

Exploring Irish Travellers' Perspectives on Accessing Audiology Services

A study submitted in partial fulfilment of the requirements for the
degree of Master of Science of the University of Hertfordshire

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May 2017

Acknowledgements

I would like to thank the following people without whom this research project would not have been possible

My supervisor, Joy Rosenberg, for the initial lecture that prompted the research question and for her guidance and direction throughout the project.

My husband, Sean, for his unfailing support in all my mad endeavours.

My children Aoife, Liam and Euan for their patience, support and willingness to eat junk food for the duration.

The Traveller families who kindly shared their experiences with me.

My Visiting Teacher colleagues for their help with data collection.

Dedication

This work is dedicated to the memory of my much loved and much missed parents, Gus and Mary Naughton; R.I.P. My first teachers. Thank you for everything.

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Word count (excluding references, tables and preliminary pages: 12,832

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Abstract

This study qualitatively explores the experiences of Irish Traveller families in attending paediatric audiology appointments. The aim of the study was to establish the underlying causes for a perceived high rate of 'Did Not Attends' (DNAs) among this ethnic minority as anecdotally reported by the professionals who work with them. A semi-structured interview method was used to collect responses from three families of Irish Travellers whose children were on the Active Caseload of the Visiting Teacher Service for the Hearing Impaired in the Republic of Ireland. Results indicated recurring themes expressed by these families as being barriers to their attendance at appointments. These included family and kinship ties, transport issues and the timing of appointments, appointment clashes and illness; either parental or on the part of the children. A secondary aim of this study was to establish if these obstacles to the uptake of offered appointments were due to cultural factors or other factors such as socio-economic disadvantage. The findings in this latter area were dominated by the importance of familial ties and kinship. Recommendations to promote increased uptake of offered appointments are also outlined.

1. Introduction

1.1 Background

In Ireland, the rate of missed appointments in our hospitals runs at 15%, or one in six patients, who do not attend their appointments and give no prior notice. 'Patients failed to show for 139,000 of 923,000 new appointments made, and for 349,000 of 2,375,000 return appointments, the figures from the Health Service Executive revealed'. Concurrently there are at least 530,000 people on inpatient, outpatient or daycase waiting lists (Cullen, 2016). A study by NHS Scotland, in March 2015, put the figure at almost 10% for all first time outpatient appointments between 2002/03 and 2011/12 (NHS Health Scotland, 2015). In the UK the rate of missed appointments stands at 4.5%-6.5% of booked consultations (Neal et al, 2005). According to Husain-Gambles et al (2004), 'People who miss appointments were viewed negatively by primary care staff, and most of the reasons for missed appointments were focused on patients'. In my opinion, this unfavourable attitude to patients who miss appointments is of even greater concern than the costs involved to the service providers over missed appointments. This study focusses on a minority population in Ireland, namely, Irish Travellers and is predicated on a belief that there are cultural reasons for the perceived high rate of missed appointments among Irish Traveller families. Irish Travellers are an indigenous minority and make up just 0.6% of the total population of the Republic of Ireland. Family sizes tend to be large and there appears to be a higher rate of hearing loss among this ethnic minority than in the settled, non-nomadic community (AITHS, 2010). However, this perception is not corroborated by census data, where the rate of deafness in both the settled and nomadic populations is 2%. (CSO, 2012)

This chapter sets out to give an overview of audiology services for children within a national Irish context, outlining the structure of hospital and community audiology services and their interaction with the Neonatal Hearing Screening Programme (NHSP). It also outlines how the Visiting Teacher Service for Hearing Impaired children (VTHI) works alongside Audiology Services to offer support to the families of children diagnosed with Permanent Childhood Hearing Impairment.

1.2 The Irish context

In Ireland, Health Service Executive (HSE) audiology services are delivered by two distinct services: Acute Audiology services based in hospitals and Community Audiology services based in clinics around the country. This dichotomy has arisen from the historical development of audiology services. For many years audiological services were provided by the National Rehabilitation Board (NRB). There were very few, if any, hospital-based services around the country. Local Ear, Nose and Throat (ENT) Consultants would refer patients for audiological assessment to NRB. The NRB provided both paediatric and adult hearing aids. They also provided ear-mould and hearing aid repair services.

Beginning in the 1970s, hospital based audiology departments slowly developed around the country, largely led by the efforts of individual ENT consultants who required a local diagnostic service (HSE, 2011). Today audiologists in hospitals support the work of the ENT clinics, providing audiological assessment for adults and children who have been referred to ENT with possible hearing or balance problems (HSE, 2011). The NHSP was rolled out in 2013 and screening is now provided for all infants born in the hospital maternity departments around the country. Most of the initial testing of neonates under Automated Brainstem Response (ABR) is carried out by the Acute Audiology departments of hospitals around the country. Very little early assessment is carried out in Community Audiology clinics. Once diagnosed with a hearing loss a child is then referred to Community Audiology for further audiological assessment and the provision of hearing aids. They are also referred to the Visiting Teacher Service.

1.3 Visiting Teacher of the Hearing Impaired Service

The Visiting Teacher of the Hearing Impaired (VTHI) is a service provided by the Department of Education and Skills in Ireland to 'children who are deaf/hard of hearing'. The service offers longitudinal support to children, their families and schools from the time of referral through to the end of post-primary education (DES, 2014). Each VTHI is responsible for a particular region and is allocated a caseload of pupils (NCSE, 2014). The role would be similar to that of a peripatetic Teacher of the Deaf in the UK. In 2014, the VTHI service was involved in

supporting 2,700 children with Permanent Childhood Hearing Impairment (NCSE, 2014).

1.4 Outline of chapters

Chapter 2 will review a selection of the literature relevant to this topic, focussing on how various ethnic minorities in different countries interact with health services.

Chapter 3 will describe the methodology used, including ethics, reasons for the choice of methodology and selection of participants. It will describe the qualitative and quantitative methods used.

Chapter 4 will detail the results of the data collection.

Chapter 5 will discuss the findings of this study including the strengths and weaknesses therein and make recommendations for the future.

2. Literature Review

2.1 Introduction

This chapter examines the possible origins of the Travelling people in Ireland and the culture and ethnicity of this minority group is explored. A review of the literature pertaining to this population's interactions with services and in particular, health services is carried out and presented as the background against which this current study has taken place. This review aims to locate the study within the context of existing research in this area while noting that the particular question of why Travellers are perceived by professionals as missing more appointments than non-nomadic people has never been directly addressed. The literature search began with broad strokes i.e. by carrying out web based searches using key words such as 'Irish Traveller', 'culture', 'health studies'. Over time this approach was fine-tuned as it was noted that a lot of the research in this area tended to appear in academic journals that focussed on social studies and health studies. Needing resources specific to the Irish context, inter-library loans were arranged to source books on Irish Traveller culture in special collections around the Republic of Ireland.

2.2 Origins

Historically Irish Travellers are considered to have lived on the island of Ireland for centuries. There are many theories about their origins but no agreement. The most common theory is that Irish Travellers descended from people who lost their land at the time of the Great Irish Famine in 1845. This point of origin tends to lead to the representation of Irish Travellers as 'failed settled people' (McDonagh, M., in Sheehan, 2000), and (Ní Shúinéar, in McCann et al, 1994) or as 'broken country people' and is strongly rebutted by the Travelling community themselves (The Travellers, 2016). An examination of the genetic makeup of Irish Travellers by researchers Wilson and Cavalleri identified the fact that Travellers have 'shared heritage with settled people but "separated" at some point between 1,000 and 2,000 years ago"(Coyle, 2011). A recent study undertaken by a group of Irish Travellers in association with academics at the National University of Ireland suggests that Travellers are descended from the original tribes of Ireland, royalty or the 'derbfine' (The Travellers, 2016).

2.3 Identity and Ethnicity

According to Cleemput (2007) Travellers and Gypsies in the UK and Wales were recognised by the Court of Appeal as a distinct ethnic grouping in 1988. The Irish Traveller Movement describes the Irish situation regarding the question of ethnicity as problematic. In 1995 the Task Force on the Travelling Community reported, and it recommended that 'the distinct culture and identity of the Traveller community be recognised and taken into account' (Task Force Executive Summary, 1995).

In 2000 the Irish government passed the Equal Status Act and defined the travelling community, for the purpose of one of the grounds under which discrimination should not occur, in the following manner:

'The community of people who are commonly called Travellers and who are identified (both by themselves and others) as people with a shared history, culture and traditions including historically a nomadic way of life on the island of Ireland'.

In April 2014, the Houses of the Oireachtas Joint Committee on Justice, Defence and Equality published their report on the Recognition of Traveller Ethnicity and concluded

'That either the Taoiseach or the Minister for Justice and Equality make a statement to Dáil Éireann confirming that this State recognises the ethnicity of the travelling community'.

Until as recently as March 1st, 2017 this recognition still had not come and Ireland as a nation was in contravention of the UN Convention on Human Rights. There also existed the anomaly that in Northern Ireland, Irish Travellers had been recognised as a separate racial group by specific legislation i.e. Article 5(2) (a) of the Race Relations (Northern Ireland) Order 1997. Thus we had the situation that depending on where you lived on the island of Ireland, as a Traveller you may or may not have had your membership of a distinct ethnic minority recognised by the government. As the data collection for this study was conducted in the Republic of Ireland in January and February of 2017, the Irish Travellers included

in the study were not at that time considered by government to have a distinct culture or ethnicity.

In the course of carrying out the data collection it became clear to me that issues of ethnicity had very little meaning for the ordinary Irish Traveller. In fact the concept had to be explained at each interview. There appears to be a disconnect between the views of the Travellers I interviewed and the views expressed by political figures within Traveller organisations and movements. The whole concept of 'ownership' of Traveller ethnicity should be researched in much greater depth than was possible during this project.

2.4 The importance of Irish Traveller ethnic recognition

For Traveller people as a community, recognition of a separate distinct ethnicity of their own should mean that cultural difference would be 'understood', 'valued' and 'taken into account at the point where services are delivered to the Traveller community' (Irish Traveller Movement, 2011). I would echo the thoughts of Roseleen Mc Donagh in her response to the announcement of ethnic recognition by the Taoiseach, Enda Kenny (The Irish Times, 2017),

Traveller ethnicity means feeling pride and confidence, having the strength to hold your head up, put your shoulders back and believe that dreams and expectations can be chased.

I would like to see a growth in confidence among Irish Travellers and a feeling that they are of worth. I believe that this recognition would contribute greatly to greater inclusion and understanding between the two groups in Irish society.

2.5 Blueprint for ethnicity and my personal view

Ní Shúinéar in McCann (1994) and McDonagh, M. in Sheehan (2000) both make reference to a definition of what constitutes an 'ethnic group' as first proposed by Frederick Barth, in 1970.

