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Educational inclusion of children who are deaf or hard of hearing and from Roma families: Implications for multi-professional working

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Abstract:	This research examined the educational inclusion of children who are deaf or hard of hearing (DHH) and from Roma families who have migrated to England. The study was co-developed with practitioners in the field and involved: a demographic survey of deaf education services; five institutional case studies of local authority services and four individual case studies of children who are DHH and from Roma families. An intersectional approach to the analysis of the data revealed the different vulnerabilities associated with being a child who is DHH and being from a migrant Roma family in England. The study provides the first estimate of the numbers of children who are DHH and from Roma families in England. It also documents an overview of the support offered to Roma children by local authority services and offers insights into the experiences of families and children. In conclusion, it considers the implications for multi-professional practice.
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Educational inclusion of children who are deaf or hard of hearing and from migrant Roma families: Implications for multi-professional working

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Keywords: educational inclusion, deaf, hard of hearing, children, families Roma, migration, multi-professional working

Introduction

This paper reports on a study that examined the educational inclusion of children who are deaf or hard of hearing (DHH) from Roma families in England. The generic term Roma is used advisedly to describe Roma communities who have migrated to the UK from Central and Eastern Europe, recognising the ethnolinguistic diversity of Roma communities in these different global contexts. Whilst research has identified a heightened incidence of deafness in Roma populations (Álvarez et al., 2005; Mašindová et al., 2015), there is very little follow-up in terms of understanding the linguistic and cultural experiences of children who are DHH and of their families.

The potential vulnerabilities of being a Roma child

The racism, hostility and persecution faced by Roma people throughout their history in Europe are well documented and remain persistent despite sustained intervention (Brüggemann & Friedman, 2017). The migration of Roma communities to the UK, following the expansion of the European Union in 2004 and 2007, has been attributed in part to families' desire for a better life for their children and as an attempt to escape from the vulnerabilities of life in Central and Eastern Europe. Roma families may have anticipated that there would be less discrimination in the UK context (Sime, Fassetta, & McClung, 2017).

However, racism and hostility to Roma communities persist in the UK (Cylkowska-Nowak & Nowak, 2011) and migration does not always lead to improved social mobility for Roma families and their children (Beluschi-Fabeni, Leggio, & Matras, 2018). The challenges of being Roma and new migrants in the UK are considerable and burdensome on children who are unlikely to be have been part of the migratory decision-making process (Pantea, 2013).

The low level of educational achievement for Roma children in Central and Eastern Europe has been extensively reported (Bennett, 2012; Danova, 2015; Dvornik, 2014; Németh, 2014). Roma communities experience marginalization and educational discrimination (Cashman, 2017; Messing, 2017) and many of the children are educated in segregated schools or classes. In 2009, 27% of Roma children were enrolled in so called ‘practical schools’ (former special/remedial schools) in the Czech Republic as opposed to 2% of the non-Roma population. In 2014, this figure was still as high as 28%. These settings only provided a reduced curricula and proliferated institutionalized low expectations of pupils. This explains, to some extent, why Roma parents are reported to have concerns about sending their children to special schools (Cashman, 2017) and segregated settings (Messing, 2017). The same issues of uncertainty and distrust were illustrated in a study of Roma mothers whose experiences of low-quality education and illiteracy, combined with external pressures around family values and parenting, inhibited their confident engagement with institutional education (Sime et al., 2017). Roma children continue to underachieve in the UK as part of the ethnic category Gypsy, Roma, Traveller which is identified as the lowest-achieving ethnic group in British schools (Penfold, 2016).

Roma children living in the UK are likely to have complex linguistic profiles and live in multilingual households. Whilst multilingualism is normally considered an asset and not a deficiency (Payne, 2017), the Romani language is sometimes devalued by professionals who may not recognise it as a proper language (Kyuchukov, Villiers, & Tabori, 2017). In terms of language experience, Romani speaking children are likely be immersed in an oral rather than written culture and experience different literacy traditions, potentially generating challenges for a successful education in the UK.

Roma people face health inequalities as migrants and in their home countries. As well as potentially experiencing a range of health conditions and disabilities, they have a life expectancy that is10-15 years shorter than the European average (Escobar-Ballesta, García-Ramírez, Miranda, & Petrova-Benedict, 2018). Roma people frequently experience difficulty in accessing health care (Bobakova et al., 2015) and the provision of care is complicated by social determinants such as racism and unemployment (Escobar-Ballesta et al., 2018). The Roma are identified as Europe's most impoverished ethnic minority (Parekh & Rose, 2011) and for many, migration to the UK is not an end to poverty. Roma communities are more likely to live in poor housing and find it more difficult to access labour markets (Morris, 2016). The paucity of accurate demographic information regarding the number of Roma children in the UK presents further problems in the light of the these inequalities (Brown, Scullion, & Martin, 2013). The relationship between labelling and policy concerning Roma is complex (Sigona, 2005) and cannot be fully addressed here. However there are important recommendations for services to address some of these issues including the importance of employing Roma staff, raising cultural understanding, supporting families through early years education and multi-agency working (Morris, 2016; Penfold, 2016; Sime, Fassetta, & McClung, 2014) . However, these recommendations have not been considered in the context of deaf education research or practice.

Roma and deafness

The research regarding deafness within the Roma population is limited and generally focuses on epidemiological questions. Álvare et al. (2005) identified a recessive gene that causes a higher incidence of hearing loss among Roma populations by screening 34 Spanish Roma families. Mašindová et al. (2015) in a study of gene testing of 85, Hungarian Roma and 143, Slovakian Roma deaf individuals, identified a genetic mutation that causes pre-lingual bilateral moderate to profound sensorineural hearing loss. A further study that surveyed the vision and hearing of 1167 Spanish Roma families (Latorre-Arteaga, Gil-González, Vives-Cases, & La Parra Casado, 2017), identified higher levels of visual and hearing loss with lower levels of hearing aids and glasses among the Roma population than the general population. The authors suggested that Roma people with a sensory loss are also more likely to have poor mental health and lower levels of social participation. This research highlights the need for further studies on the causes and consequences of sensory impairment amongst Roma communities as well as the difficulties experienced in accessing healthcare.

Deafness, migration, ethnic minority and multilingual children

Of central importance to this study are the implications of childhood deafness for linguistic, social and cognitive development. The importance of early identification of deafness, timely intervention and support for families is uncontested (Yoshinaga-Itano, 2014; Sharma, Gu, Ching, Marnane, & Parkinson, 2019). Universal neonatal hearing screening, now prevalent throughout the world, identifies deafness within days of a child's birth making it possible to bring early intervention and support to families. Importantly it provides parents with the opportunity to consider cochlear implantation (Morton & Nance, 2006).

