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'Su guagua no escucha nada': Ecuadorian families confronting the deafness of a child

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‘Su guagua no escucha nada’: Ecuadorian families confronting the deafness of a child

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In accordance with the social model of disability, this study proceeded from the assumption that parents’ experiences of a child’s hearing impairment reflect the circumstances of their lives rather than anything innate in the impairment itself. Few studies have explored the influence both of culture and social structure and of families’ economic and social resources. We studied families’ experiences of the diagnosis of hearing loss in Ecuador, a multicultural country in which family ties are strong but where pronounced social and economic inequalities persist and where many people have no access to health care. The study shows how inequality – and in particular the experience of poverty – shapes families’ experiences of acquiring a diagnosis and of trying to accommodate a child with special needs.

Keywords: Ecuador; families; inequality; poverty; hearing impairment

Points of interest

- Virtually all published studies of family responses to diagnosis of a child’s hearing impairment come from wealthy countries with well-developed health and welfare systems.
- This study was carried out in Ecuador, a country marked by considerable socio-economic inequality, where 25% of the population is estimated to live in poverty and where 25% has no access to formal health care.
- A family’s lack of resources (financial, but also social) has a major influence both on the process of obtaining a trustworthy diagnosis and on its ability to cope with the child’s needs.
- Poor families typically lack information, guidance and support from either the extended family or from support groups.
- The study sheds new light on what parenting a child with a (hearing) impairment entails.

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Introduction

When parents suspect there is something wrong with their baby they are generally anxious for a clear diagnosis. Not knowing is stressful, and parents suffer when a clear diagnosis is not readily forthcoming (for example, Timmermans and Buchbinder 2010). Parents hope and expect that diagnosis will be followed by appropriate medical treatment and support (Gilman, Heyman, and Swain 2000). Diagnosis should also help them adjust their expectations for the future: to enable them 'to regain predictability and control in life and to provide them with active coping strategies' (Graungaard and Skov 2006, 33). Disability pushes a family to try to understand what has happened and '... compels the family to seek solutions and cures to remedy this unfortunate occurrence ...' (Larson 1998, 865). The birth of a child with a disability requires a family to make material, psychological and social adaptations (Diamond and Kontos 2004). Are families equipped to do so? 'Parental coping behaviour', write Kurzer-White and Luterman (2003, 233), 'will be determined in large measure by how well they are able to deal with the feelings generated by the diagnosis and overwhelming information, regardless of the child's degree of hearing loss'. However, other authors have pointed to the effects of socio-economic factors on households containing a child with a disability: poverty (Diamond and Kontos 2004; Park, Turnbull, and Turnbull 2002), as well as class and resources more generally (Calton 2010; Rapp and Ginsburg 2001). A study of Bangladeshi and Pakistani families in the United Kingdom found that mothers of children with disabilities received little support either from their extended family or from support groups. In these families, economic deprivation was combined with high levels of anxiety and depression, and the women who bore the brunt of the responsibility for the child were often the target of blame and sometimes of domestic violence (Fazil et al. 2002).

Neonatal screening for hearing impairment, which can now be carried out within a few weeks of birth, is becoming increasingly widespread. As with screening for other impairments, it is justified by the argument that the earlier the diagnosis, then the quicker something can be done. Not all parents are convinced by the argument for early screening, however. A significant minority would like more time to adjust to parenthood before being confronted with their baby's hearing impairment (Gilliver, Ching, and Sjahalam-King 2013. Although the diagnosis of childhood hearing loss 'changes the sense of equilibrium in the lives of families' (Fitzpatrick et al. 2007, 105), the psychosocial implications, possibly implying a more cautious dynamic, have scarcely influenced professional practice. Confronted with a diagnosis of profound hearing loss, parents are assumed to then face a number of important decisions. In search of information and counsel, they turn to the professionals who are there to help them. However, empirical studies of parents' experiences suggest that unbiased information, dispassionate advice and support are not always what they are offered.

Most professional advisors, and studies adopting their perspective, appear to take for granted that a hearing impairment is in itself disabling. It then appears natural enough that parents' initial response to a diagnosis would be denial and then grief. In a pioneering study carried out in the United Kingdom, Beazley and Moore (1995), starting from the social model of disability, explored the social practices and the behaviour by which a hearing impaired child and his or her family are made disabled. On the basis of interviews with parents, they highlight the ways in which

professionals can render families vulnerable, incompetent and dependent. Many of the parents had found that information had been withheld (or at least not provided), and that much advice they had been given had been directive rather than supportive. With regard to crucial decisions, such as school placement or the use of sign language, professionals largely foisted their own unexamined views onto the parents they were supposedly supporting. Similarly, a recent Belgian study suggests that professional advisors generally discourage parents from critical reflection or from seeking information (Bosteels, van Hove, and Vandebroek 2012). The importance of these studies is their demonstration that, in understanding what parents go through, and how they cope with the diagnosis of a hearing impairment, the analytic gaze must be broadened to encompass professionals, friends and family.