"The term 'ethnic group' is generally understood in anthropological literature to designate a population which is biologically self-perpetuating, shares fundamental cultural values realised in overt unity of cultural form, makes up a field of communication and interaction, and has a population which defines itself, and is defined by others, as

constituting a category distinguishable from other categories of the same order....The itemised characteristics imply: racial difference, cultural difference, social separation, language barriers, and spontaneous and organised enmity”.

I would agree with both Ní Shúinéar (1994) and McDonagh, M. (2000) in their assertion that Irish Travellers meets the criteria of a separate ethnic minority for the following reasons:

- They form a community that is ‘biologically self-perpetuating’ in that the members of the community for the most part, marry within the group
- Membership of the group is predicated on whether at least one parent is an Irish Traveller
- A field of communication and interaction in that Travellers have their own language called ‘Gammon’ or ‘Cant’ or in academic works ‘Shelta’
- Self-ascription and ascription: by which is meant that Travellers refer to themselves as such and are in turn referred to by outsiders as such
- Shared cultural values including but not limited to nomadism, priority of kinship obligations and self-employment

2.6 Population statistics

2.6.1 Census information

The most recent census of the Irish people was carried out in April 2016. A detailed profile of the Irish Traveller population is not due to be published until October 2017. For this reason I will be using data from the 2011 census to inform this study. Based on my own data collection, I would expect an increase in population to have occurred in this ethnic grouping. The total number of Irish Travellers as found in April 2011 was 29, 573 or 0.6% of the total population of Ireland which at that time was 4.5 million. This represents an increase from 2006 of 32% when the Traveller population was enumerated as 22, 435. (Central Statistics Office, 2011) The Irish Traveller community was unevenly distributed across the country with the highest number of Irish Travellers, outside of the capital, living in County Galway (4,143 persons). It is no coincidence that this is the county in which this researcher also lives and works. More than 80% of Irish

Travellers live in an urban area. By comparison this number is 62% for the settled population.

2.6.2 Disability in the Irish Traveller population

The 2011 Census carried out in April of that year, found that the population of Ireland was 4,588,252. It also revealed that a total of 595,335 persons, accounting for 13% of the population, had a disability. A total of 92,060 people or 2% of the Irish population were Deaf or had, what the Census termed, 'a serious hearing impairment'. The number of people within the Irish Traveller population who report that they had a disability in 2011 was 5,169 of which 535 stated that they had 'deafness or a serious hearing impairment'. Subtracting the Traveller data from the data on the general population we find that the amount of deafness reported in the settled population is 91,525 persons (Central Statistics Office, 2011) or 2% of the non-Traveller population. By inference interactions between Travellers and audiology services in hospitals or the community are worthy of study and analysis, particularly so when the anecdotal evidence from the professionals involved suggests a high Did Not Attend (DNA) rate among this population. This research is concerned with attempting to establish whether this perception of non-attendance is a true reflection of the situation. It also sets out to understand why this might be the case with the aim of making suggestions for future improvements in this area.

2.7 Traveller Health studies

In looking at what is already known about this subject I began with reports of large research studies on the health of minority populations (Cleemput, 2007; AITHS, 2010). These were mainly concerned with collecting data on a population that was largely under-represented in the literature. By definition the reports from these studies tended to run along large thematic lines such as overall mortality rates or ratings of the quality of health care received. While each report noted that attention should be paid to cultural influences, none of these larger studies went into sufficient detail as to what this meant. Turning to smaller scale studies provided more insight into what these cultural beliefs, traditions or practices might be. However, it should be noted that these studies may have less generalisability.

2.7.1 Large scale studies in Ireland

In 2010 an innovative large scale health study of the Traveller population was undertaken by the Health Service Executive (HSE) in the Republic of Ireland (ROI). It was unique in a number of ways; firstly, it was carried out in both Northern Ireland (NI) and the Republic of Ireland at the same time and secondly, its methodology. The latter involved the training of Peer Researchers to carry out qualitative interviews with Traveller families throughout the island of Ireland. The All Ireland Traveller Health Study (AITHS, 2010) carried out interviews with 8,492 Traveller families; 7,042 in ROI and 1,450 in NI. The study enquired into a number of themes: Vital Statistics and Mortality, Birth Cohort and Travellers in Institutions. Of particular interest to this research work was the investigation of how Travellers interact with Services. While it does not specifically mention Audiology as one of the services surveyed, I believe the findings are applicable across many services.

Researchers for AITHS asked about the 'Interface between Travellers and Services' (p.149) and found that overall Travellers were less likely than other patients to use and access their service. The services included GP, Dentist, Hospital, Mental Health services among others. Respondents thought that Travellers were about as likely (43.6%) or less likely (35.0%) to understand how to use their service. Another question was how respondents felt Travellers understood how to access a particular health service. 43.8% of respondents rated Travellers as about as likely to understand as others and 27.3% felt this group would be less likely. This was the same for both jurisdictions, Northern Ireland and Republic of Ireland.

One finding in particular is of greater interest to the current study than all others. Travellers were considered less likely (51.0%) or much less likely (15.3%) than others to keep appointments. There was no significant difference by jurisdiction in the likelihood of Travellers keeping appointments compared with others. Respondents considered Travellers to be less likely (41.6%) or much less likely (10.7%) than other patients to be on time for appointments and there was no significant difference according to jurisdiction or professional grouping of respondents (AITHS, 2010, p.145).

Cultural factors were rated as important (83.5%) by respondents overall. Just one respondent in the survey thought culture was not important. A clear majority of

respondents in both jurisdictions (84.1% ROI and 79.2% NI) and across professional groupings thought culture important or very important, not significantly different in any category. Unfortunately the report does not discuss which 'cultural factors' they are referring to or if it is a generalised idea of Travellers having a different culture than non-Travelling people. Perhaps what they mean is ethnicity and not culture. In any case, there is not enough information for this researcher to decide exactly what is meant by 'cultural factors'.

2.7.2 Large scale studies of Travellers and Gypsies in the UK

In the UK, Van Cleemput (2007) carried out a PhD study into how Gypsies and Travellers access health care services there. She interviewed twenty seven Travellers and examined this group's interactions with health staff. She sought to investigate the beliefs and attitudes of this ethnic grouping that may be influencing how they avail of health services. She refers to a pattern of missed appointments within this population as being indicative of a lack of understanding of the cultural and socio-economic influences that impact on this ethnic minority by 'Gorgers' or settled people. In contrast to my belief that these missed appointments are due to cultural influences, Van Cleemput appears to lean more towards a belief that poor communication between Gypsies and Travellers and health service staff is a major contributing factor to poor engagement with services.

Parry et al (2007) reported on research carried out into the health status of Gypsies and Travellers in England. There were 293 participants in this study. Parry et al concluded that there were 'significant health inequalities between the Gypsy and Traveller population in England even when compared to other socially deprived or excluded groups, and with other ethnic minorities'. Bearing in mind that the research was funded by the Department of Health and the report was written with the intention of influencing policy, they felt it prudent to point out that the health-related behaviours of this group are founded on 'strong ethnic identity and coherent cultural beliefs and attitudes'.

2.7.3 Large scale study in Hungary

Voko et al (2009) conducted a comparative health survey on a representative sample of the Hungarian population and people living in Roma settlements which

involved 5,072 participants. The Roma people are an ethnic minority and are similar to Irish Travellers in that they are nomadic but their origins differ (Pavee Point, 2015). Voko et al claim that 'the association between ethnicity and health is well established'. However, they go on to state that 'interpreting ethnicity as an independent determinant of health is a simplification, present knowledge of the complex causal network of ethnicity, socioeconomic status, health behaviour, environment and health status is rather limited'. Voko et al found that socio-economic status fully explained their worse health status but only partially determined their less healthy behaviours. A variable to be considered was the role played by Roma traditions and culture in determining their health status. They proposed that 'the only productive way forward is through studies that recognise the contingency of the relations between socioeconomic position, ethnicity, and particular health outcomes'. I disagree that socio-economic status could 'fully explain' their worse health status. Voko himself acknowledges that the 'health behaviours' of this ethnic minority are influenced by other variables such as Roma tradition and culture.

2.7.4 Small scale studies in Ireland and the UK

In the United Kingdom, Gypsies and Travellers are 'known to have poorer health status and a higher risk of mortality than socio-economically matched comparison groups and to experience health inequalities which are greater than could be expected simply from socio-economic disadvantage or from belonging to a minority ethnic group (Condon and Salmon, 2014). This study focussed on the views of twenty-two Gypsy and Traveller mothers to infant feeding and found that there were three common cultural influences on infant feeding behaviour; the importance of family, beliefs and traditions related to culture, and a travelling lifestyle. A fourth theme, that of interaction with health professionals, underpinned all the others but was not a cultural phenomenon. In addition to the cultural findings in this study, what particularly interested me was the inclusion of grandmothers in the purposive sample. As Travellers tend to marry young, another generation would give access to differing attitudes across time. Their average ages across the Irish Traveller, English Gypsies and Roma groupings ranged from 43-55 years. Subsequent to this I decided to include a generational

element in my study but was only successful in recruiting one grandmother to take part.

A small scale study in Ireland in which nine ethnic minority participants with disabilities were interviewed took place in 2002. This study was carried out by the Equality Authority and was reported on as 'Minority Ethnic People with Disabilities in Ireland: Situation, Identity and Experience' by Pierce in 2003. The group of people identified to be part of this study stand at the 'intersection of two minorities' being part of an ethnic minority group and also having a disability. It should be noted that this study did not confine itself to people with a diagnosis of deafness. The participants in the research had a number of different disabilities including physical, intellectual and sensory difficulties. The study acknowledges that 'little is known about the incidence of disability among minority ethnic communities in Ireland'. It points out that this statement is true both for 'Ireland's largest indigenous minority ethnic community, the Traveller community, and Ireland's newly emerging minority ethnic communities'. Pierce also states that "Travellers with disabilities may suffer from being an almost invisible sub-group within the Travelling Community". This study introduced me to the concept of institutional racism which describes

'a situation where things are done in a way that assumes that all clients are from the same cultural, ethnic and linguistic background as the rest of the white majority population' (Baxter, 2003)

It is my belief that there may be institutional racism at play in relation to how services are delivered to Travellers. A number of years ago, I was present when clinic lists were being prepared for the coming weeks and overheard a secretary comment as he scanned a list of names that he would 'not bother offering X an appointment because they would not turn up anyway'. The family in question was from an Irish Traveller background. This situation bears striking similarities to some described by Bowler (1993) in which she describes a small ethnographic study carried out into midwives' attitudes to Asian women. Though this is now an old study I believe it still resonates today in particular in relation to Bowler's assertion that 'There is evidence that ethnicity is a powerful criterion for typification made stronger by its very visibility'. To an Irish person, a person who

is a member of the Irish Travelling community is immediately recognisable. While in the maternity hospital after giving birth to my youngest child, I shared a large ward with a number of mothers of various ethnicities. Comments overheard from midwives at that time (2011) would suggest that cultural typification of patients was still occurring e.g. 'Of course that baby has a low birth weight. These young Traveller women never give up smoking during pregnancy'.

