Early intervention 0-3 for deaf children in Northern Ireland: An investigation into the experiences and perspective of parents

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Contents

List of Tables

Abbreviations

ADY	Action Deaf Youth
AABR	Automated auditory brainstem response
AIC	Auditory Implant Centre
BATOD	British Association Teachers of the Deaf
BDA	British Deaf Association
BERA	British Education Research Association
DQTOD	Deaf Qualified Teacher of the Deaf
ENT	Ear, Nose and Throat (consultant)
HSC	Health and Social Care
LENA	Language Environment Analysis system
NDCS	National Deaf Children's Society
NHSP	Newborn Hearing Screening Programme
NI	Northern Ireland
QTOD	Qualified Teacher of the Deaf
SaLT	Speech and Language Therapist
ToD	Teacher of the Deaf
UK	United Kingdom

The term 'deaf' has been used to represent all hearing levels from mild to profound.

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Abstract

It is recognised that delays in the acquisition of language impact across a range of developmental areas, and that family-centred early intervention is the most effective method of improving outcomes for deaf children. Crucial to the success of this process are parents, who are acknowledged as the main influencers on their children’s progress. Yet there is a lack of recent research into parents’ views of early years intervention. Therefore, this study provides insight into early intervention for deaf children (0-3) in Northern Ireland through an investigation of the experiences and perspectives of parents.

The aim of the research was to identify the needs of parents and whether there was a deficit between these and the provision offered. A qualitative approach was used to collect the data; ten semi-structured interviews were conducted with parents whose children were either in receipt of early intervention at the time, or who had just completed the process. Parents were selected from both rural and urban areas to ascertain if there was equity of provision regardless of location. The interviews were analysed thematically, and the results were organised into five main themes.

The findings of the study suggested that parents were broadly satisfied with the support they were receiving. However, concerns were raised with regards to the early stages of identification of deafness and the use of monitoring and assessment tools. Parents stressed the need for more easily accessible information about deafness to enable them to support their children. The role of the Qualified Teachers of the Deaf offering guidance, practical strategies and emotional support was found to be of benefit to parents. Parent to parent support was identified by most parents as being essential in providing the emotional support which they needed. The need for young deaf children and their families to have access to sign language alongside oral language was also raised.

This study demonstrates the importance of supporting parents as this is the best way to ensure deaf children’s overall development. It provides insights into the needs of parents, as identified by them, and makes recommendations as to how these needs can be met.

1. Introduction

Research has shown that, although deafness is not a learning disability, it does have an impact on the acquisition of language which is the biggest challenge for the majority of deaf children (Curtin et al., 2021; Marschark & Hauser, 2011; Rowley & Sive, 2021). The consequences of failing to develop long term age-appropriate communication and language skills are researched and documented by many professionals in the field of deaf education. It impacts on the child’s overall development, cognitive skills, social and emotional well-being (Hall et al., 2019).

When early identification is followed by effective early intervention, this offers the best chance for young deaf children to develop age-appropriate communication and language skills. However, Holzinger et al., (2022) state that many deaf children still lag behind their hearing peers in language development. The difficulties in accessing language can lead to an increased risk of emotional well-being (Hindley, 2005). Government research suggests that more than ‘40% of deaf children experience mental health problems compared to over 25% of hearing children’ (NDCS, 2017). With regards to academic achievement, the latest figures available for Key stage 2 in 2019 show that 44% of deaf children reached the expected standard for reading, writing and maths compared with 65% of hearing children who met the standards (NDCS, 2021). This is a worrying trend as these children have come through the early intervention process and are still underachieving compared to their peers.

Over 90% of deaf children are born into hearing families with no knowledge of deafness, and who require specialist support (Wright et al., 2021). Therefore, there is a need for high quality early intervention to be put in place and the literature shows that it is most successful when the family is at the centre of it. As a Qualified Teacher of the Deaf (QTOD), the researcher is aware that the successfulness of intervention is very dependent on building a relationship with parents, recognising the needs of the family, establishing strong partnerships with parents and increasing parents’ self-efficacy (Fitzpatrick, 2008).

The British Deaf Association (BDA) and National Deaf Children Society (NDCS) met in Northern Ireland (NI) in 2014 to discuss early intervention for deaf children as it existed at the time. Recommendations were made for future practice in the delivery of early intervention. It was suggested that research should be carried out into the experiences, information and support families received in NI. To date, no such research has been undertaken. This research paper intends to fill the gap and provide useful insights into early intervention as it currently exists. The focus of this study was to investigate the perspectives and experiences of parents during early intervention for deaf children 0-3 in NI. The researcher aimed to find out:

- Is there a gap between the needs as identified by the parents and the provision on offer?
- Are parents' emotional and social needs being met during early intervention?
- Is there equitable appropriate early invention in both rural and urban areas?

1.1 Outline of Chapters

The second chapter, the literature review, examines the available literature on early intervention. It evaluates the best principles of family-centred early intervention. The third chapter discusses the methodological approach adopted for this research and in the fourth chapter the qualitative data from the interviews are analysed. The final chapter contains a critical discussion of the findings, as well as recommendations for future development in early intervention.

2. Literature Review

2.1. Introduction

This literature review contains four sections. The review begins with a discussion of the fundamental principles underpinning family-centred early intervention. The second section examines the journey from newborn screening to identification of deafness. The last two sections focus on important aspects of early intervention. Throughout this chapter, published literature regarding early intervention is examined and aspects of this are discussed. To date, no research has been undertaken in Northern Ireland (NI) into parents' views on their experiences of early intervention. Therefore, parents' perspectives included and discussed within this chapter are from other United Kingdom (UK) regions and international countries.

To find relevant information for this research, several searches were undertaken; the University of Hertfordshire electronic library, Scopus and Google Scholar were used. Information was sourced using key phrases such as 'early intervention', 'early identification', 'parental perspectives' and 'family-centred intervention', alongside the terms 'deaf children' and/or 'deafness'. To facilitate the search, the results were further refined to include the term 'Northern Ireland', but no documents were found. The research results were evaluated to identify the most relevant, current and suitable research for this study. Information was obtained from a range of sources such as educational publications, publications from deaf organisations and relevant government documents.

2.2. Family-Centred Early Intervention

Many researchers believe that, for effective early intervention to happen, the family must be central to all intervention and the support offered (Stewart, Slattery & McKee, 2021; Moeller et al., 2013; Foster et al., 2020; Tracey et al., 2018). Indeed, the effectiveness of early intervention is dependent on the value placed on it by families and how it meets their needs (Young et al., 2009). This would suggest that, as the perspectives of parents are important, they should be taken into account in both the planning and implementation of early intervention programmes, and this is supported by Stewart, Slattery & McKee (2021).

2.2.1. International Consensus on Best Practices in Family-Centred Early Intervention

Moeller et al., (2013) outlined the best practices in family-centred early intervention that were agreed upon during an international conference in Austria in June 2012. The panel members consisted of experts in early intervention including parents of deaf children, deaf professionals, early intervention specialists and researchers from ten nations (Austria, Australia, Canada, Germany, Italy, Ireland, Russia, South Africa, United Kingdom and United States). They agreed that the implementation of best practices for early intervention were variable and inconsistent across the nations. As a result, they came to an agreement on the 'essential principles that guide family-centred early intervention with children who are deaf or hard of hearing (D/HH)' (Moeller et al., 2013, p.429). The delegates agreed on ten fundamental principles contributing to family-centred early intervention which are highlighted below (Moeller et al., 2013).

1. *Early, Timely, & Equitable Access to Services*
2. *Family/Provider Partnerships*
3. *Informed Choice and Decision Making*
4. *Family Social & Emotional Support*
5. *Family Infant Interaction*
6. *Use of Assistive Technologies and Supporting Means of Communication*
7. *Qualified Providers*
8. *Collaborative Teamwork*
9. *Progress Monitoring*
10. *Program Monitoring*

The consensus statement has had significant global impact on early intervention. The principles are embedded in many legislations, policies and guidelines across the world. For example, in the UK, the NDCS (2016) has produced 'Quality Standards: Early Years support for children with a hearing loss, aged 0 – 5'. These standards reflect best practice as outlined in the 'International Consensus Statement on Best Practices in Family-Centred Intervention'. However, a recent article on the review of early intervention for deaf infants by Wright et al., (2021), whilst acknowledging the principles as best practice for early intervention, revealed a gap in the principles as little account was taken of the social and emotional needs of the child, suggesting that this is an important area that needs more attention during early intervention.

2.2.2. Northern Ireland Context

In 2014, the British Deaf Association (BDA) in partnership with the NDCS, held a conference in NI to address the issue of early intervention for deaf children. The conference was attended by key policy makers and frontline professionals in the field of health, social care and education. The principles outlined in the international consensus on Family-Centred Early Intervention were discussed and it was recommended that they be adapted. As a result of this, they published a document ‘Early Years Intervention for Deaf Children in Northern Ireland’ in which they reported the current situation and put forward recommendations for the future (BDA, 2014). For the purposes of this research, aspects of the ‘consensus document’ will be used as a framework to evaluate the Early Intervention Programme as it is currently delivered in NI.

2.3. Identification and Hearing Technology

2.3.1. Newborn Hearing Screening Programme (NHSP)

Early identification is the crucial first step in the early intervention process. Many research studies have shown the importance of identifying deafness as early as possible and the benefits of this have been demonstrated (Jackson, Traub & Turnbull, 2008; Ching et al., 2017). The Newborn Hearing Screening Programme (NHSP) was rolled out across the UK between 2002 and 2006 (Wright et al., 2021). Within the Health and Social Care (HSC) Trust in NI, it was introduced in 2005 (HSC, 2020) and, at the NI BDA conference (2014), it was acknowledged that the aim of early identification had been achieved.

Critically, it is important to emphasise that ‘identification is not of itself the end goal’ (Young, 2010, p.241). Research undertaken by Kennedy et al., (2006) stated that, although NHSP is embedded in the health care of numerous countries, many children identified with deafness through screening have language delays. Therefore, the success of NHSP is dependent on the effective ‘implementation of adequate support programmes for children and families’ (Jackson, Traub & Turnbull, 2008, p.39). This was recognised during the BDA conference (2014) and it was acknowledged that, within NI, there needed to be more consistency in the support pathway. This contributed to the rationale for undertaking this project as the researcher wished to investigate if there was consistency in the delivery of early intervention provision throughout NI.

2.3.2. Hearing Technology

Following the identification of deafness, babies are fitted with powerful digital hearing aids and/or referred to a cochlear implant centre for assessment, where the likelihood is that they will be implanted before their first birthday (NDCS, 2021). It is recommended that parents need guidance about the consistent use of hearing aids and cochlear implants, and in the maintenance of them, to support listening and spoken language development (Collinson, 2017; Munoz et al., 2019).

The development of cochlear implants has resulted in parents having to make the decision of implantation on behalf of their deaf child early in their child's life. This is difficult due to the variability of outcomes, and parents are fearful of the risks involved with the surgery (Hyde, Punch & Komesaroff, 2010). A study was undertaken by Archbold et al., (2006) to ascertain the perspectives of 101 parents whose children had received cochlear implants. It illustrated the importance parents placed on having access to as much information about implants as possible. It also revealed that parents whose priority was that their child be able to access spoken language had less difficulty making the decision than parents who worried about their child's deaf identity.

2.4. Early Child Development

2.4.2. Communication approaches

Parents of deaf children have a number of important decisions to make for their children (Carr, 2018; Johnston et al., 2008; Porter et al., 2018; Scarinci et al., 2018), one of which is deciding the communication approaches to adopt (Chang, 2017). Research undertaken by Crowe et al., (2014), involving 177 caregivers, highlighted the factors that exert influence on parents' decision making. These include choosing the communication method already used by the family and local community, the opinions of other parents and friends, professionals' input, independent research and recognition of belonging to the hearing world and/or the deaf world.

Additionally, Stredler-Brown (2010) reported that, in a survey of parents carried out by Li, Bain and Steinbery (2003), the availability of services close to home and cost of these services was also a determining factor. In the midst of all these influences, professionals should provide parents with unbiased information as to the range of possibilities available and their choices should be fully supported (Yoshinago-Itano, 2014; Stewart, Slattery & McKee, 2021). This was endorsed at the BDA (2014) conference in NI, when they recognised the importance of informing parents of all communication approaches.

2.4.3. Parent-child interaction

There is evidence that all children's early language development is 'shaped by the linguistic input to which they are exposed' (Van Dam, Ambrose and Moeller, 2012, p.403). Research shows the quality of parents' interaction with their child is central to the deaf child's overall development outcomes (Yoshinaga-Itano, Curtin et al., 2021; Levine et al., 2016). However, parents of deaf children can change their communication behaviour when they find out their child is deaf, causing them to reduce their interactions and linguistic input because of their child's lack of responses to the auditory input they provide (Van Dam, Ambrose and Moeller, 2012). Thus, development of language skills can be affected if parents are not confident or supported in communicating with their deaf child, (Curtin, 2021). However, it is incumbent upon professionals to give parents the confidence to succeed in communicating with the deaf child, thereby strengthening interactions and fostering their language development (Marschark and Hauser, 2011; Decker & Vallotton, 2016). The importance of families and professionals working together to facilitate parent-child interaction by creating suitable, rich language environments for early language learning is emphasised by Moeller et al., (2013) and Yoshinaga-Itano (2014).

2.4.4. Monitoring Early Development

It is recommended that the child's progress be monitored regularly during early intervention (Thomas & Marvin, 2016). The use of regular monitoring and assessments in early intervention was recognised as an important factor in evaluating the deaf child's progress (BDA, 2014). A range of assessments are used within NI Sensory Service to monitor and assess a deaf child's development in all areas. One assessment used is, 'Success from the Start: Early Support Monitoring Protocol' for deaf children 0 – 3, created by NDCS. It is a resource that supports families and professionals to work together to record the child’s progress, creating next steps targets, thus fostering high expectations (NDCS, 2020).

Recent research by Ma’ayan (2018) demonstrated that the Language Environment Analysis system (LENA) is a useful tool which can be used to improve interaction and the quantitative language environment between parents and deaf children. However, Curtin (2021, p.15) asserts that there are ‘no formal assessments that evaluate parents’ interaction skills when they are communicating with their deaf child’.