Deaf education research into migrant and ethnic minorities focuses predominantly on educational practice rather than the experience of the child (Willoughby, 2012). Whilst insights from practitioners may be limited, in terms of understanding children's experiences, they provide a useful context for this study (Amundsen, Wie, Myhrum, & Bunne, 2017). Migrant families with children who are DHH frequently find it difficult to navigate complex and unfamiliar UK services. It is recognised that such services are generally designed for the white British majority and need to be more culturally responsive (Lynas & Turner, 2013). Communication issues, and the need to understand cultural differences, present frequent challenges and highlight a need for more teachers who share the children’s ethnicity (Cannon, Guardino, & Gallimore, 2016). Similar issues, such as the need to liaise and communicate with parents more effectively, have also been identified in the Unites States (Wathum-Ocama & Rose, 2002). Synergies between the deaf education and Roma research such as the need for greater understanding of cultural expectations and aspirations, better communication and the importance of professionals from the same ethnic minority, underline the importance of this work.

The literature on deafness and multilingualism is more extensive than that on deafness and migration and is a developing field (Swanwick, 2016a). Children who are deaf and multilingual are seen as different from children who communicate through one sign language and/or one spoken language. Consequently there is a need to recognize the diverse language profiles of children who are deaf and multilingual (Swanwick, Wright, & Salter, 2016). Such children are growing in number and need greater support in maintaining and developing their home languages (Pizzo, 2016) whilst also acquiring new languages and cultures (Cannon et al., 2016). This presents challenges for deaf educational practitioners concerning pedagogies (Swanwick, 2016a), and language assessments (Pizzo & Chilvers, 2016), both fundamental aspects of educational provision.

There are increasing numbers of children who are DHH from Roma families in UK educational settings and practitioners need a clearer understanding of the children’s linguistic and cultural biographies. They also need to understand individual experiences of deafness, technologies, education and health organizations, to inform and optimize educational opportunities. To begin to address this changing landscape, this study was designed to:

- investigate organizational (education and health) approaches to the identification and support of children who are DHH and from Roma families
- examine the interrelated vulnerabilities associated with being a deaf child and being Roma
- consider the implications of the above for the development of multi-professional support practices.

Research approach and methods

To achieve these objectives an intersectional methodological approach was adopted that recognizes that the analysis of the singular categories of 'DHH' and 'Roma' cannot account for the multiple and simultaneous inequalities and vulnerabilities associated with being DHH and Roma (Crenshaw, 1989). The study was undertaken in consultation with a range of practitioners from local and national organizations who had an interest in the investigation and worked as partners with the project team. Partners included members of the UK Roma community, teachers of the deaf, heads of local specialist services, and national charities that represent deaf children and the Roma population.

The study design was sensitive to the methodological and ethical challenges of undertaking research with children from migrant families, and who have disabilities. A significant challenge was the development of approaches to gathering the perspectives of vulnerable participants. These issues were addressed by the use of Romani interpreters where appropriate and only collecting the necessary data directly from children in the presence of a trusted adult. Consent to be involved in the study was gained directly from the children as well as their parents. In common with many studies researching with Roma communities this was a small scale study. Full ethical approval was granted by the University of Leeds Ethics Committee.

Data collection

The study involved a demographic survey of local authority deaf education services and schools for the deaf in England. This comprised a short survey, distributed by email to heads of deaf education services and heads of school for the deaf in England that asked how many children, who were DHH and from Roma families were on their caseload.

Following this, five institutional case studies of local authority services were undertaken with the study partners. Methods included a questionnaire and interviews with key local authority personnel. Additional fact-finding interviews were undertaken with local authority representatives from two audiology departments, a support professional who worked with newly arrived families in the UK and a teacher of the deaf.

Four individual case studies were undertaken of children who were DHH and Roma, and their families. The children were between 11 months and 12 years old. Data were collected through interviews and observations. Where possible, the child was the key informant, followed by the parents and then the teacher. Full details of the participants are provided in table 4. Families, children, and services were self-selecting which influenced the findings. This is acknowledged in the discussion and conclusions.

Data analysis

The demographic survey data provided preliminary information about the number of children who were DHH and from Roma families in England and highlighted crucial issues associated national data collection. The institutional case studies generated information about the educational and audiological support provided to families. Responses from participants were examined to identify perceived vulnerabilities, support approaches and the constraints experienced by practitioners. The individual case studies provided information about the experiences of children and their families. An intersectional, inter-categorical approach to analysis, based on the methods developed by Winker and Degele (2011), was applied across the data set. Data were analysed using the distinct categories of being DHH and of being Roma in order to examine their interrelatedness at individual and institutional levels. NVIVO software was used to group and code the interview data to identify key themes and areas of complex disadvantage. Data were also examined to ascertain the ways in which individuals, families and professionals mitigated challenges. Throughout this phase emergent themes were identified, discussed and refined by the research team with input from two external readers until a consensus was reached. Findings from the three data collection points are presented separately in the following section and addressed collectively in the discussion.

Findings

Institutional demographics

This study represents the first attempt to map the number of children who are DHH and from Roma families in England. Whilst not a complete data set, it is an informative first step. The challenges of collecting this data were indicative of the complex nature of this research, revealing the invisibility of children who are DHH and from Roma families and the reluctance of families to self-ascribe as Roma.

A number of deaf education services were not confident about their statistics and suggested that the number of children from Roma families were under-reported, whilst other services were not collecting this specific ethnographic data. The case study data suggested a level of undiagnosed deafness within Roma communities. Table 1 provides details of the responses from local authorities and schools for the deaf.

Table 1. here

These figures partially reflect an understanding of the location of England's Roma populations (Brown et al. 2013). However, Table 2 presents unexpected findings. This table shows the figures for the institutional data gathered from local authorities in the study. It suggests that the proportion of children who are DHH and from Roma families is higher in Sheffield than in other local authorities with a comparable Roma population.

Table 2 here

This may in part be attributed to Sheffield's approach to the challenges of data collection and reflect localized patterns of migration and deafness within the Roma community (Álvarez et al., 2005). Additionally, the case study data indicated that there is undiagnosed deafness in Roma communities. There was a total of 344 children, who are DHH and from Roma families, reported (Table 3), however, this is likely to be low due to both undiagnosed deafness and failure to identify Roma children in local authorities

Table 3 here

Even with an incomplete data set, these children make up 0.75% of the children who are DHH in England while one recent estimate of the Roma population is that they constitute 0.3% of the total population (Brown et al., 2013). This table also indicates how the pattern of deafness in Roma children differs from the wider population of children who are DHH across England, by being clustered around the audiological criteria of moderate and severe.

Institutional case studies

The following six themes were identified in the Institutional case study data.

Family experience

Services indicated that the mobility of families, who moved within and between areas, was challenging to services particularly in being able to offer consistent support. However, they recognized that historic racism meant some families were suspicious of engagement with outsiders. They also recognized the strengths of Roma families who frequently had strong extended networks to support their children and were very concerned with their children's care and safety.

Languages at home and school

There was recognition that Roma households were multilingual, but services were generally not able to gain an understanding of a child's full linguistic profile. Practitioners had limited knowledge of Romani as a language and were concerned that children may not have sufficient access to their home languages as a result of their deafness. The challenges of working with families with an oral, rather than written, culture were also expressed.

Education: previous experience and expectations and current support

A mismatch in expectations between families and services was highlighted by many participants:

> 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. (Head of Service 1)

Services also showed awareness of how families' experience of education in Central and Eastern Europe influenced engagement, resulting in a general reluctance to access resourced provision and a suspicion of intervention.