In 2004 a study exploring the views of Irish Travellers and palliative care staff was conducted by McQuillan and Van Doorslaer. The views of both service providers and Travellers were obtained on their experiences of giving and receiving palliative care. A total of sixteen service providers were involved in focus group discussions and a further 215 staff were surveyed by questionnaire. The study does not give the total number of Traveller participants and instead refers to 'five groups agreeing to take part in the research'. As might be expected clinical staff and Travellers identified different barriers to palliative care. In the case of the former they found that poor appointment keeping and poor follow-up were areas of difficulty. On the other hand a key theme identified by Travellers was the importance of hope and its impact on how Travellers deal with health care. According to McQuillan and Van Doorslaer 'this need for hope contributed in the Travellers' view to avoidance of cancer, delayed diagnosis, avoidance of hospice admission and avoidance of open discussion of serious illness and death, in the belief that loss of hope will hasten the patient death'. It is my contention that there is an element of this thinking to be found in Traveller interactions with Audiology services. I believe that Travellers are very influenced by superstition and feel that to name an illness is bad luck. For the purposes of this discussion, I am defining hearing loss as an 'illness'.

Contrary to this view, a small scale feminist research project into thirteen Traveller women's experiences of maternity care in the Republic of Ireland (Reid and Taylor, 2007) found that 'cultural perspectives are the surface causes of existing inequities'. The authors themselves point out that it may be wise to 'avoid generalising unduly'. They found that Traveller women's maternity care experiences were not always culturally appropriate as in the case of the promotion of breast feeding as the 'better' option for infant feeding and the participation of husbands during antenatal classes, labour and delivery. These

practises were 'culturally unacceptable for Traveller women' (Reid and Taylor, 2007). While this study goes into some detail on the ways in which Traveller culture affects participation with maternity services, it did not look in particular at appointment keeping.

My own perspective on this topic and the catalyst for this research is that there are underlying cultural reasons which are as important as issues of a practical socio-economic nature or poor communication practises, in leading to missed appointments and DNAs within the Irish Traveller community.

2.8 Conclusions of the literature review

There have been a number of health studies carried out on Traveller and ethnic minority populations such as the Roma both in Ireland and Europe in the last two decades. The success or otherwise of these studies depends greatly on the methodologies used in accessing these often mistrustful populations. Yet each of the studies have made reference to cultural factors at play in influencing health behaviours. It is to be noted that these are the studies that attracted this researcher's interest and for that reason were included in a literature search. On reflection, the search parameters for the literature search and review should have been broadened to encompass data from other countries and communities on non-attendance at medical appointments.

This literature review moved from a consideration of large general health studies to more specific small scale studies. In all of these it has been difficult to find a source that did not believe that culture had some influence on health outcomes. For this reason, I feel it is very strongly indicated that there is an important question to be posited and answered in this project, namely to what extent the cultural beliefs of Irish Travellers influence their interactions with Community Audiology services particularly as it pertains to the high rate of missed appointments as reported by the professionals working with these populations.

3. Methodology

3.1 Introduction

This chapter describes the methodology chosen to address the research question outlined in the introduction, namely, why members of the Irish Traveller population appear, to the professionals working with them, to miss/not attend audiology appointments. This dissertation is built on both quantitative and qualitative data collection. The body of the work centres on semi-structured interviews as a route to capturing 'what it is like' to be in a particular situation, to catch the close-up reality and 'thick description' of participants' lived experiences of, thoughts about and feelings for, a situation (Geertz cited in Cohen, 2000).

As the topic relates to a particular cultural minority within society about whom it is often difficult to capture data, one aspect of the data collection involved establishing the actual numbers of Traveller children with hearing loss on the caseload of the Visiting Teacher Service. This quantitative aspect entailed emailing all Visiting Teacher for the Hearing Impaired (VTHI) colleagues with a number of questions about their caseloads (see Appendix D). This data is necessary to establish the context within which Audiology services are working to provide Traveller children with personal amplification. The most recent census of population in the Republic of Ireland was carried out in April 2016. However, a detailed analysis of this ethnic minority will not be published until October 2017. The statistics used in this study are perforce based on the census results from 2011 and so are out of date. Thus it proved necessary to establish more current numbers.

The core of the work involved one-to-one interviews which were semi-structured in nature and followed the interview schedule as set out in Appendix C. Interviews were recorded and then transcribed objectively by a third party. These interviews then formed the qualitative aspect of the work. These were accompanied by field notes to help capture the non-verbal information which tends to be lacking from audio recordings e.g. in one interview the mother became uncomfortable with the direction of the questioning. This was clear to me from her demeanour as we sat

at the kitchen table. At the time we were discussing marriage customs and her teenage daughter had walked into the room.

3.2 Research design

According to Nisbet and Watt and cited in Cohen et al (2000), a case study is a specific instance that is frequently designed to illustrate a more general principle. Bell (2005) explains that case study researchers aim to identify or attempt to identify the various interactive processes at work, to show how they affect the implantation of systems and influence the way an organization functions. This research proposal seeks to answer a very specific question, namely why Traveller families Do Not Attend (DNA) audiology appointments. It was expected that this question would have multiple answers or contributing factors. This study sought to examine the way in which a minority culture interacts with health and education services in relation to the hearing losses of their children. For this reason it focussed on the lived experience of a particular group within Irish society. As Cohen et al (2000) point out, a case study provides a unique example of real people in real situations. The case studies aimed to tease out the underlying causes for the perceived high rate of DNA among this population as reported by the audiology services with whom they interact. Nisbet and Watt (2000) remark that the whole is more than the sum of its parts and Bell (2005) states that a case study approach to research provides an opportunity for one aspect of a problem to be studied in some depth. One of the aims of the study was to arrive at a better understanding of what causes people to DNA with a view to influencing the ways in which populations are supported to attend appointments.

3.3 Strengths and weaknesses of case studies

Nisbet and Watt as cited in Cohen et al (2000) sought to outline the strengths and weaknesses of a case study approach as follows:

- Case studies tend to be more accessible in terms of the language used as they tend to be couched in less academic language. This leads to them being more easily understood by a wider audience.

- They tend to resonate immediately with people as they ‘speak for themselves’.
- They are strong on reality
- They provide insights into other similar situations
- They can allow for uncontrollable events occurring
- They can be undertaken by a single researcher without the need for a full team of researchers

However case studies also have the following weaknesses:

- It may not be easy to generalize the results obtained
- It can be difficult to cross-check the information obtained as they often deal with unique or particular instances or situations. Because of this they may be more prone to subjectivity and bias
- They can tend towards problems of observer bias.

A case study approach was adopted as it was felt that the evidence needed to come directly from the people who were involved. Too often, in my opinion, conclusions are arrived at about the actions or motivations of this ethnic group, without reference to the group itself. This top-down approach, as pursued by various governments, has failed to produce positive outcomes for Irish Travellers. By asking the people involved about their own experiences, it was hoped to get to the heart of the matter.

3.4 Participants

Purposive sampling was the method used to obtain a sample of participants for the case studies. This was felt to be an appropriate approach as the research question was focused on a particular population within Irish society, namely Irish Travelling people. By selecting the Traveller families on my own caseload as a Visiting Teacher of the Hearing Impaired it was considered that this subset of the total population would be representative of the overall population under survey as per Cohen et al (2000). As Robson (2002) states, in purposive sampling ‘the principle of selection is the researcher’s judgement as to typicality or interest’. I felt that the three families identified, who had eight deaf children between them,

had a lot of experience of interacting with local audiology services. I already had a good relationship built up with two of the families over many years of providing Visiting Teacher of the Hearing Impaired support. The third family was not as well known to me as their child had only recently been diagnosed with a hearing loss. The sample was chosen for a particular reason or purpose, namely to examine in depth the particular underlying reasons that may be causing Traveller parents of hearing impaired children to not attend audiology appointments. However, attention must be drawn to the fact that this method of selection tends towards a 'low level of reliability and high levels of bias' (Dudovskiy, 2016).

3.4.1 Actual sample and Ethics

The caseload of a Visiting Teacher of the Hearing Impaired is divided into two categories; Active and On Request. To be included on the Active caseload children must have moderate to profound bilateral hearing losses. Children with Mild bilateral hearing loss or Unilateral hearing loss are eligible for the On Request caseload. This latter group is seen for an initial assessment, usually in the learning environment, and recommendations are based on observation by the VTHI and a series of assessments carried out by the VTHI (e.g. L.I.F.E.). These children are typically not eligible for review for a further two years unless an updated audiogram shows a deterioration in their hearing thresholds. Because of the lack of regular contact with this group it was decided to exclude the children of Irish Traveller families with unilateral or mild hearing losses from the sample. The number of families in this sub-group was four.

Children in the Active category are seen more regularly. Frequency of visits is determined based on priority needs. For example, babies identified under UNHS would have the highest priority. There are currently twelve children from four families in the Active category on my caseload who are also members of the Irish travelling community. These children and their families formed the purposive sample cohort.

These families were approached and asked if they would be interested in taking part in the study and four families indicated that they would. In the event, one of these four families later withdrew their permission to be interviewed. Meetings

took place with these families in their own homes and semi-structured interviews were carried out. These were recorded and transcribed objectively by a third party. Ethics approval for this study was obtained from the University of Hertfordshire and is included as Appendix A.

Table 3.1 Participant details

	No. of children with > 40dB HL and on Active caseload	Level of SNHL	Family size (total no. of children)
Family A	2	1 Profound	6
		1 Severe	
Family B	1	1 Profound	1
Family C	5	2 Profound	7
		3 Moderate	
Total	10		14

3.4.2 Limits and restrictions

Within this purposive sample of eight families, there were a number of factors that placed restrictions on selection of a particular family for inclusion in the case study group. As the core data collection was to be completed by interview and a case study strategy was to be employed, it was vital that families were chosen with whom the researcher already had a good working relationship. Access to this particular community on more than a superficial level can be difficult for outsiders. A good rapport with the researcher was believed to be a vital determinant for inclusion or exclusion of a particular family. Bearing these considerations in mind, of the original eight families identified as being on the Active caseload and therefore being visited regularly, only three families were included in the end. Of the remaining five families, two families had only recently received a diagnosis of

hearing loss, one child had been placed in a fostered situation and so access to the original family was not possible, one family declined to be included and a fifth family withdrew permission to be interviewed after initially agreeing to be part of the study. The interviews were carried out by the researcher in private homes with the parents and/or extended family members over a period of two months. It was originally envisaged that a computerized data analysis program would be used to establish any recurring themes. However, the actual sample of three interviews was too small to allow for this.

