

Roma families and deaf children



Ruth Swanwick, Jess Elmore and Jackie Salter

School of Education

Faculty of Education, Social Science and Law



UNIVERSITY OF LEEDS

Foreword

Over the last eighteen months, it has been a privilege for me to work closely with the Leeds University research team led by Professor Ruth Swanwick, which has been investigating the seemingly disproportionate incidence of deafness and impaired hearing among school children with a Roma ethnic heritage. This team has worked tirelessly with their project partners to produce a piece of quality research which provides us with a much clearer picture of the reality of the situation for schools, families and policy makers in securing appropriate and adequate multi-professional support for these children and their families. In acting as a consultant on Roma issues to the City of Sheffield since 2012, it became clear early on that many schools with Roma pupils were flagging up professional concerns surrounding the hearing of many of the Roma children and the implications of this for their learning and wellbeing. In 2014, the city's hearing impaired service organised a productive one day conference on the issue. These, and other early signals of concern, eventually materialised into legitimate professional requests for a more informed analysis of the national situation and the wider implications for policy, provision and practice.

The Roma families in the UK are migrants from the European Union's (EU) ten accession states (2004 and 2007) and principally from Slovakia, the Czech Republic and Romania. Despite attempts by different governments to prevent Roma migration to the UK, very significant numbers of Roma families have come to find work and to flee from their homelands and the experience of a long history of Roma persecution and discrimination. These shameful national histories have inevitably resulted in extreme social exclusion with dire consequences for Roma families. In 2016, the Fundamental Rights Agency published the second Midis II report on the situation of Roma in the EU. The summary findings perhaps explain the motivation to migrate to another member state. *"Some 80% of Roma surveyed live below their country's at-risk-of-poverty threshold; every third Roma lives in housing without tap water; every third child lives in a household where someone went to bed hungry at least once in the previous month; and 50% of Roma between the ages of six and 24 do not attend school. This report underscores an unsettling but unavoidable reality: the European Union's largest ethnic minority continues to face intolerable discrimination and unequal access to vital services."*

Needless to say, the value, importance and timely nature of this research is evidenced by the increasing needs being assessed by schools and other services in a context in which the vast majority of the clients have previously not received adequate and appropriate diagnosis and support in their countries of origin. This research is also important because of the lack of previous research studies and its innovative approach which examines the intersectional issues associated with childhood deafness and being Roma in the UK context. The in-depth character of the study with its national (England) survey, interviews with five deaf education services and case studies, has illuminated the relevant and overlapping realities of being deaf and being Roma in school and societal settings, together with identifying models of good practice and a wealth of rich data which will hopefully facilitate and inform future research, policy, provision and practice.

These skilled efforts are to be much welcomed and there is now a need for the advocacy of the findings in the interests of focusing and funding further research and fostering an appropriate response from policy makers and practitioners alike. It is vital, of course that these responses, engage with, and involve, Roma people at every level. The launch conference event at Leeds University in early November was testimony to the on-going commitment of this excellent research team to do just that.

Arthur Ivatts OBE

Senior Educational Consultant, Open Society Foundations



About the project

Deaf Roma children in the UK was funded by a University of Leeds Institute for Social Sciences ESRC Impact Acceleration Account. It was led by Professor Ruth Swanwick with Jess Elmore and Jackie Salter at the School of Education, University of Leeds in partnership with five deaf education local authority services (Sheffield, Rotherham, Peterborough, Leeds and Bradford), BATOD (British Association of Teachers of the Deaf), The Ear Foundation and NDCS (National Deaf Children's Society). The project ran from January to December 2018.

Project partners

Bill Bell, Caroline Chettleburgh, Sandie Griffiths, Arthur Ivatts, John Lever, Mark Payne, Ania Likierska, Ian Noon, Teresa Quail, Paul Simpson, Tina Wakefield



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Executive summary

Introduction

Research at the University of Leeds investigated the educational and social needs of deaf children from Roma families who have migrated to the UK from Central and Eastern Europe. This small scale project was funded by the Leeds Social Sciences Institute ESRC Impact Acceleration Account and was undertaken in partnership with five local authorities: Bradford, Leeds, Peterborough, Rotherham and Sheffield and three voluntary sector organisations: the British Association of Teachers of the Deaf (BATOD), The Ear Foundation (TEF) and the National Deaf Children' Society (NDCS).

It is known that there is an increased incidence of deafness in Roma communities but existing research is generally epidemiological and does not consider the social and educational issues for deaf Roma children and their families. This gap in the research is problematic given the increasing numbers of deaf Roma children/young people on local authority case load from CE and EE. We examined the intersectionalities and precarities associated with being deaf and being Roma and the implications for multi-professional support

Methods

This involved a demographic survey of all deaf education services in England, a questionnaire and interviews with five deaf education services, and four case studies of deaf Roma children and their families. The data was analysed using an intersectional approach in order to identify the overlapping issues for deaf Roma children and their families, and for educational and health professionals.

Findings

Demographics

The total number of deaf Roma children reported in our survey was 344 from a total of 45,631 deaf children in England. However, due to the dual issue of undiagnosed deafness and failure to identify Roma children in services we anticipate the figure is substantially higher. There was only one Roma child in the 10 out of 17 schools for the deaf who responded. 73 out of 132 local authorities' deaf education services responded and 37 reported they have no Roma children, 25 had between 1 and 5 Roma children while 11 had more than 5 Roma children.

It is suggestive that even with an incomplete data set these children make up 0.75% of the deaf children in the England. Our data also revealed that the pattern of deafness in Roma children is different to the wider population of deaf children across England suggesting they are likely to have more severe levels of hearing loss and so require more support.

These findings represents the first attempt to map how many deaf Roma children there are in England. While it is not a complete data set it is a valuable first step and the challenges of collecting this data are in themselves indicative of the complex nature of this research. Deaf education services were not confident about their statistics with several suggesting the numbers were under-reported. These figures are therefore suggestive of the invisibility of deaf Roma children and the reluctance of families to self-ascribe.