2.5. Family Social and Emotional Support

Yoshinaga-Itano (2014) cited that being deaf affects, not only the child, but the family as well. Therefore, the family’s social and emotional well-being is a vital part of early intervention in enabling the development of young children (Jackson, Wregner and Turnbull 2010; Jackson, 2011). The statistics in the UK including NI show 90% of deaf children are born to hearing parents (NDCS, 2016; BDA, 2014). It is an unexpected event, bringing with it a new set of experiences and challenges (Scottish Sensory Centre, 2011; Crowe, et al., 2014; Jackson, Traub & Turnbull, 2008). It is documented that parents generally experience a wide range of emotions at the time of identification, some of which are denial, shock and distress (Russ et al., 2004; Jamieson, Zaidman-Zait & Poon, 2011). Young and Tattersall’s (2005) research on the experiences of parents of deaf children during the ‘diagnostic process’ highlighted that the families appreciated when the professionals were sensitive, understanding, inclusive and honest with them.

2.5.1. Parents and Professionals Partnerships

The BDA NI conference (2014) reported that a goal of family-centred early intervention is the ‘development of balanced partnerships between families and the professionals supporting them’. These partnerships are marked by trust, respect, honesty and open communication (BDA, 2014) and ensure that the family and child's needs are best supported (Maiden & Keen, 2018). Sass-Lehrer (2004) recounted that, when the relationship is valued, this encourages self-efficacy in parents, leading to greater involvement in early intervention, thus improving the outcomes for deaf children.

In NI, the BDA (2014) conference highlighted that the primary support received by families of deaf children came from Qualified Teachers of the Deaf (QToD) employed by the Education Authority NI. The QToD in NI visit the families in their own homes during early intervention; home visits are recognised as being critical in providing emotional support to the family as well as developing their skills in working with their child (Mehta et al., 2020).

2.5.2. Parent to parent support

Within the international consensus, Moeller (2013) cited that parents should have access to other families of deaf children and this type of support should be recognised as key in promoting social and emotional well-being for families. This is reinforced by Rodd, Craik and Shields (2020, p.21) who state that ‘a key source of support for families with deaf children is through meeting with other families with deaf children’. Research suggests that the support parents receive from other families can help them to feel more confident in raising their deaf child (Stredler-Brown, 2010) and provides opportunities for parents to share their experiences without being judged (Bray et al., 2017).

A study undertaken in Ontario from the perspective of seventeen parents who were part of early intervention programmes revealed ‘parent contact was acknowledged by all families as a useful adjunct to the services provided through typical health care channels’ (Fitzpatrick et al., 2008, p.48). The parents wished it to become a consistent and an integral part of the support offered to parents rather than being left to the responsibility of volunteer groups to organise. In Colorado, an organisation ‘Hands and Voices’ trains parents of deaf children to work with families of children newly identified with permanent childhood deafness (Mehta et al., 2019).

Mehta et al., (2019) carried out research on parent-to-parent support for families of deaf children in the UK. The paper reported that, during the early intervention period, programmes of parent-to-parent support schemes were not widely and consistently available in the UK compared to some countries. However, when a new-born hearing screening programme was introduced in 2002 in East London, a programme of parent-to-parent support was introduced as an addition to existing services, ‘parents overwhelmingly endorsed the emotional support and pragmatic help that they received’ (Mehta et al., 2019, p.107). Furthermore, in Bristol, a pilot parent-to-parent support scheme was set up in September 2020 where the parent volunteers were trained to offer support (Lumby, 2021). Nevertheless, concerns have been voiced firstly, as to whether the parents received the correct information from the volunteers, and secondly, that the role of specialist teachers could be undermined by employing non-professional support workers. To date, there has been no introduction of systematic programmes of parent-to-parent support in other parts of the UK (Mehta et al., 2019).

2.6. Conclusion

This review of literature has highlighted the importance of effective early intervention as an important predictor of deaf children's successes in all areas of development (Marschark and Hauser, 2011). The main goal of early intervention is to identify deafness as early as possible and then use a family-centred approach to support the child's overall development. This includes providing information and support for language development and parent-child interaction and audiological management, as well as monitoring the child's progress and meeting the social and emotional needs of the families. Throughout this chapter, literature from many countries has been reviewed and references made to the current situation in NI. The next chapter will examine the methodology used in the study to investigate the experiences and perspectives of parents involved in early intervention in NI.

3. Methodology

3.1. Introduction

Chapter Two explored and evaluated the literature on best practices for early intervention, how it is implemented and the importance of it for the families of deaf children. The review also revealed that, internationally, there have only been 12 published studies within the last 5 years evaluating and identifying the early intervention support for families of deaf children (Wright et al., 2021). To date, none of these studies have been undertaken in NI. The researcher believes it is important to explore the early intervention process, 0-3, as it currently exists in NI, from the perspective of parents to provide insights that could be useful when developing future practice.

Within this chapter, the commitment to ethical guidelines which must be followed whilst carrying out a research project is documented. The rationale for the choice of a largely qualitative research method, and the process used for data collection and data analysis is described. Information pertaining to the parents and reasons for their selection to participate in the interviews is also included.

3.2. Ethics

Before any research begins, the Ethical Guidelines pertaining to the study need to be addressed. The British Education Research Association (BERA) (2018) has set ethical standards which must be followed. These standards protect participants from harm both mentally and physically and give them rights to withdraw from the research at any given time. There is an obligation to uphold these ethical standards and maintain professionalism. To ensure that the research was carried out ethically, the guidelines which University of Hertfordshire and BERA (2018) highlighted were observed.

Prior to carrying out research, the application for ethics approval was submitted and approved by the Social Sciences, Arts and Humanities Ethics Committees and Delegated Authority (ECDA), University of Hertfordshire (Appendix A). EC3 consent forms were given to participants alongside copies of the EC6 participant information sheet about the research (Appendix B and C). Permission was gained in writing from those who wished to participate in the study and confidentiality of information given was assured. Due to the Covid-19 pandemic, the completion of an EC5 risk assessment form (Appendix D) was requested to mitigate the additional risks involved in home visits, if they were deemed necessary.

3.3. Research Design

Methodological choices were explored before deciding which method to adopt for this project. This is supported by Cohen, Manion and Morrison, (2017) who stated that, when planning research, it is important to understand the different methods, instruments used and styles of research when collecting data. The use of qualitative and quantitative research methods affects the way the data is collected, recorded and analysed (Walliman, 2018). Quantitative methods are objective, involving collecting facts and figures, whereas qualitative methods are subjective and are about gaining an understanding of people's experiences (Denscombe, 2017). Thomas (2013, p.116) argued that these two methods are not mutually exclusive, but 'complement each other'.

The use of both questionnaires (a largely quantitative method) and semi-structured interviews (a largely qualitative method) was contemplated to obtain the information from parents to afford triangulation and corroboration of different types of evidence. It is recognised by Thomas (2013) that the use of questionnaires can reach to a wider audience, providing a substantial amount of data. They can be tightly structured using closed questions and/or incorporate more open and discursive questions. However, Denscombe (2017) pointed out that the questions can be easily misinterpreted, therefore providing inaccurate information. In contrast, the use of interviews allows the participants to answer questions about the purpose of the study and address any misunderstandings experienced by the interviewee, whilst at the same time affording the participants the opportunity to voice their thoughts (Cohen, Manion & Morrison, 2017).

The researcher was mindful of Imran Mulla's suggestion on 19th June 2021 during the initial study day sessions that conducting a larger number of semi-structured interviews would be the best strategy to obtain the data appropriate to this project. It was then necessary to consider the significant time needed for planning, interviewing and analysing the data of semi-structured interviews, as highlighted by Bell (2014). After weighing up the options, the decision was made to concentrate on one method of data collection and conduct ten semi-structured interviews which were considered to be suited to the objectives of this research.

3.4.1. Semi-Structured Interviews

Semi-structured interviews provide the opportunity to gain an increased knowledge of the situation through obtaining more detailed insights into the participants' experiences and perspectives (Busetto et al., 2020; Sharp 2012; Castleberry and Nolen, 2018). This was important in terms of the higher quality responses they could generate, given the limited time available for the research. Another advantage of using interviews is that they assist in the free flowing of conversation which allows any unexpected issues arising to be picked up and further probed by the interviewer (Busetto et al., 2020).

Bell (2014) raised a concern with regards to semi-structured interviews when he argued that the selection of topics from literature could be influenced by personal views and interests and potentially lead to bias during the collection of data. The researcher acknowledged this as a possibility and took steps to mitigate against it through continuous evaluation when selecting topics. Denscombe (2017), also highlighted the danger of bias creeping into the interview because of the interaction between the interviewee and interviewer. Sometimes interviewees give the answers which they believe will keep the interviewer happy. On other occasions, if interviewees are uncomfortable with the questions, they may not respond truthfully and only respond 'fulfilling the perceived expectations of the researcher' (Denscombe, 2017, p.209). Therefore, the researcher concludes that a good interview is dependent on being self-critical and vigilant during all aspects of the interview process and this is evident in the next sections, when discussing the preparation for the interviews, the conducting of them and the analysis of the data gathered.

3.5. Procedure

Careful consideration and reflection were given to designing the interview; a list of areas of interest to be covered was compiled as recommended by Denscombe (2017). The pre-defined topics in the interview guide were derived from the quality indicators of effective early intervention, as outlined at the International Conference 2012 (chapter 2, section 2.3) and discussed within the literature review. Possible questions were considered which could be used to lead the discussion if necessary. The questions were open-ended, thus increasing the opportunity for free flow discussion between the interviewer and interviewee and for gaining more thorough, unanticipated answers (Cohen, Manion & Morrison, 2017). These were discussed with the researcher's supervisor and the Head of Sensory Service. Consideration was also given to the use of follow-up probes which could be used to encourage the interviewee to expand their answers (see appendix E). This approach to conducting interviews is supported by Thomas (2013) who believes that the schedule of issues, questions and probes used are guides to help conduct the interview and should not be restrictive but rather help as an 'aide memoire'.

Parents known to the researcher were contacted personally. They were given an EC6 participant information sheet as to the subject, purpose of the research and what would be required of them in terms of giving their time to be interviewed. Their consent was sought using the EC3 consent forms and they were assured that their consent could be withdrawn at any time. Those not known were approached through their QToD asking if they were willing to participate, and to provide their email addresses so that the contact could be made with them. All the willing participants were emailed the EC6 participant information and EC3 consent forms. When the parents agreed to take part in the research project, a date and time was agreed, via emails and text messages. Participants were asked to choose when they wished to be interviewed, and the meetings were arranged.

3.5.1. Online interviews

The intention was to carry out the interviews in person as this is a traditional form of generating data in qualitative studies. This allows for the creation of a personal connection with the interviewee which is 'crucial in achieving a successful, detailed qualitative interview' (Gray et al., 2020, p.1292) as well as analysing the participants' non-verbal cues (Vogl, 2013). At the time, the government regulations for the Covid-19 situation at the time allowed visitors in households but the participants were given a choice of either in-person or online interviews. The first interview took place face-to-face and the interviewee agreed to the interview being audio recorded. However, the re-emergence of Covid numbers resulted in it being inappropriate to continue in this manner. Fortunately, the growth and advancements in technology have allowed interviewers to use other means of collecting data such as telephones and online video platforms (Self, 2021).

The researcher is deaf; therefore, phone interviews were not considered and online video interviews via Zoom were chosen as this was the platform available to the parents. The use of Zoom provided the opportunity for the meetings to be recorded and used for transcription. This eliminated the need to take notes allowing the researcher to devote full attention to the participants (Kabir, 2016).

During the online interviews, time was set aside to put parents at ease and some personal information shared; this was useful in establishing a rapport with the parents who had not met the interviewer previously. The participants were eager to share their narrative, reflect on their experiences and share their needs during their child’s early years. The interviews were flexible with questions following naturally from the previous answer. However, to limit variability in content of the interviews, some redirection was used to ensure all the areas under investigation were covered by all the participants. This redirection was offered to all parents when they needed it.

The advantages of using Zoom were apparent; one of these was the software ability to ‘securely record and store sessions’, (Archibald et al., 2019, p. 2). This was an important feature as it was required to ensure the protection of data collected. Zoom is also a user-friendly platform and, as the participants were geographically dispersed, it saved travel time. It was also convenient for the participants, as most of them chose late evening to take part in the interview when their child(ren) was/were in bed. The main disadvantage was that there were a small number of technical difficulties due to poor connections, making it difficult at times to hear and see the participants but these were resolved by restarting the session.

3.6. Participants

To abide by the requirements of anonymity when conducting this research, each file was given a numerical identification. The deaf community within NI is very small; therefore, it was essential that the information about the child and professionals was carefully scrutinised; any identifiable information was removed from the analysis. To this end, the child’s date of birth was deliberately omitted from the data as this could have led to the anonymity of the families being compromised. Throughout the process, the importance of confidentiality and data protection was paramount. The data gathered was securely stored and password-protected on the researcher’s computer.

The sample chosen was purposeful as it included only parents of children with a sensorineural bilateral severe and profound deafness and who were currently, or had recently been in receipt of, early years support from the Sensory Support Service. The ten participants chosen were families of deaf children aged between 2 and 5 years; five girls and five boys. All of the children underwent a newborn hearing screening programme (NHSP) and were fitted with hearing aids. Seven of those children then proceeded to be implanted. Six of the participants had children who were currently in mainstream education, Nursery or Primary One, enabling them to reflect on their prior experience with the benefit of hindsight. The other four parents’ children were going through the early intervention process. They were selected from five urban and five rural locations within NI, to facilitate comparisons of available support. One of the participating parents was deaf and another had a history of deafness in their family; the other eight had no prior experience of deafness. Nine mothers were interviewed and one mother and father were interviewed together. The information pertaining to the families including type of hearing loss, assistive hearing technology and family location made available through the sensory service database is outlined below.

Table 3.1 Participants’ information.