Beazley and Moore emphasise that ‘understanding the experience of a family with a deaf child involves looking at the complex relationship between the child’s hearing impairment and the social situation in which they and their family find themselves’ (1995, 11). The social situation to which they allude has various aspects, including the composition of the family (e.g. the presence of other children whose needs cannot be ignored), access to services (which may depend on where the family lives and on its ethnic/cultural background) and whether the family is rich or poor. There are very few studies which look explicitly at socio-economic or cultural influences on family responses to a diagnosis of deafness (although see Ramsey and Noriega 2001; Steinberg et al. 2003).

Most children with (hearing) impairments do not live in countries, such as the United Kingdom, with well-developed health and welfare services and neonatal screening programmes. How a family copes will then depend not only on its own distinctive circumstances, but also on provisions available in, and the attitudes characteristic of, the society in which it lives. It cannot necessarily be taken for granted that a newly-diagnosed deaf child will grow up in a stable two-parent household; that the child’s parents have options regarding its future between which they can (or must) choose; or that they have expectations of life and for their children which they seek to re-establish.

In the present study we adopt the perspective introduced by Beazley and Moore. That is, we relate families’ experiences of the deafness of a child to the social situation in which they live. However, in ‘social situation’ we include characteristics of the broader society in which our study was conducted. Thus, the availability of health care, social organisation and culture are assumed to affect families’ experiences, in addition to their individual resources and structures. How does social situation, understood in this dual fashion, affect how families obtain a diagnosis of deafness or hearing impairment? How does it affect their subsequent attempts, and their ability, to cope? These are the questions to be addressed in this paper.

Location of the study

Historically, Latin American countries have been characterised both by low national incomes and by vast income inequalities, with many people living in poverty and access to health care varying even between neighbourhoods of a single city (Hoffman and Centeno 2003).

This has traditionally been true of Ecuador, where official statistics suggest that 25% of the population (and 45% of the rural population) still lives in poverty (Government of Ecuador 2013). Today families in poverty (defined as having an

income in the lowest two quintiles) may be eligible for a small monthly cash transfer, the *Bono de Desarrollo Humano*. Health system reform is a major concern of the government and the past few years have seen growing state investment and cautious reform (De Paepe et al. 2012). Nevertheless, the country's health care system remains highly fragmented, with a private health care sector that may represent as much as 60% of total expenditure on health care (Lucio, Villacrés, and Henríquez 2011). Making use of this private sector generally involves personal expenditure, since private health insurance accounts for only 5% of costs. Almost one-quarter of Ecuadorians have no access to health care (De Paepe et al. 2012).

Ecuadorians with disabilities, however, have benefitted from some improvements in recent years, and the country's 2008 Constitution explicitly acknowledges their rights.¹ The Solidarity Mission 'Manuela Espejo', which falls under the Vice Presidency, has despatched teams of experts throughout the country to locate disabled people, often severely neglected, and to provide technical aids and, where needed, urgent medical care.² The present study was carried out in 2013–2014 in the city of Cuenca: Ecuador's third largest city and the capital of the province of Azuay. According to one estimate, 13,000 people in the province, or 2% of the population, have a disability, including 48 children with a hearing impairment aged zero to five years, 114 aged six to 12 years and 73 aged 13–17 years (Pinos Vélez and Ingavélez Guerra 2011). Previous studies by Huiracocha, Robalino, and Huiracocha (2012) found that 11% of children younger than three years of age had delayed psychomotor development, of whom one-half had a disability

Methodology

After their directors had given permission we were able to approach parents via two institutions catering for deaf and hearing-impaired children in the Cuenca region: the (private) Centro de Estimulación Integral y Apoyo Psicopedagógico (CEIAP) attached to the University of Azuay, and the (public) Unidad Educativa Claudio Neira Garzón.³ Eleven families were recruited through CEIAP. The consent form which they were asked to complete and sign included basic information (names of family members, contact details). At Claudio Neira, 12 forms were returned. However, we discovered that not all parents or guardians who had agreed in principle were in fact willing to be interviewed. Because some had given false contact details or failed to keep appointments, we were finally able to interview only eight of these 12. Six of these families were receiving the *Bono de Desarrollo Humano*. Children ranged in age from three to 15 years. The majority had been diagnosed as deaf or hard of hearing at the age of six to nine months, although a few had only been formally diagnosed years later.

