amanda

Single parents sometimes felt professionals' attitudes were a personal challenge, coming into their house and blaming them for the child's lack of progress with language development.

But at the time you tell a young person that they just believe you. These are the professionals, you believed them didn't you [laughs]. I, I was angry. I was angry for a while. See when I was still getting, I couldnae get rid a' them, like oot in, they were constantly in, then at some points the way he was feeling they were asking me, 'are you doing what, are you doing the work in the house with him?' So then I was getting upset, sometimes questioning my, questioning myself, you know as you do as a parent. You sometimes, you're like, 'oh am I doing this?' I'd be questioning myself. So I was angry for a long time tae the point wi' (name of SLT) I'd got really, I'm nice and cheery and jolly. But she came tae ma door one day for a meeting and I was just, she, she never came back after that day. I never said any'ing but it was ma face.

Louise

Supports for language development

Support available was often a combination of finding the right external services, and making them work for the particular family through determination, maintaining control.

One way of supporting BSL development reported by a family was set up by parents in a local NDCS group. They employed the teacher who came to one of their homes, and they shared out the cost between the families. The parents valued having control over what they learnt, unlike in a class:

I think that whole signing in a group thing is amazing. And getting somebody to come to your house and pay them. So ..., you know, you get someone to do it for £30, if you could get, you know, if you could get anyone else to come, it just, it actually becomes really cheap, and you get to learn whatever you want to learn. You know, I'd sit there with a story book that I wanted to sign to her and they would teach me how to sign it, and then the next day I could sign that book to her.

Tina

One single parent who is a deaf BSL user found specialist services to help her family support her son's communication and additional needs. This took a lot of determination. She had the support of specialist services, but she also had ways of finding information on the internet in BSL, not available to her in print.

It was hard work. Communication with him was very difficult. I would unsuccessfully try to get eye contact with him so that I could sign with him. It was hard work. I looked on the internet and found information so asked my family social worker for a long meeting at my house with BSL/English interpreters. The meeting took four hours with two interpreters co-working. I insisted on this meeting ... as I wanted to understand everything and to get to the bottom of it. I wanted a full understanding of how to interact and communicate with (my son).

Cristina

Some parents had great faith in professionals and valued their expertise; they liked the clear instructions about what to do and how to rapidly move ahead with language targets:

It was, it was very structured, very intensive what she got [with Auditory Verbal Therapy] but as..., a very disciplined approach and to be honest it wasn't difficult because you were just incorporating her as, as a parent you had to know exactly what you were doing. But for Martha it wasn't, cause it was just play. All you were doing was playing and reading to her but you

were doing it in such a way that you knew these were the words that you had to get her to say, these were the things that she should be talking about.

Sue

8. Parents' and services' expectations for their children

Expectations from parents about their children and perceived expectations from statutory services often related to language development. Not all parents were asked questions about expectations because for some families there were other, more pressing issues and for some their deaf child was young, not yet in school. Sixteen families were asked about their own expectations for their deaf child / children. Three could not answer: they were not confident about their parenting skills or did not understand the question. The 13 who could answer had positive aspirations but they ranged from long-term prospects (being Prime Minister: Tina) to short term goals (improve eye gaze so he can work with interpreters: Cristina). Some parents had very generic hopes for the future (be happy: Leah).

One parent said she now had high expectations since she had found the right school for her son.

Definitely, he's super, in fact [laughs] he probably, so I think he's up [laughs] wi' the most chance a' going tae University [both laugh]. His school's great. It's like a, it's like private at school practically cause the classes are so small and they've got two teachers. And he just loves it and he's super smart. I ask him what he wants to be, he says he wants tae write books and he just wants tae live here and get a dog. But aye I definitely have no doubt. At the start obviously I was fully a' worries what's gonnae happen.... But now as I see him coming on definitely. I think he'll maybe have a quirky job though, he's a bit quirky [laughs]. But I definitely think he'll be successful.

Louise

All parents discussed the expectations they perceived that statutory services had towards their deaf child or children. Five families were happy with education services or the placement they had now found for their deaf child, though they sometimes thought previous placements were unsuitable and had lower expectations. Six families said they thought education in particular often had low expectations of their deaf child or children, in relation to expectations of numeracy, literacy, the small amount of homework, or not getting enough feedback from school about the details of their achievement. Sue felt that both education and health services had made negative assumptions about her deaf child needing help in the future, when she felt her daughter would not need any help at all.

And I mean I didn't know from anything other than watching a YouTube video, some kid in Australia speaking. That was my entire inspiration because I wasn't given any other, I wish I'd had a Martha. I wish when someone told me that Martha was deaf, that someone had brought along a Martha for me and said, 'this is what your child is capable of'. Not, 'oh no she's really gonnae struggle and she probably won't learn to speak properly. And people won't, you know, .. she might be more difficult to understand', and all that sorta stuff. You know, that was what we were told....my expectations for Martha were exactly the same as they were for Rowena as far as hearing. And there was never, 'Martha's not gonnae do as well at this or ...you know, Rowena'll, you know, she'll be able to do this but Martha won't'. I never differentiated between the two a' them. Martha, as far as I was concerned, from day one would, would be, would be able to do everything and, you know. And you couldn't tell them apart. You couldn't tell which, which kid's speaking. They're identical obviously, they look exactly the same but they sound exactly the same, there's no difference. So yeah just, you know, don't lower your expectations.

From this same group came responses indicating the parents' independence in finding out about future possibilities online, and belief in themselves as being the people who would make most difference to their children's outcomes.

9. Advice to other parents

All parents were asked for their general advice to other parents as a way to listen to the positive strategies families had found through their experiences of bringing up a deaf child.

The most important theme from six parents was to keep control of the information, ask questions, and realise you know best, don't just accept everything you are told and make your own decisions.

Well mainly I'd just be involved, you know, and make sure you know everything that's going on and make sure everything goes through you, especially wi' school.

Carri

I was just constantly, I was just answering loads and loads a' questions. And like I was dead curious. I think if other mums have got any doubts and stuff about it they should definitely, for instance the deaf teacher, just ask for as much stuff as you can. Find out groups, find out, just things about like maybe when they're going tae school and they're gonnae be older.

Eilidh

The next related theme from four parents was to show unconditional love to your deaf child, and treat them as equal to hearing children.

yeah just...try not to listen to other people too much. You know, it's your child, you know them the best and do what's best for you and your child and try not to get too upset by the judgmental people.

Rose

Four parents focused on learning BSL as a priority.

So the only advice I can offer them is to, the first step is obviously communication and communication is so important. So with a, with a parent I would advise them first and foremost to try and go to any class that they may have in terms of learning BSL or even an online course or something if it, if nothing's available locally. Because what that does is you have that connection with your child first and foremost where you're able to sign with them. Even if it's basic, basic sign language, it is still a lot for a child.

Ahmed

Three parents stressed the importance of moving quickly in the early years to establish treatment or provision, working hard, and establishing support from organisations like NDCS.

So yeah, as I say, do your research, work your ass off wi' your child for the first three years ...You put that effort in when they're born and, you know, even, you know, from six, nine months ... we were reading to her, everything, we were getting all the sounds in. So...and, and have, yeah don't have low expectations for your child because they've got a hearing loss because they're just as capable if you put the work in but you have to put the work in. I think that's it, I think that is key, you have to put the work in.

Sue

Practical advice was suggested by two parents, both deaf: apply for tax credits as well as DLA and look for specialist tutoring in BSL for your deaf child. Two parents, Mariam and Natalie, found this question impossible to answer as they didn't feel they had anything to offer others at the stage they were at.

I feel I want advice.... It's really hard for me to accept this.

Miriam

Advice to other parents about language and literacy strategies

Strategies suggested for improving speaking and listening skills were talking at the meal table every night, taking turns in games and chatting with your children to really get to know them.

Well, we always sit down at the dinner table to eat dinner. ..All of us round the table. And I've found that that has been absolutely excellent, because they talk, they interact, and so they're not frightened of having a conversation... It's like, so every single day there's quality time where everyone has to turn-take, and focus, and make sure they're understood... and everybody's looking at each other cause it's an oval table, and so it's, you know, and we all sit round, and they all get their say, and it doesn't matter how old they are, or who comes, we will sit round the table.

Amanda

Ideas for cognitive strategies to develop language included making shopping lists for children to find and talk or sign about, going to the science museum, matching animal names and sounds and asking trick questions to encourage your child to look round them and read environmental print.

And if we go shopping, I'll make a list, and I'll give that to the two older ones, and they tend to sign it to the younger ones, so that's quite good. I'll walk along with the trolley, and my second eldest son, who's not overly interested, but the oldest daughter will tell the younger ones, and they'll run off and pick up the items and put them in the trolley.

Danielle

Strategies to improve literacy included going to the cinema to see subtitled films, using fingerspelling, introducing new words with real objects then moving to the printed name, using picture books, and regularly reading books with children.

We show her objects. We show her the object or a picture... If you mean, if you mean an actual thing in real life we'd actually show her the object and then show her the sign of those ...she gets the connection... that ain't a problem. Yeah you only have to show her a sign once or twice and she'll remember, or a word. I think a sign she'd learn quicker actually.