Institutional data

All services recognised the historic and current challenges that Roma families faced and how this affected the support they could offer their children. Services also recognized the resources of Roma families and how they prioritized their children's care and safety.

There was recognition that Roma households were multilingual but services did not generally know children's full linguistic profiles particularly once children were school age. The particular status of Romani as a language and the issue of working with families with an oral rather than written culture were also highlighted.

The mismatch in expectations between families and services was highlighted by many participants. Services also showed awareness of how families' experience of education in CE and EE affected how their engagement with education with a general reluctance to access resourced provision and a suspicion of intervention.

All services described households where there were multiple family members who were deaf. Questions were raised about how deafness was viewed in the Roma community and it was recognised that some families did not see the need for intervention.

Concern was expressed that it was difficult to get families to attend audiology appointments. The need for a flexible approach was recognised with multi-agency working, for example between teachers of the deaf and audiologists a successful strategy to improve attendance.

Late diagnosis was identified as a significant problem with children who were new to the UK and had missed new-born screening. Services identified some issues around engagement with hearing technologies particularly hearing aid use for younger children and more suspicion of cochlear implants. However, the dissemination of knowledge within extended families and within communities was identified as Roma communities were become more settled in the UK.

Services recognized that building trust with Roma families was essential as was helping families develop the skills and resources to advocate for their children.

In summary we found that deaf education services were responding thoughtfully to the needs of deaf Roma children. However, a common theme identified across the services was the need to learn more about families' perceptions of deafness, and their experiences of family, language, health and education.

Case Studies

All the case study participants described homes where more than two spoken languages were in use. Written language was not salient in any of the homes and some parents relied on interpreters for translation of health or education letters from written Slovakian into spoken Roma.

All the families understood access to spoken language and progress in language development to be a priority. Families also understood the importance of the consistent use of hearing technologies for the development of spoken language, and although some anxieties about the use of sign language were expressed the role of sign language support was recognized.

A compounding factor for language development was the delay in receiving hearing technologies. Three of the four families had a late diagnosis of deafness; only one was identified through new-born hearing screening in the UK.

Roma parents found it difficult to access and navigate educational and audiological agencies. This was compounded by access to the language of the institutional contexts and the need to work with interpreters, along with uncertainties about the UK institutional contexts of health and education, and how they interact.

The family structure was a strong resource through which the issues of being Roma and being deaf were to some extent reconciled and where the essential experiences of being a child, a parent and a family were primary.

In all four families there were other deaf members. Through this prior experience families had developed some understandings of deafness and strategies for communication and interaction

Families were generally very positive about their children's education prospects with high expectations for the future. They also spoke of the positive changes that the technology had made and expressed a commitment to engaging with the educational and audiological needs of their children.

Conclusions

Our findings suggest that the number of deaf Roma children is under reported due to families' reluctance to self-ascribe and yet the high prevalence of deafness in Roma communities has significant implications for education, health and social participation. Through our examination of the relationship between being deaf and being Roma we also identify overlapping areas of precarity that have serious implications at an individual level for childhood development, education and achievement, as well as for longer term health and wellbeing.

Recommendations

We recommend that deaf education professionals find appropriate ways to ask families if they are Roma rather than relying on external data. There is also a need for further outreach within Roma communities to identify these individuals and offer appropriate support. The value of employing Roma staff within organisations not only as interpreters but at all levels is evident within our research and the wider literature.

Professionals can usefully develop a greater understanding of these families who are already managing complex lives where a diagnosis of hearing loss can compound a general mistrust of education and health authorities. An understanding of families' previous experiences and current expectations, and recognition of their existing resources is key to successful partnerships.

Finally, we identify a need for further research that investigates the cultural, linguistic and social experiences of Roma families with deaf members and develops understandings of the exceptional circumstances and precarities in terms of individual development and societal inclusion.

Introduction

This report will provide a summary of the small scale research project undertaken by a team of researchers from the University of Leeds in conjunction with eight partners including five local authorities: Bradford, Leeds, Peterborough, Rotherham and Sheffield and three voluntary sector organisations: the British Association of Teachers of the Deaf (BATOD), The Ear Foundation (TEF) and the National Deaf Children' Society (NDCS).

The report outlines the aims of the project, how the project was carried out and presents the findings and suggestions for the next steps.



Significance of this project

I consider as a Roma woman with a deaf sister that the research project Deaf children from Roma families in the UK has an important significance within the Roma families and a huge impact on those families who have deaf children. Awareness is a key factor to understand the importance of a sensitive issue like this one but also awareness is a key factor to find a solution to a problem, whereas this is what the project does. Raising awareness of the gravity of the problem and then explore and plan an appropriate multi-professional intervention to support those in trouble is what is necessary. That is why I truly believe the project is pivotal in understanding, first of all, the difficulties a Roma family with a deaf member is facing and secondly how can be supported. I am already part of these Roma families with a deaf member and I can share that it is a challenge because there are so many barriers (psychologically, morally, and financially) and there is a lack of knowledge in how to support and even understand your own family member. And here is where the project comes up and offers that knowledge by sharing other people's good or bad experiences from where you can learn and moreover offers you a platform of services that we can all access to improve the development and integration of deaf Roma children in the UK.

Nicoleta Calin

The background to the study

This project sits within the deaf education research, development and training portfolio in the School of Education at the University of Leeds and builds on established research with multilingual deaf children and their families. The aim of the project was to begin to identify the learning, development and social needs of deaf children of Roma families to inform the planning of appropriate multi-professional intervention and support. Health and educational professionals working in the field of deafness have become increasingly aware of a growing population of deaf children among Eastern and Central European migrants to the UK and in particular those of Roma heritage. Low levels of educational achievement of Roma children in their countries of origin have been extensively reported. In addition the low level of educational achievement of deaf children has also been widely documented. Deaf children and young people of Roma families, therefore, would seem to face a particular set of complex challenges. It is important that practitioners have knowledge and understanding of these experiences in order to support this cohort and optimise their educational experiences.