Eleven interviews were conducted in the family home and eight at the school or CEIAP. Five interviews were with both of the child's parents, 10 with the mother alone, one with the father alone, one with both parents and a grandparent, one with the mother plus both grandparents, whilst one was with the grandmother alone. Interviews were conducted in Spanish⁴ and lasted from 20 to more than 90 minutes (average 51 minutes). Transcripts were manually coded and the analysis discussed in meetings of the research group to which representatives of the Azuay Association of the Deaf were also invited. All names used are pseudonyms.

Given the country's social, ethnic and cultural diversity, and the real possibility that some impairments are never diagnosed, the study cannot be taken as representative of Ecuador as a whole.

Results

From suspicion to diagnosis

Earlier or later, all of the parents and grandparents we interviewed began to suspect that their child had a hearing problem. But their experiences thereafter, the processes leading to a medically confirmed diagnosis, were far from uniform. We can distinguish two ideal–typical configurations of experiences.

One group of parents had moved from doctor to doctor, from clinic to clinic, in search of a diagnosis in which they had confidence. The parents of three-year-old Toñito describe their experiences thus:

- Mother: His paediatrician never did any auditory stimulation tests, with the bell no he never did it and we had no idea, but we then changed our paediatrician and we told him about Toñito's symptoms: that he would not sit, babble, or anything, so he then started to use the bell and Toñito would not turn around.
- Interviewer: How old was he?
- Mother: Nine months old, after that he told us to get some auditory tests at CEPRODIS. We went to CEPRODIS⁵ and they did a simple audiometry test by using a small machine that measured his hearing and there it said he did not hear anything from both ears, so since Toñito had a cold at that time, they said it was because of that and told us to come back in a week. We went back in a week and they did the same test on him. Toñito no longer had a cold and they told us the same thing, that he could not hear anything. That's when they told us to get an evoked potential test at the regional hospital but the machine there was not working, as usual, so we could not get it there. We had to spend our own money and get it at [...] Clinic with doctor [...]. She carried out the evoked potential test while he was sedated and the results said that Toñito could not hear absolutely anything from either ear, he was immediately a candidate for a cochlear implant.

Still uncertain, they consulted a different doctor in a different clinic (whose advice was the same), and then an otolaryngologist whom they were able to contact via friends of friends. He in turn sent them to yet another doctor, this time in Quito:

We went to Quito and took the test results from Cuenca with us, there they examined the results and decided to get new evoked potential tests. We got other results from those tests, it said that he had profound hearing loss from his right ear but that his left ear had moderate hearing loss and that he could use a hearing aid in that ear. They said he could get by without an implant, and we were relieved with that diagnosis because they were very experienced. In Cuenca we did not really see that kind of experience. (Mother of Toñito)

Maria is four years old. Her parents had somewhat similar experiences. Their paediatrician sent them to a clinic to have their daughter's hearing tested. Tests showed that there was nothing wrong, which the paediatrician simply did not believe. They then went to a different clinic:

Well she got another test and on this test we were told that she did not hear 120 decibels, that she had severe hearing loss, but we did not totally agree because some said she had hearing loss and others said she didn't. (Father of Maria)

Faced with conflicting results, unsure what to do, they took their daughter to Quito to be tested again:

This doctor said that she did not hear anything, that she was completely deaf, but we knew that already, we wanted to verify again so we took her to Dr. [...] in [Clinica Suramericana] and he also said she could not hear anything but we did not believe him that much because he was very arrogant. They should get him to calm down. (Father of Maria)

Convinced there is a problem, these parents do not accept the initial (re)assurances they are offered. They move from doctor to doctor in search of what they feel is a trustworthy diagnosis. Frequently they have contacts, or the family provides access to a wider network which could be mobilised: for example, Anita's mother said 'It was hard to digest, it was horrible like it wasn't true. So my sister was there and she said, don't worry Chichi, doctor [...] is my friend, let's go with him, let's take these tests'.