Amy

For those learning BSL, parents recommended going to a class, sign all the time, use Mr Tumble on TV to start children off, and use a simple sign reference book. This family were teaching themselves BSL using the internet after finding no classes in their local area:

So it's like what do you do? You have to learn yourself. You have to stay at home and you have to, while they're at school you're, we're watching videos, ain't we? We're reading books and we're basically teaching ourselves.

Dave

Many parents used language resources from outside the family: rhythm and rhyme groups, being filmed by the teacher of deaf children and receiving feedback on their play and interaction techniques (2 families), taking in a story book to a deaf BSL using tutor and learning how to sign it well (2 families).

I get books, signing dvds, people... So Eric (sign language teacher at resource school), he'll show you the book and then sign the story and then tell you.

Louise

Even though as a group the parents did not have a large amount of knowledge about language development, they did have useful strategies from their experience or other resources available to them.

Chapter 4 Discussion and Conclusion

The main findings from the interview stage of the project were:

- Many families living on a low income are not receiving as much discussion and support as they need around language and communication choices and equipment in the early years. This was particularly true for parents with weak reading skills and where English was not the main spoken language in the home.
- Parent confidence was often related to having good information and an alternative source of information such as someone who knows about the education system. Many families on a low income did not have alternative sources of help and advice.
- Families did not have a way of independently offering feedback to professionals until matters came to a crisis, when it was often expressed very dramatically (i.e. by moving or insisting on a different professional).
- Newborn screening and early intervention is not proving very effective for families on a low income. From this small sample, deaf children from families on a low income are more likely to experience delays in starting aiding and intervention.
- In our sample, 76% of the parents used BSL or some sort of sign language at home, well above the levels used by deaf children at school. Professionals often tried to discourage this, saying it was not needed, but parents found it useful. Their access to learning BSL was very limited and courses expensive.
- NDCS was effective at supporting these families in claiming DLA, but could have done more after that to support families on a low income in new ways. Existing NDCS activities were sometimes inaccessible or off-putting.
- Parents living on a low income have a wide range of skills and strengths, which are not necessarily recognised by the professionals they meet.

The conclusions of the literature review part of the research from Chapter 3 were that a number of approaches could lead to better success for language and literacy outcomes of deaf children from low-income families:

- Parents can be taught ways to interact more effectively with their deaf children
- Fluency in one or more languages is a pre-requisite for educational progress and is an organisational task which can be tackled in relation to both spoken languages and BSL.
- School systems could become more culturally sensitive to the needs of families living on a low income with deaf children.
- The 1/3/6 month targets of screening, diagnosis and aiding, and starting work with the family offer the best chance for higher language outcomes for deaf children from low-income backgrounds.
- Knowledge of the language acquisition process in deaf children can be taught, but needs focus in situations where parents are not confident with written English.

Why do families living on a low income have these experiences?

In sociological studies there is wide discussion about the idea of *social or cultural capital*. This theory has been put forward in two main ways. In the 1980s Bourdieu proposed that cultural capital was closely related to actual capital, a way in which people who have connections to people with power, money or information use it to help themselves (Crossley, 2012). Social networks with people with this information are crucial to other outcomes. So for example, families living on high incomes may use contacts with friends to find out about Auditory Verbal Therapy, find the money for it, and make a very early start on early intervention, being very compliant with hospital rules, that is conforming because they know from in-depth discussions with experts that this is likely to lead to the best outcomes for spoken language for their deaf child. This view of cultural capital has a socialist or Marxist analysis of class relations in society as its basis. The analysis doesn't necessarily help with solving the problem for families living on a low income, other than working towards a systematic change in the way society is organised.

A variant of this theory has been put forward by Coleman, also in the late 1980s, who suggested social capital was based on trust between people in society; to get on materially, people trust each other and are socially closely associated. They help others partly in order to help themselves and when they need help, they can call in favours (Coleman, 1988). Coleman looked at this idea in an educational context arguing that the social networks and social capital surrounding a school, for example clubs and parents' groups, could support pupils through the system and prevent them from dropping out. A collaborator, Putnam (1995) argued that American society was experiencing a sharp decline in social capital in the form of civic and political engagement. Civic society was aided by voluntary activities, building social capital, but was in retreat partly because of more women going out to work rather than volunteering in civic groups, and TV keeping people in the home. This second more descriptive view of social capital could also be applied to the situation of low-income families bringing up a deaf child. The trust and friendship relationships between teachers of deaf children and parents can bring real benefits for families: more time spent, more information gained, more opportunities opening up. Compliance, though, is often the basis of this trust relationship (Mathews, 2017).

In this study we use the idea of parent confidence, shown by Vance and Brandon (2017) as being closely related to parental self-efficacy. These researchers focus on the skills of adjustment, developing new skills and strategies for balancing bringing up a child with additional needs with other responsibilities. These are all individual characteristics. We add to this concept by including the ability parents have to resolve issues for themselves, drawing on support and information from a wide range of sources. Real capital makes a difference – those parents who had access to some capital were able to make more independent decisions and stand their ground. Confidence in this study was related to parents' access to actual capital and social capital: social support, positive attitude to deafness and involvement with third sector organisations where they can talk to other parents and deaf people.

An implication of this idea is that having a deaf child is a learning journey, one for which families on a low income often have unequal resources from the start. The families we interviewed did use their social contacts, which often led parents to finding the NDCS and other voluntary organisations which could help them. However, the depth of information and support they needed was usually not available through social contacts or from professionals, particularly for those with weak English or literacy skills.

Further research

From the literature review it was found that there is currently little research on the attitudes of professionals such as teachers of deaf children, speech therapists and audiologists towards families living on a low income. This research could lead to professional services improving their relationships and effectiveness with a wider range of families.

Early intervention services could be much more systematically evaluated. For example:

- There could be a regular follow-up survey of parents who have experienced all aspects of the newborn hearing screening and audiology investigation.
- An independent team could evaluate the Republic of Ireland's home visiting Irish Sign Language service, not available in the UK.
- The 1 / 3 / 6 month targets for screening, diagnosis and aiding, and starting work with the family, could be more widely advertised to parents. Then parental understanding of the significance of these benchmarks could be evaluated.

From the literature review we have seen that it is parents living on a low income who benefit most from these benchmarks being attained. Particular interventions, such as text message encouragement and tips (Hurwitz et al., 2015) or LENA plus language acquisition knowledge and video feedback on early years and play, could be implemented and evaluated to give information, encouragement and support to families living on a low income about the language development of their deaf child. It would be important to ensure that parents living on a low income are involved with the development of this research to check that it would be supportive rather than interfering or patronising.

Limitations of the study

The aim of doing qualitative research is to explore viewpoints and experiences then attempt to build theory from the findings which may be of wider use in further enquiries. It is not a study in which we take a representative sample then generalise the results to all parents on a low income with deaf children. Thus we cannot generalise from this study, but we can point out suggestions which may be useful based on the wider literature and on the experiences shown by this small group of families.

There are several limitations to this study. The original aim of the research group was that all the interviewees should be parents who had brought up a deaf child while living on a low income. While the main interviewer conducting 16 of the interviews was in this position, the other five interviews were carried out by researchers without this first-hand experience, which meant that the relationships established between interviewer and interviewee were not exactly comparable across the interviews. In addition, in two cases the interviewer knew the interviewee, which could have led these interviews to unfold in slightly different ways. Two interviews were conducted through a spoken community language interpreter. To mitigate this difference, in one case the interviewer briefed the interpreter in advance about the purposes of the interview, the content and the British Educational Research Association's code of ethics (Firas' interview). In the other family a professional interpreter was refused and a family member interpreted which could have compromised the quality of our understanding of this interview (Leah). For this family we booked a Punjabi interpreter to continue the dialogue and check the accuracy of the family summary.

Recommendations

It is difficult to generalise from these findings, as it is a small sample of parents which may not be representative of the wider group of parents living on a low income with deaf children in the UK today. However, ideas raised by the parents and issues from the literature review could be explored by NDCS and other voluntary sector organisations, teachers of deaf children and NHS staff.

NDCS

- Having staff with personal knowledge of bringing up deaf children on a low income would encourage parents to open up and explore more options. There were many positive role models amongst the parents we interviewed who would be skilled in this role if they had a training course.
- Telephone or Skype peer support to other families may be a useful service for parents who can't get out easily. Information from other parents, we have seen, is crucial for building up knowledge of deafness and the education system.
- Do not publish information just in English. Parents who don't read English were at a huge disadvantage. NDCS used to provide information in a range of community languages, but the parents we talked to were not always literate in their home language. These parents would benefit from listening to community language voice files on the internet as a first step, and having skilled, unbiased staff to talk to who shared their home language.
- Consider providing transport to events because travelling on public transport with deaf children can be impossible for some parents, especially if they don't have good communication with their children. DLA is partly for transport, and NDCS clearly support parents very effectively in claiming DLA, but it is not just about the money. Childcare and child supervision were raised by several parents.
- Grants for holidays for families with deaf children living on a low income are very important and should be prioritised, particularly if they give the opportunity to meet other families and share ideas and information.
- Investigate the loan FM scheme further in relation to families on a low income: for example, what are the benefits of FM use at home (already some very good videos on NDCS website), what insurance needs to be in place, what repair facilities, how to explain FM checking routines in more ways than just written English, how to ensure home and school FM systems are compatible.