Deafness: prevalence and understandings

All services described households where multiple family members were deaf. Questions were raised about how deafness was viewed in the Roma community and it was recognized that some families did not see the need for intervention. This was sometimes framed positively:

> Families with children who are DHH may well have deaf adults who have not had access to services and are OK. (Head of Service 1)

and sometimes negatively:

> Families have low expectations of outcomes for children who are DHH – there are often deaf adults in the family who don't speak or have any form of communication. (Head of Service 2)

Audiological support and engagement

Local authority services identified that Roma families were frequently reluctant to attend audiology clinics. Reasons for this were postulated, however, professionals acknowledged a lack of understanding regarding Roma families’ experience of audiology appointments. They considered, however, that developments in provision to embrace more flexible approaches for multiagency working, such as outreach clinics in school, were resulting in improved attendance. Services also identified some issues around engagement with hearing technologies, particularly with younger children. However, as families and communities learnt more about deafness and the medical and educational support available for their children they were more willing to engage with clinics and the technologies.

Relationships and communication

Building trust with families was described as essential, as was helping families develop the skills and resources to advocate for their children. Services were keen for families to engage in group sessions although such opportunities were frequently poorly attended. Complex interpretation routes were identified as particularly challenging for building relationships:

> (…) parents speak Slovakian … we're speaking English, the interpreter is speaking Slovakian and the parent will interpret in Romani to the child. (Audiologist 1)

One service employed a Roma worker and identified this as invaluable for interpretation, wider trust and cultural understanding.

In summary, local authority services were responding thoughtfully to the needs of children who are DHH and from Roma families. They identified the need to better understand Roma families' perceptions of deafness, along with their experiences of family, language, health and education. This set the context for the analysis of the family perspective that is often missing from research in this area.

Individual child and family case studies

The four individual case studies of Martin, Peter, Zuzana and Eva (names have been changed) involved interview and observation data. Table 4 gives details of each child and the adult respondents in each family.

Table 4 here

Three main themes emerged from the case study data analysis: language and communication, family resources, and the navigation of complex systems. These themes encapsulated complex and intersecting issues for the families in this study and highlighted ways in which identified challenges and vulnerabilities were mitigated.

Language and Communication

All case study participants described homes where more than two spoken languages were used (English, Romani, Slovakian, Czech and Pakistani). 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 Romani. Both children interviewed talked about the different use of languages with their parents, siblings and friends. For example, Zuzana spoke English to her brother and sister, Slovakian to her mum and dad and spoke Romani. In addition she was exposed to Pakistani as spoken by her father.

Families understood language development to be a priority and they recognized the importance of the consistent use of hearing technologies. Although some expressed anxieties about the use of sign language, they recognized the role of sign language and sign language support. A disadvantageous factor for these individuals was the delay in receiving hearing technologies. Only one child was identified through newborn hearing screening in the UK.

All teachers emphasized the vulnerabilities of language development delay and discussed the appropriate provision of sign language support, audiological intervention and consistent use of technologies. Teachers were aware of the multilingual nature of the children's homes. Whilst in some cases they attempted languages assessments using Romani or Slovak they generally acknowledged a lack of understanding of this aspect of a child's linguistic profile.

Family resources

Family and home as a domain of resource, where the issues of being Roma and

DHH were to some extent reconciled, and where the essential experiences of being a family member was the priority, emerged as salient themes. The case studies revealed that all four families had other DHH members in addition to those included in the study. Through this experience, and despite the lack of institutional support, families had developed understandings of deafness and strategies for communication:

> (…) when we've spoken about Grandma; she didn't have a hearing aid (…) She said it was OK... (Teacher 1)

It was also evident that the family structure provided strong support networks and that the sense of family was not disrupted by childhood deafness:

> His father says they want the best for their children. They are happy with the hearing aids, happy with their teacher… Their children are their responsibility and they will take care of them; they make them wear their hearing aids and take them to their appointments. (Parent 2)

Participants talked openly about general issues of parenting and of growing up and did not always dwell on the challenges of being DHH and being Roma. Parents were concerned with keeping the family close and seeing their children grow up happily. Children spoke of what they liked to do as well as their home and school friendships, irrespective of deaf/hearing status or ethnicity.

The navigation of complex systems

Parents found themselves acting as advocates for their children within unfamiliar specialist agencies and organizational structures. For families, this sometimes required them to approach other professionals to mediate on their behalf. Families expressed anxieties regarding the need to make decisions about unfamiliar educational contexts such as mainstream, resourced or special school provision for their child. They did not always seem sure of what should be expected from their visits to an audiology clinic and what the sequence of events should be. This was compounded by language differences and the need to work with interpreters, along with uncertainties of how health and education services interact. One family was confused about the different roles of the teacher of the deaf and the clinical professionals.

Families' previous experiences of clinical support were a further compounding factor where there had previously been an absence of, or a late, diagnosis:

> They took him to audiology in Slovakia but were told he wasn't deaf. However, when he came to the UK he was given hearing aids. (Teacher 2)

Despite the prior experience of deafness in all of the families, the use and understanding of audiological support were variable. Parents had to engage with professionals, develop new understandings of deafness and become familiar with technologies not previously accessible to them:

> His father says he is also deaf (…). He says he knew he was deaf in Slovakia but didn’t have a hearing aid until he came to the UK (…). (Parent 3)

Whilst there was some consternation about sending their children to a school out of the local area at a very young age, families were generally very positive about their children’s education prospects:

> She’s got the problem with the hearing, but she is still doing well. (…) The teacher said she worked hard so I’m happy (…) Continue with her education, start high school or college (…) she will be something and not have a life like me. (Parent 5)

Families also spoke of the positive changes that the technology had made and expressed a commitment to engaging with the audiological needs of their children:

> If she is playing, I don’t need to shout (…) she can hear the noise around her, the cars so she’s safe (…). (Parent 5)

It is important to acknowledge that these case studies are not necessarily representative of wider Roma populations. The families engaged with services and were willing to participate in the study, so they were likely to have had a positive experience. Additionally, they were either Czech or Slovak Roma and their experiences, particularly of deafness, may not be comparable to other Roma populations. Nevertheless, the central findings may resonate beyond these cases.

Discussion

Three overarching themes - language and communication, family resources and the navigation of complex systems - emerge from the institutional and case study data. These are discussed and implications of each of these for multi-professional working are considered in the following section.

Language and communication

There are recognised challenges in terms of the support and development of language at home and in school for all children from Roma families which relate to proficiency in the language of the home and the school environment (Payne, 2017; Sime et al., 2017). The perceived low status of Romani, combined with the use of Romani and other languages in their daily lives may lead to tensions (Kyuchukov, Villiers, & Tabori, 2017). As childhood deafness impacts on early interaction and language development, it adds significantly to these linguistic challenges (Kral & O'Donoghue, 2010). Whilst these challenges may, to some extent, be mitigated through early diagnosis, intervention and support, this may prove problematic for some Roma families. Additionally, opportunities for gaining an understanding of deafness and for learning sign language in Central and Eastern Europe may be limited. Anxieties expressed, and shared with other parents of children who are DHH including their lack of skills, the status of the language and its potential to be supportive of, rather than detrimental to, spoken language development (Ching, Scarinci, Marnane, Sjahalam-King, Button, & Whitfield, 2018).