This has been a collaborative project from the start. In order to begin to identify the needs of these deaf children and young people it was evident that practitioners would need to be involved from the outset of the project, as well as the children and their families. A general invitation was, therefore, sent to local authority Heads of Support Services for deaf children, Heads of Schools for the deaf voluntary sector organisations and other researchers in the field. An initial network meeting was set up for all interested parties and the project team emerged from this symposium. The project proposal and funding application was led and coordinated by Professor Ruth Swanwick, supported by Dr Jackie Salter and Dr Jess Elmore and contributions were made by all partners.

What do we mean by Roma?

The Roma originate from a number of Central and Eastern European countries including Bulgaria, the Czech Republic, Poland, Hungary, Romania and Slovakia and are distinct from the indigenous Gypsy and Traveller Community in the UK. The Roma are a specific ethnic group that has experienced racism, hostility and persecution throughout their history so shaping their cultural response to other communities. Families with a Roma ethnic heritage that have migrated to the UK are also part of the wider social and economic forces of migration seeking a better life for their children. However, Roma communities in the UK continue to experience poverty, discrimination and health and educational inequality.

Why is deafness significant for Roma communities?

Deafness is reported to be more common among Roma families than across the wider population. There is established research that confirms and explains this linking the high incidence of deafness to the presence of a recessive gene in some Roma populations that leads to pre-lingual moderate to profound deafness being passed onto children (Araceli et al., 2005, Mašindová et al., 2015).

Research also indicates there is a higher level of hearing and sight loss than in the general population but a lower level of use of hearing aids and glasses and that Roma with hearing or sight loss are more likely to have poorer mental health and lower levels of social participation than other members of their community (Latorre-Arteaga et al., 2017).

Understanding different levels and types of deafness is complex and the exact nature of an individual's hearing loss and the impact on their lives will be unique to each person. Simply put, we can understand deafness in terms of being able to hear, or not, another person talking at a normal conversational level. With a moderate loss a person will have difficulty following speech even in a quiet situation. A profound hearing loss means a person will be unable to follow speech even with hearing aids. We have focused on childhood deafness and the crucial implications for early language development and learning although we recognise that there are also issues of undiagnosed and/or untreated deafness among the adult Roma population.

What did we do?

The study comprised three stages of data collection undertaken in the order indicated below. Results from the national survey informed the approach to the institutional questionnaire and interview which in turn shaped the nature of the case study interviews. For each stage all the partners were instrumental in deciding the focus and developing the questions.

1. **National Survey:** A brief questionnaire was sent out to all Heads of Support Services for deaf children (132 authorities) and Heads of the 17 Schools for the Deaf in England. This very short on line survey consisted of just 5 questions and aimed to provide a snapshot of the number of deaf Roma children and where they currently live.
2. **Institutional questionnaires and interviews:** Detailed questionnaires were sent to our local authority partners. The five authorities were Bradford, Leeds, Peterborough, Rotherham, and Sheffield. The questionnaire consisted of a range of questions exploring how services engage and work with deaf Roma children and their families, including the challenges and successes they have experienced. Once the questionnaire had been completed and reviewed the authority representative who provided the answers, often with other key member of the support team was interviewed to provide clarification and further details.
3. **Case Studies:** Finally the representatives from the deaf education services helped us to identify four deaf children and their families willing to take part in an interview to discuss and share their experiences. This included two families with preschool children, a KS2 child and a KS3 student.

How many deaf Roma children are there?

Responses to the National Survey were received from 10 out of the 17 schools for the deaf and 73/132 Local Authority Services for deaf children. As anticipated there were some LAs who supported a number of deaf Roma children and their families whilst the highest proportion reported none on their caseloads. There was just 1 Roma child identified as attending a school for the deaf. Table 1 provides an overview of LA services and the number of deaf Roma children they support.

Institution	Number of deaf children	% of total institutions
School for the Deaf (17)	0	53
	1	6
	No Response	41
Deaf education service (132)	0	28
	1-5	19
	5+	8
	No Response	44

Table 1

The 11 LA services that reported 5 or more deaf Roma children were Bradford, Derby, Doncaster, Kent, Leeds, Manchester, Medway, Newcastle-upon-Tyne, Rotherham, Sheffield and Warwickshire. These are all areas known to have significant Roma communities. However, further analysis of the number of deaf Roma children in our case study local authorities suggests that there are discrepancies in these figures. As table 2 shows Sheffield has a far higher case load of deaf Roma children than other areas despite a similar Roma population.

Name of deaf education service	Total caseload	Deaf Roma children	Percentage of LA Case load	Estimate of Roma community in LA
Bradford	805	41	5%	6000 ¹
Leeds	920	8	1%	5000 ²
Peterborough	252	4	2%	1500 ³
Sheffield	643	110	17%	5000 ⁴
Rotherham	383	34	9%	4000 ⁵

Table 2

¹ (Ingold,2016)

² (Jeffreys et al, 2016)

³ (Fremlova, 2009)

⁴ (Willis,2016)

⁵ (Jamroz &Tyler,2016)

One reason for this may be localised patterns of migration and deafness but it may also indicate that the number of deaf Roma children is under reported in other areas. Evidence from previous research identifies that Roma families are reluctant to self-report their Roma origins. An additional factor in this is that many local authorities were not following best practice in obtaining this ethnic data. Only 9 local authorities said that Roma was treated as a separate ethnic category (as recommended within education (Penfold, 2016)), the others either did not know or used the category Gypsy, Roma, Traveller. Services also generally relied on data collected elsewhere in the local authority. Where data collection was more effective, services re-visited the question once trust had been established. One service reported that families were more likely to say they were Roma to a member of staff who was also Roma.