Services for deaf children, Local Authorities, Teachers of deaf children

- Spend as much quality time as possible with families on a low income, particularly those who you know are less likely to have access to written English. The level of deafness of the child is not important – these families need more information about audiology, language development, cognition, reading, maths and science development in the home, social and emotional development and the education system because they are systematically excluded from it. This may include continuing home visits beyond the start of school, running regular sessions in schools for some parents, using text message contact, and maintaining home-school books.
- Improve the speed and quality of early intervention so that parents understand the need for these services, because families on a low income will benefit most. Reduce institutional barriers, such as poor communication between several authorities, i.e. work for the child not the health or education authority.
- Be more impartial around decision making with parents living on a low income. Provide them with the full range of information they need and let them take the lead. Don't threaten or chide – treat them as equals and recognise their strengths.
- Consider training teams in awareness raising around the effects of living on a low income on life, bringing up a deaf child and educational attainment. This should lead to more positive approaches. Some staff currently go the extra mile for families in crisis – this should be the aim for all professionals.

- Offer more support to families about buying or getting a grant for an FM system at home, checking to make sure that insurance, repairs and compatibility with school systems don't raise more issues; be positive not punitive.
- Train a teacher of deaf children in Auditory Verbal Therapy so that this service becomes available as an option for families living on low incomes, and that this professional can provide advice to other teachers of deaf children in the authority.
- With the local authority and colleges, make free BSL tuition available for parents and families from birth to school leaving age, at a time and place to suit the families. Investigate the Irish home visiting model.
- Consider setting up a group for parents around finding out more about language and deafness, providing BSL and community language interpreters where needed and internet access at the venue; this could be very helpful for families living on a low income, especially if transport were provided. Working closely with the adult education service and other council agencies there may be referrals to adult literacy, college classes, third sector organisations, food banks, social work and welfare rights.
- Many deaf parents are living on a low income. Make sure professionals are available to give detailed advice and discuss early years language development, audiology, reading, social and emotional development etc in very fluent BSL. If not, share specialist staff with a nearby authority.

NHS staff

- Work closely with local authorities, as the best health authorities currently do, to achieve the early years 1/3/6 month targets for screening, diagnosis and aiding, and starting work with the family. Publish these standards in ways all parents can understand.
- Consider update training for the paediatric audiology team in relation to socioeconomic risk factors for deafness, and improve follow up for children who fail the screen but pass the audiology test if risk factors are high.
- Consider training for speech and language therapists and paediatric audiology teams in awareness raising around the effects of living on a low income on life, bringing up a deaf child and health outcomes. This should lead to more positive approaches to missed appointments, building up better knowledge about deafness with parents, and cultural awareness, such as making better use of interpreters.
- In CI centres, focus more attention on families whose children are not suitable for a CI because of 'non-compliance', i.e. poor hearing aid use, or coming to CIs as an option very late. Work much more closely with local authorities and accept joint responsibility for these children's language development.
- The NHS Personal Child Health Record (Royal College of Paediatrics and Child Health, 2017) could have an expanded section on language development using pictures (see pp. 44 – 46 of current record book).

**Please contact me if you would like to discuss any aspect of this study:
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Appendix 1: Search terms used

Database searches

deaf AND child AND deprivation

deaf AND child" AND NOT "auditory deprivation" AND NOT "linguistic deprivation" AND NOT "sensory deprivation" PUBYEAR AFT 1990

deaf AND child AND poverty

TITLE-ABS-KEY (deaf AND poverty AND child) PUBYEAR > 1990

Deaf AND child AND low income (abstracts) after 1990

deaf* and child* and low income

TITLE-ABS-KEY (deaf * AND "low income" AND child*) PUBYEAR > 1990

deaf and poverty OR SES (deaf in subject line)

deaf (Key Word) and poverty OR SES

Deaf AND poverty OR SES, 2000-2019, full text, abstracts

TITLE-ABS-KEY (deaf AND poverty) PUBYEAR > 1990

TITLE-ABS-KEY (deaf AND 'maternal AND education') PUBYEAR > 1990

TITLE-ABS-KEY (deaf AND SES) PUBYEAR > 1990

hearing impaired AND child AND poverty (abstracts) after 1990

hearing impaired AND economic AND child

TITLE-ABS-KEY (hearing impaired AND poverty AND child*) PUBYEAR > 1990

hearing impaired AND child AND low income

hearing impaired and child and low income (child in abstract)

hearing impaired AND deprivation

Main subject (Hearing impaired) AND Poverty OR SES

Main subject (Hard of Hearing) AND Poverty OR SES

hard of hearing AND child AND deprivation

hard of hearing AND poverty

hard of hearing AND poverty OR SES

Deaf education journal searches

poverty OR SES OR low income

poverty

SES

deprivation

disadvantaged

Abbreviations from search terms:

ABS – abstract

AFT – after

KEY – key word in the abstract

PUBYEAR – year of publication

* any ending to this search term e.g. children, childhood, child

> Later than

Appendix 2: Studies reviewed in Chapter 2

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Appendix 3: Interview schedule

Introduce yourself. Explain your experience with raising a deaf child briefly (not too much detail on your own decision making). This project is trying to find out the views of families who are sometimes not listened to – families living on a low income. There are extra challenges but also important insights which other parents can learn from. We are interested to find out what has been tough, and what has gone well. We are particularly interested in language and how families are supported to develop their child’s language / languages. We want them to tell it like it is. Explain about confidentiality. We will not tell service for deaf children or any other person any details. The names / parts of the country / identifying features will not be used. We may use quotes. Check the family is happy to carry on. Turn on the sound recorder. Introduce the date / town and first names of people present.

<i>Issue or theme to explore & reason for asking at this stage of the interview</i>	<i>Specific questions to ask</i>	<i>Supplementary questions to ask depending on how much time you have. These won't all be relevant.</i>
1. Warm up question – this is a very open question which could lead to a lot of information from the family about many of the later questions. We want it to be non-threatening and open.	Can you tell me about your deaf son / daughter / children and what it has been like to bring them up?	When did you find out she / he was deaf?
2. Back to chronological questions now from the early years. Focus on early years because most language development occurs then. We know from the literature that experience across the UK is very variable.	What was your experience of the early years team (that support families from 0 – school age usually)?	Did you have some professionals visiting your home? How did that go?
3. Focusing in on the main topic of the interview – first looking at community resources	What sort of information and advice did you get from friends, family, or other groups about language choices and developing (name)’s language?	How did you find out about language choices and what was available to support your family?
4. Looking at the issue of informed choice – the literature shows that it is not just giving information, but contextualising it, not being biased, providing guidance if parents ask for that e.g. about what research tells us on outcomes.	What information did you get from professionals, like the teacher of deaf children, about language development and what did you think of this advice?	How many choices did you get to find out about? Was the information given easy or difficult to understand? How easy or difficult was it for you to use and act on the information given?

<i>Issue or theme</i>	<i>Specific questions to ask</i>	<i>Supplementary questions</i>
<p>5. This is a check – we know before the interview if they prefer a community language and we will have an appropriate interpreter present if so. This question is to establish if the family is multilingual, because often unexplored.</p>	<p>What languages does your family use? What about (name of deaf child)?</p>	<p>Reading, writing, listening, speaking, signing. You may be able to establish for what purposes, e.g. Arabic may be used in the mosque in an after school club, Punjabi for talking about family things etc.</p>
<p>6. Questions about hearing technology. These are deliberately very open questions because there is often some conflict or pressure about this subject from agencies: keeping hearing aids in needs a lot of persistence. Also FM systems in the early years are very useful, but many families can't afford them.</p>	<p>How do you feel about hearing aids? Radio aids? Have they helped communication? Did you have discussions about cochlear implants?</p>	<p>Has anyone ever suggested that you get an FM system or radio aid to use at home with (name)? At what age was (name)? Have they mentioned grants? What was the approach of the ToD to the subject of hearing aids and FM / radio aids? How old was your child when CIs were raised? What happened next? Do the staff at the CI centre treat you with respect? (ask why to encourage them to give evidence for viewpoints)</p>
<p>7. Focus in on sign language discussions. It is deliberately vague because there is a huge amount of polarisation about sign language use. So we want to see the views of the family without pressure. Also parents' conceptions of what acquiring a language like BSL will depend on their own experience of learning other languages. Also ToDs and school services may not know what becoming fluent in another language entails.</p>	<p>Have you had discussions about sign language use with (name)? Does (name) have friends who can use sign language and teachers who can use it fluently?</p>	<p>How old was your child when sign language was discussed? What happened next? What was the attitude of different people in the family and the ToD about sign language? Sign language classes are often expensive – were you able to get to any? What did you think of them? Do you have other ways to learn sign language and find out about Deaf culture?</p>