Participants	Sex	Urban/rural	Level	Hearing aids (HA) or Cochlear implants CI)
1	F	Urban	Profound.	CI x 2
2	M	Rural	Severe/profound	HA x 2
3	M	Rural	Profound	CI x 2
4	F	Rural	Profound	CI x 2
5	F	Urban	Severe	HA x 2
6	M	Urban	Profound	CI x 2

7	M	Urban	Severe	HA x 2
8	F	Urban	Profound	CI x 2
9	F	Rural	Profound	CI x 2
10	M	Rural	Profound	CI x 2

3.7. Data Analysis

The initial plan to use ‘Word’ dictation to transcribe the interviews automatically unfortunately did not pick up the accent of participants and these had to be transcribed manually and checked for accuracy. Cohen, Manion and Morrison (2017, p. 647) commented that the ‘reliability of the transcription is influenced by the accuracy of the speech recognition and clarity of the speaker’. Transcribing the interviews manually, although time consuming, was useful in increasing familiarity with the subject matter.

The interviews were analysed using thematic analysis (TA). TA is a method for ‘identifying, analysing and interpreting patterns of meaning (themes) within the qualitative data’ (Clarke & Braun, 2017, p. 297). This process involved reading and re-reading the data and making casual notes about the participants’ demeanour.

3.7.1. NVivo

Consideration was given as to the best method of sorting and organising the data: manually or using a software programme. After seeking the advice of another researcher (Davis, 2021), who advised that NVivo is a useful tool for organising and working with a large amount of data, the decision was taken to use NVivo. It is a qualitative data analysis computer software and this was downloaded on the researcher’s computer. The data was imported into NVivo, then each line of the data was read and reread to generate preliminary codes, and these were labelled. The codes were then sorted into categories and sub-categories. This allowed for a further examination of the content of the categories, evaluation of the emerging themes and ensuring there was enough data to support each theme. The content of the codes was then transferred into tables for analysis.

3.8. Reflexivity

Berger (2013) highlighted that reflexivity is generally viewed as the process of continual awareness and self-evaluation of the researcher’s views, whilst acknowledging that this may influence both the approach and outcome of the research. I am deaf and being part of the deaf community enables me to relate to deaf children and their families. I am a deaf qualified teacher of the deaf (DQToD), working in the Sensory Support service and I am passionate with regards to my work with deaf children. I recognise that my experiences to date, especially working with pre-school children in their home environments alongside their parents, has led me to believe that quality early intervention is key to the linguistic and social and emotional development of deaf children. Therefore, it is important to me to contribute to the research on early intervention through the evaluation of current practice from the perspective of parents, and to identify any gaps which could be targeted for future improvement. I believe that continuous critical self-evaluation will negate the potential for my own personal bias to impact on this research.

3.9. Conclusion

This chapter discussed the research method chosen and the rationale behind it was clarified. Ethics approval was sought and obtained from University of Hertfordshire to conduct ten semi-structured interviews. The rationale for the participants selected to take part in the interviews was explained and the procedures used for the collecting of the data were detailed. A thematic analysis approach was adopted using the software programme NVivo to facilitate the organisation and interpretation of the data. Five main themes were identified, and they were transferred into tables to be explained in the following chapter.

4. Results

4.1. Introduction

The aim of this research was to gain an insight into early intervention for deaf children aged 0-3 in NI by investigating the experiences and perspectives of parents with the view to informing future provision for families of deaf children. The review of the literature in Chapter 2 established the importance of early intervention as a determining factor in developing communication and language, achieving academic success and social and emotional well-being for deaf children. Parents' perspectives within the UK and internationally were included but, to date, no research has been carried out in NI on parental experiences during the early intervention period. Therefore, as discussed in chapter 3, a mostly qualitative method of research in the form of ten semi structured interviews was adopted to provide an insight into the perspectives of parents in NI. The researcher thematically analysed the responses, and the results were organised into five main themes. These are: (a) early identification (b) access to early intervention services (c) support for child development (d) decision making and (e) parents' emotional and social well-being.

4.2. Early Identification

4.2.1. Newborn Hearing Screening

All the participants' children in this study underwent newborn hearing screening within a couple of days of birth. Seven participants stated that, when their child's screening showed no clear responses, they were told it was probably due to *fluid*. Factsheets on the NI Health and Social Care website (2021) confirm that, if the screening does not show clear responses, it does not necessarily indicate deafness; when this occurs, the screening is routinely repeated. The participants reported that, as a result of this second screening still being inconclusive, they were referred to the audiology services for automated auditory brainstem response (AABR). In the words of one parent when sharing her experience of the initial assessment *it is embedded in our heads'.*

Table 4.1: interview extracts about newborn screening and identification process.

P3	It started the day he was born with the newborn screening thing in the hospital, he failed it, they said 'they would have me back for another one and that it was just his ears clogged up'. I came back and he failed that one as well. It was probably a month or two when we got to audiology for a deeper investigation.

P4	She failed the new-born screening and they said ‘it could be fluid,’ so they repeated it a day later and she failed again. I knew in my heart it wasn’t fluid. Four weeks later we went to the audiology department and they did all the different tests. We were told that day she was profoundly deaf.
P7	He failed new-born screening in the hospital. It was rescheduled then for about three weeks later in the GP surgery. He failed that too; we were then referred to audiology in the hospital.
P10	When he was born, he did not pass his hearing test in the hospital. We were released the next day and they said that ‘he had too much mucus in his ears’ and we were referred to audiology. They confirmed he was profoundly deaf.

4.2.1.1. Multiple screening appointments.

Within HSC NI (2021) it states that, if there are no clear responses on the second screening, the child should then be referred to AABR. However, three of the participants reported having to undergo the screening test more than twice before being referred for AABR; they were still told it could be fluid.

Table 4.2: interview extracts about having more than two screening tests.

P1	It was inconclusive, we were told it was probably fluid so we didn’t think much of it at the time. We were called back for outpatient screening four times then she was referred to audiology when she was four weeks old, they told us not to worry about it, it would be just fluid. The audiologist did a test and said that she had a sensorineural severe hearing loss; I was there by myself because we weren’t expecting anything.
P5	They did a newborn hearing screening and she failed the first one. Then they did two more screenings and failed them both. This all took place on the first night she was born. The lady who was testing her said ‘it is just water in her ears’ so I wasn’t too bothered. Then the next day when we were leaving the hospital, they did another test. They still told us they thought it was just water in her ears, the next week we went to the audiology clinic and they did a wee test and they were still not getting any response. I started to panic but they told us not to worry and it could still be water in her ears. I could see the monitor and nothing was showing so I knew it wasn’t nothing. They made an appointment for us to come back when she was six weeks old to the audiology clinic. After the audiologists finished the testing, I was told she needed hearing aids.

4.2.2. Impact of receiving the identification of deafness

Eight of the participants who had no history of deafness reported feeling shocked when they received the news of their child’s deafness, three of these participants cried when reliving their experiences. For example, one parent likened her experience to a bomb dropping.

Table 4.3: interview extracts on emotions when parents were told their child was deaf.

P1	I was there by myself because we weren't expecting to get news like this. It was an absolute shock. We had 4 appointments; they never once mentioned the possibility of hearing loss. We have no history of deafness; it was like a bomb had been dropped; it provokes you not to believe what you have been told. During those first weeks, you almost go through a grieving process. You've lost that person you thought you had and it's overwhelming.
P3	I was shocked; you never forget that drive home, and I was with my husband.
P5	I just sat there in shock and in silence. I didn't talk the whole way home; I was just trying to hold it all together. I felt really bad as a Mum because I carried her for 9 months and I wondered if I did something wrong. As a couple we found it hard at the beginning and we weren't talking to each other.
P7	It was just such a shock, and you don't expect to have a deaf child especially when there's no history of deafness in the family. Then there is the guilt, I wondered if I did something to cause the deafness. We didn't know what it really meant for him for the future and for us a family.
P9	We were devastated. I didn't know anyone who was deaf so I think that's why we were like scared.

4.2.2.1. Hereditary deafness

In contrast to this, two participants reported they were not shocked due to hereditary deafness in their families. An example from one family with a history of deafness shows that they were prepared for the possibility of their child being deaf, comparing this to finding out if they had a girl or boy.

Table 4.4: interview extract regarding hereditary deafness.

P2	Hearing loss is strong in our family, so we were prepared for the possibility of him being deaf. For our family it's not is it a boy or a girl, it is more of can they hear or not.

4.2.3. Audiological information

The participants expressed confusion and frustration during the hospital appointments at the beginning stages because of not being able to understand the specialist language used or the lack of information given. Three parents voiced their exasperation at the way the audiological information was delivered to them and one reported that she had to make an access request to view her child's audiogram notes

Table 4.5: interview extracts about the information they received at the hospital.

P8	We had to make an access request for information and looked through the notes ourselves.
P1	We asked what our child could hear and couldn't; the audiologist used specialist language and we had no idea what we were being told. The levels didn't mean anything to us. I wanted to know exactly what my child's test result meant on the chart, we were basically told you won't understand. We were told we had to apply for freedom of information to receive our child's chart. We spent the night researching, processing information. At a later date, from talking to different parents, we came to know that different trusts share information differently; some hospitals share more information with parents.
P3	At every appointment at the beginning, they were saying all those big words and it was hard to understand. It was overwhelming, and I still couldn't tell you half of what they were saying.
P10	They showed us the audiogram at the hospital but I didn't understand it; it was rushed. When he was wee, it was hard to understand all the hearing tests that were carried out.

In contrast to this, two participants stated they had a positive experience; their child's audiogram was explained to them. The reason for this may have been that, as indicated by one participant, the way in which information is shared with parents varies in different trusts, resulting in an inconsistency in parents' experiences.

Table 4.6: interview extract on a positive experience of the information received at the hospital.

P9	The audiologists explained and showed us how to use the hearing aids. They also showed us the audiogram and the scores that our child was getting.

4.2.4. Parents' reflections on the identification process

When reflecting back on the process, two of the participants expressed annoyance as to how they were not prepared for the news that their child was deaf. They felt they should be given information to understand the process and possible outcomes.

Table 4.7: interview extracts about being unprepared.

P1	We believe that the initial process needs to be handled better. If the child fails initial screening, more information needs to be given, even a leaflet. We could have used the NDCS website, it could have prepared us for the possible outcomes or we could have been put in touch with the Sensory Support Service.
P5	Parents need more support. If the baby fails the first screening, they need to be told of all the possibilities rather than it could just be water and the next part of the process needs to be explained.

A further two participants reported that they needed more emotional support at the time of identification, and both suggested a counselling service.

Table 4:8: interview extracts suggesting counselling services.

P5	I received emotional support from my family but if I didn't have my family, what would have I done? You need someone to talk to. There needs to be someone such as a counsellor to speak to right at the very beginning.
P7	To be honest, probably a massive change that I would like would be a counselling service for parents to come to terms with their child's hearing loss. You don't know what to think. It would be helpful and it's just someone you could rant to.

4.3. Access to Early Intervention Services

4.3.1. The professionals involved

When asked about where they received the support which was needed, the participants' answers were wide-ranging. During the interviews, the parents named a number of professionals from the Health and Education Boards involved during the early intervention process. These professionals were QToDs, Speech and Language Therapists (SaLT), audiologists, Ear, Nose and Throat (ENT) consultants and social workers, and the amount of involvement varied between families and during the different stages in the early years, as seen below.

Reference was made by all participants to the support they received from their QToD in their homes, and five of these participants also commented on the support their family received from their SaLT. Some examples can be found below.

Table 4.9: interview extracts about the professionals involved.

P1	We received support from audiology and our ENT consultant initially and then the ToD and Speech & Language therapists. The most consistent and regular input has been the ToD; she was our main support for the last four years.
P7	We met our ToD almost immediately, she is fantastic. She came out to see our child every two weeks. We got all the advice we needed from our ToD. We had a sensory support worker for hearing loss but we didn't see her until he was two. We also had a speech and language therapist that started early; that was from about 4-5 months.
P9	We got our Speech & Language therapist early and I love her. I think she's brilliant; we see her once a month.
P10	The professionals involved with our family were audiologists and an ENT consultant followed by ToD and a Speech & Language therapist. We saw our ToD about once a fortnight at home.

4.3.1.1. The number of professionals involved

One participant admitted that she felt overwhelmed and confused by the number of professionals involved. She explained that, when she was asked how often she would like their support, she said she would rather contact them when needed.

Table 4.10: interview extract about the number of professionals involved.

P4	It was very confusing, there was so much to take in and I didn't even know the job roles of the different people. It was too much to take on which is why I said I would contact them. I was all mixed up.

4.3.2. Voluntary organisations

4.3.2.1. National Deaf Children's Society (NDCS)

All of the participants spoke of their contact with the NDCS and they praised the support they received from them. The NDCS supports families all over NI, and organises events for families to support them at 'key points in their deaf child's life' (NDCS, 2022). Five participants commented on the support they received from the NDCS in the form of leaflets, through their website, video links and events, including the weekend for parents of Newly Diagnosed deaf children.

Table 4.11: interview extracts about the support from NDCS.

P3	The NDCS gave us pamphlets with information about deafness and implants and about older deaf people. This was good as I was able to try and read about it at my own pace. At some of the events, the professionals were brought in to tell us about aspects of deafness.
P5	The NDCS had weekends for recently diagnosed babies; it was really good and we got to meet other parents.
P7	The NDCS is great; we got lots of information from them and they organise lots of events.
P8	NDCS have lots of useful information on their website.
P9	At the start the NDCS were brilliant; they have clips of everything on their website. They did a parent's day for newly diagnosed children. We knew nothing and they provided us with so much information.

4.3.2.2. Action Deaf Youth (ADY)

Another service that six participants mentioned was Action Deaf Youth (ADY). This is a charity that is unique to NI which supports deaf children, young people and their families; it is situated in Belfast. Three participants praised the opportunity it gave for their children to play together, although one participant mentioned the long journey, they travelled to attend ADY.

Table 4.12: interview extracts about the support from ADY.

P1	ADY has been great; it normalises her deafness as she gets to meet with other deaf children.
P2	We go to ADY playgroup during the week; it is a long journey for us but he absolutely loves it. He gets the opportunity to play with other deaf children weekly.
P5	The support we had at ADY has been brilliant for us as a family. My child loves it.

One participant in the rural area did not know about ADY and those that did know reported that the location was prohibitive, as illustrated by two participants who wished their child to attend ADY.

Table 4.13: interview extracts about the location of ADY.

P4	I would love my child to go to ADY but it is too far away and it is during the week and I work. They tried to set up a wee group for deaf children and parents to meet with each other near where I live but there weren't enough numbers.
P9	Our child went to the playgroup at ADY which was great; she was with other deaf children but I can't go anymore because it is a journey and I have work.