The educational challenges for children who are DHH, which are mostly contingent on language experience and proficiency, are well documented in terms of progress and achievement. These challenges are exacerbated where the Roma families of children who are DHH are reluctant to engage with services particularly when their children are very young (Sime et al., 2017). This reticence is understandable given the educational discrimination and exclusion that some parents have experienced, combined with the complexities of provision, advice and the need for decision making encountered within the UK.

The same pattern of disadvantage applies within the health and audiological provision. Roma families are unlikely to have received much information, treatment or support with regards to deafness before arriving in the UK which may compromise their early and informed access to the appropriate support. Parents may not be aware of the potential benefits of technologies or know how to access them. Additionally, children may have lived with undiagnosed deafness and/or without technology for substantial periods of their early childhood.

Family resources

Despite these multiple disadvantages, families demonstrate and deploy several resources in ways that mitigate some of the circumstantial challenges. These resources related to family experiences, values and expectations. The families in the research were notable for their strengths in parenting and in the support of their children. Through personal experience of having one or more deaf family members, families in the study were all informed about deafness to some extent. This was sometimes technical knowledge but was mostly related to confidence in managing day-to-day communication. This aspect of the family experience may have mitigated the challenges of coming to terms with childhood deafness in an unfamiliar environment and have been facilitative of establishing diverse communication strategies in the home. Communication among the families, despite different proficiencies and preferences, was largely successful. Families knew how to use the shared language resources and deployed creative solutions to work around challenges, by using gestures and visual strategies. All of the families communicated optimism for the future of their children and in some cases celebrated what they had already achieved. Despite the vulnerabilities involved in adjusting to new systems, for these children and their families, migration to the UK provided them with support that was not available in their home countries. Families seemed motivated to respond to and build on the support that professionals offered. The emphasis on the value of the family and the responsibility of parents to keep their children close and safe was also evident as a resource that kept the family cohesive and protective around the child. The authors drew these conclusions whilst recognizing that the families in this study were already proactively engaging with services and that within the wider context of Roma migration, those families who choose to migrate are generally those with more resources (Grill, 2012).

Navigation of complex systems

Using the resources and support offered by the practitioners, the case study families were navigating the education and health systems for the benefit of their child. Whilst some problems were reported, such as confusion and linguistic obstacles, there was a commitment to work with the support available. Successful navigation of the education and health systems was seen where adequate interpreting and mediating support was available, where trust and working relationships were established between professionals and families, and where services had developed effective strategies for assessment, engagement and multi-agency working. The successful strategies adopted by professionals, who work with children who are deaf, are similar to recommendations in wider research and policy relating to Roma integration and engagement with services (Morris, 2016; Penfold, 2016).

Implications for multi-professional support

Two main challenges for support centres were the visibility of Roma people, and how services collect ethnic data. Findings suggest that the number of children who are DHH and from Roma families is under-reported and yet the high prevalence of deafness in Roma communities has significant implications for education, health and social participation. Professionals who work with children who are deaf need to develop appropriate ways to ask families if they are Roma rather than relying on external data such as asking what language families use. This is a sensitive approach that reflects how language is an integral part of identification as Roma (Friberg, 2018). Another strand of this invisibility is evidence of undiagnosed deafness amongst both Roma adults and children. There is a need for further outreach within Roma communities to identify these individuals and offer appropriate support. The final strand of this invisibility is within services. The value of employing Roma staff within organizations, not only as interpreters but at all levels, is evident within the research and the wider literature.

Building on previous research of multilingual children who are DHH (Swanwick, 2016b), it would be beneficial for teachers of the deaf to gain a full understanding of children's language profiles, including the distinctive characteristics of Romani where possible. Professionals need a greater understanding of these families who are already managing complex lives and where a diagnosis of deafness may compound a general mistrust of education and health authorities. An understanding of families' previous experiences and current expectations, combined with an understanding of their existing resources, is key to successful partnerships.

Conclusion

Through an examination of the relationship between being DHH and being Roma, overlapping areas of vulnerability that have serious implications for childhood development, education and achievement, as well as for longer-term health and wellbeing have been identified. Awareness of these factors can inform the development of professional practice by providing a better understanding of the issues and influences that shape the lives of children who are DHH and Roma, and their families. Wider issues of social exclusion and marginalization follow from these risks exposing a compelling case for probing these issues further. Within the UK there are pressing questions of how to approach the inclusion and representation of Roma communities in general. Additionally, there is a need to look to Central and Eastern European contexts to fully understand how Roma families' prior experiences have shaped their understandings of deafness, the potential role of technology and sign language, and influenced their expectations of, and engagement with, institutional support.

This also work reveals 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, whilst children's voices are missing (Curtis, Thompson, & Fairbrother, 2018). The "double jeopardy" of being DHH and of being Roma highlights an urgent need to develop a more extensive intersectional understanding of the experiences of these children. The heightened incidence of generational deafness, associated communication challenges, complexities of the home language and literacy environment, the historical drive to migration from discrimination and social exclusion, fear of self-ascription and the culture of mobility present exceptional circumstances. To conflate or lose sight of these particularities within the development of support practices would perpetuate and add further layers to the complex influences. Future work should, instead, inform sensitive approaches to education and heath, and support and signpost appropriate strategies for inclusion.

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Table 1. Response to the demographic survey to identify the number of children who are DHH and from Roma Families in England

Type of provision	Number contacted	Number of Responses	Number of children from Roma Families		
			0	1-5	5+
local authority Services	132	73	37	25	11
Schools for the deaf	17	10	9	1	0

Table 2. Number of children who are DHH and from Roma families in institutional case study local authorities

Name of deaf education service	Total caseload	Children who are DHH and from Roma families	Estimate of Roma community in authority
Bradford	805	41	6000
Leeds	920	8	5000
Peterborough	252	4	1500
Sheffield	643	110	5000
Rotherham	383	34	4000

Table 3. Comparison of children who are DHH and from Roma families to general population of children who are DHH

	Roma children	All children who are DHH
Mild	13%	26%
Moderate	42%	32%
Severe	24%	9%
Profound	14%	12%
Unilateral	7%	20%
Total number	344	45,631

Table 4. Details of case study families

Child	Martin Male	Peter Male	Zuzana Female	Eva Female
Age	11m	3yrs	10yrs	12yrs
Country of origin	Slovakia	Slovakia	Slovakia	Czech Republic
Hearing loss	moderate	moderate	moderate with conductive overlay	moderate to severe (*sic)*
Age of diagnosis	birth	2yrs	8yrs	3yrs
Current School	Preschool (plan for nursey at 3yrs)	Preschool will start nursey next term	Mainstream	Resourced provision
Lives with *denotes deaf family member	Mother Father Sibling 1*, 2	Mother* Father* Sibling 1	Mother* Stepfather Sibling1,2,3,4,5	Mother Father Siblings 1,2,3
Data collection	Interview & Observation: Father(P1) Mother (P2) Interview:	Interview & Observation: Father(P4) Mother (P3) Interview:	Interview: Child Mother (P5) Teacher (T3)	Interview: Child Teacher (T4)

	Teacher (T1)	Teacher (T2)		

Educational inclusion of children who are deaf or hard of hearing and from Roma families: Implications for multi-professional working

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This research examined the educational inclusion of children who are deaf or hard of hearing (DHH) and from Roma families who have migrated to England. The study was co-developed with practitioners in the field and involved: a demographic survey of deaf education services; five institutional case studies of local authority services and four individual case studies of children who are DHH and from Roma families. An intersectional approach to the analysis of the data revealed the different vulnerabilities associated with being a child who is DHH and being from a migrant Roma family in England. The study provides the first estimate of the numbers of children who are DHH and from Roma families in England. It also documents an overview of the support offered to Roma children by local authority services and offers insights into the experiences of families and children. In conclusion, it considers the implications for multi-professional practice.