I ask do you use Roma at home. As a gentle question ... It can be difficult working out what languages are used. Some will say straight away but the minority. Others will wait. Once they get to know you and feel comfortable they will say or I can ask. Teacher of the Deaf

Equally the case study stages of our research suggest that undiagnosed deafness is a significant issue for both adults and children from Roma communities as it was common for children to be diagnosed late and for there to be adults whose deafness was undiagnosed or had been diagnosed late.

This under-reporting raises a number of issues for the deaf children and their families as well as policy development. The consequences in terms of undiagnosed and untreated deafness are significant for the development of language, speech and learning skills. In order to affect appropriate policy change accurate data regarding the number of deaf Roma children is an essential prerequisite.



What is the nature of deaf Roma children's hearing loss?

Whilst it is fully acknowledged that every person and child's hearing loss is unique, in order to provide a basic understanding of the types of hearing loss deaf Roma children experience, the deaf education services were asked to provide basic information regarding the level of hearing loss using standard audiometric descriptors. Table 3 provides a summary of the information provided by the demographic survey in comparison with national data. Even with the under-reporting discussed above, it is also significant that according to our statistics Roma children make up 0.75% of the deaf children in England while one estimate suggests that Roma make up 0.3 of England's population (Brown et al., 2013). It is also noteworthy that Roma children are more likely to have more severe levels of hearing loss than the general population of deaf children and so require more support.

	Deaf Roma children	All deaf children (CRIDE 2017)
Mild	13%	26%
Moderate	42.%	32%
Severe	24.%	9%
Profound	14%	12%
Unilateral	7%	20%
Total number	344	45,631

Table 3

What did we learn from our case studies?

The case studies were the most challenging aspect of the project but the most rewarding. We were very concerned about intruding on the privacy of families and asking them to talk about potentially difficult issues. The local professionals, interpreters and key workers helped us to do this with sensitivity. These studies helped us to understand more about the children's home and school lives and the parents' experiences and understandings of deafness, and their hopes and expectations for the future.

We took an intersectional approach to understanding the precarities of being deaf and being Roma (Crenshaw, 1989, Kóczé 2009). This means that we tried to understand the overlapping layers of disadvantage associated with being deaf and being Roma. The use of this approach is helpful for seeing and reporting the interaction between complex and multiple identities. In our project the two intersections are being deaf and being Roma. We explore how they intersect in terms of language and navigating complex systems but also recognise the resources that Roma families possess. In the following sections we look across our institutional and family case studies, drawing the data together across the three themes.

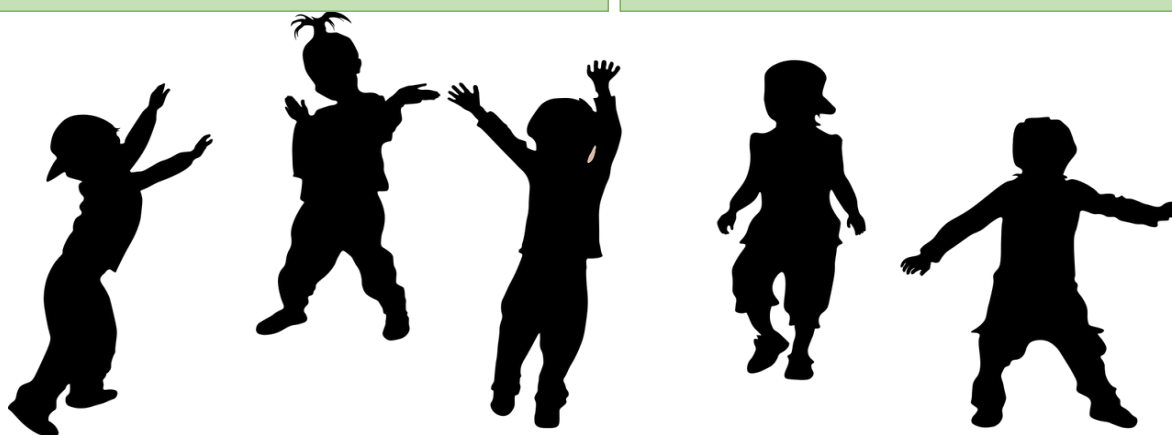
Who are the children and families in our study?

Eva is a 12 year old Czech Roma girl. She lives with her parents and three siblings. She has a moderate to severe hearing loss which was diagnosed at 3. One sibling is also deaf. She goes to resourced provision in a secondary school and her favourite subjects are English and History. She likes hairdressing and watching YouTube videos. She uses sign language, English, Czech and Roma.

Martin is an 11 month old Roma Slovak boy. He lives with his parents and two siblings. He has a moderate hearing loss in both ears which was diagnosed at birth. One of his siblings, his grandmother and his cousins are deaf as well. He likes playing with pots and pans. His parents speak Roma and Slovak and his older siblings also speak English.

Zuzana is a 10 year old Roma Slovak girl. She lives with her mother, stepfather and five siblings. She has a moderate hearing loss in both ears which was diagnosed at 8. Her mother is also deaf. She goes to her local primary school. Her favourite subject is Maths. She likes riding her bike and dressing up. Her family use English, Slovak, Roma and Pakistani.

Peter is a three year old Roma Slovak boy. He has a moderate hearing loss in both ears which was diagnosed when he was 2. He lives with his parents and younger sibling. His parents and his step-siblings are also deaf. He is looking forward to starting nursery soon. His favourite toys are bikes and cars. His family speak Roma, Slovak and a little English.