<i>Issue or theme</i>	<i>Specific questions to ask</i>	<i>Supplementary questions</i>
8. Focus here is on <i>agency</i> – the power of parents to make a huge difference to outcomes in relation to language development. The supplementary question may also probe relationships with professionals. Specialist services often make a lot of difference – and best language outcomes occur if children start young. We want to find out if these families were actually given information about them.	What sort of activities do you enjoy doing with your deaf child that might help his / her language develop?	What worked well and what didn't go so well in the years from 0 to starting school with (name of deaf child)? In the early years, did your son / daughter have anyone else who helped with language development apart from the ToD, e.g. Speech and Language Therapist, Auditory Verbal Therapist, Deaf BSL teacher or role model? Ask about these roles and the family's knowledge of them. (AVT is often private). Ask how / if the family has got access to these specialist services.
9. Moving on to discuss support at school – be very careful as interviewer not to react to what may seem not much support, or a lot.	Can you tell me about the sort of support (name) has had at school? Do you feel involved in these arrangements?	What types of support? ToD time. Specialist classroom assistant? Sign language tuition? Deaf awareness for the peer group / teachers. How did (child) learn to read? Did you learn any ways to help them with decoding words from print?
10. Focus is the relationships with professionals here: information and good relationships can affect language outcomes.	Can you tell me about the way you communicate between you and the service for deaf children? How do you get on? How well or badly has the service met your family's needs?	What's worked well? What's worked less well? Ask also about other relevant services: Speech and Language Therapy, CI centre, BSL tutor.
11. Focus here is on finance available for enrichment activities and social engagement which boosts communication skills, vocabulary and world knowledge.	Does (name) join in any trips or clubs in school or out of school, e.g. in the holidays?	Tactfully discuss if funding is available? Does s/he enjoy these? Any specialist areas s/he has developed? These may be whole family activities rather than clubs.
12. What support is there from voluntary organisations?	Have you been to NDCS activities for parents or children? Have they given you any advice about language development? Tell me about what you do with them.	Also see about other types of 3 rd sector supports, e.g. deaf youth club, Brownies etc. What is the parent's confidence level about going to these events?

<i>Issue or theme</i>	<i>Specific questions to ask</i>	<i>Supplementary questions</i>
13. Focus on school – teachers and specialist ToDs. Finding out what the parents views are about teachers’ attitudes. How much say parents feel they have.	<p>Do you think the teachers at your child’s school have high or low expectations for (name)? What makes you think that?</p> <p>Do they have review meetings at school for (name)? What preparation do you get for the meetings? How do you feel when you go? Does the school / service listen to you and your child’s ideas, and do you see these in the plans?</p>	<p>If it seems appropriate, ask parents about their own relationship with school and teachers growing up.</p> <p>What is your relationship with the teacher of the deaf like – do you get information regularly and can you talk to them openly about your concerns?</p> <p>If the family do not use spoken English, ask about interpretation at review meetings.</p>
14. Focus on literacy – which develops after a strong first (or several) languages have been established.	<p>What about home reading with your child? Do you feel confident doing that? What sort of advice have you had about reading? What do you do to support reading at home? Do you use subtitles much? Fingerspelling new words or other ways? What do you do as a family to support your deaf child about learning new words?</p>	<p>Do you read books with your child? How do you feel if your child seems to be struggling with words, understanding them, pronouncing them etc?</p> <p>Writing skills are often difficult for deaf children. Have you found out about this yourself or from any other professional?</p>
15. Final question – appealing to altruism. Everyone likes to offer advice and it is a non-threatening way to find out what they would like to see changed.	<p>What advice would you give to other parents living on a low income if they have a deaf child? What can you pass on to them about things you have discovered, especially about your deaf child learning to speak, listen, sign, read & write?</p>	<p>What are your own expectations for (name) in the future – do you expect she / he will go to college, get a job, go to university? Do you know how to find out about these routes?</p>

Appendix 4: Family Summaries

Ahmed

Ahmed and his wife, both hearing, have an eight-year old deaf daughter and her ten-year old hearing brother. They live in a city. The languages used at home are English and Bengali as well as BSL. The daughter was diagnosed with a severe hearing loss when she was less than a year old, and has a cochlear implant only on one side due to absence of auditory nerves on the other. It was very difficult when the parents discovered their daughter was deaf, but after they were offered a lot of support they felt easier dealing with things. Receiving support played an important part in accepting their child's deafness.

Since the early days, a teacher of the deaf went to their house offering assistance, advice and information on different organisations, and teaching the family basic sign language. The parents started attending sign language courses at a local place; the mother is now fluent in BSL and the father feels fairly confident. The daughter's main language is BSL. Her brother does basic signing. They got information about language development and the mother attended a playgroup with other families of deaf children. Sharing stories with other parents was really helpful. The daughter attends a school for deaf children. She is learning to read and write, and she gets speech and language therapy at school. She has also verbal dyspraxia, so it is difficult to articulate words.

At school, the teachers use BSL for communicating, and also teach lipreading. The school uses an app to keep the parents informed about what they do, which the family find very useful. The daughter loves listening to music, and the parents do activities with her for language development such as reading, playing with cards or sounds.

I really actually enjoy doing reading with her. What I do every week, or every two weeks, I try and go to the library and get books for her. And books, books that are obviously suitable for her. And we sit down and we read together and she really enjoys it. Sometimes she will read the book and other times I will read the book and sign, sign to her. And we do that a lot.

Ahmed says it helps to live in a place where there many services available for families with deaf children and it is important to take care of communication from the very beginning, attending BSL courses (in person or online if too far away), playgroups, social media, and interacting with the school. He is a parent governor at his daughter's school and keeps up to date. He is also the secretary of the local deaf children's society and the family help organise outings. Their daughter's school is quite a long way away, so Ahmed and his family help organise activities for deaf children and their families nearer to home. His advice to other parents would be to ask around, don't wait for services to come to you.

Amanda

Amanda is a hearing woman who lives with her husband and their family of more than five children in a rural area. Three of their children did not pass the neonatal hearing screening test; for the oldest, the hospital nurse kept on testing him until he passed. The other children are hearing.

The parents found out about their children being deaf when they asked a health visitor about behavioural issues. The girl was behaving like her older brother, possibly ADHD. The health visitor suggested a hearing test and after the girl was found to be mildly deaf, they tested the other children, two of whom were diagnosed deaf as well. Since the family was living in a border area between councils, they were referred from one service to another for more than a year after the diagnosis, not getting any intervention until the mother did a self-referral and finally a teacher of the deaf came to their house.

Language development was delayed for all three children. The early years teacher of deaf children was very helpful at explaining speech and language development. They noticed an improvement in their daughter's speech once she had hearing aids. NDCS and a local deaf association supported the family. In the family they use basic sign language, but they had to pay themselves for training. Through NDCS they have made some deaf friends, and they find sign is useful in their noisy house. The parents were told by the teacher of the deaf that sign language was not necessary but decided to use it anyway; they also fingerspell. They use family meal times as a way of listening to their children and encouraging them to speak. One time they lost the hearing aid shoes at home,

You know, he's five, he's put them somewhere. I mean, we literally ransacked the house. We were going through boxes in the loft.And we got home one day from shopping and we found this message on our answer machine saying, 'Hello, this is your teacher for the deaf, I hear you've lost £500 worth of (name) shire County Council's property and we really need to talk about this now, so ring me'. [Laughs]. I was like, oh my God [laughs]. And so, they did turn up.....it was windy, but he was colouring, he'd put them in the pen box. The pen box had been put in the shed [both laugh].

The parents would like to have a radio aid at home for their oldest son but cannot afford it. A Soundfield system is in place for their daughter at school. They are not satisfied with the services, which seem more for their youngest son who is moderately deaf and doing well than for the two older ones who are mildly deaf, but both have difficulties. Amanda thinks the lack of teacher of the deaf time and radio aids for her two older children are due to Council budget cuts: the two eldest children get just one hour per year specialist teacher support each. They have had no review meetings with the schools. Amanda thinks they have low expectations – the schools say the children are doing all right considering. The parents buy resources for their children, such as vibrating alarm clocks, and they didn't know that these services are often social services funded. She wishes she had known earlier about specialist clubs like the NDCS swimming club she discovered. Her daughter did so well there compared to the usual club where she was shouted at, and she got to see other children with hearing aids.

Amy and Tony

Amy and Tony, both hearing, live in a city with their deaf daughter aged five. As a baby she was in neonatal care in the hospital for several weeks, then failed the hearing screening test. She also has cerebral palsy, which makes walking and balancing unsteady. Their daughter received hearing aids before the age of one. She has auditory neuropathy, which means hearing aids didn't help much. They decided on a CI, and the difference has been really positive. She responds to sound much better now. The decision to get a CI was partly based on their daughter having cerebral palsy, because they realised signing would be difficult for her.

We had Viv didn't we? This was all before nursery... ..we had Viv, we had a teacher of the deaf ... She came to our house a couple of times. I don't really, I think, oh god it's cos so much happened. I think if I remember correctly there was a teacher of the deaf and then she left and there was a gap. Do you remember? We lived in the hostel. But I don't really remember the teacher of the deaf much. But Viv the speech and language therapist, she was amazing, oh my god! ... Yeah she works in (name of school) now as well.

When Amy was living in a housing association flat the workers helped her find funding for a beginners sign language course. She went on an NDCS course at the school, Raising a Deaf Child,

which was very helpful because it showed them how to focus and observe their daughter, how to encourage her to point and sign, and signs for feelings.