Perhaps unsurprisingly, these parents were often critical of the way they had been treated. Studies elsewhere have suggested that the way in which unwelcome news is delivered affects how parents cope with it, and that lack of empathy adds to parents' stress (for example, Beazley and Moore 1995; Gilbey 2010; Huiracocha, Almeida, and Huiracocha 2013). These parents criticised their doctors' insensitivity, lack of experience or inability (or unwillingness) to understand what the diagnosis would mean in the light of a particular family's circumstances:

As we told you, the first doctors we went to seemed to be a little inexperienced in this sense so they didn't really know how to tell us, one of the doctors wanted us to get the implant right away, as soon as possible, and we didn't like that so we never went back, he treated us badly ... He was very rude, we were both crying when we left. We desperately thought that the only solution was to have 30 thousand dollars, which we didn't. (Mother of Toñito)

Seven-year-old Anita's parents had also been shocked by the way in which they had been given the test results. Accompanied by some relatives they waited for a period of time that her mother described 'as about 15 or 20 minutes I don't know, it was a lifetime to me': 'And then she [the doctor] called out: [child's name]. So we approached her, she had a yellow envelope and she said: "*Su guagua no escucha nada* [your baby can't hear anything]". She turned around and left. We just stood there'.

The experiences of the second group involved no such critique of doctors' expertise or behaviour. For some, that their child's hearing was impaired came as no surprise because there was deafness in the family.

The mother of 15-year-old Nestor had an older daughter with a hearing problem and she did not find it so strange:

I figured it's like someone with vision loss who wears glasses and she has hearing loss so she has to wear a hearing aid, now my daughter is 32, I mean she was my first daughter and I didn't know how, but then I paid more attention to the others that's why I knew Nestor didn't hear well, I thought it was minimum but my son's hearing loss is serious, it was a little late, but he already had his cochlear implant. (Mother of Nestor)

That a diagnosis comes as no surprise, and is not questioned, is not always because deafness is known in the family. Sometimes it seems due to experience of life, in which misfortune has never been far away. As one mother put it, 'as parents you just have to accept problems'.

Julio, now 10 years old, is his mother's fifth child. She comes from a different province and lives apart from Julio's father. Asked how she learned that her son was deaf, she explained:

When he was one, because when I called him he would not obey ... he used to walk away and I would say to myself: What's wrong with him? ... That's when I thought that there was something wrong with my baby, so I took him to the hospital and there they checked him and told me to wait, they were like just starting. So then I separated from my baby's father and came to live in Cuenca. I took him to INNFA⁶ and there they told me he had hearing loss. (Mother of Julio)

Paula is 13 years old. Her mother lived in the countryside when Paula was born (her second child). When the little girl was five her mother brought the two children to live in Cuenca, and although her daughter had not learned to speak it was only after the move that the child was definitively diagnosed:

I was told about the Regional Hospital, that there were good doctors over there. I met Doctor [...], I don't remember his surname, who was the language therapist. He told me that he needed the diagnosis of the girl otherwise he couldn't do anything for her. He asked for an audiometry. That was very expensive and the hospital didn't do it at the time. It was usually done at the INNFA. I didn't know the city well. I got lost several times carrying my 5 year old daughter on my back. (Mother of Paula)

In the Ecuadorian context it is difficult to generalise about how parents act when they suspect their baby has a hearing impairment. On the one hand we have a group of parents whose search for a diagnosis they trusted took them from doctor to doctor, from clinic to clinic. Their search often required the mobilisation not only of economic resources, but also of family and social networks. These are people who expect to be treated courteously, and respected as competent decision-makers. Carers in the second group lack the economic resources but just as importantly the social resources, and the self-confidence, that the first group could rely on. Their options, and perhaps their expectations, are limited by their lack of resources and by their previous experience of life.

Coping and support

How do Ecuadorian families cope once their child's hearing impairment has been confirmed? What resources can they draw on? How far can they rely on extended families and support groups (as suggested by the literature) for help and reassurance?

We have to start by asking: who is doing the coping? As noted previously, most studies of coping and decision-making assume a two-parent nuclear family. That cannot be done here. Eight of 19 children are not being raised by their two biological parents. Thalia's mother, for example, who is herself deaf, shares responsibility for the child's upbringing with her own parents. The child's grandfather explained that:

as grandparents we have done everything for her, she's like a daughter to us, I regard her as my daughter and along with my wife we have tried to move on as long as God gives us life and good health.

Pepito's grandmother explained that her daughter, Pepito's mother (working in the United States), could not accept that her son was deaf (although he was already known to have cerebral palsy). Of the child's father she said:

Let's not talk about his dad, I mean they have their father's last name and everything but my daughter broke up with him and we don't count on him, we have not asked him for a single penny, we don't want him to get close because he means nothing to us.