Language

Language experience and development through childhood and beyond is at the heart of this study. Many of the issues associated with being deaf, being Roma and being deaf Roma come back to how we learn, develop and understand the world through language and the role that our environment and those around us play in this. Childhood deafness has a profound impact on language development and being Roma often implies a richly complex language experience and environment. It is not surprising therefore that the educational support of deaf Roma children in school focuses primarily on language use and development.

What do services say?

All services recognised that Roma households were using multiple languages. Services used a range of strategies to try and capture children's language profiles and were aware of the complex issues of multi-lingual testing. However older children were often only assessed in English with time and budget constraints a limiting factor.

Late diagnosis was seen as one of the primary issues for language development in terms of lost opportunities for timely audiological and educational support.

Often with these children there is quite a lot in their heads. They are amazing they've been using coping strategies for years but with no spoken or sign language it's quite tricky to get that out...They have sat in rooms where education has been happening around them but haven't been accessing it per se. They can therefore come into secondary with no or very limited language. Teacher of the Deaf

There were also some concerns expressed that households were not providing a rich enough language environment for their children and that some families had low expectations for deaf children.

The thing that would help enormously is language in the home. Many of our parents don't speak English at home and so that interaction with parents is missed and that's quite unfortunate. And because the children are deaf they also don't pick up on the home language so where they speak Romanian for example the children aren't picking up on that and so don't have a strong home language and that's unfortunate because that would really help their language skills. Teacher of the Deaf

What do families say?

All the households in our research had two or more spoken languages (combinations of English, Roma, Slovakian, Czech and Pakistani were reported). The two older children reported using different languages with different people with both showing a preference for English.

She has learnt in English. She can't even read in Slovakian. She doesn't know the alphabet, the colours or the letters. When the children talk between themselves at home it's English. When they fight or argue it's always in English. Zuzana's mother

Each household also had more than one deaf member and there was evidence they had developed their own communications strategies, for example, Martin's family depended on visual communication with his grandmother. No families were using a recognised sign language although Eva was learning BSL (British Sign Language) at school and was enthusiastic about it after initial reluctance.

In Maths it's hard to understand the teachers. And then [she signs a teaching assistant's name] signs and I know. Eva

Families also recognised the importance of hearing technologies for language development. Three of the four families had a late diagnosis of deafness; only one was identified through new-born hearing screening in the UK. However consistent hearing aid use was an issue for Peter and Zuzana. These families also seemed to see hearing aids as important for safety rather than language in the first instance.

If she is playing I don't need to shout. And if she is playing she can hear the noise around her, the cars so she's safe. If she doesn't have the hearing aids she can't hear anything... in the morning she puts them on and takes them off in the evening. Zuzana's mother

There was also evidence that written language was of limited importance in these households; Martin's family asked for help reading a letter written to them in Slovakia.

Navigating systems

We bring to this work a recognition that many parents of deaf children feel initially overwhelmed by the new information, demands, expectations and decisions that they encounter as they enter into the world of audiological and educational support for their deaf child. For Roma families, to engage with these new challenges in an unfamiliar context, with uncertainty about the language of the organisations and anxiety about attitude and safety is hugely burdensome. We explored professional perspectives on this and also examined ways in which families approached these challenges.

What do services say?

There was a recognition that families had different expectations to services about the early intervention of a Teacher for the Deaf.

Families are reluctant to engage if children are young; they don't understand what the role of an educational professional might be when children aren't expected to start education until much later. That contrasts with new born hearing screening where we are in straight away. Head of service

There were similar issues around families' attitudes to audiological support for very young children where families may be unsure about the need for hearing aids for this group.

I think hearing aid for really young children following diagnosis isn't great. That takes some time to establish. And again I can't prove this but I have this feeling it is because they are a baby so you don't need to do this yet. It's that understanding we need to do it as soon as possible.
Audiologist

Families' historic experiences of discrimination and racism were also seen to affect how they engaged with services. Teachers of the Deaf recommended taking a holistic approach, focusing on the whole family rather than just the deaf child. They described relationships built up over time; such as having to make multiple visits in order to win families' trust before effective intervention could take place.

Attendance and engagement with audiology services was a particular issue. Some services had adopted effective strategies to address this using outreach and a multi-professional approach.

It has been a massive issue over the last years but I would say we had a multiple pronged strategy to get that particular community to come in for appointments. We went to schools to get the initial testing to get over the [Do Not Attend] so they didn't have to get in touch with us. They were happy to consent through schools because it was easier. Getting interpreters to ring up before the appointment to remind families. We did have a good action plan to reduce the DNA rate for this community.
Audiologist

Interpretation was recognised as essential for helping Roma families navigate complex systems. One service found employing a Roma member of staff rather than relying on Slovakian interpreters invaluable. For other services there were issues around interpretation and one case where use of the wrong language had led to misdiagnosis. These communication challenges were compounded by many families not being literate in any language. Our findings revealed the complexity of the interpreting issues in these contexts in relation to expectations and practices as well as financial constraints but also highlighted that the most positive experiences of families were those where communication was appropriately mediated. Interpretation was an issue because of the pressure it placed on limited budgets and because it was a barrier to communication.

I think because of the language barrier and the fact that you are usually interpreting through an interpreter you don't always get all of it. You aren't always sure how much they've understood or how willing they are to say they've not understood. And how much is just nodding because we are expecting them to understand so they just give us the response they think we want. It's hard to gauge. Audiologist

The mobility of Roma families was identified as another challenge for services. Families would move within and between areas meaning it was difficult to offer a consistent approach. This was difficult when resources had been put in place to support a child.

Families did not always want to engage in the way that services expected or wanted. This was evident in three services who had tried to encourage Roma families to attend coffee mornings or toddler groups. However, they all reported that these activities had not been successful.

Concern was expressed that Roma families were not always able to advocate for their children to get them the support they needed.