3.5 Validity and Reliability

Definitions of validity and reliability differ depending on the type of research that is being pursued i.e. whether the hypothesis under consideration is part of a quantitative or qualitative research design. As this research is concerned with how a particular community of people, Irish Travellers, interact with a particular aspect of the Health Service Executive (HSE) in Ireland i.e. Audiology services, the research will be mostly of a qualitative nature. Morse et al (2002), state that “without rigor, research is worthless, becomes fiction, and loses its utility”.

Guba and Lincoln (1981 in Morse et al, 2002) point out that the nature of knowledge in a rationalistic or quantitative paradigm is different from the knowledge in a naturalistic or qualitative paradigm and that each paradigm requires specific strategies for addressing rigor. With a study that is quantitative in nature, the necessary criteria to achieve rigor are internal validity, external validity, reliability and objectivity. Guba and Lincoln (1985, in Morse et al, 2002) suggested that the equivalent criteria in a qualitative study are “credibility, transferability, dependability, and confirmability”. Applying these latter tenets to the question of why Irish Travellers appear to have a high rate of not attending audiology appointments, credibility will be apparent from the verbatim quotations of the people being interviewed; transferability will be apparent if recurring reasons for non-attendance emerge from the interviews with participants; dependability will be inherent from the relationship already built up with the researcher prior to data collection and in the course of the interview itself and finally confirmability was achieved by examining the reasons why the participants who are also the parents of children on the caseload of the VTHI, cancel

appointments with the VTHI. There is a striking similarity between this latter set of data and the outcomes of the broader research study.

In a qualitative study, the data-gathering instrument is often the researcher himself (Brink, 1993). Consideration must then be given to the impact of the researcher on the process of data collection in terms of researcher bias and competency. According to Brink the very presence of the researcher may affect the validity of the data being collected from the participants. The participants may seek to present themselves in a favourable light to the researcher. Bearing in mind that this research is attempting to elicit the reasons governing a type of behaviour that could be interpreted as negative, there needed to be considerable sensitivity and flexibility demonstrated during the interview process. Leininger (1991, in Brink 1993) states that researchers need to be trusted before they will be able to obtain any accurate, reliable or credible data. In planning this research, attempts were made to deliberately choose participants with whom the researcher had developed a good working relationship over many years. In the event one of these families dropped out and another family had to be recruited at short notice. This latter family were relatively recent additions to the researcher's caseload as a Visiting Teacher of the Hearing Impaired. However, the researcher was known to the family from having worked previously with a member of the extended family who also had a hearing loss. When it came to analysis of the interviews, I was concerned that this one would be less informative. Ultimately, though, these concerns were unfounded.

3.6 Researcher bias

By definition, the researcher in this work, is an outsider. The researcher is a settled person by which is meant a person who resides in the one place and is not nomadic. According to Ní Shúinéar, (in McCann et al, 1994) "the one absolutely decisive factor in whether an individual is a Traveller or not is whether he has at least one Traveller parent". Accordingly the researcher in this case is not a Traveller but a 'country person' by which is meant a non-nomadic person. The Task Force on the Travelling Community (1995) concluded that complex relationships existed between Travellers and the settled community and that there was a need for measures aimed at reducing conflict and strengthening

mutual respect between the two communities. This did not apply to work in this study as it was carried out by a researcher who had worked for a number of years with the families or the extended family of the people involved in the data collection. A good working rapport based on mutual respect had already been established between the researcher and the participants.

The work of sociologist Dr Micheál Mac Gréil is described in 'The Irish Paradox' (Moncrieff, 2015) as he 'has tracked the tides of intolerance in Ireland for many years'. Mac Gréil reports that since the 1970s intolerance has increased markedly towards Travellers. Moncrieff goes on to quote the following statistics: In 2011, 60% of people would not welcome a Traveller into their family, 40% would not employ a Traveller and almost 20% would deny them citizenship. This background serves to illustrate the attitudes and perceptions about Travellers that are prevalent in Irish society at this time. It is necessary to note that this is the social context within which this study is located.

In examining my own motivations for pursuing this area of study and in attempting to dissect any personal bias towards the participants and/or the topic, I discovered the writings of Finlay (2002) on reflexivity in which she outlined its usefulness as a technique

As part of laying claim to the integrity and trustworthiness of qualitative research, it is vital for researchers to find ways to analyse how subjective and intersubjective elements influence their research. Reflexivity offers one such tool. Here, the researcher engages in an explicit, self-aware meta-analysis of the research process. Through the use of reflexivity, subjectivity in research can be transformed from a problem to an opportunity.

My very first job as a newly qualified teacher was with a group of deaf Irish Travellers in a special class in an urban setting. This experience was a very positive one that has left me fascinated with Traveller culture and society ever since. Colleagues, with longer experience of working with this population and with more Traveller families on their caseloads, would view my attitude as one of naiveté as the families I worked with at that time were very traditional Traveller

families who held teachers in high regard and placed a value on education. Over time my positive attitude towards this community has been tempered by experience when in the course of my work as a Visiting Teacher of the Deaf I have had a significant number of deaf Travellers on my caseload. Personal frustrations arising from a difficulty in working consistently with children from Traveller backgrounds due to cancelled appointments led to the original question of why Travellers Do Not Attend appointments. I have observed a similar frustration on the part of the hospital and community audiologists with whom I work. A new audiologist had the experience of having a completely empty clinic one afternoon when he scheduled several members of the same Traveller family for back to back appointments. None of them turned up. Despite a general consensus that the rate of missed appointments is considerably higher in this ethnic group there has been little investigation into this. This became clear during the literature review in which the various studies each referred to cultural factors at work influencing health behaviours (AITHS 2010, Parry et al 2007, Voko 2009). Only in one case was Traveller behaviour around appointments actually captured (McQuillan and Van Doorslaer, 2004). In this study poor appointment keeping was found to have a negative impact on the delivery of palliative care services.

In considering my own biases and motivations, I arrived at the conclusion that I am positively biased towards the Irish Traveller population with whom I work. One of the unexpected outcomes of this project has been an increase in rapport between the families involved and the researcher. While non-attendance at appointments continues to be a frustrating part of my working life, it is now possible to set it in context.

3.7 Interviews

According to Cohen et al (2000), interviews enable participants to discuss their interpretations of the world in which they live, and to express how they regard situations from their own point of view. It is this richness of the lived experience that I hoped to access by choosing to use interviews as a method of data collection. As previously mentioned, there was much anecdotal evidence to illustrate the high DNA rate among this population but there had been little attempt to explore the underlying causes or the participants' perceptions of why

this situation was so common. My interest lay in understanding the underlying behaviours or motivations that led to not turning up for an appointment or as expressed by Seidman (2006), an interest in understanding the lived experience of other people and the meaning they make of that experience. Interviews in this study were conducted with five parents from three families in their own homes who had experience of interacting with the local hospital and community audiology services. Bell (2005) and Cohen et al (2000) all assert that interviews provide greater insight into a topic. Kvale (1996) describes an interview as “a conversation that has a structure”. In this manner then the main research tool was words; using words to prompt discussion and then using the real words of real people in real-life situations to describe their lived experience. A narrative inquiry approach, (Bell, 2005) in which the choice of words used by participants to describe their interactions with service providers, formed the core of this active research study. These interviews once transcribed were examined for recurring themes. It was originally intended to carry out a computerized analysis of themes, however, the actual sample of three families, was not sufficient for this approach to be indicated. Themes were colour coded instead and each transcript then checked to see what themes were present in each of the transcripts. Themes that occurred but were not present in all interviews were included in the Results chapter as incidental findings.

3.8 Conclusion

The methodology outlined above was chosen very deliberately to suit the research enquiry which focussed on why a certain population within Irish society, namely, Irish Traveller families, seemed to not attend appointments with audiology services more often than ‘buffers’ (house dwelling, non-nomadic people). A narrative inquiry style, based on semi-structured interviews in private leading to a case study approach to the presentation of findings was felt to be the most appropriate framework within which to work. The interviews were then transcribed objectively and analysed for recurring themes or reasons for not attending appointments. This formed the qualitative aspect of the work. The quantitative work involved establishing the numbers of Irish Traveller children on the caseloads of VTs around the country and correlating this with census information on the Irish Traveller population collected in 2011.

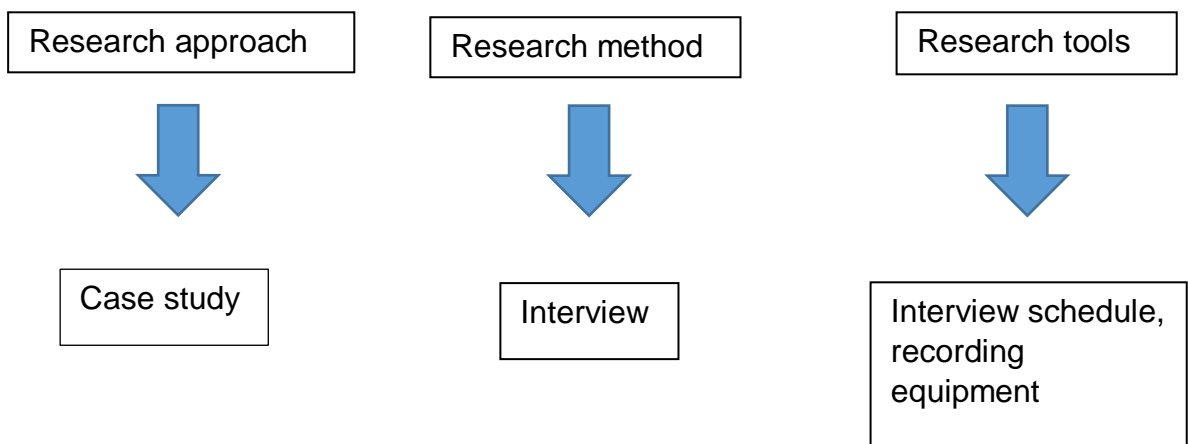


Figure 3.2 Methodology

4. Results

4.1 Introduction

This chapter centres on collating the results of the quantitative and qualitative research carried out into the reasons why Irish Traveller families appear to often not attend appointments. The quantitative research involved analysing census data already available on Irish Travellers from a national census carried out in the Republic of Ireland in April 2011 and published in 2012. The most recent national census was carried out in 2016 but results are not yet available. Another quantitative aspect that was researched, were the numbers of Traveller children on the caseloads of my Visiting Teacher of the Hearing Impaired (VTHI) colleagues. I expected to find that caseload numbers reflected census data and this was largely the case.