Paula's mother explained that during the five years in which her daughter remained undiagnosed she had lived with her children's father: 'I don't want to talk about that, but he was a *machista* [male chauvinist]. I didn't know it'. She left her husband and moved to Cuenca, where she lives with her two children and her younger sister. Manuel's father had left the child's mother when he learned that Manuel was deaf, but had returned when Manuel was six and about to start school.

It cannot be taken for granted that household structures remain stable over time. For example, at the time of the interview Martha's mother was in the midst of divorce proceedings. Majo's mother is a single mother who works 12 hours per day. Her daughter, now 13, was diagnosed at the age of 14 months. At that time she lived with her mother, but later decided to move out. She explained her decision:

I lived with my mom until my daughter was almost eight, and then I left because I started dating someone, he's my other daughter's father, so I left. My mom didn't want me to take my daughter with me, she wanted to take care of her, but how was I going to abandon my daughter? I had a bad experience with my brother when I was a little girl, so I didn't want my daughter to go through what I had to go through. My mother wanted custody of my daughter, through court and everything. I said no, that I was not going to leave my daughter. She wasn't old yet, she's now like 65, back then she wanted to care for my daughter but I said no, after all I am her mother and I am responsible for my daughter. She got mad and I got into a fight with my family, and since then I hardly ever see my family. I go there for a bit, but not much. (Mother of Majo)

For many families, again according to the literature, grandparents and other extended family members play an important role in providing advice and support. Family relationships tend to be close and important in Ecuador, and for some the extended family is indeed an important source of advice, emotional support and (financial) help:

My husband's family would find things out for me, they would get me appointments at [a Quito hospital], and luckily as if it were a miracle from God, that year [the hospital] offered the first cochlear implants and logically there was a lot of demand, we were not the only case. So we were put on a waiting list, only to check if he qualified. They always put lots of ideas in our head. (Mother of Juanito)

The parents of Felipe (now 11 years old) are both deaf. His mother told us:

We first took him to INNFA ..., we then went to the hospital and we paid to get those tests [...] my mom would get upset with the doctors, we didn't know exactly what was happening, we had to be patient, my brother was also upset with the doctors, my family got together and they each helped by giving some money so we could buy the

hearing aid at INNFA. They started teaching him once he had the hearing aid, he didn't like it and he used to get sad. (Mother of Felipe)

But not all parents can rely on their extended families in this way. In vulnerable families, families that may have suffered discrimination in the past, there may be shame or resentment and tensions may arise. For example, Kiki's father explained that his family was ashamed of his deaf daughter and had as little to do with her as possible. For Majo's mother, relationships with her family have been more a source of stress and of difficulties than of support. Her daughter's father had moved to Spain and for years had refused to accept that Majo was his daughter. Moreover:

I've had problems with my own nephews because they say things like: don't talk to her because she can't hear anything, don't say nothing to her, just let her sit there, she's deaf, she's sick. They discriminate her; if her own family discriminates her, just imagine what happens out there, so in that time I stood up for her and I had problems with my nephews, I told them not to treat her like that, that she was not different, that she simply had a problem that she would get over, that they shouldn't say she's deaf because she felt bad, since she could read people's lips she would feel bad, when she sees people's reactions she sits all by herself, and that's why I had problems with my brother, I told him: 'tell your son not to call her that,' you know in a good way, but my brother said: 'what? you want to evade reality, you want him to say she's normal'. That's discrimination, there was lots in my family, I had lots of problems, so I decided to move away from them. (Mother of Majo)

Various studies have found that being able to share experiences, doubts and anxieties with other parents of hearing-impaired children is a valued source of support and advice in coping with the uncertainties involved. For example, parents in Beazley and Moore's (1995, 107) study 'felt the best source of support for deaf children and their families comes from people like themselves' (see also Blume 2010; Hyde, Punch, and Komisaroff 2010; Jackson 2011). Parents in Cuenca had felt this need, as 10-year-old Pedro's father explained:

We didn't know what we were facing, we didn't know, we had never seen a case like this in our lives ... the lack of information was shocking, it cost us an arm and a leg. We then started to do some research, we had information on the web, but we wanted to have someone who had a child with an implant or see a child with a hearing aid, we wanted to know people that reflected us, that's why when we went through all this there were also a lot of other people who went through the exact same thing, some of us wanted to set up a foundation to give psychological, emotional and spiritual support. (Father of Pedro)