The parents managed to get their daughter into the deaf school when she was two, now a full time place in the reception. The main language they use at home with their daughter is BSL. Tony went to a BSL class too but due to his dyslexia and the focus on fingerspelling, he found it very difficult. Amy's family is Spanish, so Spanish is also used at home a little and with family and friends.

Amy says her daughter knows phonics from school. Amy loves signing books to her daughter at bedtime and she's used the internet to find books suitable for deaf children.

The parents feel involved in the planning at school and attend meetings every six months. Amy's sister is a teacher in the UK and she has provided quite a lot of information that helped with preparing for review meetings. One of the CIs failed recently, and they don't know how long it has not been working. Going to a deaf school, her school friends are far away which makes parties with them impossible.

They started taking their daughter to a gym club for children with disabilities, but found that they assumed she would be able to jump, so it was not designed for children with physical disabilities. They go to the beach sometimes; their daughter can sign about what happened last summer now. Amy's advice to other parents is to learn sign language, even though that's difficult to achieve.

Carri

Carri is a hearing mother who lives in a city with her five-year old son, who is moderately deaf, another son who is fifteen, and the father. The family speaks English. The son was diagnosed and fitted with hearing aids when he was four months old. The doctors told the mother to continue with hearing aids. The mother did not know anything about deafness before but they received support from a teacher of the deaf coming to their house and NDCS. The parents also attended groups for children with hearing aids. The son also had four years of weekly speech and language therapy from before he was one, which finished last year. The boy's language development was a bit delayed at the beginning but he has caught up since starting nursery. He is now in the first year of school and starting with reading and writing.

So when the hearing aid came out in the school the teacher had no idea how you put it back in. So she said then she was sitting for fifteen minutes. Now she's supposed to be teaching a class and had to sit for fifteen minutes and try and put in this hearing aid because nobody had went into the school and showed her. And they were supposed to be in during the summer... But somebody had rung me from somewhere to do with education during the summer to say (name of teacher of deaf children) was off sick.

At school, there is no additional support in the classroom but if it is needed, it will be provided and in the first year there are only sixteen children in the class. The mother is active and satisfied with the services so far, apart from the missing teacher of deaf children at transition to primary school. Carri has not been involved in any NDCS activities for parents and children, but she did receive help with the DLA form. They did not receive information about language development from them. Carri and her partner do some reading at the minute as a language activity / homework. She would say to other parents of deaf children – be involved with school and make sure everything goes through you.

Danielle

Danielle is Deaf and has four deaf children under ten. She is a single parent and lives in a small town. She attended a bilingual deaf school herself and has confident English literacy skills as well as very fluent BSL. Her own parents are also deaf. When Danielle's first baby was born, she didn't pass the newborn screen and the audiologist said he was sorry about the news. Danielle was positive about having a deaf baby. The audiologist started talking about CIs from the start, but Danielle said she didn't want one. The questioning carried on from several health officials, so in the end Danielle asked for a note to be put in her daughter's file so they didn't ask any more. The audiologists didn't ask again when the other babies were found to be deaf. When her first child was two, Danielle emailed the council to see if she could get a place in the local nursery, but they said she had to wait. Her eldest child started at the local nursery with a CSW. She received very little input from speech therapy, though she wanted more. Eventually Danielle managed to get them into a deaf school which has a nursery place for the three-year old.

Really, my first daughter, we had no support from any deaf organisation or teacher of the deaf. Nothing at all. So myself and my parents, who are also deaf, and me and my partner obviously encouraged my daughter to sign. By the age of two and a half, she was a fluent signer, yeah. We focused on signing. BSL in particular, obviously, until she was very competent with that, and she is an absolutely beautiful signer. I would say, her English probably started when she was at school. I would say that her English is very good for a deaf child, but she's fluent in BSL. That's my first child. We decided to teach her sign, and we do books, we do books every day. Every night I would sign books, and she reads really well herself now. She's aged nine.

The three in primary are now all confident readers. Danielle has helped out at the deaf school to teach other parents how to improve reading with their children. They are doing well at school, and she has been pleased with the level of the staff BSL skills, though she would like more discussion about her children's learning. Her children are active members of a local deaf club and local deaf children's society. She spends a lot of time signing and playing with her children, encouraging them to be independent, for example asking the children to follow a shopping list in the supermarket. She thinks the school sometimes expects clothing to be in place at very short notice, which she can't easily find the money for. She would like higher academic expectations from the deaf school. Danielle has a good network of deaf friends and so receives and passes on information about the education system this way.

Cristina

Cristina's family came from Romania when she was ten. She is deaf and went to mainstream schools in the city where she lives now, but didn't develop speech. She married a partially deaf man who uses SSE, and she started to sign BSL from the age of eighteen, paying for BSL classes herself. She now has three deaf children aged fourteen, eleven and five, the first two diagnosed aged two as moderately deaf and the third at birth as profoundly deaf. Cristina felt that when hearing professionals came to her house to talk about her deaf children they were nosy and as they couldn't sign well, she didn't take much notice of them. She refused further support for her two oldest children.

Her middle child has dyslexia. Both of her oldest children use speech at the local schools they attend and sign at home. Her youngest child has ADHD or autism, which includes severe behavioural difficulties. Cristina's mother is quite involved with her children, and in the case of her youngest child has pressurised Cristina to get a CI for him. Cristina has found out about CIs from BSL on the internet and insisted on hearing aids, not CIs. Cristina has had a very difficult time since her husband left.

Marius would throw tantrums. He didn't like going outside, I would try to take him out but he would get angry. The police arrested me time and time again and I would try to explain Marius was deaf. I had to physically hold my son and wrap him up in my arms to try to calm him down. He was only one year old at the time. Communication was very difficult. When police arrested me, my partially deaf daughter would use her voice and interpret for me. She explained to the police what had happened and that other hearing people discriminated against me because I am Deaf. I said this is not acceptable, get out. I was proud of my daughter who was 10 at that time, my son was 1 year old and I didn't understand what was being said while my daughter was talking to the police.

Cristina is desperate for information about child development. She attended a course about parenting a deaf child, but was disappointed there were no other deaf parents there. She needs a carer for her youngest child and a BSL interpreter at meetings, which most health bodies do not understand. Gradually from the ages of three to five her youngest child's behaviour has improved, and she has learnt about the importance of very regular routines to help him. The youngest child is in a deaf school, which she thinks is very suitable for his needs.

Diane and Stuart

Diane and Stuart, hearing parents, have three children; the twins are the eldest, now aged five, with one twin moderately deaf. They were very premature and the deaf twin was born with cerebral palsy and serious health issues. The first few years of his life he was having operations so the deafness issue was put to one side. He was aided from two with hearing aids. The other health conditions and CP seem to be the more prominent issues for him.

As the family had three children under three they were able to get full time nursery places from when the twins were two. The family really like the teacher of the deaf support as she has advocated for him and spent several sessions a week with their son coming up to transition from nursery to primary.

He now attends the local school with his twin and he uses a radio aid. Diane and Stuart can see a big improvement in his speech. They are worried about his sometimes erratic behaviour at school, but the school is well equipped and have put one to one support in place.

The family has fundraised to buy a wheelchair for him, because he was not entitled to one from the NHS. NDCS helped them with applying for DLA.

We've got nursery tae fill in just certain bits and the head a' the centre she put in a, a bit as well. And I said, 'it's always a worrying time'. She's like, 'why are you worried?' I goes, 'but it's all this stories that you hear, "oh such and such a kid hasnae got it. They've been refused and having tae fight and go tae tribunal and things". You're thinking, "why do you need to actually go and fight for something that they should be entitled to?'

Their deaf son does have some behaviour difficulties as well as his physical disabilities and deafness and he is still not toilet trained. He behaves like a younger child and seems to have cognitive delay. Speech and language therapy is very important for the family, but it has currently been cut because the teaching assistant said it wasn't needed. The family have had mixed experiences with other professionals dealing with various aspects of their son's health. Generally in relation to his deafness they have been very happy with the efficiency of audiology and education. They were told they must not lose the aids and how expensive they are; a few times they have lost but luckily found pieces of his hearing aids. It had been difficult to persuade him to wear them after school. The family have taken part in some NDCS social events, which they enjoyed.

Eilidh

Eilidh is a hearing woman who lives in a small town with her moderately deaf son aged four. Her son failed the newborn screen but she had several tests over the first few weeks of his life because they said it would be fluid in his ears. She had to go to lots of appointments, but eventually he received hearing aids at eleven months. She felt the health professionals were worried to tell her, but she was fine about him being deaf. She is very pleased with the visiting teacher of deaf children who came to the house every week from early on. She understands something of the speech sounds that her son can and can't hear. She can contact this teacher by text message.

Two years ago he went into the early years nursery. Cause obviously I was working and you need like a good reason for them to go into nursery at two. And mine's was so that we brought on his speech and stuff, get him interacting wi' other children and stuff. And it's worked wonders I think. That's because he has been in there.

Eilidh meets the teacher of the deaf in the local nursery now where her son has a full time place, because Eilidh works. She is very happy with the support in school: her son is taken out for thirty minutes a day with another child for extra story time. She had not heard about radio aids. His speech has come on well since being in nursery full time.