The qualitative work centred on semi-structured interviews with three families on my caseload as a VTHI in County Galway in the West of the Republic of Ireland. These interviews were then transcribed and analysed for recurring themes. These themes are detailed below. Quotations used from these transcripts are the verbatim accounts of the participants themselves. Families are referred to as Family A, B or C.

4.2 Quantitative results analysis

During the literature review it became clear from census figures that Traveller families were not equally distributed throughout the country. That being the case then, this situation should be reflected on the caseloads of Visiting Teacher (VT) colleagues throughout the country as caseloads are mostly organised on a county basis with most Visiting Teachers responsible for one county or part of a county. I collected data from my VT colleagues on the numbers of Traveller children and families on their caseloads. I wanted to see if the numbers on VT caseloads reflected what could be expected based on a national incidence of 1-1.2 per thousand of permanent childhood hearing impairment rising to 2-2.5 per thousand by school entry age (NAR, 2011). Based on a population of 4,588,252 (CSO, 2012) this should give an expected rate of hearing loss in the overall population of between 4,588 and 11,470 (mean=8,029) for moderate or greater bilateral sensorineural hearing loss. The Irish Traveller population represents 0.6% of the total Irish population or 29,495 persons in 2011 (CSO, 2012) and this

is illustrated in Figure 4.1 below. Extrapolating the same rate of hearing loss then we should expect a total of 29-73 (mean= 51) Irish Traveller children on the caseload of the VTHI service. In actual fact, the reported number on VTHI caseloads is 167. The difference is perhaps explained by the fact that this data from colleagues represents the latest figures available for 2016-2017 academic year and the census figures relate to 2011. One of the preliminary figures available from the 2016 census is that the population of the Republic of Ireland has increased to 4,757,976 from 4,588,252 (+3.69%).

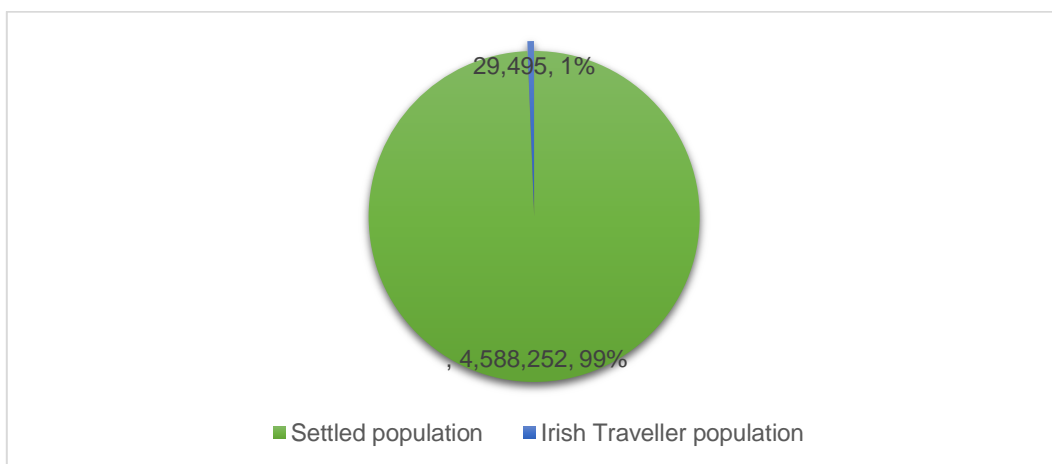


Figure 4.1 Comparison of settled and Irish Traveller populations

4.2.1 Census information

Figure 4.2 below shows the total number of Irish Travellers enumerated in each administrative county in April 2011. This graphic illustrates the fact that the population of Irish Travellers is not evenly distributed around the country. The largest population of Irish Travellers were living in Dublin city and county, with 5,935 individuals enumerated there. Galway County, in the West of Ireland, had the second largest number of Irish Travellers living there with 4,143 persons. Next highest was Cork city and suburbs, in the South of the country, at 1,867. In contrast to these figures, there were only 258 Irish Travellers enumerated in Co Monaghan, which shares a border with Northern Ireland.

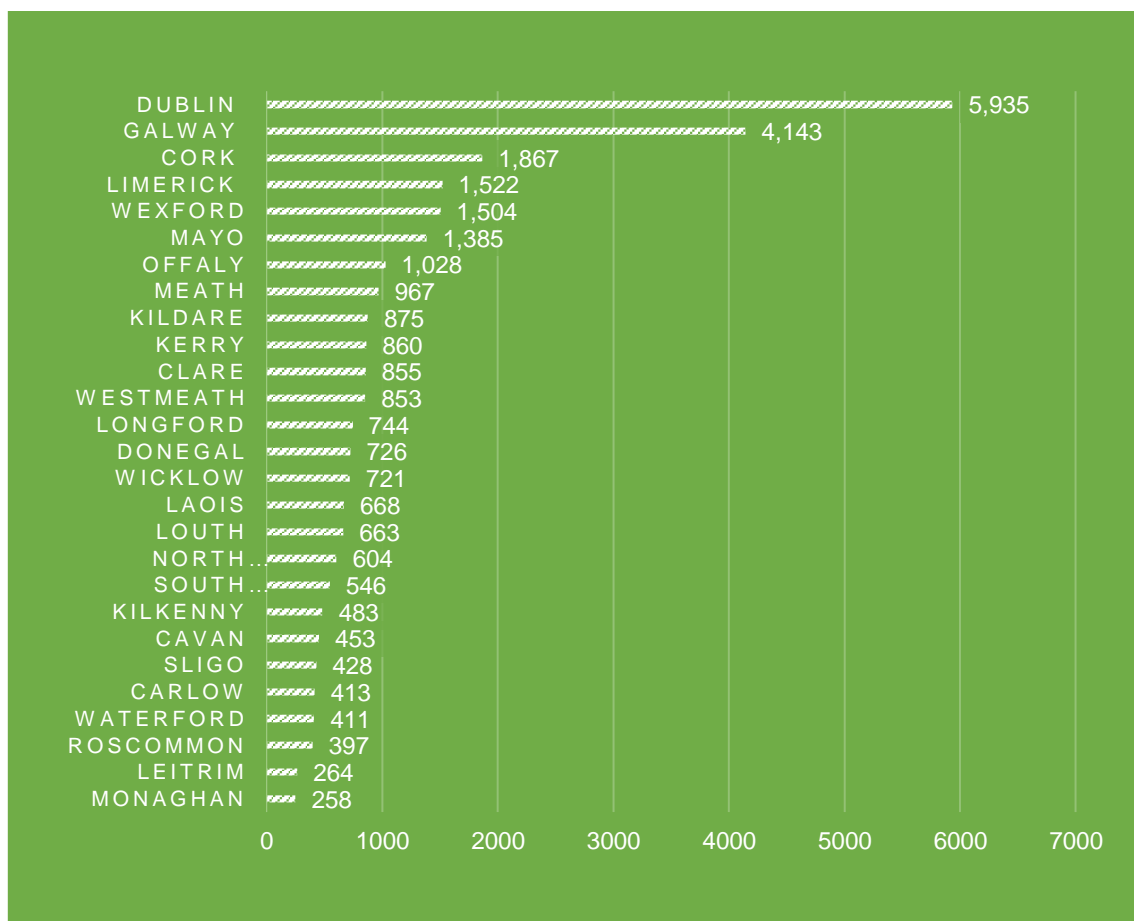


Fig 4.2 Irish Travellers enumerated by administrative area (CSO, 2012)

Overall, there is a trend away from rural settlement as was the case in the 1950s and 60s, towards more urban dwelling (McDonagh, M., 2000). This is reflected in the largest populations of Irish Travellers now living in counties that have a large urban centre, namely, Dublin, Galway and Cork as can be seen in Figure 4.2 above. Figure 4.3 illustrates the settlement trend of Irish Travellers as centring around urban areas with 81.7% of Irish Travellers choosing to live in an urban area as compared to rural areas with just 18.3%. This figure contrasts strongly with the rural totals for the general population which is 38%. The three counties with the lowest numbers of Irish Travellers living there; Roscommon, Leitrim and Monaghan are very rural counties with low-density populations.

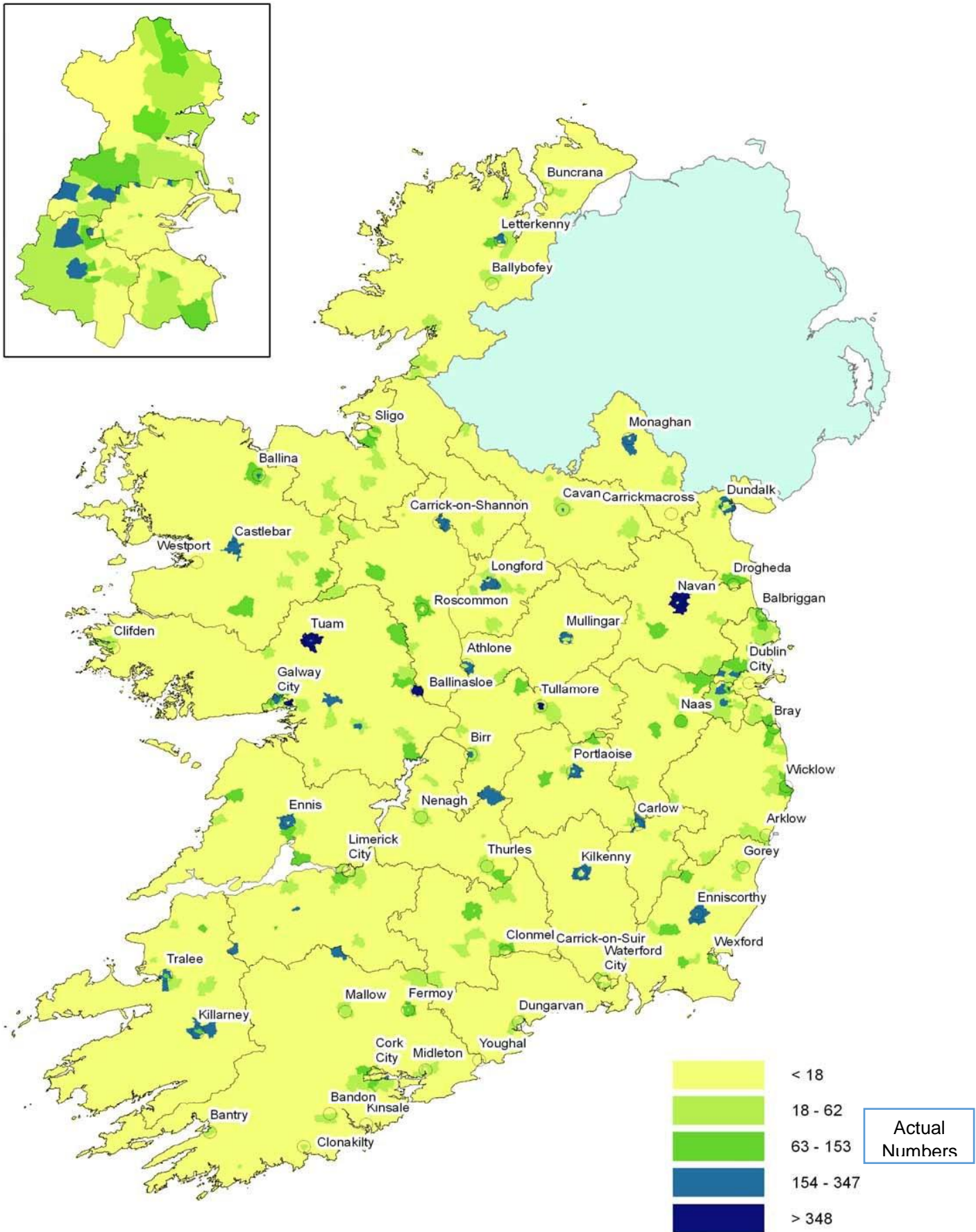


Figure 4.3 Irish Travellers by settlement area

(CSO, 2011)