We need to educate families about the systems; they are a disadvantaged group and can find it difficult to fight for their child. Their children have experienced discrimination. I can find it a difficult balance between being a council officer and helping them fight their corner. Families aren't articulate enough to fight for their children. Native populations know they need to fight the system. I worry about families who say 'Whatever you think is best' as they won't always have access to me. Teacher of the deaf

However, it was recognized that over time Roma families were learning how to engage with services to better support their children.

It comes from the positive community thing. They are close knit. They do share information and knowledge. And there has been, education have done a huge amount of work around it. And they do have some key people who are part of their community who will go in and get parents on board, share information, give information. And that's helped a lot. Audiologist

What do families say?

It was difficult for families to understand the complex landscape of support they had to navigate. For example, there was confusion about whether Teachers of the Deaf were doctors or educators.

Peter's mother asks their teacher if it is OK if they go on holiday. ToD is confused about what she means. She says they can go on holiday when they want; they just need to change the appointment. She explains that once your child is at school then you need to be more careful about when you go on holiday. She explains that ToDs aren't the hospital.

Zuzana's mum found it difficult to describe what happened at audiology appointments as did the two older children.

She look in your ears and then [makes the sign for headphones]... and you pick a toy that you like. Eva

However, there was again evidence that families learnt over time how to navigate systems. In contrast to Zuzana's mum, Martin's family had learnt from their previous experiences of engaging with health services.

Martin's hearing loss was discovered at newborn screening. They explain they had to go for a second appointment; a bone conduction test. They say his deafness is inherited and they know about it from their older son.

The families relied on and valued interpreters for hospital appointments. This reflected a wider appreciation of the support their children had received and recognition that this support would not have been available to them in their home countries.

Family resources

Our research explored the precarities and disadvantages of being a deaf Roma child but one important finding that emerged was the strength of these families in supporting their children. With the negative attention directed towards Roma families it is important to acknowledge this. However, we recognise that the families in our research were successful families. They had the resources to move to the UK and to engage not only with services but with the research team.

What do services say?

Services recognised that many families had difficult personal circumstances; poverty, poor housing, limited education and precarious work. However they recognised that families prioritised their children's care despite these precarities. Generally this was seen as families being caring and protective of their children and having large extended networks to care for their children. More specifically, families had an understanding of deafness because of their family histories that meant they could support their children.

What do families say?

We saw in our research families who were chiefly concerned with the normal preoccupations of family life; of parenting and growing up. The older children enjoyed going to school and playing with their friends while Peter was looking forward to starting nursery.

I ask Peter if he is [looking forward to nursery] and he says yes [in Roma] and smiles and laughs... His mother says the other day he was cross because he went to nursery to visit and wanted to stay.

The families were also very keen to ensure that their children were given the opportunity to flourish and achieve in a safe and supported environment and took appropriate action to help them.

Peter's mother says before he got his hearing aids his speech was OK but he couldn't understand...She says at first she thought he was fine; he learnt to walk when he was seven months and she thought he was developing well. She phoned the doctor and got a referral to the hospital. She says it is better now he's got hearing aids and she thinks they are helping.

They also had an understanding of deafness. All our case study families reported that there were other members of the family and/or extended family members who were deaf and so they were familiar with strategies for communication.

I mean they seem to have an awareness because family members are deaf. But when we've spoken about Grandma; she didn't have a hearing aid and when I talked about that and why she might benefit... I think they understand that because we've got in early with Martin it will be easier for him, they understand that and the need for him to wear his hearing aids so he can make sounds and develop speech and language; they do understand that.

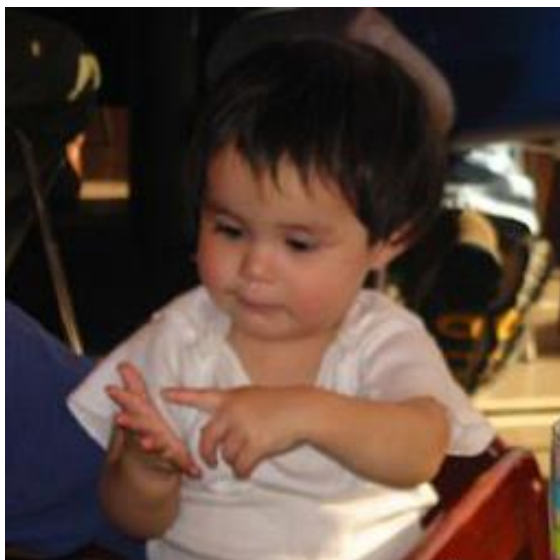
Teacher of the Deaf

Overall, the families were then happy with their children's progress, the support they were receiving and were positive about their future prospects.

Continue with her education, start high school or college. That she will be something and not have a life like me. Like I was without school. It's different here and in Slovakia with the school. Zuzana's mother

Summary

We were very grateful that these four families gave us their time and shared their experiences with us. We recognise that every Roma family is different and do not want to generalise. However what these families told us was invaluable in helping understand what it might mean to be deaf and Roma.



The project produced quality information concerning Roma deaf children and young people – an area in which there was previously little firm national data. I am sure it will aid Teachers of the Deaf and others in the field to reconsider the needs of Roma deaf children, and help improve implementation of best practice in this area.

Tina Wakefield, Ear Foundation

The outcomes of this project will assist Teachers of the Deaf in their work with a wide range of deaf pupils – not just those from the Roma community. It is of particular value to the profession as it is the first time that these issues have received such detailed consideration. BATOD looks forward to supporting the next phase of research.

Paul Simpson, British Association of Teachers of the Deaf



The project has enabled me to reflect on my own practice, develop a better understanding of the needs of deaf children from Roma families and to learn from colleagues across local authorities about strategies for meeting these needs. Although many challenges remain I feel that this project has helped me gain greater insight and provides a firm foundation for building engagement and trust with families in the future. We as a service look forward to reading the final report.