Keywords: educational inclusion, deaf, hard of hearing, children, families Roma, migration, multi-professional working

Introduction

This paper reports on a study that examined the educational inclusion of children who are deaf or hard of hearing (DHH) from Roma families in England. The generic term Roma is used advisedly to describe Roma communities who have migrated to the UK from Central and Eastern Europe, recognising the ethnolinguistic diversity of Roma communities in these different global contexts. Whilst research has identified a heightened incidence of deafness in Roma populations (Álvarez et al., 2005; Mašindová et al., 2015), there is very little follow-up in terms of understanding the linguistic and cultural experiences of children who are DHH and of their families.

The potential vulnerabilities of being a Roma child

The racism, hostility and persecution faced by Roma people throughout their history in Europe are well documented and remain persistent despite sustained intervention (Brüggemann & Friedman, 2017). The migration of Roma communities to the UK, following the expansion of the European Union in 2004 and 2007, has been attributed in part to families' desire for a better life for their children and as an attempt to escape from the vulnerabilities of life in Central and Eastern Europe. Roma families may have anticipated that there would be less discrimination in the UK context (Sime, Fassetta, & McClung, 2017).

However, racism and hostility to Roma communities persist in the UK (Cylkowska-Nowak & Nowak, 2011) and migration does not always lead to improved social mobility for Roma families and their children (Beluschi-Fabeni, Leggio, & Matras, 2018). The challenges of being Roma and new migrants in the UK are considerable and burdensome on children who are unlikely to be have been part of the migratory decision-making process (Pantea, 2013).

The low level of educational achievement for Roma children in Central and Eastern Europe has been extensively reported (Bennett, 2012; Danova, 2015; Dvornik, 2014; Németh, 2014). Roma communities experience marginalization and educational discrimination (Cashman, 2017; Messing, 2017) and many of the children are educated in segregated schools or classes. In 2009, 27% of Roma children were enrolled in so called ‘practical schools’ (former special/remedial schools) in the Czech Republic as opposed to 2% of the non-Roma population. In 2014, this figure was still as high as 28%. These settings only provided a reduced curricula and proliferated institutionalized low expectations of pupils. This explains, to some extent, why Roma parents are reported to have concerns about sending their children to special schools (Cashman, 2017) and segregated settings (Messing, 2017). The same issues of uncertainty and distrust were illustrated in a study of Roma mothers whose experiences of low-quality education and illiteracy, combined with external pressures around family values and parenting, inhibited their confident engagement with institutional education (Sime et al., 2017). Roma children continue to underachieve in the UK as part of the ethnic category Gypsy, Roma, Traveller which is identified as the lowest-achieving ethnic group in British schools (Penfold, 2016).

Roma children living in the UK are likely to have complex linguistic profiles and live in multilingual households. Whilst multilingualism is normally considered an asset and not a deficiency (Payne, 2017), the Romani language is sometimes devalued by professionals who may not recognise it as a proper language (Kyuchukov, Villiers, & Tabori, 2017). In terms of language experience, Romani speaking children are likely be immersed in an oral rather than written culture and experience different literacy traditions, potentially generating challenges for a successful education in the UK.

Roma people face health inequalities as migrants and in their home countries. As well as potentially experiencing a range of health conditions and disabilities, they have a life expectancy that is10-15 years shorter than the European average (Escobar-Ballesta, García-Ramírez, Miranda, & Petrova-Benedict, 2018). Roma people frequently experience difficulty in accessing health care (Bobakova et al., 2015) and the provision of care is complicated by social determinants such as racism and unemployment (Escobar-Ballesta et al., 2018). The Roma are identified as Europe's most impoverished ethnic minority (Parekh & Rose, 2011) and for many, migration to the UK is not an end to poverty. Roma communities are more likely to live in poor housing and find it more difficult to access labour markets (Morris, 2016). The paucity of accurate demographic information regarding the number of Roma children in the UK presents further problems in the light of the these inequalities (Brown, Scullion, & Martin, 2013). The relationship between labelling and policy concerning Roma is complex (Sigona, 2005) and cannot be fully addressed here. However there are important recommendations for services to address some of these issues including the importance of employing Roma staff, raising cultural understanding, supporting families through early years education and multi-agency working (Morris, 2016; Penfold, 2016; Sime, Fassetta, & McClung, 2014) . However, these recommendations have not been considered in the context of deaf education research or practice.

Roma and deafness

The research regarding deafness within the Roma population is limited and generally focuses on epidemiological questions. Álvare et al. (2005) identified a recessive gene that causes a higher incidence of hearing loss among Roma populations by screening 34 Spanish Roma families. Mašindová et al. (2015) in a study of gene testing of 85, Hungarian Roma and 143, Slovakian Roma deaf individuals, identified a genetic mutation that causes pre-lingual bilateral moderate to profound sensorineural hearing loss. A further study that surveyed the vision and hearing of 1167 Spanish Roma families (Latorre-Arteaga, Gil-González, Vives-Cases, & La Parra Casado, 2017), identified higher levels of visual and hearing loss with lower levels of hearing aids and glasses among the Roma population than the general population. The authors suggested that Roma people with a sensory loss are also more likely to have poor mental health and lower levels of social participation. This research highlights the need for further studies on the causes and consequences of sensory impairment amongst Roma communities as well as the difficulties experienced in accessing healthcare.

Deafness, migration, ethnic minority and multilingual children

Of central importance to this study are the implications of childhood deafness for linguistic, social and cognitive development. The importance of early identification of deafness, timely intervention and support for families is uncontested (Yoshinaga-Itano, 2014; Sharma, Gu, Ching, Marnane, & Parkinson, 2019). Universal neonatal hearing screening, now prevalent throughout the world, identifies deafness within days of a child's birth making it possible to bring early intervention and support to families. Importantly it provides parents with the opportunity to consider cochlear implantation (Morton & Nance, 2006).

Deaf education research into migrant and ethnic minorities focuses predominantly on educational practice rather than the experience of the child (Willoughby, 2012). Whilst insights from practitioners may be limited, in terms of understanding children's experiences, they provide a useful context for this study (Amundsen, Wie, Myhrum, & Bunne, 2017). Migrant families with children who are DHH frequently find it difficult to navigate complex and unfamiliar UK services. It is recognised that such services are generally designed for the white British majority and need to be more culturally responsive (Lynas & Turner, 2013). Communication issues, and the need to understand cultural differences, present frequent challenges and highlight a need for more teachers who share the children’s ethnicity (Cannon, Guardino, & Gallimore, 2016). Similar issues, such as the need to liaise and communicate with parents more effectively, have also been identified in the Unites States (Wathum-Ocama & Rose, 2002). Synergies between the deaf education and Roma research such as the need for greater understanding of cultural expectations and aspirations, better communication and the importance of professionals from the same ethnic minority, underline the importance of this work.