4.3.3. The impact Covid had on the services

Rose-Hardman (2021), who is the Head of Family Programmes and Involvement for the NDCS, commented that thousands of families with deaf children have been hit hard by the pandemic and been cut from the support networks that they relied on. The impact that Covid had on the families was raised by seven participants, with one reporting that the online support was not the same as face-to-face support.

Table 4.14: Interview extracts about the impact Covid 19 had on early intervention.

P2	When Covid hit, we had to isolate and couldn't meet with our ToD.
P3	Our speech and language therapy stopped but the ToD did video chats with me every two weeks but it was not the same as face to face because she couldn't work with my child.
P5	Her behaviour was difficult; I think it had something to do with lockdown. Being stuck in the house, she wouldn't wear her aids and wouldn't communicate, she was missing ADY.
P7	Covid stopped a lot of things; we haven't been to any NDCS events since Covid.
P8	Covid made it harder to meet professionals and other families.
P9	Everything went online during Covid, so I found that difficult, but my ToD was great at sending me information through email. I would have loved to have seen our ToD face to face not online but that was nobody's fault. We had to wait longer for the CI surgery because of Covid. I think our experience probably would have been quite different if there hasn't been Covid.
P10	Everything sort of stopped; we tried Zoom meetings with Speech and Language therapists and the ToD but they did not work for us.

However, one parent shared an advantage that lockdown had on their family. She felt their child's oral language developed because of the quality and quantity of time spent with their child in the house.

Table 4.15: Interview extract about the process a child made during lockdown.

P10	During lockdown when we were in the house a lot with our child and talking, his speech started to develop.

4.4. Support for Child Development

4.4.1. Access to Information

Following the identification, all parents wish to learn as much as possible to help support their child's development. A recurring theme during the interviews was the importance parents placed on receiving information pertaining to their child's deafness. Four of the participants reported that they took it upon themselves to learn more by doing their own independent research on the internet. One parent summed this up; *You know knowledge is power, you can then work with people and ask the right questions and make plans.*

Table 4:16: interview extracts about independent research.

P1	We spent nights researching about deafness. You know knowledge is power, you can then work with people and ask the right questions and make plans.
P2	I searched through the internet myself to learn more about deafness.
P6	I did a lot of my own research.
P9	I found a lot of information on online. I did quite a few AVT online webinars about how to raise a deaf child and I also looked at the Elizabeth Foundation. It had a lot of information and ideas for activities to try to encourage language development.

One participant reported that she would have liked to obtain an early years' plan and another would have appreciated receiving a list of useful websites from QToD to make her independent research easier.

Table 4:17: interview extracts about an early years' plan and list of websites.

P5	Parents need to be told what is available, who does what and where to get the information. Like an early years' plan.
P8	I would have liked to have a list of websites at the beginning from our ToD; it would have made searching the web a lot easier.

4.4.2. Language Development.

Seven participants commented on the importance of language development and the advice they received from their QToD. They received information about the importance of interacting with their child to develop their language skills. It is accepted that high quality parent-child interaction is 'positively associated with language learning' (Curtin, 2021, p.15). Four participants highlighted particular strategies discussed and modelled by their QToD, and one parent talked of feeling 'completely useless' until the QToD intervened.

Table 4.18: interview extracts on the information received about deafness and language development.

P1	Our ToD visited our home regularly; we were able to ask questions and she was able to answer them in layman's terms. I felt completely useless, but the ToD helped me with how to interact with my child. We were told that interacting with our child was the most important thing I could do to help my child's language development.
P3	My ToD gives me pointers and information about deafness when I see her every two weeks. We were told to bring language into our daily routines. Our ToD gave us ideas about how to use language during play. She also demonstrated by playing with our child.
P7	Our ToD was brilliant; she gave us advice and information we needed. If I had any questions, they would be answered. She did a lot of explaining and showed us how to name objects to develop his understanding of words. It was more repetitive than it would be for a hearing child.
P8	We get a lot of our information from our ToD. She emphasised the importance of play and reading with my child for language development
P10	Our ToD helped us to understand about deafness; if we wanted to know anything we would contact her. The ToD told us to make sure to do face to face contact and to make sure he saw our mouth and our facial expressions. We were told to use gestures to help him to understand.

In addition, two participants mentioned that the S&L therapists also reinforced the importance of language development.

Table 4.19: interview extracts about the information they received from SLT.

P2	Our Speech and Language therapist explained about language development and gave us some tips like playing, talking and reading.
P7	The Speech and Language therapist did a lot of explaining about the importance of language development and his understanding of language.

4.4.3. Child's behaviour

During the interview, four of the participants raised the issue of their child's behaviour. They commented on their struggles in dealing with their child's behaviour and their need for support as to how to deal with their children's frustrations. One participant expressed concern with the way her child would not share with other children.

Table 4:20: interview extracts about child's behaviour.

P1	My child's behaviour can be hard to manage at times, so I spoke to the NDCS and they were able to give me some advice. They said they will set up a course about it as a few parents were ringing about their children's behaviour.
P5	My child's behaviour was very challenging especially during lockdown. I talked to my ToD about this
P7	My child can get very frustrated; it is hard to deal with.
P10	He is a very frustrated little boy at times; he doesn't understand what we are saying sometimes. He would not share toys with other children.

4.4.4. Assessments

When asked about assessments, nine of the participants recalled doing the assessments: for example, the 'integrated scales of development' and the 'monitoring protocol' with their QToD. The response from parents when talking about assessments was unexpected; four did not comment further on the subject other than to say they were used. The tone used by four other participants indicated that they were overwhelmed by them and did not see the value in them. One participant stated that the assessment used was complicated because of the language; another did not view them as a priority and two found them distressing.

Table 4.21: interview extracts about assessments used.

P4	I did the 'Listening Child' assessment; it was very complicated because of the language. I tried to fill it out myself but my TOD had to come back and do it with me.
P5	I found it useless. The integrated scales assessment was used. I didn't like it when I saw how far behind my child was. It doesn't make you feel good as a parent. I found it hard during the first couple of years.
P6	I think we did use them to monitor progress but I didn't find them very useful; they were not my priority.
P8	I know they can be useful I did them with my ToD but it can be upsetting seeing the gap between my child and hearing children.

Only one participant interviewed was positive about the use of assessments. She used the Success from the Start and was encouraged to see the progress her child was making.

Table 4.22: interview extract about the usefulness of assessments.

P9	I like Success from the Start; I like to see progress you know and what she should be doing.

4.5. Decision Making

4.5.1. Communication approaches

All participants discussed modes of communication with their QToD, S&L therapists and/or members of the NDCS. Family sign language courses are offered by the NDCS. Parents should be informed of the communication options and the information they receive from professionals is important (Decker, Vallotoon & Johnson, 2012). One participant stated that her QToD 'was always an encourager of any form of communication'. Six of the parents interviewed chose spoken English and examples of the reasons chosen are included in the table below.

Table 4.23: interview extracts about the oral route.

P1	We found some deaf forums on the internet; they were all about signing, and they didn't want to talk about oralism. We chose to move away from them because we felt our child lived in a hearing world that was not going to change for her. The main mode we are using is spoken English.
P3	We have chosen the oral route; it suited us best as a family. We did start level 1 before Covid but it was too difficult.
P4	We speak to our child. We were given the option to learn sign language, but we decided that it was better to wait until our child was older and so that we can do it together. We use gestures as well as words.
P10	The NDCS put us onto a 6-week sign language course. We stopped signing because we wanted to use the words. We found that it was better than sign language. It was useful when he was young when we had no other communication for him, but it became easier for us to communicate with him through words. It suited us a family to use words as not a lot of people use sign language like in a shop or anywhere, so we didn't want him to have more barriers. It was too difficult for Granny and Granda and cousins to use sign language.

One participant explained that they initially adopted the use of signs but reduced their use of them as their child acquired more oral language and preferred to talk.

Table 4.24: interview extract about communication options.

P9	We went for sign supported English before she was implanted, we always spoke while we signed. She doesn't really sign much now, as she likes to talk so we mainly use speech now.

Four families, one of which is a deaf family, are pursuing a total communication route, using both signs and spoken English simultaneously. Examples of the reasons chosen for using both modes of communication are shown below.

Table 4.25: interview extract about total communication.

P2	We want him to do both, we want to be able to communicate with him when he doesn't have his aids on.
P5	She didn't wear her hearing aids at the start. I wanted to be able to communicate with her. ADY influenced me too, and she loves it when people are signing to her, I want her to have both, BSL and Spoken English.
P6	I want bilingual. I want to give my child choices. It makes sense really. Why would I focus on one language when they can have more than one? Then he can choose whichever they prefer.
P8	I was worried that when my child got older that she would miss things with her hearing friends and if she couldn't sign with her deaf friends, she would miss out there too. I didn't want her to be isolated. I wanted her to have speech and sign. I enjoy learning how to sign.

4.5.1.1. Attitudes towards sign language

Two of the families reported that they experienced negative attitudes from the hospital and a SaLT when exposing their child to sign language and that they were discouraged from doing so. This is well illustrated by one parent who said she had to argue her case for using sign language.

Table 4.26: interview extracts about negative attitude towards sign language.

P5	ADY influenced me to sign but my speech and language therapist discouraged sign language, saying that we needed to work on her speech. I argued that we all are signing but we are speaking as well. This is what we will be doing as a family.
P8	The hospital and my initial ToD were against signing but I wanted my child to have both, speech and sign language.

4.5.2. Cochlear Implants

Nine of the participants faced the decision during the early intervention process as to whether their child should undergo cochlear implants surgery, and seven of these participants went ahead with the surgery. When asked how they made their decision about the cochlear implants, the participants reported they were influenced in the decision-making process by the information given to them by the audiologists, consultant, Auditory Implant Centre (AIC), QToDs and by talking to other parents.

The following examples from two participants highlight the difficult process which parents have to navigate, with one participant reporting that; *it was horrendous.*

Table 4.27: interview extracts about the difficult decision for cochlear implants.

P1	This was a very big decision for us. We got support from other parents when it came to making our decision. We spoke to a lot of parents and they all reassured us but the only thing was that she wasn't profoundly deaf from birth like others; she still had a little hearing. We wrote down her hearing levels and showed them to our ToD, and she said to get the implants.
P10	We were sent to the implant centre and they said that he did not have enough access to sound with his hearing aids. We decided to go for implants; it was a hard decision. I was so scared at the thought of somebody working on my baby's head it was horrendous. I was ever so scared at the time but it was something I just kept bottled up and didn't speak to anyone about it.

In contrast, two participants explained that the decision for them was an obvious one as they wanted their child to have the best possible access to sound.

Table 4.28: interview extracts about making the decision for cochlear implants.

P3	It was very straightforward for us; we were told he needed them to hear.
P9	The consultant said there's so much hope with cochlear implants. For us it was a bit of a no brainer in that it was either accept she never hears anything at all even with the use of hearing aids or try this and if it helps even a little bit or if one ear worked, you know that would be great.

4.5.2.1. Deciding against Cochlear Implants

Two participants decided against cochlear implants as they felt their child was getting enough access with their hearing aids but they wished to leave the option open. However, they explained that they felt under pressure to agree to implants.

Table 4.29: interview extracts on deciding against cochlear implants.

P2	At the start, the implant centre said he was making good progress but when he was one years old, they said the gap was widening and they were not happy. Then there was Covid and he hadn't been to the implant centre for a few months and when we went back, he was very shy. They didn't take that into consideration; they said he should have implants. We said we're not saying no to implants but just not now. The next time we went back to the implant centre it was said 'either he gets them or talks, or he doesn't, and he won't.'

P7	The decision of whether to go cochlear implants, that was the biggest challenge and that was something that I thought about every single day, thinking am I making the right decision? Should I trust the experts and let them make the decision? I felt like everybody I had spoken to had said it's the best thing we've ever done but I made the decision to refuse them.

4.5.2.2. Complications with the cochlear implant surgery

Two of the participants experienced complications from their child's cochlear implant surgery and this resulted in more stress for the families. One of these participants reported that she felt very guilty and would have appreciated more emotional support during and after the surgery. The other participant referred to the stress she experienced but acknowledged the support she received from her consultant.

Table 4.30: interview extracts about complications from the surgery.

P4	My child's right implant got infected, and it took a year to get that sorted and 4 surgeries. It was a very stressful experience, but my ENT consultant was brilliant.
P6	The operation took longer than expected. It should only take 5 hours but it took 7/8 hours. I remember the assistant surgeon came and said I'm really sorry it took longer than expected, there were some complications. I was like oh what have I done?! He was already perfect before so why did I do this? I felt really guilty, even now I am still not over the guilt because of my child's balance. It's been three years now. It is only recently I'm starting to see that his balance is improving but it's been a long three years. I felt we didn't get a lot of support around the surgery.

4.6. Parents' Emotional and Social Well-Being

4.6.1. Concerns/ Anxieties around their child's future

The ten participants interviewed were experiencing, or had experienced, worry and stress around their child's deafness in the early years; this is understandable as over 90% of deaf children are born into hearing parents with no history or knowledge of deafness (Wright et al., 2021). It is further endorsed by Marschark (2007) that parents worry about their child's welfare and future. Examples of the worries that parents reported included: speech and language development, choice of schools, being accepted by their peers, teenage years, employment and even marriage.

Table 4.31: interview extracts about their parents' worries.

P2	I worry about his future; I have thought about everything to be honest. I was anxious about his speech and language development.
P4	I was worried about whether she would get married. All sorts of things go through your head.
P7	I was thinking all sorts, what if he doesn't talk? Or you know what if he gets bullied?
P8	I love music, I was upset that my child would not hear music and what she would miss out on. I was worried about how she would feel as a teenager. Would she be embarrassed? I was worried about what happens if she loses her hearing aids on a night out when she is older, how would she cope?
P10	I was scared when I thought about school, I wanted him to have the same possibilities as other children. Is he going to be able to go to mainstream nursery, primary and secondary? Is he going to be bullied because he is different?

In contrast to this, the deaf parent did not have the same level of worry around the social wellbeing of their child, but their concerns centred around access to education.

Table 4.32: interview extract from a deaf parent concern.