Sandie Griffiths, Teacher of the Deaf Bradford

Our reflections and conclusions

Being deaf and Roma

From our research we can begin to understand the overlapping experience of being deaf and being Roma, the associated precarities for growth and development and the priorities for education and health services. For a hearing Roma child there are already challenges for their language and literacy while childhood deafness equally impacts on language development. For young deaf children from a Roma context there is then an additional and extended risk of 'lost time' in terms of the critical period for early language development. The educational challenges for deaf learners are also exacerbated for Roma children. There is the same pattern of double disadvantage in health services and hearing technologies; lack of information and support for Roma families' compromises informed early access to hearing technologies.

The significance of our research

This research has not been done before. The issues of childhood deafness are not examined in the Roma research and the issues of being Roma in the UK are not discussed in the deaf education and studies research. It is important that the issues surrounding childhood deafness are seen and addressed for Roma communities and that the issues associated with being Roma in the UK are understood within deaf education. Our research, for the first time makes visible these issues.

An understanding of deafness and Roma as intersectional issues helps us place our research in a wider context. We already know that the health inequities experienced by Roma communities are made worse by issues such as racism, poverty and low educational achievements but also contribute to their social exclusion Escobar-Ballesta et al. (2018). And we can see the same pattern in our research.

The undiagnosed deafness among the Roma adults that we encountered is likely to have impacted on their own educational achievements and so social integration, this will then affect their access to services and so make further missed diagnosis possible.

The mobility of Roma families, often due to factors such as poor housing and insecure employment (Morris, 2016) decreases their visibility in the system and compromises informed educational and clinical support.

The issue of data collection where families are reluctant to self-ascribe adds another layer of disadvantage as it means they are not visible to services and are so not prioritised. This is connected to the wider issue that services need to be culturally representative rather than only reflect white British attitudes and values (Ahmad et al., 1998).

The families in our case studies are generally hopeful for their children's future and happy with their progress. However the wider analysis of these issues is more pessimistic. The risks to language, social development and school achievement associated with childhood deafness combined with the precarious education and health support available to Roma families are considerable.



It was an honour to attend the event and to see so many interested and diverse people from various sectors, at the symposium. I would have loved to have seen some of the families and the children also included. I think also inviting Roma families that were not directly involved in the project would have been nice. It would have opened up a space and allowed the various participants to connect. I also appreciated the variety of presentations. On that note, it was inspiring to see that intersectionality was considered in the research and that the Principal Investigators were so careful and sensitive with their language. The classifications that were presented at the beginning were very useful as it contextualized the framework of the project and the research. However, it was equally inspiring to see that those classifications or titles were simply benchmarks and that the research team was not held hostage by those terms. The information and the potential of the project opens up several research avenues that need exploring. This is exciting and I imagine daunting. As a Roma woman, mother, activist, artist and researcher these interdisciplinary projects offer me hope and inspire me.

Rosa Cisneros, Roma Futures

Engagement and impact



Our plenary conference was the first step along the way to disseminating new information about deaf Roma children and bringing together a new community for further developing these networks. Feedback from our delegates suggests our research is already making an impact.

Having an understanding of some of the preconceptions Roma families may have about my profession will help me adapt my practice to reach out, connect and try to make myself and my service approachable

The way we interact with families- how we present information, finding out how the school/authority collect data on ethnicity, thinking of ways to include families as children get older and less home visits.

My experience today will encourage me to try and connect with a deaf child's parents who have given permission for us to support their daughter but not their deaf baby boy

Recommendations for deaf education services

There are several clear recommendations that we can make for services who work with deaf Roma children. These recommendations come from the good practice we learnt about in our discussions with services and from the direct experience of case study families.

There is a need for better data collection. Services should have Roma as a separate ethnic category from Gypsy, Roma, and Traveller. This information needs to be collected locally where possible and the question re-visited once trust has been established.

The mobility of Roma families was identified as an issue for services. We suggest the development of a national system to track children who move between local authorities so their support can move with them.

Services identified particular issues around assessments. It would be beneficial for services to have a better understanding of Roma children's multilingual language profiles. The language planning tool is one way to develop this understanding: <https://deafed.leeds.ac.uk/language-planning/introduction/>

Connected to the issue of assessment we found that services had developed bespoke resources such as translated assessments and leaflets. It would be beneficial to have a mechanism to share these resources.

We recommend that a multi-professional approach is needed. In our research, we saw audiologists, health visitors, teachers of the deaf, speech and language therapists and new arrivals teams working together to effectively engage with Roma children and their families. This approach is particularly needed for outreach work to identify undiagnosed children.

It would be valuable to develop a resource of positive Roma role models. This could include families and children who feel they have benefitted from support but also deaf Roma adults who are leading fulfilling lives.

It would be good to develop some kind of system of champions within the community, where parents who have seen what progress their children can make, could share this with others. Often this is a community who are told from outside what to do and not do, they are suspicious of authority. Head of Service

More broadly, services need to understand the exceptional circumstances of Roma families. This includes developing an understanding of the CE and EE context these families come from. However it is also important for services to recognise the strengths of Roma families and communities in supporting their children.

Employing Roma staff and making services culturally representative would help services address many of these other recommendations.

We need managers to understand and appraise our role! We are not just interpreters. We are crucial in those specific services. We need to feel valued, be promoted and be offered relevant training. Conference delegate

Develop a recognised route for parents of children with a hearing impairment to train as TAs to support deaf Roma children. Conference delegate

Recommendations for policy makers

It is important to recognise that there is likely to be undiagnosed deafness in some Roma communities amongst adults and children. This has wider implications for these communities' access to education and services. This needs proactive efforts to raise awareness of deafness and the support available among the Roma community and creative approaches to service delivery, mediated where needed through trained interpreters and community workers.

Improving outcomes for deaf Roma children is linked to the need for wider policy in relation to the Roma community and should not be viewed in isolation. These include better access to family learning, advancing employment opportunities and tackling racism. This implies a commitment at Government level to addressing the current precarities facing migrants in the UK and future risks associated with Brexit.