The literature on deafness and multilingualism is more extensive than that on deafness and migration and is a developing field (Swanwick, 2016a). Children who are deaf and multilingual are seen as different from children who communicate through one sign language and/or one spoken language. Consequently there is a need to recognize the diverse language profiles of children who are deaf and multilingual (Swanwick, Wright, & Salter, 2016). Such children are growing in number and need greater support in maintaining and developing their home languages (Pizzo, 2016) whilst also acquiring new languages and cultures (Cannon et al., 2016). This presents challenges for deaf educational practitioners concerning pedagogies (Swanwick, 2016a), and language assessments (Pizzo & Chilvers, 2016), both fundamental aspects of educational provision.

There are increasing numbers of children who are DHH from Roma families in UK educational settings and practitioners need a clearer understanding of the children's linguistic and cultural biographies. They also need to understand individual experiences of deafness, technologies, education and health organizations, to inform and optimize educational opportunities. To begin to address this changing landscape, this study was designed to:

- investigate organizational (education and health) approaches to the identification and support of children who are DHH and from Roma families
- examine the interrelated vulnerabilities associated with being a deaf child and being Roma
- consider the implications of the above for the development of multi-professional support practices.

Research approach and methods

To achieve these objectives an intersectional methodological approach was adopted that recognizes that the analysis of the singular categories of 'DHH' and 'Roma' cannot account for the multiple and simultaneous inequalities and vulnerabilities associated with being DHH and Roma (Crenshaw, 1989). The study was undertaken in consultation with a range of practitioners from local and national organizations who had an interest in the investigation and worked as partners with the project team. Partners included members of the UK Roma community, teachers of the deaf, heads of local specialist services, and national charities that represent deaf children and the Roma population.

The study design was sensitive to the methodological and ethical challenges of undertaking research with children from migrant families, and who have disabilities. A significant challenge was the development of approaches to gathering the perspectives of vulnerable participants. These issues were addressed by the use of Romani interpreters where appropriate and only collecting the necessary data directly from children in the presence of a trusted adult. Consent to be involved in the study was gained directly from the children as well as their parents. In common with many studies researching with Roma communities this was a small scale study. Full ethical approval was granted by the University of Leeds Ethics Committee.

Data collection

The study involved a demographic survey of local authority deaf education services and schools for the deaf in England. This comprised a short survey, distributed by email to heads of deaf education services and heads of school for the deaf in England that asked how many children, who were DHH and from Roma families were on their caseload.

Following this, five institutional case studies of local authority services were undertaken with the study partners. Methods included a questionnaire and interviews with key local authority personnel. Additional fact-finding interviews were undertaken with local authority representatives from two audiology departments, a support professional who worked with newly arrived families in the UK and a teacher of the deaf.

Four individual case studies were undertaken of children who were DHH and Roma, and their families. The children were between 11 months and 12 years old. Data were collected through interviews and observations. Where possible, the child was the key informant, followed by the parents and then the teacher. Full details of the participants are provided in table 4. Families, children, and services were self-selecting which influenced the findings. This is acknowledged in the discussion and conclusions.

Data analysis

The demographic survey data provided preliminary information about the number of children who were DHH and from Roma families in England and highlighted crucial issues associated national data collection. The institutional case studies generated information about the educational and audiological support provided to families. Responses from participants were examined to identify perceived vulnerabilities, support approaches and the constraints experienced by practitioners. The individual case studies provided information about the experiences of children and their families. An intersectional, inter-categorical approach to analysis, based on the methods developed by Winker and Degele (2011), was applied across the data set. Data were analysed using the distinct categories of being DHH and of being Roma in order to examine their interrelatedness at individual and institutional levels. NVIVO software was used to group and code the interview data to identify key themes and areas of complex disadvantage. Data were also examined to ascertain the ways in which individuals, families and professionals mitigated challenges. Throughout this phase emergent themes were identified, discussed and refined by the research team with input from two external readers until a consensus was reached. Findings from the three data collection points are presented separately in the following section and addressed collectively in the discussion.

Findings

Institutional demographics

This study represents the first attempt to map the number of children who are DHH and

from Roma families in England. Whilst not a complete data set, it is an informative first step. The challenges of collecting this data were indicative of the complex nature of this research, revealing the invisibility of children who are DHH and
from Roma families and the reluctance of families to self-ascribe as Roma.

A number of deaf education services were not confident about their statistics and suggested that the number of children from Roma families were under-reported, whilst other services were not collecting this specific ethnographic data. The case study data suggested a level of undiagnosed deafness within Roma communities. Table 1 provides details of the responses from local authorities and schools for the deaf.

Table 1. here

These figures partially reflect an understanding of the location of England's Roma populations (Brown et al. 2013). However, Table 2 presents unexpected findings. This table shows the figures for the institutional data gathered from local authorities in the study. It suggests that the proportion of children who are DHH and
from Roma families is higher in Sheffield than in other local authorities with a comparable Roma population.

Table 2 here

This may in part be attributed to Sheffield's approach to the challenges of data collection and reflect localized patterns of migration and deafness within the Roma community (Álvarez et al., 2005). Additionally, the case study data indicated that there is undiagnosed deafness in Roma communities. There was a total of 344 children, who are DHH and from Roma families, reported (Table 3), however, this is likely to be low due to both undiagnosed deafness and failure to identify Roma children in local authorities

Table 3 here

Even with an incomplete data set, these children make up 0.75% of the children who are DHH in England while one recent estimate of the Roma population is that they constitute 0.3% of the total population (Brown et al., 2013). This table also indicates how the pattern of deafness in Roma children differs from the wider population of children who are DHH across England, by being clustered around the audiological criteria of moderate and severe.

Institutional case studies

The following six themes were identified in the Institutional case study data.

Family experience

Services indicated that the mobility of families, who moved within and between areas, was challenging to services particularly in being able to offer consistent support. However, they recognized that historic racism meant some families were suspicious of engagement with outsiders. They also recognized the strengths of Roma families who frequently had strong extended networks to support their children and were very concerned with their children’s care and safety.

Languages at home and school

There was recognition that Roma households were multilingual, but services were generally not able to gain an understanding of a child's full linguistic profile. Practitioners had limited knowledge of Romani as a language and were concerned that children may not have sufficient access to their home languages as a result of their deafness. The challenges of working with families with an oral, rather than written, culture were also expressed.

Education: previous experience and expectations and current support

A mismatch in expectations between families and services was highlighted by many participants:

> 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. (Head of Service 1)

Services also showed awareness of how families' experience of education in Central and Eastern Europe influenced engagement, resulting in a general reluctance to access resourced provision and a suspicion of intervention.