Census 2011 also collected information on the numbers of Irish Travellers who had been diagnosed as having a serious hearing impairment. This is further analysed by age group as can be seen in Figure 4.4 below. The age group of most interest to me as a VTHI is the 0-14 year olds as this category would cover the majority of Irish Traveller children on my caseload. This age group has an incidence of 106 cases of hearing loss from an overall total of 535 giving a 19.8% occurrence rate of a serious hearing impairment. The rate of occurrence of hearing loss in the general population is 3.1 per thousand of a population at the time of 4,588,252 (HSE, 2011). Thus the rate of hearing loss appears to be very high in this age group. The rate of hearing loss in the Irish Traveller population according to census information is 1.8% which is more congruent with the national data.

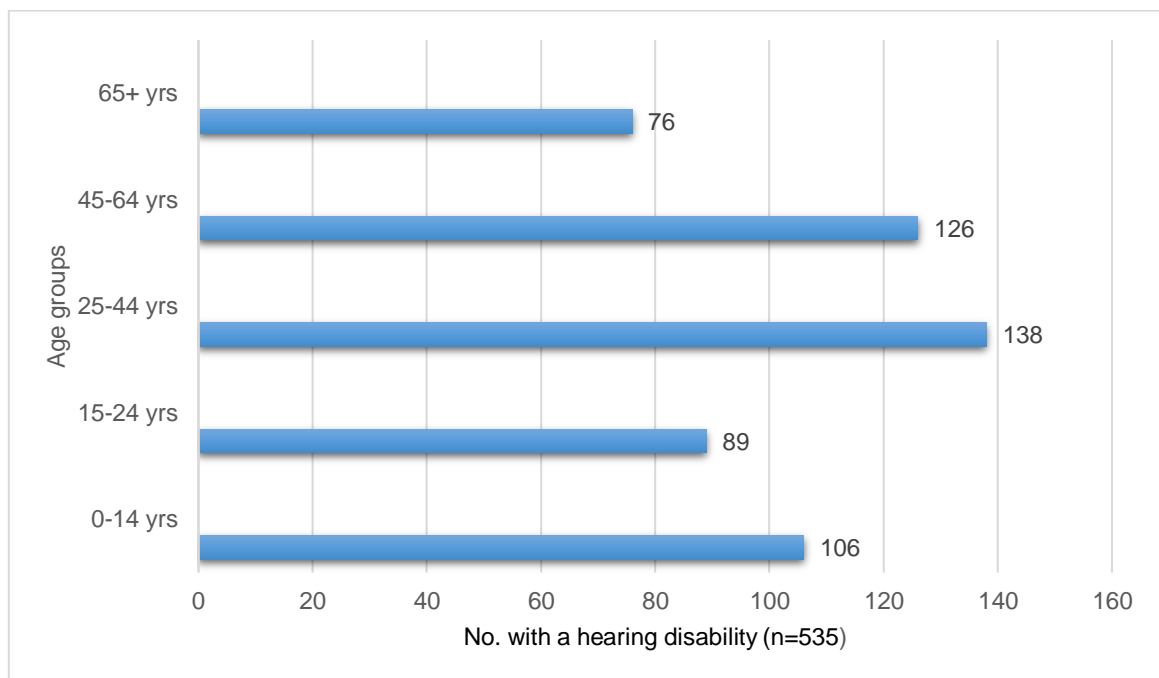


Fig.4.4 Irish Travellers diagnosed with deafness or a serious hearing impairment

4.2.2 Information from Visiting Teacher databases

I collected statistical information from my colleagues on the numbers of Irish Travellers on their caseloads. This was done by means of an online survey and is included as Appendix D.

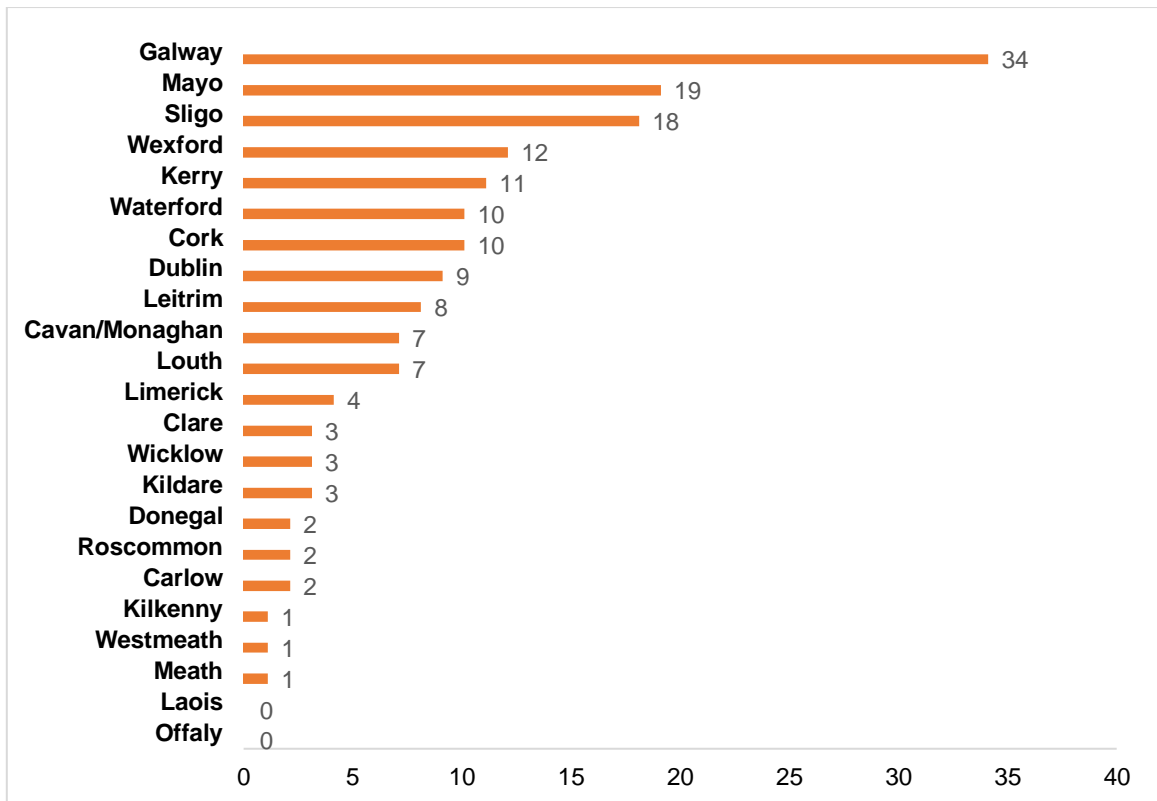


Figure 4.5 Irish Traveller children on VTHI caseloads in Republic of Ireland

Figure 4.5 above shows that there is a concentration of Irish Traveller children on the caseloads of Visiting Teachers who have a large urban centre within their assigned regions, as shown by the numbers for Galway, Dublin and Cork. These are the three largest cities in the Republic of Ireland. The numbers reported for Dublin, the capital city, are unexpectedly small. This is possibly explained by the fact that the special schools for the Deaf are located in Dublin and children who attend there are not on the caseloads of the Visiting Teachers for that area.

4.2.3 Analysis of my caseload

The families that were involved in the data collection are also families on my caseload as a Visiting Teacher. Appointment cancellations are noted in each family's file. Analysis of this information in terms of the reasons giving for cancelling appointments with the VT proved enlightening. Figure 4.6 shows the number of appointments Families A, B and C were offered and missed with me, their Visiting Teacher of the Hearing Impaired.

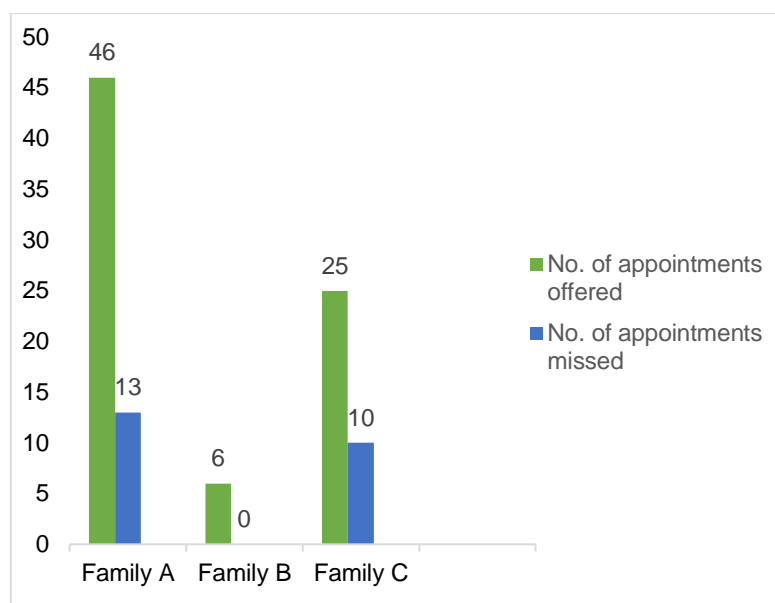


Fig. 4.6 Appointments offered and missed with VT

Family B missed no appointments with the VT as this child was a late diagnosis and was already attending pre-school when referred to the Visiting Teacher Service. I worked with this child in pre-school rather than the home setting. Table 4.1 below summarises the reasons given by families for cancelling appointments with the VT. It is noteworthy that the reasons given for missed appointments since I began recording cancellations are very similar to those that emerged during data collection. This data lent external validity to the results of the overall data collection as it was obtained over years of working with these families before the research topic had even been proposed and so was objective.