There is a need for adequate funding for deaf educators and Roma professionals to work with Roma communities to support children better. This would in turn be beneficial more generally for enabling the integration of Roma migrants in the UK. This implies the development of specialist courses and materials that enable the delivery of informed support and joined up intervention.

For families

We understand that once you find out your child is deaf you have to engage with lots of different services, are given lots of different information and need to make difficult decisions. It is a confusing time for any family. However, the families in our research showed us the resources that Roma families have in supporting their children. We hope that you can recognise and draw on these strengths when you engage with services.

It is important to develop the confidence to ask questions and ask for the support your family needs. This might be that you want a Roma interpreter or that your child needs more support at school. It might be that you don't understand what the audiologist told you or that your child's hearing aid doesn't fit them properly. Services will try to help you but they might not always understand your perspective, your culture or your past experience. You are the expert in your children's lives.





Your research project could become something bigger for the Roma community and for your department if this is what you are looking for. Your full approach and view on the conference was a warm one and kind towards the Roma community.

It gave me hope that you will continue to complete this project and challenge or attract the necessary governing bodies or SEN institutions and make it more public and visible for the relevant institutions who could make a huge change on the Roma's hearing Impairment progress at international level. I am aware that you have tried to engage with various families ...we need to work together with the Roma families and ask them as well, to be part of the research or project.

The fact that you are specialised in hearing impairment, it gives me hope that with your experience Roma people with hearing loss could have their image and their needs promoted and defended better in the society.

Terezia Rostas, Roma futures

At the National Deaf Children's Society, we support all deaf children and their families, and work with professionals to overcome the barriers that hold deaf children back. This includes deaf children from Roma backgrounds. The research undertaken by the University of Leeds is already making a huge difference in helping us better understand their needs and the barriers they and their families face in accessing services. We look forward to working with the University to make sure the findings are translated into improved provision, so that deaf Roma children get the same opportunities as any other child.

Ian Noon, National Deaf Children's Society

Further research

This study highlights the need for further research into the integration and representation of Roma communities in general in the UK. There is also a need to look to CE and EE contexts to fully understand Roma families' prior experiences of education and health/audiology support, how this has shaped their understandings of deafness and the potential role of technology and sign communication, and influenced their expectations of, and engagement with, institutional support.

The lack of research about deafness in the Roma community raises wider research questions about the education and health support of deaf children from other migrant populations at risk of exclusion. There are questions here about the development of language and communication strategies among families of deaf children with no audiological or educational support and wider demographic and epidemiological questions relating to the histories of non-diagnosis and aetiologies of deafness in families with multiple deaf child and adult members.

We also identify a wider research agenda around migrant children and disability. There is little existing research in this area from either migration or disability studies. What research there is focuses on service providers and parents while children's own voices are not heard (Curtis et al., 2018). The "double jeopardy" faced by these children means that there is an urgent need to develop an intersectional understanding of understanding of their experiences.

That said, we argue that the case of deaf Roma children presents exceptional circumstances relating to the heightened incidence of generational deafness among Roma families and the associated communication challenges, the complexities of the home language/ literacy environment; the historical drive to migration from discrimination and social exclusion, fear of self-ascription, and the culture of mobility. To conflate or lose sight of these particularities within wider migration issues could perpetuate deaf Roma invisibility in society. Future work should instead inform sensitive approaches to educational and health and support and sign post appropriate strategies for integration

Glossary

Audiologist - qualified professional who carries out hearing tests (in clinic) and interprets the results to determine individual levels of deafness and assess the options available for technological support

Cochlear implant - provides a means of hearing for children and adults who otherwise receive no or limited benefit from conventional hearing aids. A cochlear implant consists of an internal receiver/electrode package that is surgically implanted behind the ear and into the cochlea, and an external speech processor worn on the ear like a hearing aid.

Deaf - refers to all levels of hearing loss (mild, severe and profound), including unilateral deafness and temporary deafness such as glue ear.

Levels of hearing loss –the severity of the loss as classified by audiologists.

Mild Hearing Loss - a person cannot hear sounds soft such as a ticking clock or dripping tap. Although they can follow a one-on-one conversation, it can be difficult to catch every word in noisy environments.

Moderate Hearing Loss - a person may have difficulty understanding normal speech. One may be unable to hear the ringing of a doorbell or a telephone. Also, it can be difficult to follow or hear sounds during normal conversations.

Severe Hearing Loss – a person will have difficulty following a conversation without wearing a hearing aid.

Profound Hearing Loss - a person will not even hear loud sounds, such as airplane engines or fire alarms and will usually rely on the use of sign language and/or speech reading, gesture or other visual cues

Hearing aid - an in the ear device that amplifies sound by channelling the amplified sound through an ear mould into the ear using digital technology.

Migrant - a person who is moving or has moved across an international border or within a State away from his/her habitual place of residence

Radio aid – a device for improving access to sound in noisy environments that consists of a transmitter (used by the person who is talking) and a receiver (used by the deaf child/adult). A microphone picks up the speaker's voice. The sounds are then transmitted by radio waves to the receiver.

Roma - an Indo-Aryan, traditionally itinerant ethnic group living mostly in Central and Eastern Europe (Slovakia, the Czech Republic and Romania). As Europe's largest ethnic minority the vast majority live in severe poverty, suffer from poor health and are victims of racism and systematic exclusion.

Sign language –a visual means of communicating that uses the visual-manual modality to convey meaning. Sign languages are full-fledged natural languages with their own grammar and lexicon that have regional and national dialects. Sign languages are not universal and they are not mutually intelligible, although there are similarities among some sign languages.

Teacher of the Deaf - a teacher who is additionally qualified to work with deaf children in special school, resourced or mainstream contexts

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