There have been a few examples in the community of other children pointing out his hearing aids or being cruel, but generally most children are fine and she explains to her son why he needs the aids.

Eilidh knew in quite a lot of detail what her son was doing about language development in nursery and why. Her advice to other parents would be to ask lots of questions, as she had done, to find all the information you need. She couldn't get to groups with her son because of working, but she is aware of them.

Firas

Firas and his wife are Syrian refugees, both hearing, who came to the UK via Lebanon three years ago. They now live in a city, and feel they don't know their way round well yet. They have four children aged six to eighteen, three of whom are deaf. There is deafness on both sides of their extended family; the families are also related. The parents speak Arabic at home, no English, so they use clear lip movements in Arabic and some home signs to communicate with their children. Despite these communication barriers, they are very interested in their children's opportunities in the UK. One of the reasons they chose to come to the UK was because they thought their profoundly deaf daughter aged ten now would be able to get a CI, but she was refused because of being too old.

I was a little bit suspicious due to the interpreter, you know, sometimes I don't know, I can't understand the interpreter clearly, but I don't know, I'm not sure if he is interpreting quite right, or ... I have to rely on the interpreter. He's speaking about his daughter who is ten-years-old now. We wanted to do the surgery, but we were told that if she's over five, that wouldn't work right now. My nephew, he is eight-years-old and although he is eight-years-old, he went to Turkey and he's done the surgery there. It worked. It worked. Although he is eight-years-old. He can hear now... he can understand.

The efforts of the family are now focused on the youngest boy aged six who is moderately deaf and attends the local school where he has a visiting teacher of the deaf. The eldest deaf daughter

is at college, and the ten-year old attends a resourced school where she uses sign language and some speech.

Firas feels disconnected with much of life in the UK. He can't read English and he doesn't know the names of organisations that can help him. He regularly takes his children to a deaf centre where they use sign language. On the whole he prefers them to use speech and try to lipread. He has heard about radio aids, he knows what they do and would like one at home. He pays a home tutor to come to his house to teach his children written Arabic. The family attend parents' evening and the school books an Arabic interpreter.

The family are assigned a case-worker who supports refugees. They were here two years before they had help with DLA forms from this agency.

Firas has not had any information about language development in deaf children, but he has seen the positive effects of hearing aids on his son, who had no speech at three when he arrived. He knows his son's spoken Arabic is much better than his comprehension of English at the moment. He has discovered from his son that he understands little in school. From his daughter's school they receive information in English so they use Google Translate to understand it. The school says she is learning very well.

Kayley

Kayley, a hearing woman, lives with her six-year old daughter who uses BSL. She lives in a small town and has no partner. Her daughter was not born deaf but was diagnosed profoundly deaf when she was three, after many ear infections which affected her hearing. Kayley's daughter had several operations before being diagnosed and was provided with hearing aids. Audiology referred her daughter to the CI team, but eventually this was not possible because of the damage caused by ear infections. She does not have any support from family. Kayley's mum did not accept the deafness of the child and turned away at first with the shock of all the health problems. The child attended a mainstream nursery where a teacher of the deaf worked with her. A person from the local Deaf Children Society came to Kayley's house when her daughter was two and a half. The nursery and a person from the council helped her with school placement.

We were meant to put her to (name of resourced school)... ..but they had changed how you come for a visit. You had to fill out a form. So it got to a point where I said, 'I'm no doing this'. I said, 'this is causing me too much stress, she's picking it up. I can't. I says, 'get me a school where I can meet the headteacher. The headteacher can meet Tracey, I can go to the school whenever I feel like it. So Anne (the Principal) came in and she was telling us about the school..

The only support she has is from the resourced primary school her daughter is attending, outside her home authority. In school, Kayley received help and advice on BSL. Her daughter attends a class with three other deaf children. As a parent, she would really like to attend BSL classes at the college and work with children with additional needs, but lack of money prevents this. She says she cannot receive funds from her council for learning BSL because the school her daughter attends is in another county.

The mum refers to other additional needs due to underlying health problems, other than the deafness without specifying what these are. Kayley and her daughter are very close; she is with her all the time when the child is not at school. Her daughter doesn't really have local friends and doesn't go out even to the garden. Kayley finds it difficult to control her daughter on public transport so she does not go on any trips out. She goes to the church four times a year, and has

been to a deaf club. Having a small bus, Kayley says, or people who could support the child during journeys with BSL, would help parents like her who live on a low income.

Leah

Leah, a hearing woman, lives in a city with her husband and four children, three of whom are deaf ranging from ten to fourteen years old. Her first language is Punjabi, she had deaf siblings herself, and she came to the UK fifteen years ago. Her husband is from the same Pakistani community, born in the UK and is deaf. He attended a deaf school in the city and uses BSL and some speech. Leah has a small amount of spoken English, and she often asks her oldest hearing child to interpret for her between Punjabi and English. She does not read English and neither does her husband, so a lot falls to this hearing child to explain official letters and interpret. Two of her deaf children had some hearing in one ear at birth, but this faded over time. When her children were small a deaf and a hearing women used to come to their house together to play to get them used to going to nursery, possibly from speech therapy. When her oldest son was young, a hearing woman came with a Punjabi interpreter and they played with the boy. They left a book of simple signs for Leah to learn some sign language. The doctor recommended a deaf school and at the time her oldest son was five, there was one nearby, though it has since closed.

Their information about education has come mainly from their doctor, who speaks Punjabi. He suggested putting fingers on the neck when the eldest boy reads aloud so he gets the feeling of speech sounds. The family pay for a home tutor to come to the home to teach the children the Quran. The middle deaf child, a daughter, is learning well. The family are hoping their children's hearing will improve.

Leah is very happy with her family, they are all good children, and she enjoys their company. She treats them the same, deaf or hearing.

If you, if you are thinking... you know, I've received a deaf child, not good enough, then you should change your, you know, chain of thought because there are so many children that, you know, are facing worse. And you, in comparison to that, you've received better. So you should appreciate what you've got and not consider them less than anyone. You should thank God for what you've got, treat them all the same and try to fulfil their needs.

Leah found the information about school hard to understand as it was written in English. She also found the hearing aids difficult to tell apart at first and sometimes got muddled up, though the audiology department helped her with a sticker system. The family did consider a CI for the youngest boy, but her husband was against the risks of a brain operation.

The family has had support from a deaf organisation in the city for ethnic minorities. One of the workers is deaf and a family friend, providing information and support.

Leah goes to the schools on parents' evening and they book a Punjabi interpreter for her and a BSL interpreter for her husband. There is no home-school communication book. The family have not seen a speech and language therapist for years and were not really aware of their role. They get notice of what will be discussed at school meetings, but they don't get support to prepare. The children don't go to clubs or activities, but stay at home and play with each other.

Leanne

Leanne, a hearing woman, lives with her 20-month old severely deaf daughter and her older hearing son. She lives in a village in a rural area. She had a very difficult pregnancy and was told her baby might not survive. Her ex-partner was a drink and drug taker. He left once before when their son was two, but came back and decided to try the relationship again, and try for a baby.

Her partner was very unreliable and left again during her pregnancy. Leanna's daughter was just diagnosed deaf at four weeks. On the day of getting her daughter's hearing aid fitted, her partner said he would never be back. It caused Leanne to have what she describes as a nervous breakdown. She was very ill, not eating or drinking and felt suicidal. Her mum supported her at that time. Leanne has had many agencies coming to her house: speech and language therapist and a teacher of deaf children. The most useful one is a general support agency which does not know much about deafness, but they don't tell her what to do. Keeping the aids in is a struggle but has been the main focus of the health and education agencies.

So she does have that little bit of hearing there and they're very good at telling me how important it is that they keep them in, these hearing aids in for at least ten hours a day and how, and they're very, very good at telling me how important it is and, 'you must keep them in and if you don't keep them in, she won't get her speech' which I completely understand. They've been telling me this for almost two years [laughs] and I understand that but what they don't seem to grasp is I have, life then gets in the way, I am on my own. So it's very, very intense to follow a two year old, almost, round all the time [laughs], stopping her from taking these hearing aids out plus I have a son, an eight year old and he needs my attention as well. And I need to cook dinner ... and all these little things, if I leave the room, it takes a second for them to come out and throw them away. So it's all very well in different agencies saying, 'do this, do that' but in reality, it's very, very tough and I am, I am struggling with that.

Leanne has at times felt a failure as a mother because of these attitudes. She doesn't see her daughter respond to any sound at home. Leanne has good support from her neighbour, who has a son of a similar age to her daughter. Leanne is very aware that her neighbour's hearing son is now talking a lot, though slightly younger. She tries to socialise as much as she can with parents and other children. When Leanne goes to a mother and toddlers club for deaf children she feels judged because her daughter is not keeping her aids in. There is, surprisingly, a BSL class in the village which she attends, and it is free because Leanne is on benefits. The deaf tutor has given her a lot of good ideas about communication with her daughter. Leanne wants to take the signing further. She had support from NDCS with DLA forms, and attended one workshop for parents and children, but nothing since. Health appointments are eighteen miles away. Leanne is studying at home to become a teacher, so she feels one strength she has is that she understands about children's language development.