Deafness: prevalence and understandings

All services described households where multiple family members were deaf. Questions were raised about how deafness was viewed in the Roma community and it was recognized that some families did not see the need for intervention. This was sometimes framed positively:

> Families with children who are DHH may well have deaf adults who have not had access to services and are OK. (Head of Service 1)

and sometimes negatively:

> Families have low expectations of outcomes for children who are DHH – there are often deaf adults in the family who don't speak or have any form of communication. (Head of Service 2)

Audiological support and engagement

Local authority services identified that Roma families were frequently reluctant to attend audiology clinics. Reasons for this were postulated, however, professionals acknowledged a lack of understanding regarding Roma families' experience of audiology appointments. They considered, however, that developments in provision to embrace more flexible approaches for multiagency working, such as outreach clinics in school, were resulting in improved attendance. Services also identified some issues around engagement with hearing technologies, particularly with younger children. However, as families and communities learnt more about deafness and the medical and educational support available for their children they were more willing to engage with clinics and the technologies.

Relationships and communication

Building trust with families was described as essential, as was helping families develop the skills and resources to advocate for their children. Services were keen for families to engage in group sessions although such opportunities were frequently poorly attended. Complex interpretation routes were identified as particularly challenging for building relationships:

> (…) parents speak Slovakian … we're speaking English, the interpreter is speaking Slovakian and the parent will interpret in Romani to the child. (Audiologist 1)

One service employed a Roma worker and identified this as invaluable for interpretation, wider trust and cultural understanding.

In summary, local authority services were responding thoughtfully to the needs of children who are DHH and from Roma families. They identified the need to better understand Roma families' perceptions of deafness, along with their experiences of family, language, health and education. This set the context for the analysis of the family perspective that is often missing from research in this area.

Individual child and family case studies

The four individual case studies of Martin, Peter, Zuzana and Eva (names have been changed) involved interview and observation data. Table 4 gives details of each child and the adult respondents in each family.

Table 4 here

Three main themes emerged from the case study data analysis: language and communication, family resources, and the navigation of complex systems. These themes encapsulated complex and intersecting issues for the families in this study and highlighted ways in which identified challenges and vulnerabilities were mitigated.

Language and Communication

All case study participants described homes where more than two spoken languages were used (English, Romani, Slovakian, Czech and Pakistani). 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 Romani. Both children interviewed talked about the different use of languages with their parents, siblings and friends. For example, Zuzana spoke English to her brother and sister, Slovakian to her mum and dad and spoke Romani. In addition she was exposed to Pakistani as spoken by her father.

Families understood language development to be a priority and they recognized the importance of the consistent use of hearing technologies. Although some expressed anxieties about the use of sign language, they recognized the role of sign language and sign language support. A disadvantageous factor for these individuals was the delay in receiving hearing technologies. Only one child was identified through newborn hearing screening in the UK.

All teachers emphasized the vulnerabilities of language development delay and discussed the appropriate provision of sign language support, audiological intervention and consistent use of technologies. Teachers were aware of the multilingual nature of the children's homes. Whilst in some cases they attempted languages assessments using Romani or Slovak they generally acknowledged a lack of understanding of this aspect of a child's linguistic profile.

Family resources

Family and home as a domain of resource, where the issues of being Roma and

DHH were to some extent reconciled, and where the essential experiences of being a family member was the priority, emerged as salient themes. The case studies revealed that all four families had other DHH members in addition to those included in the study. Through this experience, and despite the lack of institutional support, families had developed understandings of deafness and strategies for communication:

> (…) when we've spoken about Grandma; she didn't have a hearing aid (…) She said it was OK... (Teacher 1)

It was also evident that the family structure provided strong support networks and that the sense of family was not disrupted by childhood deafness:

> His father says they want the best for their children. They are happy with the hearing aids, happy with their teacher… Their children are their responsibility and they will take care of them; they make them wear their hearing aids and take them to their appointments. (Parent 2)

Participants talked openly about general issues of parenting and of growing up and did not always dwell on the challenges of being DHH and being Roma. Parents were concerned with keeping the family close and seeing their children grow up happily. Children spoke of what they liked to do as well as their home and school friendships, irrespective of deaf/hearing status or ethnicity.

The navigation of complex systems

Parents found themselves acting as advocates for their children within unfamiliar specialist agencies and organizational structures. For families, this sometimes required them to approach other professionals to mediate on their behalf. Families expressed anxieties regarding the need to make decisions about unfamiliar educational contexts such as mainstream, resourced or special school provision for their child. They did not always seem sure of what should be expected from their visits to an audiology clinic and what the sequence of events should be. This was compounded by language differences and the need to work with interpreters, along with uncertainties of how health and education services interact. One family was confused about the different roles of the teacher of the deaf and the clinical professionals.

Families' previous experiences of clinical support were a further compounding factor where there had previously been an absence of, or a late, diagnosis:

> They took him to audiology in Slovakia but were told he wasn't deaf. However, when he came to the UK he was given hearing aids. (Teacher 2)

Despite the prior experience of deafness in all of the families, the use and understanding of audiological support were variable. Parents had to engage with professionals, develop new understandings of deafness and become familiar with technologies not previously accessible to them:

> His father says he is also deaf (…). He says he knew he was deaf in Slovakia but didn’t have a hearing aid until he came to the UK (…). (Parent 3)

Whilst there was some consternation about sending their children to a school out of the local area at a very young age, families were generally very positive about their children’s education prospects:

> She’s got the problem with the hearing, but she is still doing well. (…) The teacher said she worked hard so I’m happy (…) Continue with her education, start high school or college (…) she will be something and not have a life like me. (Parent 5)

Families also spoke of the positive changes that the technology had made and expressed a commitment to engaging with the audiological needs of their children:

> If she is playing, I don’t need to shout (…) she can hear the noise around her, the cars so she’s safe (…). (Parent 5)

It is important to acknowledge that these case studies are not necessarily representative of wider Roma populations. The families engaged with services and were willing to participate in the study, so they were likely to have had a positive experience. Additionally, they were either Czech or Slovak Roma and their experiences, particularly of deafness, may not be comparable to other Roma populations. Nevertheless, the central findings may resonate beyond these cases.

Discussion

Three overarching themes - language and communication, family resources and the navigation of complex systems - emerge from the institutional and case study data. These are discussed and implications of each of these for multi-professional working are considered in the following section.

Language and communication

There are recognised challenges in terms of the support and development of language at home and in school for all children from Roma families which relate to proficiency in the language of the home and the school environment (Payne, 2017; Sime et al., 2017). The perceived low status of Romani, combined with the use of Romani and other languages in their daily lives may lead to tensions (Kyuchukov, Villiers, & Tabori, 2017). As childhood deafness impacts on early interaction and language development, it adds significantly to these linguistic challenges (Kral & O'Donoghue, 2010). Whilst these challenges may, to some extent, be mitigated through early diagnosis, intervention and support, this may prove problematic for some Roma families. Additionally, opportunities for gaining an understanding of deafness and for learning sign language in Central and Eastern Europe may be limited. Anxieties expressed, and shared with other parents of children who are DHH including their lack of skills, the status of the language and its potential to be supportive of, rather than detrimental to, spoken language development (Ching, Scarinci, Marnane, Sjahalam-King, Button, & Whitfield, 2018).