P6	I wasn't bothered about him being deaf but I did worry about the education and the barriers that he might come across.

4.6.2. Emotional support offered by QToDs

Four parents indicated that their main emotional support came from their QToDs. Wright et al., (2021) defined the role of QToDs as being holistic and not just focused on language development; this was aptly illustrated by one parent who defined their QToD as their 'total rock'.

Table 4.33: interview extracts about emotional support received by QToD.

P1	Our ToD was a total rock. She was the lead, the bridge sorting out difficulties as they arose. I questioned whether I should give up work because I heard other mums were doing this and I was like I can't give up work, I have a mortgage you know, and we were trying to strike this balance and doing the right thing by this wee baby. Our ToD said you have a family to consider, a household to consider, a life ahead of this, we will get your child sorted and so she was just kind of level headed and she put things into perspective for us.
P3	My Tod is great with my child; she plays with him, supports me and gives me advice.
P4	Our ToD was brilliant; she sometimes came out to see us in our house. She was positive and reassured me, particularly with my concerns about schooling.

P7	Our ToD is fantastic; she is the one we rely on and she put everything into perspective for us, so she is all we really have.

4.6.3. Parent to Parent support

Nine of the participants spoke about the parent-to-parent support; they shared how they were put in contact with one another. They made contact either through the QToDs, NDCS, ADY, AIC or wider community connections. Yoshinaga-Itano (2014), cited that families reported the value of receiving support from other parents 'who have been there' as no one else understands them as well. Six of the participants interviewed highlighted the advantages and these included the sharing of information, practical advice, experiences and concerns. One participant described the contact with other parents as being their 'most important network'.

Table 4.34: interview extracts about parent-to-parent support.

P1	Being in touch with other parents is our biggest and most important network.
P3	It was great to speak to other parents; they helped me a lot.
P4	Talking to another parent was the best thing. She lives locally and has two older deaf children. She gave me a lot of support. It was helpful to us as nobody else got you except them.
P5	Meeting with other families of deaf children was useful. I was able to share my concerns with other parents of deaf children.
P7	Meeting other parents helped us to see how they deal with things and they gave advice.
P9	Through NDCS I met other mums, and this was helpful because they bring with them real life experiences and ideas for what to do in different situations.

Upon reflection, one participant reported that she wished she had known another family at the beginning of their journey.

Table 4.35: interview extract about receiving parent to parent support earlier.

P8	I know a few families of deaf children now but I would have liked to have met another family at the very beginning.

4.6.3.1. Parent to Parent support in rural areas

Furthermore, two parents from rural areas disclosed that they did not have much contact with other parents. One said she would have liked to have had more contact, but the opposite was true for the second parent, as she was fearful that meeting with other parents would be a negative experience.

Table 4.36: interview extracts about parent-to-parent support in rural areas.

P4	I would have liked to be put in contact with more parents of deaf children.
P10	I do not know many parents. We were invited to NDCS events, but we didn't go. I didn't want to hear about bad experiences; it would make me worry. I just wanted to focus on my child. I didn't want to participate.

4.6.4. Deaf community

Parents also talked about the support they receive from the deaf community. They appreciated when the NDCS and ADY gave them the opportunity to meet with deaf adults and members of the deaf community. Four participants described the benefits of meeting with deaf adults when looking towards the future.

Table 4.37: interview extracts about the deaf community.

P1	During a course with a deaf adult, just talking to her about her personal experiences was helpful. It helps to build your confidence in the situation.
P5	The ADY welcomed us into the deaf community; it helped us to understand more about deafness. Meeting other deaf adults has helped us to see what the future could be like for our child.
P8	My ToD is deaf and it is good for my child to know she can achieve anything she wants.
P9	Since our child was born, we met some deaf people and this was through ADY. At a NDCS event we met some ex-pupils of Mary Hare and Jordanstown school, and they spoke about themselves. It was great to see what jobs they had and it reassured me what the future could hold.

Two of the participants interviewed from a rural location asked the researcher questions about her life as a deaf person because they wanted to hear from a deaf perspective. One participant explained that she did not know any other deaf people that she could ask.

P10	I don't want to be nosey but I don't know any deaf adults so can I ask you some things about your life?

4.7. Summary of the Results

This small-scale research study set out to investigate the early intervention process in NI from the perspectives of the parents and the findings from the semi-structured interviews revealed an insight into this. The five themes, as identified in the results, highlight satisfaction with aspects of the early intervention provision but also reveal areas which could be further developed. It is important to note that the onset of Covid had an impact on the services delivered. The next chapter will contain a detailed and critical discussion of the results.

5. Discussion

This chapter is a detailed analysis and discussion of the key qualitative results collected during the ten semi-structured interviews with parents of deaf children. The aim of this project was to investigate the perspectives and experiences of parents during early intervention for deaf children (0-3) in NI with the view to making recommendations for future practice. The findings of the parents' interviews will be discussed further in this chapter by using four categories: (1) Initial identification process (2) Informed choice and decision making (3) Family support network (4) Recommendations.

5.1. Initial identification process

5.1.1. Newborn hearing screening

The process of assessments and identification of deafness is a very difficult and overwhelming time for parents (Russ et al., 2004; Gilbey, 2010; Scarinci et al., 2018a). During the interviews, eight of the parents interviewed had no prior experience of deafness. They reported that they were reassured that the unclear responses to their child's newborn hearing screening(s) were most likely due to fluid, leading to them being unprepared for the possibility of deafness. Two parents reflected that this was unacceptable and it would not have been such a shock if they had been more prepared. Indeed, similar experiences were reported in a study undertaken by Elliot et al., (2022) in Australia to explore the needs of parents during the screening and identification of deafness.

In the guidance published by HSC NI (2021), the common reasons for unclear responses during newborn screening include: baby being unsettled at the time of the test, background noise interfering with the test, or fluid in the ear. The HSC Trust states that approximately 'one to two in every 1,000 babies are born with a permanent hearing loss in one or both ears' (HSCNI, 2021). It is understandable, given the low statistics, that screeners would not wish to distress parents at this early stage. However, this is contrary to guidance from Public Health England (2021) which explicitly states that parents should not be overly reassured that fluid is the reason for the hearing screening results being inconclusive. The researcher acknowledges that it is difficult to find the balance between giving information and reassuring parents. Moving forward, the way information is given to parents during screening should be reviewed: for example, Young and Tattersall (2005) believe that, during each stage of testing, there is a need to ensure parents understand what is happening, whilst at the same time limiting unnecessary worry. Another possibility, as cited by Elliot et al. (2022) is to involve parents in developing the best way of delivering information.

5.1.2. Parents' need for information

The views of parents on the content and the way information was imparted to them varied. Three parents reported feeling overwhelmed at the use of new, specialist, audiological language about their baby's hearing. However, one was happy with the information received and another reported having a very supportive relationship with her ENT consultant. These differences would suggest that audiologists should be mindful that the delivery of information will be different for every family and that they should abstain from using technical terminology that will confuse parents (Davis, Knowd & Jones, 2021).

Two parents interviewed voiced dissatisfaction with the information given about their child's hearing. This is consistent with Gillver et al.'s (2013, p.8) research into parents' experiences after their child was identified deaf; they 'expressed a desire for more information than they received'. Another parent interviewed felt the appointments at the hospital were rushed; again, this was also evident with Scarinci et al.'s (2018a) findings, where some parents reported that their time with the audiologists was brief. In contrast, Davis, Knowd & Jones (2021, p.54) made the point that, due to busy caseloads, factors outside the audiologist's control place limitations on available time to spend with patients.

Research shows parents attending St Thomas's Hospital London reported favourably on the approaches adopted to support parents during their audiological visits. Jackson & Vickerstaff (2020), audiologists at St. Thomas' Hospital, explained that, initially, parents are given information about their child's audiogram, neuroplasticity and auditory deprivation. Then, when they receive confirmation of deafness, they are given a 'Question Prompt List' (QPL) to use at their next appointment. In this way, they are supported in knowing what questions to ask and are better able to understand their child's deafness. The researcher believes this is a practice that could be adapted and piloted within the audiology departments in NI.

5.1.3. Parents’ emotional needs

Eight of the parents reported feeling shocked, grief stricken, confused, guilty, stressed, overwhelmed and alone during the identification period. Two parents felt a need for counselling to come to terms with their child’s deafness. This happens in Colorado, USA, where a counselling service is offered to all families of deaf children at the beginning of the early intervention process (Wright et al., 2021).

Luterman (2020) advocates a client-centred model be adopted, whereby audiologists blend the giving of information with meeting the emotional and psychological needs of parents, by creating an emotionally secure environment, where priority is given to listening to their feelings. The researcher agrees with Luterman (2021, p, 227) that the involvement of a counselling element during identification will result in ‘informed, empowered, and emotionally grounded parents.’ Unfortunately, current research suggests that students training as audiologists are not being adequately trained to counsel clients effectively (Luterman, 2021).

One potential solution to reduce parents’ frustrations could be found in Maiden & Keen’s (2018) suggestion that Educational Audiologists who are QToDs are in a better position than clinical audiologists to answer parents’ questions about their child’s deafness and the support available. This resource has not been used in NI; however, it is noteworthy that the Sensory Service has recently appointed two Educational Audiologists and they will take up their positions in September 2022. Alternatively, Scarinci et al.’s (2018a) article states that professionals working with families of deaf children should be prepared to take on a counselling role within their practice. The possibility of workshops offering training for professionals in counselling would be worth exploring in the future.

5.2. Informed Choice and Decision Making

All parents stressed the importance of receiving information, including hearing parents with no knowledge of deafness, parents who are deaf and those with deafness in their extended family. Parents of deaf children have to make many choices and there is a need for information in order to make informed decisions for their children (Scarinci et al., 2018b; Tracey et al., 2018). It is evident from the interviews that information is available to parents from multiple sources, health and educational professionals, voluntary organisations, pamphlets, literature, the internet and from other parents of deaf children.

5.2.1. Early Years Plan

Gilbery (2010) states that parents need guidance through the early intervention process. One parent reported that, upon the identification of deafness, parents needed more information as to what to expect going forward and suggested the need for an Early Years plan. As a QToD working in the homes with families, it is evident to the researcher that the creation of the Early Years plan would be beneficial in helping them on their journey through the intervention process. Parents also stated that they spent a lot of time on the internet searching for information. According to Hyde, Punch & Komesoraff (2010), the gathering of relevant information is a difficult and stressful experience for parents. The plan could include information about deafness, the services available to families and pointers to the most relevant websites. This is currently under review within the Sensory Service, NI.

5.2.2. Communication approaches

Early exposure to language and communication (spoken language and/or sign language) is vital, as research shows that there is a critical period for language development (Davis, Knowd & Jones, 2021; Rowley & Sive, 2021). The BDA conference in 2014 documented that the communication policy in NI leant towards the medical model, focusing on an oral approach to language acquisition. The delegates recognised that, moving forward, all communication methods needed to be equally valued. Although the results from this study showed that the majority (six) of parents interviewed have opted for the oral method, four families are pursuing a total communication route (one is a deaf family).

As discussed in the literature review, a number of factors influenced parents' choice of communication methods. The findings from the interviews revealed that the majority of parents wished their child to adopt spoken language, as it was used in their families. This is facilitated with the consistent use of hearing aids and cochlear implants (Ambrose et al., 2020). However, hearing technologies are not always successful and they do not restore normal hearing (Humphries et al., 2019; Hall et al., 2019).

Humphries et al., (2019) argued that no one should wait until their child is implanted to see how well-spoken language is accessed with the use of CIs, as this could delay the child's language skills. One parent in the study explained that, prior to implantation, the family learnt how to sign but reduced using signs when their child's listening and oral language developed. This is consistent with the findings of Watson et al. (2008) that, out of 142 parents surveyed, 113 changed their communication approach towards spoken language following cochlear implantation; this decision was 'child-led and driven by increased audition' (2008, p.100).

Two parents expressed disappointment at being advised not to sign by professionals who showed a bias towards the use of spoken language. Hall et al., (2019) reported that it is concerning when families are advised not to use sign language as research shows that the deaf population are still 'significantly underperforming on standardised assessments of speech and spoken language development'. These professionals may have been worried that sign language would hinder the child's spoken language, but this view is outdated, not supported by research, and it puts the child at risk of not achieving a fluent language (Knoors and Marschark, 2012; NDCS, 2016b, Hall et al., 2019). The need for professionals to be impartial in providing information, and supporting family choices is recognised by researchers (Moller et al., 2013; Stewart, Slattery & McKee, 2021).

Rowley and Sive (2021) strongly believe that parents should be encouraged to use both languages to ensure deaf children 'maximise their language learning potential' (2021, p.34). The researcher has found from her own experiences that the most effective way of developing young deaf children's communication and language skills is through the use of both languages, signed and spoken. Signed and spoken languages are not mutually exclusive and using them simultaneously limits language deprivation.

The researcher recognises that, although there has been movement away from an oral only approach in NI, more remains to be done and this needs greater emphasis. Given the benefits of using both sign and oral language, the professionals working with families of deaf children in NI should be encouraged to use sign language when working with young children.

5.3. Family Support

5.3.1. The role of QToDs

The support received from QToDs during the early stages was a recurring theme throughout the interviews, with one parent stating their QToD ‘put everything into perspective’ for them. The Sensory Service in NI policy is that, once the QToD receives a new referral from the hospital, contact is made with the family within two days and they are met within ten days. This family-centred support in the home continues during the early years until the child enters a preschool setting focusing on developing language and communication as well as on the social and emotional wellbeing of the child (Wright et al., 2021). The aim of these visits is to empower the parent by providing them with the knowledge they need to support their deaf child’s development (Eleweke, 2008).

Seven parents recognised the importance of the role of the QToD in enabling them to promote language development through interaction with their child. One parent felt that he ‘knew nothing’ until the intervention of the QToD. Raising parents’ awareness of their role in developing their child’s language is important, as highlighted within the international consensus (Moeller et al., 2013). The results from the data demonstrated that the QToD provided information and modelled strategies during home visits including eye contact, joint attention, the use of language during play and the use of day-to-day activities. However, upon reflection, the researcher realises that, whilst four parents referred to strategies, the others were non-committal. More probing would have given a better insight into parents’ perceptions of the effectiveness of the delivery of the information as well as their evaluation of the interactions with their children.