Letitia

Letitia is a deaf single parent of Black British heritage who lives in a city. She comes from a hearing family herself, and her ex-partner is deaf. Both her babies were diagnosed deaf at birth.

I had postnatal depression and I was put into hospital at that time and my daughter was taken for a short while. Then somebody was brought in with an interpreter and also a teaching support. I think her name was Rita ... and she sorted everything out for me, as I say, with regards to schools....At that point, I was obviously still very confused so I just followed what was being said, ... I got the health visitor, and they were saying to me, I wanted to get out of the house more often. ... There was like a drop in centre and it was all hearing people and I was the only deaf person. But I went along with this person just to get out of the house because of the advice of just staying in the house would affect my postnatal depression more. But as I say, I had to go along with this Rita. And we did that regularly, probably from my daughter being about six months old til she was about one year old and I knew that if it was reported that I didn't go along that they would come to my house and see me, so I

did go along regularly to these classes. And joining these classes, no interpreter would be provided, so I would just write back and forth.

As Letitia had hearing aids from a young age herself, she was keen that both her own deaf babies should be aided from a few months old. The language used in the home is BSL, and Letitia's mother also talks to her grandchildren too. Letitia would like them to be bilingual and use BSL and speech.

She has found communication with NHS staff difficult – for example they don't think there is a need to book an interpreter for appointments. Her partner at the time was very much against CIs. Letitia found out a lot about them, but they decided against them. She noticed that the health staff tried to persuade her when her husband was not at the appointments, for example saying that sign language would be used less in the future and that it would be difficult for her child to find work.

Letitia did not receive any early years support from a teacher of deaf children, but she managed to move her oldest child to a resourced school. In this school her first child was encouraged to speak not sign. Now she has got both children in a deaf school and she is happy. Her youngest child has more hearing, but has some other language difficulties, so this was her reason for getting him into the deaf school.

Letitia is very aware of the advantages hearing children have in being able to find extra tuition and clubs outside of school, whereas for deaf children there is little available. She would like to be able to find a deaf tutor to support their learning at home. When she has the money, she pays for leisure classes for her children.

Louise

The mum, Louise, a hearing woman, lives with her six-year old deaf son who has two implants. She was nineteen when he was born. She lives in a small town and most of the time her partner and his son stay over. Her son was diagnosed at six weeks after being referred from the newborn screen. Audiology recommended CIs. Louise noticed that professionals talked to her mum at appointments. She knew there was an early years teacher of deaf children in her area, but she only had two visits. She went to a four-week course in BSL run by NDCS. She found out about CIs herself. She felt that there was no real information about the CIs, especially about all the work parents need to do after switch-on, at fifteen months for her son. She noticed that her son gained confidence to speak by using sign, but the visiting teacher of deaf children said just to speak. The professionals didn't know how to sign themselves. She went to a local deaf children's society activity but felt out of place because the other parents were older and married. Her son's behaviour was terrible until she started using made up signs with him. Through her mum, Louise found out about sign language classes, but she has to pay and she is on benefits. Through a contact from her BSL class, Louise found out that her son may be able to get into a deaf school.

but even.. when I did find out about it, the teachers a' the deaf and speech and language therapist said to me, 'no don't, don't send him there. I don't think he would benefit fae there blah blah blah'. so he ended up missing his year tae go tae school and got held back a year cause I was like, 'no this is what I want tae do'. And I had tae get approval fae a' these people and written letters. And but luckily the teachers at (name) Nursery were totally on my side and they could see the way that Mary (ToD) and that were. And he's now caught up. ... he's caught up wi' them doing his maths and his English and his talking's coming on great. And I'm like, 'see I knew it [laughs], I knew it was'. But people don't listen. I think it is cause I'm younger and I'm quite, like I'm quite a relaxed person, quite calm and stuff. I just think people sometimes don't...like take my opinions seriously but as if I don't know what I'm talking about.

The speech therapist said that her son would catch up in speech with other children with speech. She was very negative about the way she was interacting with her son. Louise made it clear that the SLT's approach upset her and she didn't want to see her again. Since starting at school her son has got much more confident at sign and teaches her and other family and friends. She has had help with DLA forms from the local deaf children society but not joined in other NDCS events. Louise does art and craft with her son, and they go to the science centre. She can't afford to go to events at the school, but she has been in to meet the teachers. Because of his good progress at school she is confident about her son's future.

Mariam

Mariam, a hearing woman, has a seven-year old boy, who was diagnosed severely deaf when he was six. She lives with him, the father and her three older children in a city. The family are North African and have been in the UK for over ten years.

The mother tells of the struggle of finding out about the deafness of her son: he did not pass the first neonatal screening test in hospital, but passed the second one in audiology. When he was two years old, the boy was tested again but they said he was hearing, although the mother said his language was delayed. Years after year, at the nursery and then at primary school, the boy's language was still delayed but when the family took him back, audiology said he could hear.

Just they did, the hospital they didn't give me...or, or tell me he's, you know, they didn't give me, give him like chance but, he have problem, I said can you just test him. But they said, 'he is okay, he is, he don't have any, he's normal hearing'. ... Yes I thought maybe he's had autism or some, I search about this a lot. But I, when I, I went and see a doctors he said, 'no he don't, he don't have any autism, he's okay'. And I try again with the hospital. They said, 'he don't have any problem with hearing'.

In primary school a teacher suggested to go and do the test again at the hospital last year, Mariam went and they found out that the boy is severely deaf. Mariam is very upset and disappointed because her son did not have any help or support up until the diagnosis.

The mother and father speak Arabic and English, so she thinks this may have been the reason why the health service expected a delay in her son's language development. The boy now has two hearing aids. The parents now have a little support from family and friends. Mariam did the search online herself to understand what could cause the delay in her son, thinking about autism. Nobody seemed to listen to her and professionals kept on saying he could hear and did not have autism.

Her son has just started learning to read; he speaks some words in Arabic and in English, but not yet without help. The boy signs as well, he is getting it in school with a support worker every day. The parents are keen on learning sign language and are waiting for someone from NDCS to go to their house. The parents asked for a CI, but the doctors said it was too late because the boy was already six. It is very difficult and upsetting for the family because they cannot communicate with their son. The boy gets speech and language therapy at home once a month and a friend of the mother goes there to help as well. The boy now attends a youth group at a deaf club and an Arabic school on Sunday. The mother is keen to get the best for her son, despite the delayed diagnosis and the upsetting experiences with medical professionals.

Natalie

Natalie, a hearing woman, lives in a city with her five children aged two to thirteen. Natalie decided to get her daughter's hearing tested because her friend who is a hairdresser came to the house to cut her hair when her daughter was four and recognised she might be deaf. She told her about NDCS and DLA. Natalie followed this up, which led to lots of appointments, difficult to manage with four other children and no transport. Her seven year old had fluctuating moderate hearing loss, grommets and now hearing aids with a radio aid in school.

Natalie has some support sometimes from a former partner, and from her sister who also has four children. Natalie also is concerned about two of her other children, one who has ADHD and the other who has been bullied on transition to secondary school. Her deaf daughter also has social and emotional difficulties and has been referred to the Child and Adolescent Mental Health Service (CAMHS).

Natalie has a good relationship with the visiting teacher of the deaf who has been doing some video play work with her, giving her feedback about how not to react to small irritations and keep conversation going. Natalie does not know about how to support her daughter's reading, though she knows it is delayed. Her daughter has recently been referred to speech and language therapy, she thinks possibly because of a little stutter. With the teacher of the deaf her daughter gave a successful deaf awareness talk to the class. Her daughter received praise for this from the school.

Through contacting NDCS she had good support from a deaf worker who helped her fill in the DLA form. They failed, then appealed and finally succeeded in gaining DLA.

He (NDCS worker) got me a grant for the family fund as well, so we went away at the end of September there, went to Craig Tara. We have never been away. .. It's so good just to be away, just to spend time with them. And she absolutely loved it, she was in her glory. She really enjoyed it.... And the school had noticed a big difference when she came back as well... She must have needed that wee break away. She came into school dead happy and things like that.

Natalie's deaf daughter enjoys dancing, a free activity. It is very difficult to get to other events because of the need to supervise her other children and transport costs.

Nicole

Nicole, a hearing woman, lives in a town with her nine-year old deaf son. She is a single parent who was a qualified teacher, currently working as a support worker. Her son was born hearing with additional difficulties, later diagnosed as autism. He is moderately deaf in one ear, profound in the other and diagnosed at 5.

When he first was diagnosed the paediatrician audiologist was there on the end of July and he said, 'don't worry', oh in October. When I finally met with him [laughs] after I'd had this letter he said, 'don't worry, you're fine because when he goes fully deaf he'll have a cochlear and everything will be sorted'. I said, 'oh thank goodness, great'. I felt such a relief. Went to the (name) Centre for the Deaf and they, a lot of people were like, 'whoa hang on, you need to research this, it is not a quick fix'.

Her son could become profoundly deaf in both ears in the future, so they have been learning BSL, Nicole to an advanced level. Her son uses spoken English to communicate but likes the benefit of understanding BSL in noisy surroundings. He attends a resourced school and is making good progress. Nicole has access to a great deal of information about deafness as she works in the local service, and she has found out more through her BSL courses.