The educational challenges for children who are DHH, which are mostly contingent on language experience and proficiency, are well documented in terms of progress and achievement. These challenges are exacerbated where the Roma families of children who are DHH are reluctant to engage with services particularly when their children are very young (Sime et al., 2017). This reticence is understandable given the educational discrimination and exclusion that some parents have experienced, combined with the complexities of provision, advice and the need for decision making encountered within the UK.

The same pattern of disadvantage applies within the health and audiological provision. Roma families are unlikely to have received much information, treatment or support with regards to deafness before arriving in the UK which may compromise their early and informed access to the appropriate support. Parents may not be aware of the potential benefits of technologies or know how to access them. Additionally, children may have lived with undiagnosed deafness and/or without technology for substantial periods of their early childhood.

Family resources

Despite these multiple disadvantages, families demonstrate and deploy several resources in ways that mitigate some of the circumstantial challenges. These resources related to family experiences, values and expectations. The families in the research were notable for their strengths in parenting and in the support of their children. Through personal experience of having one or more deaf family members, families in the study were all informed about deafness to some extent. This was sometimes technical knowledge but was mostly related to confidence in managing day-to-day communication. This aspect of the family experience may have mitigated the challenges of coming to terms with childhood deafness in an unfamiliar environment and have been facilitative of establishing diverse communication strategies in the home. Communication among the families, despite different proficiencies and preferences, was largely successful. Families knew how to use the shared language resources and deployed creative solutions to work around challenges, by using gestures and visual strategies. All of the families communicated optimism for the future of their children and in some cases celebrated what they had already achieved. Despite the vulnerabilities involved in adjusting to new systems, for these children and their families, migration to the UK provided them with support that was not available in their home countries. Families seemed motivated to respond to and build on the support that professionals offered. The emphasis on the value of the family and the responsibility of parents to keep their children close and safe was also evident as a resource that kept the family cohesive and protective around the child. The authors drew these conclusions whilst recognizing that the families in this study were already proactively engaging with services and that within the wider context of Roma migration, those families who choose to migrate are generally those with more resources (Grill, 2012).

Navigation of complex systems

Using the resources and support offered by the practitioners, the case study families were navigating the education and health systems for the benefit of their child. Whilst some problems were reported, such as confusion and linguistic obstacles, there was a commitment to work with the support available. Successful navigation of the education and health systems was seen where adequate interpreting and mediating support was available, where trust and working relationships were established between professionals and families, and where services had developed effective strategies for assessment, engagement and multi-agency working. The successful strategies adopted by professionals, who work with children who are deaf, are similar to recommendations in wider research and policy relating to Roma integration and engagement with services (Morris, 2016; Penfold, 2016).

Implications for multi-professional support

Two main challenges for support centres were the visibility of Roma people, and how services collect ethnic data. Findings suggest that the number of children who are DHH and from Roma families is under-reported and yet the high prevalence of deafness in Roma communities has significant implications for education, health and social participation. Professionals who work with children who are deaf need to develop appropriate ways to ask families if they are Roma rather than relying on external data such as asking what language families use. This is a sensitive approach that reflects how language is an integral part of identification as Roma (Friberg, 2018). Another strand of this invisibility is evidence of undiagnosed deafness amongst both Roma adults and children. There is a need for further outreach within Roma communities to identify these individuals and offer appropriate support. The final strand of this invisibility is within services. The value of employing Roma staff within organizations, not only as interpreters but at all levels, is evident within the research and the wider literature.

Building on previous research of multilingual children who are DHH (Swanwick, 2016b), it would be beneficial for teachers of the deaf to gain a full understanding of children’s language profiles, including the distinctive characteristics of Romani where possible. Professionals need a greater understanding of these families who are already managing complex lives and where a diagnosis of deafness may compound a general mistrust of education and health authorities. An understanding of families’ previous experiences and current expectations, combined with an understanding of their existing resources, is key to successful partnerships.

Conclusion

Through an examination of the relationship between being DHH and being Roma, overlapping areas of vulnerability that have serious implications for childhood development, education and achievement, as well as for longer-term health and wellbeing have been identified. Awareness of these factors can inform the development of professional practice by providing a better understanding of the issues and influences that shape the lives of children who are DHH and Roma, and their families. Wider issues of social exclusion and marginalization follow from these risks exposing a compelling case for probing these issues further. Within the UK there are pressing questions of how to approach the inclusion and representation of Roma communities in general. Additionally, there is a need to look to Central and Eastern European contexts to fully understand how Roma families’ prior experiences have shaped their understandings of deafness, the potential role of technology and sign language, and influenced their expectations of, and engagement with, institutional support.

This also work reveals 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, whilst children's voices are missing (Curtis, Thompson, & Fairbrother, 2018). The “double jeopardy” of being DHH and of being Roma highlights an urgent need to develop a more extensive intersectional understanding of the experiences of these children. The heightened incidence of generational deafness, associated communication challenges, complexities of the home language and literacy environment, the historical drive to migration from discrimination and social exclusion, fear of self-ascription and the culture of mobility present exceptional circumstances. To conflate or lose sight of these particularities within the development of support practices would perpetuate and add further layers to the complex influences. Future work should, instead, inform sensitive approaches to education and heath, and support and signpost appropriate strategies for inclusion.

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Table 1. Response to the demographic survey to identify the number of children who are DHH and from Roma Families in England

Type of provision	Number contacted	Number of Responses	Number of children from Roma Families		
			0	1-5	5+
local authority Services	132	73	37	25	11
Schools for the deaf	17	10	9	1	0

Table 2. Number of children who are DHH and from Roma families in institutional case study local authorities

Name of deaf education service	Total caseload	Children who are DHH and from Roma families	Estimate of Roma community in authority
Bradford	805	41	6000
Leeds	920	8	5000
Peterborough	252	4	1500
Sheffield	643	110	5000
Rotherham	383	34	4000

Table 3. Comparison of children who are DHH and from Roma families to general population of children who are DHH

	Roma children	All children who are DHH
Mild	13%	26%
Moderate	42%	32%
Severe	24%	9%
Profound	14%	12%
Unilateral	7%	20%
Total number	344	45,631

Table 4. Details of case study families

Child	Martin Male	Peter Male	Zuzana Female	Eva Female
Age	11m	3yrs	10yrs	12yrs
Country of origin	Slovakia	Slovakia	Slovakia	Czech Republic
Hearing loss	moderate	moderate	moderate with conductive overlay	moderate to severe (*sic)*
Age of diagnosis	birth	2yrs	8yrs	3yrs
Current School	Preschool (plan for nursey at 3yrs)	Preschool will start nursey next term	Mainstream	Resourced provision
Lives with *denotes deaf family member	Mother Father Sibling 1*, 2	Mother* Father* Sibling 1	Mother* Stepfather Sibling1,2,3,4,5	Mother Father Siblings 1,2,3
Data collection	Interview & Observation: Father(P1) Mother (P2) Interview:	Interview & Observation: Father(P4) Mother (P3) Interview:	Interview: Child Mother (P5) Teacher (T3)	Interview: Child Teacher (T4)

	Teacher (T1)	Teacher (T2)		

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