As previously discussed in the review of the literature, there are no assessments to evaluate parent-child interactions. Curtin (2021) believes that a professional should have a good level of understanding and skill in assessing parent-child interaction. This knowledge can be used to empower parents and give them the confidence to interact with their deaf child effectively. Therefore, Curtin (2021, p.15) is currently developing an assessment tool that ‘evaluates a parent’s interaction skills when they are communicating with their deaf child’. The researcher recommends this as an important tool which should be explored by the service and employed to support parent-child interaction.

Parents’ views on the child’s development assessments used with their QToD was surprising. An overwhelming number (nine) of parents did not find the assessments beneficial and this was a concerning finding. Two parents found them upsetting, describing how they did not like to see their child’s progression when measured against typical milestones; they reported feeling like a failure. This is in stark contrast to the aim of assessments such as ‘Integrated Scales of Development’ and ‘Success from the Start’. These are designed to empower parents as they work with professionals to gain an understanding of their child’s development and participate in using and evaluating appropriate strategies to support further development (Cochlear 2009; NDCS, 2020).

The researcher has witnessed this phenomenon within her own practice in addition to it being highlighted by so many parents; therefore, the use of assessments needs to be explored further by the QToD in the Sensory Service. It is necessary that parents understand the value of them as a learning tool.

5.3.2. Parent support network

Nine out of ten parents clearly ranked parent to parent support as one of the most important supports they received, with one stating that it was their ‘biggest and most important network’. Many researchers recognise that social support is important in reducing parents’ stress and this is largely achieved through meeting with other families of deaf children (Eleweke, et al., 2008; Hintermair, 2000; Zaidman-Zait, 2007; Jackson, 2011).

One of the questions posed in this study was that of equitable access to services in all regions of NI. The NDCS and ADY are a vital part of the support network provided for families. The NDCS events take place in different locations, but ADY is located in Belfast and for those living in the city it provides easy access to a weekly family network. Therefore, the parents in urban areas had more regular contact with other families compared to those living in rural areas, due to work commitments and the distance involved in travelling to ADY. This aligns with evidence from the literature. ‘Children in regional, rural and remote areas have less access to services than those living in urban areas’ (Barr, Duncan & Dally, 2018, p.118).

One parent from a rural area interviewed wished she had been introduced to another family after the identification of deafness. In St. Thomas’s hospital, the audiologists, Jackson and Vickerstaff (2020) reported that they have a ‘buddy parent scheme’. It allows families with a child who has been newly identified to be offered a ‘buddy parent’. The researcher recommends that a similar practice be implemented in NI as it would be particularly beneficial for parents living in rural areas.

5.3.2. Deaf adults

Research has shown that, when families have contact with deaf adults, it provides many advantages. They provide a unique perspective from their own experiences, which develops parents’ positivity (Gale et al., 2021) and their competence in raising their child. Deaf adults are employed within the NDCS and ADY, and parents welcomed the opportunity to interact and learn from them as they saw them as positive role models for their children. Another parent reported that she appreciated that her QToD is deaf. However, two parents admitted that the researcher was the first deaf adult they had met and they were keen to hear about her personal experiences. There is a need for equality of interaction with deaf adults for parents living in rural areas.

The inclusion of deaf adults offering family social and emotional support and engaging in collaborative teams in early intervention is advocated within the best principles in the international consensus statement (Moeller et al., 2013). The researcher believes that there is a necessity for deaf professionals to be embedded within the early intervention services. Although there are deaf QToDs within the Sensory Service in NI, it is not possible to reach to all families that would benefit from it. Therefore, the researcher suggests continuous collaborative links with charitable organisations such as NDCS, ADY and NI BDA to ensure families benefit from meeting a deaf adult, whether it is for informal chats or 1:1 play/story sessions with their child.

5.4. Further Recommendations

A QToD undergoes training and works with children across all age ranges. However, from the study, it is clear that working with young babies and their families in the home or pre-school setting requires a specific set of skills and knowledge. This is supported by Yoshinaga-Itano (2014) who claimed that recent research suggests the outcomes for deaf children and their families are better when professionals have specific training tailored for work with young babies and toddlers who are deaf, and their families. Nelson (2020) advocates that, to support families from the point of identification, further specialised training should be undertaken. However, the postgraduate qualification in working with deaf babies and toddlers previously offered at Mary Hare, in partnership with the University of Hertfordshire, is no longer available, although there are modules focusing on Early Years within the Educational Audiology programme. Many services in the UK have a specialist QToD who works with families in the Early Years (Wright et al., 2021). It may be worth considering creating a designated specialist (for children 0-3 years) within the NI sensory service in the future.

5.6. Limitations

This research project was restricted to the small number of ten families. A larger number would have provided more perspectives, but the time constraints meant this was not possible. Only one method of data collection was used; however, upon reflection, a questionnaire would have been useful to gather information from a wider audience across NI and to provide quantitative data to support the findings of the interviews.

It would have been the researcher's preference to conduct face to face interviews but, because of Covid 19, this was not feasible. The online interviews, whilst successful, were more formal and at times it was difficult to sustain a natural flow of conversation due to connection issues. The study conducted is particular to NI, so care should be taken when drawing conclusions from it. On the positive side, this research method produced a valuable insight and understanding into the experiences of parents.

5.7. Summary

During this chapter, the parents' perspectives, as revealed in the research, were analysed and discussed. In the light of the findings from the interviews and drawing on evidence from literature, recommendations for future practice were made. The conclusion of this study follows in the next chapter.

6. Conclusion

This study investigated the perspectives and experiences of parents during early intervention for deaf children aged 0-3 in Northern Ireland (NI). Three questions were posed for consideration:

- Is there a gap between the needs as identified by the parents and the provision on offer?
- Are parents' emotional and social needs being met during early intervention?
- Is there equitable appropriate early invention in both rural and urban areas?

Quality and equitable early intervention is essential for the families of deaf children, as outlined in the international consensus for best practice in family-centred early intervention (Moeller et al., 2013). These were the targets set at the BDA conference in 2014 in NI. An extensive examination of the literature revealed a large body of evidence showing the importance of family-centred early intervention in supporting the development of deaf children. The researcher agrees with this evidence that the success of this intervention is dependent on the partnership and mutual respect between parents and professionals.

Parents shared their experiences of early intervention across the various areas: early identification; services available; support from professionals; information received on deafness; parent-child interaction; the use of assessments and communication choices. These were analysed, discussed and evaluated in line with the findings identified in literature.

The parents were very forthcoming in sharing their stories and in identifying their needs; they were happy with many aspects of the intervention process, but they were also honest when they revealed some gaps in the provision. The results showed a mixed level of satisfaction during the initial identification process; at a time when parents were at their most vulnerable, some felt unsupported due to their lack of their understanding of the process. Similar to previous studies cited from the literature, the need for clearer, more easily accessible, impartial information about their child's deafness and development was apparent from the interviews. There was also a clear need for parents to be given an overall plan as early as possible explaining the details of the whole intervention network and the type of support on offer.

With regards to the emotional support offered, the majority of parents appreciated the role of the professionals and the home visits from the QToDs. The importance of having parent-to-parent support was clearly the most beneficial emotional support to the majority of parents. Parents involved with NDCS and ADY highly valued the support from these organisations as it gave them the opportunity to meet with deaf adults. However, some parents felt there was a need for a counselling service during the initial identification period.

With regard to the equitable provision of early intervention services across NI, it is more difficult for the families living in rural areas to have regular access to all services, and this correlates with the evidence found in the literature. According to this study, most parents within the rural areas received equitable support in terms of professional services. Unfortunately, comparisons between urban and rural areas showed parents in rural areas missed out on some of the voluntary services and the very important deaf social network.

The nature of this study and its findings raises awareness of the importance of listening to parents, thus enabling their views to be included in the future development of early intervention in NI. Several aspects as outlined within the international consensus document on family-centred intervention were discussed and evaluated. The results suggest there is potential for further in-depth study into any one of these areas in the future to continue to inform best practice within NI.

References

Ambrose, S. E., Appenzeller, M., Mai, A., & DesJardin, J. L. (2020) ‘Beliefs and Self-Efficacy of Parents of Young Children with Hearing Loss.’ *Journal of early hearing detection and intervention*, *5*(1) pp. 73–85.

Archbold, S., Sach, T., O’Neill, C., Lutman, M. and Gregory, S. (2006) ‘Deciding to Have a Cochlear Implant and Subsequent After-care: Parental Perspective’. *Deafness & Education International,* 8(4) pp. 190-206.

Archbold, S.M., Sach, T.H., O'neill, C., Lutman, M.E. & Gregory, S. (2008) ‘Outcomes from Cochlear Implantation for Child and Family: Parental Perspectives.’ *Deafness & Education International,* 10(3) pp. 120-142.

Archibald, M. M., Ambagtsheer, R.C., Casey, M.G. & Lawless, M. (2019) ‘Using Zoom Videoconferencing for Qualitative Data Collection: Perceptions and Experiences of Researchers and Participants’. *International Journal of Qualitative Methods*,18 pp 1-8. Available at: Using Zoom Videoconferencing for Qualitative Data Collection: Perceptions and Experiences of Researchers and Participants (sagepub.com)

Barr, M., Duncan, J. & Dally, K. (2018) ‘A Systematic Review of Services to DHH Children in Rural and Remote Regions.’ *Journal of Deaf Studies and Deaf Education*, 23(2) pp. 118–130.

Bell, J. (2014) *Doing Your Research Project*. 6th edn. Buckingham: Open University Press.

BERA (2018) Ethical Guidelines for Educational Research. Available at: https://www.bera.ac.uk/publication/ethical-guidelines-for-educational-research-2018-online [Accessed: 19.10.21].

Berger, R. (2015) ‘Now I see it, now I don’t: researcher’s position and reflexivity in qualitative research’. *Qualitative Research,* 15 (2) pp 219-234.

BDA Deaf Association Northern Ireland (2014) *Early Years Intervention for Deaf children in Northern Ireland*. Available at: BDA-NI-Report-Early-Years-Intervention-for-Deaf-Children-in-Northern-Ireland-2014.pdf [25.09.21].

Bray, L., Carter, B., Sanders. C., Blake. L. and Keegan, K. (2017) Parent to parent peer support for parents of children with a disability: A mixed method study. ‘Patient Education and Counselling’, 100(8) pp. Available: Parent-to-parent peer support for parents of children with a disability: A mixed method study | Elsevier Enhanced Reader

Busetto, L., Wick, W. & Gumbinger, C. (2020) ‘How to use and assess qualitative research methods’. *Neurological Research and Practise.* 2 (14) pp 1-10. Available at: https://neurolrespract.biomedcentral.com/track/pdf/10.1186/s42466-020-00059-z.pdf

Carr, G (2018) ‘Informed Choice: a view through the lens of then and now’. *BATOD.* March 2018. Pp. 4-5.

Carter, C. (2014) *Successful Dissertations: The complete Guide for Education, Childhood and Early Childhood Studies Students*. 2nd edn. London: Bloomsbury. [Online]. Available at: https://ebookcentral.proquest.com/lib/herts/detail.action?docID=5389336

Castleberry, A. & Nolen, A. (2018) ‘thematic analysis of qualitative research data: Is it as easy as it sounds? *Currents in Teaching and Learning.* 10 (6) pp 807 – 815. *Available at: https://www-sciencedirect-com.ezproxy.herts.ac.uk/science/article/pii/S1877129717300606?via%3Dihub*

Chang, P. F. (2017). ‘Breaking the sound barrier: exploring parents' decision-making process of cochlear implants for their children’. *Patient Education and Counselling*, *100*(8) pp.1544–1551.

Ching, T., Dillon, H., Button, L., Seeto, M., Van Buynder, P., Marnane, V., Cupples, L., & Leigh, G. (2017) ‘Age at Intervention for Permanent Hearing Loss and 5-Year Language Outcomes’. *Pediatrics*, *140*(3) pp. 1-11.

Cochlear (2009) *Scales of Development (ISD).* Available at: https://mss-p-007-delivery.sitecorecontenthub.cloud/api/public/content/23d4d0f914ea48ffb17122db10af6ef0?v=cb03eab8 [Accessed: 01.03.22].

Cohen, L., Manion, L. & Morrison, K. (2017) *Research Methods in Education*. 8th edn. London: Taylor & Francis Group.

Collinson, S. (2017) *Early years language and development in deaf children – a best evidence scoping review*. NatSIP. Available at: natsip_paper_synthesis_of_key_findings.pdf (ndcs.org.uk). [Accessed 12.11.21].

Clarke, V. & Braun, V. (2017) 'Thematic Analysis.' The Journal of Positive Psychology, 12(3) pp. 297-298. Available at: https://www-tandfonline-com.ezproxy.herts.ac.uk/doi/pdf/10.1080/17439760.2016.1262613?needAccess=true

Crowe, K., Fordham, L., McLeod, S. & Ching, T. Y. (2014) 'Part of our world: Influences on caregiver decisions about communication choices for children with hearing loss.' *Deafness & Education International,* 16(2) pp. 61–85.

Curtin, M. (2021) 'Early Parent Interaction in Deafness'. *BATOD.* January 2021. pp 14-15.

Curtin. M, Dirks. E, Cruice. M, Herman, R. Newman. L, Rodgers. L, & Morgan, G. (2021) 'Assessing Parent Behaviours in Parent-Child Interactions with Deaf and Hard of Hearing Infants Aged 0-3 Years: A Systematic Review'. *Journal of Clinical Medicine*, 10 (15) pp. 1 – 30.

Davis, S. (2021). Conversation with Sarah Davis, 29th October.

Davis, A. and Hind, S. (2016). The Newborn hearing screening programme in England. Volta Review, 110(2), 1117 – 128.

Davis, B., Kowd, E. & Jones, A.L. (2021) Hearing Loss Diagnosis Provision of Information and Support: Audiologist and Parent Perspectives. The Journal of Early Hearing Detection and Intervention, 6(2) pp. 45-61.

Decker, K. B., Vallotton, C. D. & Johnson, H. A. (2012) 'Parents' communication decision for children with hearing loss: sources of information and influence.' *American annals of the deaf*, *157*(4), pp. 326–339. Available at: https://doi.org/10.1353/aad.2012.1631

Decker, K. B. & Vallotton, C. D. (2016) 'Early Intervention for Children with Hearing Loss: Information Parents Receive About Supporting Children's Language', *Journal of Early Intervention*. 38(3) pp. 151–169.