Table 4.1 Reasons given by families for cancelling appointments with VT

Reasons given	Family A	Family C
Personal or family illness	23%	50%
Family event	15%	20%
Appointment clash	23%	30%
No reason given	38%	0%
Totals	n=13	n=10

4.3 Qualitative analysis

A case study approach focussing on semi-structured interviews was chosen as the main method of data collection because like Seidman (2006) 'I am interested in other people's stories' and 'At the heart of interviewing research is an interest in other individuals' stories because they are of worth'.

I had access to four families during the interview stage. Unfortunately one family who had previously given consent to be included withdrew from the study. In this case, my close working with the family proved to be a disadvantage. I had not supported the family in a disagreement they had with a local school over the educational placement of their deaf children. In my opinion, this influenced their decision to withdraw. I held hour long interviews with those who had consented, in the privacy of their own homes. I counted the number of times the same answers occurred with different families and decided that if each family had the same response to the same question then the theme could be considered recurring. Thus a number of themes emerged during my enquiries into what causes underlie the non-attendance at appointments, in this case audiology appointments. These were: family and kinship, transport and timing, appointment clashes and illness.

4.3.1 Family and kinship

It was notable the importance each family placed on ties of family and kinship. Prioritising attendance at a family event was the number one reason in all cases for not attending an appointment with professionals and services. Included in this category are family events such as funerals, marriages and christenings. One father stated

Well, how can I put it to you, our appointment could be postponed, a funeral can't.

There is a strong cultural motivation in attendance at funerals as the mother in Family A describes

It'll be always thrown into your face. Why didn't you turn up to the funeral?

Family B described the same attitude towards family events particularly funerals.

But if something happened, something sudden like and there's a funeral, you'd hafta go [and never mind the appointment]

Family C felt the same way.

And then they cock their nose to you kind of, do you know what I mean. If you turn to one or the other, if it's an outsider, you either go to the funeral or you go to the wake and then you're fine. But when it's your own family.... (mother)

But for your family, I mean for your brothers, sisters, uncles, aunts, first cousins, you have to go to them like (father)

Within the category of family events that were imperative to attend, there also appeared to be a hierarchy. Both Family A and Family B put funerals top of the list of events that must be attended, closely followed by marriages of near relatives

Ah you'd need to turn up to that, especially if it's your own sister that's getting married or your own brother, you'd have to be there to see them off. (mother)

It'd have to be a brother or a sister, though, wouldn't it? (father)

Yeah. It'd have to be close family to you. (mother)

4.3.2 Transport and timing

Families raised a number of issues around the timing of appointments and appointment clashes. In the Republic of Ireland, we have one cochlear implant centre (CIC). It is situated in the capital city, Dublin, on the East coast. For people living in county Galway, where all these interviews took place, travelling to Dublin is at least a two and a half hour journey by car. Public transport involves a train journey and then a bus or taxi to the hospital itself. Family A explains the practicalities of attending an appointment in a difficult to reach place

Or the hours, it could be too early to get there (father)

Yes. Especially if we've to attend to Dublin, the appointments would be awful early so it would be hard on the kids (mother)

Transport wise (father)

Because we have to go by public transport, so... (mother)

We have a car but, but full licence, you can't drive on a motorway unless you have a full licence holder with you (father)

And we haven't got a full licence, so, we're just provisionals (mother)

Only provisional (father)

Until we pass our test (mother)

Family B, on the other hand, also have a car and are only 'provisionals' (learner driver on first provisional licence) but are willing to chance it on the motorway and risk getting caught for driving without a full licence. The mother in this case has no one else to ask as her husband is currently serving a prison sentence and her mother-in-law with whom she is living while on the housing list is a non-driver.

Sure I know I've only 'L' plates but I drive it anyway. I won't get caught.
(mother)

All families who were attending the CIC were dis-satisfied with early appointment times there and usually did not attend appointments arranged for earlier than 11am if they were dependent on public transport. However, they did not always remember to cancel the appointments and this resulted in difficulties with the CIC. Family A had this experience and described it thus

Because up there like they are really professional you know and they know what they're doing as well, I'm not saying, you know the clinics you know but like and if you don't get to see them like and they miss their appointment they're awful altogether. (father)

In contrast to this, Family C's difficulties with appointment timings were due to behaviour management

So it could be, for instance, it would be, now, for instance, if there's an appointment on a Saturday at nine o'clock there's no way in the world X would get up at nine o'clock for an appointment, not on a Saturday especially being in school from Monday to Friday.

The father is talking about his eleven-year old daughter who will not co-operate with early appointments on a Saturday.

4.3.3 Appointment clashes

In large families, with a number of children to be attended to, there were often times when a number of appointments clashed. Family A explains

Like it could be a doctor's appointment at the same time, you'd have to postpone it or just forget about the day because.... (mother)

The mother in Family B really wanted the different agencies involved with her family to co-ordinate their appointments so she wouldn't have to choose which ones to attend when they clashed. When asked what would help her not to miss appointments she explained

If they all had a collection [sic connection] together. And they said, well the hearing aid clinic said, 'Well I'm seeing him today at two o'clock on the 14th. So [Cochlear Implant Centre] then says, 'Well I'll see him here then on the 15th at eight o'clock or whatever' and then you know like that and then speech and language says, 'We'll see him on the 16th', even if it was days but it wasn't travelling to Dublin the whole time. (mother)

If it was around the place, do you know what I mean? They've them clashing like, they had kind of communication with each other, it'd be better. (grandmother)

One aspect of the audiology services this family found particularly helpful was the text reminders that were used in the community hearing aid clinic. At the time of writing, this service had been temporarily suspended. When asked what might cause the family to miss an appointment with the local services the mother replied as follows

You know, you might forget about it or whatever. There used to be a text the day before...
(mother)

The father in Family C referenced the huge waiting lists in the Republic of Ireland for diagnostic health services.

If I had an appointment myself on the day right and it was more important than, for instance, [the audiology clinic], is down the road, I could be waiting for two years for an appointment for it to be a scan or for an x-ray or whatever right and they can get their appointments within six, seven weeks sometimes. So I would nearly have to put theirs off just to go to my own.

4.3.4 Illness

As expected all families had had to cancel appointments due to personal illness or because the children were ill. Family A said

....and if they're sick sure they've no interest in you know, learning on the day because it's hard on kids like. Especially if they're sick.
(mother)

Checking the field notes I made on that day, it appears the mother was thinking of the testing that goes on in the audiology clinics either locally or in the CIC. What she is referring to is conditioning the children for play audiometry when she mentions 'learning on the day'.

4.4 Conclusion

In this chapter on Findings, I have detailed the quantitative and qualitative aspects of the work involved in researching why Irish Travellers Do Not Attend their appointments with services and in particular with audiology services. The statistical elements were based on public information freely available on the Central Statistics Office website. I collected data from my colleagues on the numbers of Irish Traveller children on their caseloads. I carried out semi-structured interviews with participants in the privacy of their own homes. These interviews led to the identification of certain recurring reasons for non-attendance; family and kinship ties, transport and timing issues, appointment clashes and illness.

5. Discussion and Conclusions

5.1 Introduction

The aim of this research was to explore the reasons why Irish Travellers appear to not attend appointments more often than the general population. Taking a qualitative narrative enquiry approach my aim was to interrogate the lived experience of a particular ethnic grouping in Irish society. In this final chapter I intend to discuss the findings of this piece of research. I also plan to discuss the strengths and limitations of this work and make recommendations for ways in which appointment attendance may be improved.

5.2 Research findings

The recurring themes that were expressed by participants for not attending appointments were:

- Family and kinship ties
- Transport and timing
- Appointment clashes
- Illness

5.3 Incidental research findings

A number of unexpected sub-themes emerged during the data collection phase. These included

- Vehicle ownership as an indicator of socio-economic status. This proved to be an unreliable measure as described below
- Institutional racism proved not to be a barrier in attendance at appointments contrary to the findings of the literature review
- The use of and belief in “cures” for hearing loss was a persistent theme that emerged in addition to the perception of HL as an “illness”
- A belief among Irish Travellers that census data are inherently flawed

5.3.1 Vehicle ownership as an indicator of socio-economic status

It is of note that all the families interviewed had access to a car or other vehicle. This contrasts with the census data from 2011 which found that more than one in four or 27.3% of Irish Traveller households in permanent accommodation were without such access. Van Cleemput (2007) was of the opinion that socio-economic factors had an impact on attendance at appointments. This was not

borne out in the interviews I had with this group of families. Each family had their own transportation. If we accept car ownership as one indicator of socio-economic standing, then Van Cleemput's arguments are not substantiated in this study. However, this may be an unsafe conclusion to draw as Travellers see the owning of a vehicle as essential and a way of keeping their wealth portable; making it easier to move from place to place (Binchy, 1996 cited in Sheehan; Moncrieff, 2015).

5.3.2 Institutional racism

Another theme that emerged during the literature search was that of 'institutional racism'. If present, I felt this could be a barrier to attendance at appointments. However, none of the three families interviewed felt that this was something that they had experienced.

Family A: No never. No, no, I've never been treated different I mean never
(mother)

Family B: No, I think people use that for excuses, saying it (mother)
And that was out in the Stone Age (grandmother)

Family C: Like there is none, for us we don't experience that (mother)

Field notes indicate though that I did not think this point was well understood by participants. Racism seemed to be associated with 'other' groups and didn't appear to be relevant to the lives of Irish Travellers. Institutional racism as a topic was not introduced directly to the interviews as I felt it would further obfuscate the matter.

5.3.3 "Cures" and healers

Family B reported several instances of bringing their profoundly deaf son to see healers

But I find with healers like that now, like that man back there, they only work for certain people, you know. It's like I don't know, it's like someone, like God picks them, you know, because it worked for that boy with the glasses, it worked for that child with the hips, worked for a few people, but some people it didn't, you know it doesn't work you know, straight away.
(grandmother)

This theme came up incidentally in discussion; it was not part of the schedule of interview questions. Cathleen McDonagh (2000) describes the Irish Traveller practise of visiting “curing people”. Indeed I have witnessed this strong tradition first hand when masses said locally by a particular ‘curing’ priest are very well attended by Travellers. This tradition would merit further research as part of a more generalised cultural study.

5.3.4 Reliability of national census data

Both Family B and Family C questioned my facts when I mentioned the total number of Travellers in Ireland i.e. that there are a lot more of the sedentary population.

I don't think so no, because if you look at it, settled people is there having one or two children, Travellers for years are there having 10 children, 7 children, so there has to be the same amount or even more
(mother, Family B)

The grandmother of Family B adds to this point as follows

You see you know when them census forms were getting filled in, they could be gone to England on holiday or something, you know, half the forms mightn't even have been filled

The father in Family C was of the same opinion

No you see most of them, I think myself half of them could be signing on [collecting Social Welfare allowance] from the house and they didn't want them to know they're living there

This topic would merit further study because if it is a true reflection of the situation then it would mean that the main source of statistics used by the government for planning services is inherently flawed as regards this ethnic minority.