Nicole was not well supported by the audiologist at the time of diagnosis, but she did get a referral to the local authority service for deaf children. The teacher of deaf children was a crucial early point of support for her. She has joined a local deaf organisation which has helped her and her son, and she is now involved in helping other families. She has high expectations for her son, but she thinks the schools he has gone to sometimes expect less because of him. She reports that her son sees himself as a hearing aid user who uses speech, and he is positive about his deafness. Nicole has found it difficult to pay for equipment she needs such as a vibrating alarm, and can't get to NDCS events because they are in the next town. She has used grants to apply for support to fund a radio aid to use at home, but she decided against it because the fitting was complicated. She takes an active part in her son's review meetings, and has been pleased with support received from NDCS in relation to statements in the past. Nicole is a very sociable person who has many friends in her church, some of whom are also learning BSL to support her and her son.

Rose and Dave

Rose and Dave, both hearing, are mum and dad of more than five children and live in a town. Two of their children are deaf, the younger is three years old, and the older is eight. The language at home is English and basic BSL.

The older deaf daughter was diagnosed as severely deaf when she was seven. She passed the neonatal screening and another hearing test aged two and four, so she probably became deaf after four. The younger one was diagnosed profoundly deaf after failing the hearing screen when she was born. Both girls have hearing aids, not CIs. The younger child signs a bit and does not attend nursery, the older attends a mainstream primary school.

It was like entering a whole new world. ... Like, you know, it was really, it was difficult, it's still difficult, you know, because but signing, we've, we've had a few classes and that but it doesn't seem to be that much out there, you know, really. I mean we've applied for college and they've wrote back saying that cos the night course two nights a week and they've said the waiting list is too long, you're gonna have to wait. Now we, we need it. We're not, we're doing it to learn for the sake of learning, we need it and they, so (name of teacher of deaf children) she's trying to contact them and see if she can...but I mean they said no. We was in a sign group but that stopped.. So now it's basically we're trying to learn ourselves, ain't we, with books and YouTube and internet. So it's, it's, it is difficult, you know.

Their families are supportive, Rose's family living nearby. A speech therapist comes to the home, but not regularly. Their younger daughter has about fifty signs and no speech. Dave does not want a cochlear implant because he is worried about making such a large decision – it would take his daughter's residual hearing away. Rose, the mother, would be more inclined to have CIs. They received conflicting information from the BSL teacher and the speech therapist about how to sign – with voice or not, which makes it difficult for them to know what to do.

The older daughter likes her hearing aids and uses them all the time, the younger one often pulls them out. The older daughter was in a large class in school, but the parents asked if she could move to a smaller one because she was feeling it was too much for her. They did not feel listened to by the school and had to push for it, with the help of a teacher of deaf children. They don't like the unannounced changes in teachers of the deaf, which happens sometimes. Rose and Dave attend a toddler group offered by the education deaf services. They attend NDCS events at a local level, but since they do not drive it is difficult to attend events elsewhere. Their main concerns are desperately wanting more BSL classes, and finding the decision about the CI so difficult to make.

Sara

Sara, a hearing woman, lives in a small town with her five-year old daughter who wears hearing aids. Her daughter is severely deaf and has another physical disability. Sara is a single parent, but her partner looks after the children at the weekends. Her daughter was diagnosed very early after the screen and aided from six weeks. Sara had postnatal depression and her partner left her when her daughter was eight months old. Sara has an older son who has behavioural difficulties which made it difficult to focus on her daughter's speech or sign in the early years.

It's all the hospital appointments and like just trying tae keep up with it.... so it's trying to juggle all this on your own, it's just hard going. But obviously at one point I did think she was better off not with me, with someone who could do this cause obviously I was, it was like jumping in the deep end, you know. I had no idea how to help her and then I thought she'd be better off with someone else but then obviously I was, like I could never do that cause she was my baby [laughs] but... ..yeah I think as a parent, I think everybody has thought sorta feeling. Like unless you've sorta got other people within a family that's been through the same situation your sorta like, I'm just not cut out for this sorta thing and she'd be better off with someone that knew how to cope..

Keeping the hearing aids in was a challenge. At the age of three her daughter had speech like a one year old, the paediatrician told her. Her daughter attended the local nursery and all contact with health and education has been positive - she can ring them up and get through to people she knows well. She has good information about audiology. Sara is now going to a signing class once a week, but she is not very confident as a learner. Her daughter was held back a year at nursery and she is not learning sign quickly. Her daughter has a short attention span so the speech and language therapist and school have been working on that. She is now supported in school three times a week by a sign language support worker and Sara can see that her daughter is looking at the interpreter and the teacher well. All the children in her daughter's class are learning some sign. There is a Soundfield system in the class. She gets the NDCS newsletter, they helped with the DLA application, but she can't get to their events because of the children behaving badly on the bus. She would like more contact with other parents. Her daughter doesn't have real friendships at school because of the communication difficulties. Sara is trying to toilet train her daughter, but she is still in nappies in the first year of school. Her daughter has temper tantrums and is sometimes very stubborn, for example at the shops. In the summer her daughter was included in the school summer playscheme but Sara didn't like to ask about a signing support worker.

Sue

Sue, a hearing mother, has twin daughters aged eight, one deaf and one hearing. They live in a small town and the mother is divorced. The parents found out their daughter was profoundly deaf with the neonatal screening. The baby was born premature, ten weeks before the expected date.

Sue says it was difficult to find the right support at the beginning but then since her daughter was four she did not need any additional support in school, except from pieces of technology. This was thanks to early intervention with cochlear implants and auditory verbal therapy. NDCS came to their house, as well as a speech and language therapist, and a teacher of the deaf, but the parents felt these specialists had very low expectations for the child. The speech therapist said the child would have struggled in school, e.g. in reading, and she would have needed mixture of signs and speech. The parents did a lot of research online themselves and found out about cochlear implants and auditory verbal (AV) therapy.

We had to raise everything by ourselves. And it was £200 an hour, the speech and language therapy. It was, it was the best investment I've ever made obviously because of where Martha is now but that's how much it cost. We were able to get a bursary with regards to some of the funding because we earned less than £30,000 with regards to paying for the actual speech and language therapy. But with regards to taking, flying down to or driving down to Oxford from (name of place) [laughs] and having to stay overnight when we, the baby and she was only, she was only nine months old when we started taking her. ..To help pay, we had to pay something towards the...we raised all that by ourselves. I think we were given...we got, my husband was ex armed forces so they gave us £4,000. Thomas Cook, my father's ah, he used to be a regional manager there, they gave us £10,000. So we raised about £20,000 to pay for it. ... But for expenses and travelling expenses, cause we didn't have any money. I wasn't working and my husband wasn't working, he was, he was a student at the time. So yeah so, so we had to raise it all by ourselves and pretty much sell everything we owned. But, but we, we could see the results coming in, you know. We could see earlier on our achieving...speech milestones.

The mother sees her child as normal; she has not seen a teacher of the deaf in two years. Having a twin sister helped her know what usual spoken language development was like - they went to nursery and school together. At school she started in a small class with a Soundfield system, and now she is in a larger class she uses a radio aid with Bluetooth. The family attended some NDCS events in the early days but did not like it because everyone was signing, then went to a cochlear event and liked it because everyone was speaking and not signing.

Tina

Tina is the hearing mother of an eight-year old daughter who was diagnosed profoundly deaf when she was seven weeks old. The mother lives in a city with her deaf daughter and a younger child. She uses English, Sign Supported English (SSE) and BSL at home. The daughter was implanted with a cochlear implant (CI) and now uses speech but also signs.

The parents used to live together in a small town at the time the baby was diagnosed. Tina had been to university and by chance had a deaf friend and knew a bit about BSL and Deaf culture. When her daughter was born a teacher of the deaf came to their house who told them not to sign at all and use speech, but the parents found this difficult and ineffective and asked for another teacher. The other teacher used the same approach, also saying if they kept signing their daughter would not learn to read and write and not get a statement. Through a friend of her neighbours she met another family with a deaf child. Tina wrote to the teacher of the deaf refusing any more services.

The parents decided to move to a town and later a city to have better support with language for their daughter.

I went to the (name of town) one and there was some signing there, a little bit, and there were a couple of parents that were learning sign language at home, and they had the deaf person come and teach them on a Wednesday night, so I managed to get myself into that group, so that was really nice. We used to sit around and have a glass of wine, eat chocolate, and the teacher would, she would say what do you wanna learn, and we'd say, well, we wanna learn this, or we wanna sign this....We just all paid, we all paid a fiver.

They moved to a city and found more resources, including a school for deaf children. Their daughter was then three and she started attending this school part-time, and lately attending also a local school.

The mother did not work, and although the father was working they found it difficult to pay for BSL courses because they were on benefits. The mother also attended a level three BSL course at a college which cost a lot. When the child was three and a half she got a cochlear implant on both sides. The professionals recommended to stop signing, but the family did not follow the advice. They used cued speech after being involved with the Cued Speech Association and getting training for free. The Cued Speech Association had amazing camping holidays and Tina was impressed that they were also fluent in BSL. Her deaf daughter is now more self-conscious about signing in hearing settings and uses only speech there.