Denscombe, M. (2017) *The Good Research Guide for small-scale research projects*. 6th edn. London: Open University Press.

Eleweke, C.J., Gilbert, S.L., Bays, D. & Austin, E. (2008) 'Information about support services for families of young children with hearing loss: A review of some useful outcomes and challenges.' *Deafness & Education International,* 10(4) pp. 190-212.

Elliott, K., Vears, D. F., Sung, V., Poulakis, Z., & Sheehan, J. (2022) 'Exploring Parent Support Needs during the Newborn Hearing Diagnosis Pathway'. *Journal of clinical medicine*, 11(5) pp. 1- 16.

Foster, T. D., Decker, K. B., Vaterlaus, J. M., & Belleville, A. (2020). 'How early intervention practitioners describe family-centred practice: A collective broadening of the definition'. *Child: care, health and development*, *46*(3) pp. 268–274. Available at: https://doi.org/10.1111/cch.12749

Fitzpatrick, E. Angus, A., Durieus-Smith, A., Graham, I., & Coyle, D. (2008) 'Parents' needs following identification of childhood hearing loss'. *American Journal of Audiology*, 17 (1) pp. 38-49. Available at: https://doi.org/10.1044/1059-0889(2008/005)

Gale., E., Berke, M. Benedict, B., Olson, S., Putz, K. & Yoshinaga-Itano, C. (2021) 'Deaf adults in early intervention programs.' *Deafness & Educational International,* 23(1) pp. 3-24.

Gilbey, P. (2010) 'Qualitative analysis of parents' experience with receiving the news of the detection of their child's hearing loss.' *International journal of pediatric otorhinolaryngology*, *74*(3) pp. 265–270. Available at: https://doi.org/10.1016/j.ijporl.2009.11.01 [Accessed: 14.02.22].

Gilliver, M., Ching, T. Y., & Sjahalam-King, J. (2013) 'When expectation meets experience: parents' recollections of and experiences with a child diagnosed with hearing loss soon after birth.' *International journal of audiology*, *52* (0 2) pp.2–13. Available at: https://doi.org/10.3109/14992027.2013.825051 [Accessed: 15.02.22].

Gray, L. M., Wong-Wylie, G., Rempel, G. R., & Cook, K. (2020) 'Expanding Qualitative Research Interviewing Strategies: Zoom Video Communications'. *The Qualitative Report.* 25(5), 1292-1301. Available at https://nsuworks.nova.edu/cgi/viewcontent.cgi?article=4212&context=tqr [Accessed: 29.12.21].

Hall. M, Hall, W. and Caselli, N. (2019) ‘Deaf children need language, not (just) speech’. *First Language,* March 39 (4) pp. 367 – 395.

Hardonk, S., Desnerck, G., Loots, G., Van Hove, G., Van Kerschaver, E., Sigurjónsdóttir, H. B., Vanroelen, C. & Louckx, F. (2011). ‘Congenitally deaf children's care trajectories in the context of universal neonatal hearing screening: a qualitative study of the parental experiences, *Journal of deaf studies and deaf education*, *16*(3) pp. 305–324.

Hindley, P.A. (2005). ‘Mental health problems in deaf children.’ *Current Paediatrics,* 15, pp. 114-119.

Hintermair, M. (2000) ‘Hearing impairment, social networks, and coping: the need for families with hearing-impaired children to relate to other parents and to hearing-impaired adults.’ *American annals of the deaf*, 145(1) pp. 41–53.

Holzinger, D., Hofer, J., Dall, M., & Fellinger, J. (2022) ‘Multidimensional Family-Centred Early Intervention in Children with Hearing Loss: A Conceptual Model.’ *Journal of clinical medicine*, 11(6) pp. 2-21.

HSC Public Health Agency (2020) *Newborn Hearing Screening in Northern Ireland Annual Report 2018 – 2020.* Available at: Newborn Hearing Screening Annual Report _2018 to 2020.pdf (hscni.net) [Accessed: 04.10.21].

HSC Public Health Agency (2021) *Newborn Hearing Screening Programme.* Available at: Your baby's hearing screen English 0321.pdf (hscni.net) [Accessed: 04.10.22].

Humphries, T., Kushalnagar, P., Mathur, G., Napoli, D. J., Rathmann, C., & Smith, S. (2019) ‘Support for parents of deaf children: Common questions and informed, evidence-based answers.’ *International journal of pediatric otorhinolaryngology*, 118 pp. 134–142. Available at: https://doi.org/10.1016/j.ijporl.2018.12.036 [Accessed: 27.02.22].

Hyde, M., Punch, R. and Komesaroff, L. (2010) ‘Coming to a Decision About Cochlear Implantation: Parents Making Choices for their Deaf Children’. *The Journal of Deaf Studies and Deaf Education*, 15(2) pp 162–178.

Jackson, C.W., Traub, R.J. & Turnbull, A.P. (2008) ‘Parents’ Experiences with Childhood Deafness: Implications for Family-Centered Services’. *Communication Disorders Quarterly*, 29(2) pp. 82-98. Available at: doi:10.1177/1525740108314865

Jackson, C. W., Wegner, J. R., & Turnbull, A. P. (2010). Family quality of life following early identification of deafness. *Language, speech, and hearing services in schools*, *41*(2) pp.194–205. Available at: https://doi.org/10.1044/0161-1461(2009/07-0093)

Jackson, C. W. (2011). ‘Family Supports and Resources for Parents of Children Who Are Deaf or Hard of Hearing.’ *American Annals of the Deaf*, 156(4) pp. 343–362.

Jackson, C. and Vickerstaff, R. (2020) ‘Positive Support for Parents: getting it right from the start.’ *BATOD Magazine*. March 2020 pp. 28-29.

Jamieson, J. R., Zaidman-Zait, A. & Poon, B. (2011) ‘Family Support Needs as Perceived by Parents of Preadolescents and Adolescents Who are Deaf or Hard of Hearing’. *Deafness & Education International,* 13(3) pp.110-130.

Johnston, J.C., Durieux-Smith, A., Fitzpatrick, E.M., O’Connor, A., Benzies, K. and Angus, D. (2008) ‘An Assessment of Parent’s Decision-Making Regarding Paediatric Cochlear Implants’. *Canadian Journal of Speech-Language Pathology and Audiology*, 32(4) pp. 162-182.

Kabir, S.M.S. (2016) ‘Methods of Data Collection’. *Research Gate. Available at* MethodsofDataCollection.pdf [Accessed: 08.04.2022].

Kennedy, C.R., McCann, D.C., Campbell, M.J., Law, C.M., Mullee, M., Petrou, S., Watkin, P., Worsfold, S., Yuen, H.M. & Stevenson, J. (2006) ‘Language ability after early detection of permanent childhood hearing impairment’. *The New England journal of medicine*, 354(20) pp. 2131–2141.

Knoors, H.E.T. & Marschark, M. (2012). Language Planning for the 21st: Revisiting Bilingual Policy for deaf Education. *Journal of Deaf Studies and Deaf Education,* 17 (3) pp. 291 - 305

Levine, D., Strother-Garcia, K., Golinkoff, R. M. & Hirsh-Pasek, K. (2016) 'Language Development in the First Year of Life: What Deaf Children Might Be Missing Before Cochlear Implantation'. *Otology & neurotology,* 37(2), pp. 56–62.

Li, Y., Bain, L., & Steinberg, A. G. (2003). 'Parental decision making and the choice of communication modality for the child who is deaf'. *Archives of pediatrics & adolescent medicine*, 157(2) pp. 162–168.

Lumby, M. (2021) 'From personal experience to building a structured support scheme'. *BATOD*. January 2021. pp. 29-30.

Luterman, D. (2020) 'On Teaching Counseling: Getting Beyond Informational Counseling.' *American Journal of Speech-Language Pathology*, 29(2) pp. 903–908.

Luterman D. (2021) 'Counseling Parents at the Time of Diagnosis: Moving Toward Client-Centered Practice.' *American journal of audiology*, 30(1), pp.

Ma'ayan, A. (2018) 'The role of quantitative linguistic feedback in early intervention for deaf children: using LENA to influence language environments and maternal self-efficacy'. Dissertation. Available at: AMa'ayan2018.pdf (maryhare.org.uk)

Maiden, H. & Keen, P. S. (2018) 'Support from Education Audiologists'. *BATOD.* March 2018. pp. 33-15.

Marschark, M. (2007) 'Raising and Educating a Deaf Child'. New York: Oxford University Press.

Marschark, M. and Hauser, P.C. (2011) How Deaf Children Learn: What Parents and Teachers Need to Know. USA: Oxford University Press.

Marschark, M. & Knoors, H. (2012) 'Educating Deaf Children: Language, Cognition, and Learning'. *Deafness & Education International*, 14(3) pp. 136-160.

Mayberry, A. 2010. 'The Impact of Early identification of Deafness on Hearing Parents'. In Marschark, M. & Spencer, P.E. (ed) *The Oxford Handbook of deaf studies, language and education*, New York: Oxford University Press Inc. pp. 241-250.

Matthijs, L., Loots, G., Mouvet, K., Van Herreweghe, M., Hardonk, S., Van Hove, G., Van Puyvelde, M. & Leigh, G. (2012) 'First information parents receive after UNHS detection of their baby's hearing loss.’ *Journal of Deaf Studies and Deaf Education*, 17(4) pp. 387–401.

Mehta, K. Hilton, E., Baldwin, M., and Watkin, P. (2020) ‘Parent-to-parent support for the families of deaf children identified by the newborn hearing screen’. *Deafness & Education International,* 22(2) pp. 96-112.

Moeller, M.P., Carr, G., Seaver, L., Stredler-Brown, A. & Holzinger, D. (2013). ‘Best practices in family-centered early intervention for children who are deaf or hard of hearing: an international consensus statement.’ *Journal of deaf studies and deaf education*, 18(4) pp. 429–445.

Mouton, B., Loop, L., Stievenart, M. & Roskam, I. (2018) ‘Child differential sensitivity to parental self-efficacy improvement: A micro-trial perspective’. *International Journal of Behavioral Development*, 42(2) pp. 203-213.

Mulla, I. (2021). Conversation with Imran Mulla, 19th June.

Munoz, K., Larsen, M., Nelson, L., Yoho. S & Twohig, M. (2019) ‘Paediatric Amplification Management: Parent Experiences Monitoring Children’s Aided Hearing’. *The Journal of Hearing Detection and Intervention,* 4(1) pp 43-83.

Nelson, H. (2020) Early Years Training for QTODs’. *BATOD Magazine*. March 2020. pp. 31-32.

NDCS (2016a) *Quality Standards: Early years support for children with a hearing loss, aged 0 to 5 (England).* Available at: www.ndcs.org.uk/qualitystandards

NDCS (2016b) *Helping your child to develop communication and language for parents with a 0–2-year-old*. Available at helping-your-deaf-child-to-develop-language-and-communication-0-2.pdf

NDCS (2016) *Right from the Start. A campaign to improve early years support for deaf children*. Available at: right_from_the_start_campaign_report_final.pdf (ndcs.org.uk) [Accessed: 14.10.21].

NDCS (2017) *Emotional well-being and mental health of deaf children and young people position statemen.* Available at: Emotional well-being and mental health of deaf children and young people position statement (ndcs.org.uk) [Accessed: 14.10.21].

NDCS (2020) *Success from the Start; A development resource for families of deaf children aged 0-3.* Available at: www.ndcs.org.uk/successfromthestart

NDCS (2021) *Cochlear Implants*. Available at: Choosing a cochlear implant | Cochlear implants for deaf children (ndcs.org.uk) [Accessed: 24.12.21].

NDCS (2021) *National Deaf Children's Society note on Department for Education figures on attainment for deaf children in 2021 (England).* Available at: ndcs-note-on-attainment-data-2021.doc (live.com) [Accessed: 14.10.21].

Peterson, C.C., O'Reilly, K. and Wellman, H.M., (2016) 'Deaf and hearing children's development of theory of mind, peer popularity, and leadership during middle childhood'. *Journal of experimental child psychology*, 149, pp 146-158.

Porter, A., Creed, P., Hood, M., & Ching, T. (2018) 'Parental Decision-Making and Deaf Children: A Systematic Literature Review'. *Journal of Deaf Studies and Deaf Education*, 23(4), pp. 295–306.

Rodd, C. Craik, E. and Sheils, D. (2020) 'Family Support and Creating Networks'. *BATOD*. March 2020. pp. 20 – 21.

Rowley, K. and Sive, D. (2021) 'Preventing Language Deprivation.' *BATOD Magazine.* November 2021 pp. 32-34.

Russ, S.A., Kuo, A.A., Poulakis, Z., Barker, M., Rickards, F., Saunders, K., Jarman, F. C., Wake, M., & Oberklaid, F. (2004). 'Qualitative analysis of parents' experience with early detection of hearing loss'. *Archives of disease in childhood*. *89*(4) pp. 353–358. Available at: https://doi.org/10.1136/adc.2002.024125

Sass-Lehrer, M. (2004). 'Early detection of Hearing Loss: Maintaining a Family-Centered Perspective'. *Seminars in Hearing*. 25(4) pp. 975-307.

Scarinci, N., Erbasi, E., Moore, E., Ching, T. & Marnane, V. (2018a) 'The parents' perspective of the early diagnostic period of their child with hearing loss: information and support.' *International journal of audiology*, 57(2) pp. 3–14.

Scarinci, N. A., Gehrke, M. J., Ching, T., Marnane, V. & Button, L. (2018b) 'Factors Influencing Caregiver Decision Making to Change the Communication Method of their Child with Hearing Loss.' *Deafness & Education International,* 20(4) pp. 123–153.

Self, B. (2021) ‘Conducting interviews during the COVID-19 pandemic and beyond’. *Qualitative Research*, 22(3) pp. 1-18. Available at: https://www.qualitative research.net/index.php/fqs/article/view/3741

Sharp, J. (2012) *Success with Your Education Research Project*. 2nd edn. London: SAGE publications.