5.4 Strengths and limitations of the study

5.4.1 Recruitment of participants

When it came to recruiting participants it seemed an advantage that I had access to a number of Irish Traveller families as part of my everyday work as a Visiting Teacher of the Hearing Impaired with the Department of Education and Skills in the Republic of Ireland. Up to a point this access did indeed prove beneficial as I already had a good working relationship with the families I interviewed. In fact, purposive sampling resulted in my deliberate choice of participants with whom I had a good rapport. I was motivated to produce a piece of work that was not superficial; that engaged with people 'where they were'. However, one unexpected side effect of this was that a greater closeness emerged between the participants and myself as researcher. This has had implications for my continued work with these families since completing the data collection stage of this thesis. I have become more understanding of having my own appointments with families cancelled; often at the last minute. This tendency continues to be a frustrating part of my work, just more comprehensible.

5.4.2 Pilot of email survey

A pilot of the email survey to my Visiting Teacher of the Hearing Impaired colleagues would have been of huge benefit. The question box which I had intended to be ticked if people had no Irish Traveller children on their caseloads was redundant as people put a zero in the previous box to indicate that they had no children from an Irish Traveller background on their caseloads. Similarly, the question about numbers of families in addition to the question about number of children also became meaningless. I had been hoping for a way to illustrate the size of Irish Traveller families and also perhaps a pattern of genetic deafness among families. There was not sufficient detail asked for, to enable me to come to any conclusions about either of these themes.

5.4.3 'Interviewer effect'

Denscombe (2005) refers to 'the interviewer effect' by which is meant that people respond differently depending on how they perceive the person asking the questions. In particular, he feels that the sex, age and ethnic origins of the interviewer have a bearing on the amount of information people are willing to divulge and their honesty about what they reveal. I felt this to be of particular

importance in this qualitative research study in that I was endeavouring to find out sensitive information about which it was conceivable that people could be defensive i.e. I was trying to find out why an ethnic minority, Irish Travellers, were considered by professionals to have a high rate of DNA at clinic appointments. As a middle-aged female from the settled community I would always be regarded as an outsider. The fact that in two of the three families interviewed I had built up a good rapport and working relationship with parents and children was certainly an advantage. The third family proved more difficult to interview as they were relatively new to me.

5.4.5 Sample size

This study could have been considerably richer in depth and in detail if there had been time to interview more participants. Three families is a small scale study.

5.5 Recommendations

The following recommendations may help improve uptake of offered appointments with services:

- With regard to attendance at the Cochlear Implant Centre by families who live at some distance from the centre and who need to use public transport, consideration should be given to the timing of their appointments so that they can get to their appointments without undue stress on the family. However, there are times when the family will be required to attend for a full day of clinics. There seems to be no way to avoid an early appointment in this instance.
- Awareness among professionals of the over-riding importance of kinship ties among Irish Travellers. Events within the family will take precedence over any other considerations including attendance at appointments
- Irish Travellers need to be reminded of the need to cancel appointments so as not to inconvenience other people and allow the appointment to be given to another person on the waiting list. This would help in developing better relationships between services and Traveller clients.
- The re-introduction of the text reminder service by local community audiology services would be greatly welcomed. Traveller families found this service helpful and bemoaned the recent cessation of it.

- An analysis of missed appointments in general needs to be undertaken by the HSE in the Republic of Ireland. Ethnic identifiers could perhaps be used to establish concrete data which could then be used to develop strategies to improve attendance at appointments

5.6 Conclusion

This chapter draws together the various strands involved in this research study into the factors that contribute to a perceived high rate of DNA at audiology appointments by Irish Traveller families namely; family and kinship ties, transport issues, timing of appointments, appointment clashes and illness. Incidental findings contradicted the literature review in two instances i.e. vehicle ownership and the existence of institutional racism. A strong belief in the power of 'cures' and 'healers' and a belief by Irish Travellers themselves that census data is fundamentally flawed merits further research. Overall, I believe that my original proposal that there is a cultural influence at work in shaping the behaviours of Irish Travellers when it comes to attending appointments with health services is substantiated. I agree with the observations of the Equality Authority in 2006 who opined that

"Traveller ethnicity is a key factor that has to be taken into account in identifying and responding to the needs of the Traveller community. Culture and identity shape the needs of a group. Policies and programmes that respond to needs will only be effective to the extent that they take into account the culture and identity of the group concerned" (AITHS 2010)

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Appendix A

SOCIAL SCIENCES, ARTS AND HUMANITIES ECDA

ETHICS APPROVAL NOTIFICATION

TO Martina Farren

CC Joy Rosenberg

FROM Dr Tim Parke, Social Sciences, Arts and Humanities ECDA Chairman

DATE 31/01/2017

Protocol number: aEDU/PGT/CP/02246(1)

Title of study: Exploring Irish Travellers perspectives on accessing Audiology Services'
Your application to modify and extend the existing protocol as detailed below has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below.

Modification: Revised title as above.

This approval is valid:

From: 31/01/2017

To: 31/05/2017

Additional workers: no additional workers named.

Please note:

Any conditions relating to the original protocol approval remain and must be complied with.

Appendix B

UNIVERSITY OF HERTFORDSHIRE

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

FORM EC6: PARTICIPANT INFORMATION SHEET

Title of study: Exploring Irish Traveller’s Perspectives on Accessing Audiology services

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 research that is being done 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 regulations governing the conduct of studies involving human participants can be accessed via this link:

<http://sitem.herts.ac.uk/secreg/upr/RE01.htm>

Thank you for reading this.

What is the purpose of this study?

I want to examine the interaction of Irish Traveller’s with the audiology system, both hospital and community based. I want to find out if Irish Traveller’s experience difficulty accessing audiology services and if so, what changes could be made to make access easier.

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. A decision to withdraw at any time, or a decision not to take part at all, will not affect any treatment/care that you may receive (should this be relevant).

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

There are no age restrictions on taking part in this study. All that is required is that you have experience of audiology services in Ireland.

How long will my part in the study take?

If you decide to take part in this study, you will be involved in it for an interview session lasting either 1 hour or 2 half hours, whichever suits best.

What will happen to me if I take part?

The first thing to happen will be that I will ask you some questions about your experience of interacting with audiology services in Ireland. I will record your answers on my iPad.

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

The only disadvantage of taking part is the time commitment. I will need to meet with you for at least an hour.

What are the possible benefits of taking part?

You will be helping me complete a course of study. You will be contributing information that may help change the way services are delivered to Irish Travellers who need to access audiology services in Ireland.

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

There will be no surnames, or identifying nicknames used in the written dissertation. My supervisor and I are the only ones who will have access to the transcripts of the interviews I will carry out. These will be destroyed at the end of the course of study, July 2017.

What will happen to the data collected within this study?

My supervisor and I are the only ones who will have access to the transcripts of the interviews I will carry out. These will be destroyed at the end of the course of study, July 2017.

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

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 phone or by email: Martina Farren [REDACTED]
[REDACTED]

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.

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

Appendix C

Schedule of questions for semi-structured interviews

1. Tell me how you discovered X had a hearing loss?
2. Who looks after hearing aids in the house?
3. Sometimes you have had to cancel appointments with audiology services. Can you remember the reasons that you had to do so? Tell me the reason.....
4. Of the following services, which do you feel you need most?
 - a. Audiology Sea Road (Community audiology)
 - b. Audiology Department in the local hospital/Beaumont CI centre
 - c. Speech and Language Therapy
 - d. Visiting Teacher Service
 - e. Other

Why is this important to you?

5. Can you think of any things that stop you getting to appointments?
6. Have you ever experienced racism in your dealings with audiology services? (If yes, expand)
7. Is the wearing of hearing aids a difficult thing for a Traveller? If yes, explain the difficulty.....
8. Would you describe yourself as 'settled'?
9. If so, why did you decide to become 'settled'?
10. Would you describe yourself as an Irish Traveller?
11. Would you consider yourself to be part of an ethnic minority? What does that mean to you?
12. Are you a member of any of the organisations for Travellers?
13. Anything else you want to tell me?

Appendix D

Email survey of colleagues:

Hello everyone,

Some of you may know that I am in the final year of a M.Sc in Educational Audiology at Mary Hare in the UK. It is now dissertation time and the topic I have chosen is "Exploring Irish Travellers' Audiological Perspectives".

I need to include current numbers of children from travelling backgrounds who are on the caseloads of VTs around the country. To that end I would really appreciate if you could fill in the box below and email me back. If you have no Traveller children on your caseload, please tick the 'none' box as this is also useful information for me. Your name will not be included in the research. I ask for it purely so I can map where these children are around the country and see if it corresponds with census information.

I appreciate how very over-worked everyone is, so I thank you in advance for taking the time to do this.

Best regards,

Martina Farren

VT name	
Area covered	
No. of children from a Traveller background on your caseload	
No. of families from a Traveller background on your caseload	
None	

Appendix E

Collation of email replies from Visiting Teacher colleagues by province

Connaught

County	Irish Traveller pupil numbers
Mayo	19
Galway	16
Roscommon	20
Leitrim	8
Sligo	18
Total:	81

Leinster

County	Irish Traveller pupil numbers
Dublin	9
Carlow	2
Kildare	3
Kilkenny	1
Laois	0
Longford	Included with Cavan/Monaghan
Louth	7
Meath	1
Offaly	0
Westmeath	1
Wexford	12
Wicklow	3
Total:	39

Munster

County	Irish Traveller pupil numbers
Clare	3
Cork	10
Kerry	11
Limerick	4
Tipperary	included with Limerick
Waterford	10
Total:	28

Ulster (3 counties of ROI)

County	Irish Traveller pupil numbers
Cavan/Monaghan	7
Donegal	2
Total:	9

Overall total: 167

Appendix F

List of acronyms/ Irish words

CIC	Cochlear Implant Centre
Dáil Eireann	One of the houses of the government of Ireland
Derbfine	Royalty in Ancient Ireland
ENT	Ear, Nose and Throat
HSE	Health Service Executive
L.I.F.E	Listening Inventories for Education
NHSP	Neonatal Hearing Screening Programme
NI	Northern Ireland
NRB	National Rehabilitation Board
Oireachtas	The government of Ireland
ROI	Republic of Ireland
RTE	Radio Teilifís Eireann- the national broadcaster
SNHL	Sensori-neural hearing loss
Taoiseach	Prime Minister
VT	Visiting Teacher
VTHI	Visiting Teacher of the Hearing Impaired