SSC Scottish Sensory Centre (2011) *Scottish standards for deaf children (0-3): Families and professionals working together to improve services.* Available at: scottishstandards.pdf (ed.ac.uk) [Accessed: 25.09.21].

Stewart, V., Slattery, M. & McKee, J. (2020) ‘Deaf and Hard of Hearing Early Intervention: Perceptions of Family-Centred Practice’. *Journal of Early Intervention*, 43(3) pp. 221–234.

Stredler-Brown, A. (2010) ‘Communication Choices and Outcomes During the Early Years: An Assessment and Evidence-Based Approach’. In Marschark, M. & Spencer, P.E. (ed) *The Oxford Handbook of deaf studies, language and education*, New York: Oxford University Press Inc. pp. 292-315.

Thomas, G. (2013) *How to do your Research Project*. London: SAGE publications.

Thomas, A.E & Marvin, C. A. (2016) ‘Program Monitoring Practices for Teachers of the Deaf and Hard of Hearing in Early Intervention’. *Communication Disorders Quarterly*, 37(3) pp. 184-193.

Tracey, D., Johnston, C., Papps, F.A. & Mahmic, S. (2018) ‘How do parents acquire information to support their child with a disability and navigate individualised funding schemes?’ *Journal of research in special educational needs.* 18(1) pp. 25.35. Available at: https://doi.org/10.1111/1471-3802.12390

Tracy, S. (2019) *Qualitative Research Methods: Collecting Evidence, Crafting Analysis, Communicating Impact*. 2nd edn. Newark: John Wiley & Sons.

Walliman, N. (2018) Research methods: the basics. 2nd ed. London: Routledge.

Watson, L.M., Hardie, T., Archbold, S.M. & Wheeler, A. (2008) ‘Parents' Views on Changing Communication After Cochlear Implantation.’ *The Journal of Deaf Studies and Deaf Education*, 13 (1) pp. 104–116.

Wright, B., Hargate, R., Garside, M., Carr, G., Wakefield, T., Swanwick, R., Noon, I. & Simpson, P. (2021). 'A systematic scoping review of early interventions for parents of deaf infants.' *BMC paediatrics*, 21(1) pp. 1-13.

Young, A. & Tattersall, H. (2005) 'Parents' of Deaf Children Evaluative Accounts of the Process and Practice of Universal Newborn Hearing Screening'. *Journal of Deaf Studies and Deaf Education*, 10(2) pp. 134–154.

Young, A., & Tattersall, H. (2007) 'Universal newborn hearing screening and early identification of deafness: parents' responses to knowing early and their expectations of child communication development.' *Journal of Deaf Studies and Deaf education*, 12(2), pp. 209–220.

Young, A., Gascon-Ramos, M., Campbell, M. & Bamford, J. (2009). 'The design and validation of a parent-report questionnaire for assessing the characteristics and quality of early intervention over time'. *Journal of deaf studies and deaf education*, 14(4) pp. 422–435.

Young, A. (2010) 'The Impact of Early Identification of Deafness on Hearing Parents'. In Marschark, M. & Spencer, P.E. (ed) *The Oxford Handbook of deaf studies, language and education*, New York: Oxford University Press Inc. pp. 241-250.

Yoshinaga-Itano C. (2003). 'From Screening to Early Identification and Intervention: Discovering Predictors to Successful Outcomes for Children with Significant Hearing Loss'. *Journal of deaf studies and deaf education*, 8(1) pp. 11–30.

Yoshinaga-Itano, C. (2014) 'Principles and Guideless for early intervention after confirmation that a child is deaf or hard of hearing'. *Journal of Deaf Studies and Deaf Education*, 19(2) pp.143 – 175.

VanDam, M., Ambrose, S.E. & Moeller, M.P. (2012) 'Quantity of Parental Language in the Home Environments of Hard-of-Hearing 2-Year-Olds'. *The Journal of Deaf Studies and Deaf Education*, 17(4) pp. 402–420.

Vogl, S. (2013) 'Telephone versus face-to-face interviews: Mode effect on semi structured interviews with children'. *Sociological Methodology*. *43*(1) pp. 133-177.

Zaidman-Zait, A. (2007) ‘Parenting a Child with a Cochlear Implant: A Critical Incident Study.’ *The Journal of Deaf Studies and Deaf Education*, 12 (2) pp. 221–241.

Appendices

Appendix A – Ethics Approval

SOCIAL SCIENCES, ARTS AND HUMANITIES ECDA

ETHICS APPROVAL NOTIFICATION

TO Lauren Millar

CC Dr. Joy Rosenberg

FROM Dr Ian Willcock, Social Sciences, Arts & Humanities ECDA Chair

DATE 28/10/2021

Protocol number: **EDU/PGT/CP/05279**

Title of study: Early Intervention for Deaf children 0-3 years in Northern Ireland: An investigation into the experiences of parents during the initial period of intervention.

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

no additional workers named

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

Permissions: Any necessary permissions for the use of premises/location and accessing

participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

Submission: Students must include this Approval Notification with their submission.

Validity:

This approval is valid:

From: 28/10/2021

To: 18/12/2021

Please note:

Failure to comply with the conditions of approval will be considered a breach of protocol and may result in disciplinary action which could include academic penalties. Additional documentation requested as a condition of this approval protocol may be submitted via your supervisor to the Ethics Clerks as it becomes available. All documentation relating to this study, including the information/documents noted in the conditions above, must be available for your supervisor at the time of submitting your work so that they are able to confirm that you have complied with this protocol.

Should you amend any aspect of your research or wish to apply for an extension to your study you will need your supervisor's approval (if you are a student) and must complete and submit form EC2.

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1A. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.

Failure to report adverse circumstance/s may be considered misconduct.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately.

Appendix B - Ethics Consent Form

UNIVERSITY OF HERTFORDSHIRE

ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS

('ETHICS COMMITTEE')

FORM EC3 CONSENT FORM FOR STUDIES INVOLVING HUMAN PARTICIPANTS

I, the undersigned *[please give your name here, in BLOCK CAPITALS]*

…….…

of *[please give contact details here, sufficient to enable the investigator to get in touch with you, such as a phone number or email address].*

…..………………………………………………………………………………………………………

hereby freely agree to take part in the study entitled

Early Intervention for Deaf children 0-3 years in Northern Ireland: An investigation into the experiences of parents during the initial period of intervention.

(UH Protocol number **EDU/PGT/CP/05279**)

1 I confirm that I have been given a Participant Information Sheet (a copy of which is attached to this form) giving particulars of the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on this form will be stored and for how long. I have been given details of my involvement in the study. I have been told that in the event of any significant change to the aim(s) or design of the study I will be informed, and asked to renew my consent to participate in it.

2 I have been assured that I may withdraw from the study at any time without disadvantage or having to give a reason.

3 In giving my consent to participate in this study, I understand that voice, video or photo-recording will take place and I have been informed of how/whether this recording will be transmitted/displayed.

4 I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used, including the possibility of anonymised data being deposited in a repository with open access (freely available).

5 I understand that if there is any revelation of unlawful activity or any indication of non-medical circumstances that would or has put others at risk, the University may refer the matter to the appropriate authorities.

6 I have been told that I may at some time in the future be contacted again in connection with this or another study.

Signature of participant…………………………………..…Date…………………………

Signature of (principal)
investigator……………………………………………………Date…………………………

Name of (principal) investigator: *LAUREN MILLAR*

Appendix C – Participant Information Sheet

UNIVERSITY OF HERTFORDSHIRE

ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS ('ETHICS COMMITTEE')
FORM EC6: PARTICIPANT INFORMATION SHEET

1. Title of study

Early Intervention for Deaf children 0-3 years in Northern Ireland: An investigation into the experiences of parents during the initial period of intervention.

2. Introduction

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University's regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link:

https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs

(after accessing this website, scroll down to Letter S where you will find the regulation)

Thank you for reading this.

3. What is the purpose of this study?

The research aims to explore parents' experiences and perspectives from the identification of their child's deafness and the early intervention provided until entry into Nursery. To investigate the support the families are receiving with the aim that the evidence gathered will inform future professional practice.

4. Do I have to take part?

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form.

Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a reason.

5. Are there any age or other restrictions that may prevent me from participating?

You must be a parent of a deaf child (ren) aged 0 - 6 and have gone through/or going through the early identification and intervention process within Northern Ireland.

6. How long will my part in the study take?

If you do decide to take part in this study, you will take part in an informal interview either online or face to face, it will not take more than one hour. Your views will be video recorded and then analysed at a later time.

7. What will happen to me if I take part?

A mutually convenient time will be arranged for the interview to take place, either in the home or via Microsoft Teams, depending on the participant preference and taking into consideration of the changing covid situation.

8. What are the possible disadvantages, risks or side effects of taking part?

The disadvantage if you agree to participate is, if you have had negative experiences during the identification of your child's deafness and/or in the early intervention process you will revisit these memories.

9. What are the possible benefits of taking part?

To share your experiences and insight from when your child was identified as being deaf and the early intervention process in Northern Ireland. The information gathered can be used to inform better future practices for young deaf children and/ to identify any gaps between the parents' perceptions of what they need and the service as it currently operates.

10. How will my taking part in this study be kept confidential?

Your name will be anonymised so that you cannot be identified. The consent forms obtained from you and video recordings of our interviews will be kept securely and confidentially in password-protected electronic storage.

11. Audio-visual material

If you participate in the interviews in your home environment or online using Microsoft Teams, it will be recorded to aid the transcription of the answers given. The video recordings will not be shared with anyone.

12. What will happen to the data collected within this study?

The data collected will be stored electronically, in a password-protected environment, for 9 months, after which time it will be destroyed under secure conditions. The data will be anonymised prior to storage.

13. Will the data be required for use in further studies?

The data will not be used in any further studies.

14. Who has reviewed this study?

This study has been reviewed by:

The University of Hertfordshire Social Sciences, Arts and Humanities Ethics Committee with Delegated Authority

The UH protocol number is <**EDU/PGT/CP/05279**>

15. Factors that might put others at risk

Please note that if, during the study, any medical conditions or non-medical circumstances such as unlawful activity become apparent that might or have put others at risk, the University may refer the matter to the appropriate authorities and, under such circumstances, you will be withdrawn from the study.

16. Who can I contact if I have any questions?

If you would like further information or would like to discuss any details personally, please get in touch with me by email: Lauren Millar, *Lauren.Millar@eani.org.uk*

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar

University of Hertfordshire

College Lane

Hatfield

Herts

AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study.

Appendix D – Risk Assessment Form

UNIVERSITY OF HERTFORDSHIRE
ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS (‘ETHICS COMMITTEE’)

FORM EC5 – HARMS, HAZARDS AND RISKS:
ASSESSMENT AND MITIGATION

Name of applicant: Lauren Millar

Date of assessment: 26.10.2021

Title of Study/Activity: Early Intervention for Deaf children 0-3 years in Northern Ireland: An investigation into the experiences of parents during the initial period of intervention.

If you are required to complete and submit a School-specific risk assessment (in accordance with the requirements of the originating School), it is acceptable to make a cross-reference from that document to form EC5 in order not to have to repeat the information twice. The purpose of Form EC5 is to consider how a participant might react to the activities in the study and to indicate how you will manage such reactions; the Form also addresses the safety of the investigator and how any risks to the investigator will be managed.

Activity Description					
1. IDENTIFY RISKS/HAZARDS	2. WHO COULD BE HARMED & HOW?		3. EVALUATE THE RISKS		4. ACTION NEEDED
Contracting Covid-19 Spreading Covid-19 to child, parents, co-workers, other pupils and into the wider community.	Me (the researcher) Co-workers Parents Children Wider community	How could they be harmed? Develop Covid-19 symptoms. Isolate for 10 days.	Are there any precautions currently in place to prevent the hazard or minimise adverse effects? Education Authority Northern Ireland Sensory Service risk assessments for home visits as part of the researcher’s day to day	Are there any risks that are not controlled or not adequately controlled?	**At the moment in Northern Ireland, visiting other people’s homes is allowed. Constantly check and read the updated government guidelines regarding home visits.** **Prior to a face to face interview the following measures must be conducted:** Ensure that informed consent has been given, i.e., check with parents that they (and the child) are happy for the visit to take place. If parents wish not to do the interview in the homes, offer online interviews via Zoom. The researcher has confirmed with the parents within 24 hours before the visit that the child is healthy and that nobody within the

			job as a peripatetic teacher of the deaf. Follow the current government guidelines regarding Covid.		household is showing any symptoms. If the child or anyone in their household has symptoms, is self-isolating or awaiting the result of a Covid-19 test, **postpone your visit or do online interviews via TEAMS instead.** **When doing home visits:** Carry anti-viral wipes, tissues and hand sanitiser. Interview in a well-ventilated room which has not been in recent use and/or has been cleaned using anti-viral materials since its most recent occupants. Wash or sanitise hands on entering and leaving the homes. Leave all bags coats and other materials not essential to the interview in your vehicle. **<u>Face to face interviews</u>** • Carry anti-viral wipes, tissues and hand sanitiser. • Interview in a well-ventilated room, leaving the room door and windows open. • Ensure that appropriate distancing arrangements are facilitated. • Wash or sanitise hands on entering and leaving the homes. • Avoid sharing resources. • Take care not to touch your face. Re-sanitise hands when this happens. After the interview has been carried out: • Ensure parent has a record of your visit along with your contact number, in the event that anyone in their household tests positive for covid-19 within the next 10 days. • Inform parents if you have been contracted Covid within the 10 days after the interview. • Wipe down all equipment (video recording equipment) which have been used during session using **anti-bacterial wipes or spray containing minimum 60%alcohol**.

Signed by applicant: Lauren Millar	Dated: 26.10.21

Appendix E - Semi-structured Interview schedule

Can you share about the initial identification period? What impact did fining out that your child was deaf have on you and your family?

What kind of emotional support did you receive initially and during ……'s early years?

What information did you receive about deafness?

What were the different communication options given and what influenced your decision?

What/which professionals have given you support?

Did you receive information and support about parent-child interaction? (How to communicate/play with your child and how to encourage your child's communication skills).

What assessments were used to progress your child's development and how often was it used?

Did you feel involved in the early intervention process?

Personal evaluation

Can you share two good experiences of the support you received during the Early Intervention period for your child? Did you get what you needed from the service?

If you could change something to make the service better for parents and child in the early years what would you change?