Some parents had recently taken the initiative to establish such a parents' group:

Chichi has gotten encouragement everywhere, she has created a foundation 'Escuchame' or Listen to me, Chichi is the president, she's one of the founders, she done a lot there. We're happy, there's been more support, we think that Ecuador is constantly changing and that now there's more opportunities for people with disabilities, not only hearing loss. (Father of Anita)

But not all parents could benefit from this group. For one thing, at present it only includes parents of oral deaf children. Moreover, the lives of many parents did not allow them time or opportunities for meeting other parents of deaf children. Teresa's mother knew about Escuchame but was not part of it because her work did not leave her time. Similarly, Paula's mother explained that her work meant that she had no contact with other parents.

Lacking support from partner, family or peer group, some of these mothers draw comfort and meaning from their faith. For example, one mother told us that one day she had spoken to a priest who had told her:

‘This is not a punishment from God, you should feel proud that God has chosen you to be the mother of his saint, feel proud that you have an angel in your house that will always be at your side’. That is when my will to resist began, I am always there for him.

Another mother told us that when she learned of her child’s deafness she had joined the Evangelical Church, whilst Manuel’s mother said:

I thank God for giving me a child like that because I have a good time, even if I don’t have anything to eat I have a good time with my children. When I used to go crying around the streets because of my child being like that, a lady told me ‘Don’t cry. Thank God because he gave you a son in a home like that. He is an angel you have at home. He is an angel’. (Mother of Manuel)

As discussed earlier, most studies of how parents deal with a diagnosis assumes that decisions have to be taken regarding language, schooling, use of assistive devices, and so on. It is taken for granted that choices are available and that parents can and must make those choices. For some parents in this study, this was true: they were well aware of the decisions they had taken:

I thought we had to leave Cuenca, go live someplace else. At first I thought about the USA because it’s a place where people with disabilities ... we lived there some time, we studied there and were able to see the alternatives people with disabilities had, people with different situations who took the bus, go places by themselves, have their own lives, but here there are many barriers and we realized that there are so many limitations ... we have thought of so many options, and finally we decided to stay here because it’s not only Anita, it’s the whole family, we have two more sons and we wanted to do our best here ... (Father of Anita)

Other parents’ decision-making is foreshortened, because they are led to see the cochlear implant as their child’s only hope, whether it is accessible to them or not. Martha’s mother (who has an older daughter with cerebral palsy) recalled the doctor having told her that ‘when she’s eight or nine years old she’ll hear like the rest, that’s what he said’. Twelve-year-old Teresa’s mother told us about going to Quito for a diagnosis:

well I was very naïve and I thought there was hope that there would be a cure or something so I said: doctor, what kind medicine can she take?, the doctor looked at me and said there is no medicine, there is no doctor in the world who can cure your daughter, no magicians, not God, no one. I am catholic but I was quiet, I then asked what I could do, and he said he recommended a cochlear implant, [...] we thought that maybe the doctor wanted our money that maybe it wasn’t true, maybe there was something else they could do, something. But that was reality, we didn’t want to face reality ... We finally accepted and knew we had to get the implant and that that would help us, we knew it was expensive and we didn’t have any money, if we had had the money we would have gotten the implant the first time they told us about it, and it would have given her a better life, but we did not have the money. We didn’t know where to get it. (Mother of Teresa)

However, some carers express no sense of having had choices or of major decisions ever having been required or taken. Asked about the decisions she had taken on behalf of her son, Julio’s mother told us about an event the previous week in which he had misbehaved with a girl and she had had to punish him.

Discussion

Following Beazley and Moore, we set out to examine the ways in which families' experiences of having a deaf or hearing-impaired child are shaped by the situations in which they live, rather than being inherent in the impairment itself. We hypothesised that parents' experiences would all reflect certain features of (Ecuadorian) society, but that in other respects their accounts would differ according to their diverse social and economic circumstances.

Despite considerable progress in recent years, Ecuador is still marked by the great social and economic inequalities that have characterised Latin America for generations. Many people live in poverty and many, especially from the country's indigenous communities, have no access to formal health care. Among the country's striking features, aside from its ecological diversity, are the importance of the family and the importance of religious faith for much of the population. The Constitution adopted in 2008 acknowledges the country's multicultural character. It recognises the rights of people with disabilities as well as of the country's cultural minorities. Many general features of Ecuadorian society – the importance of family and of religious faith (which hardly figures in European studies), lack of access to or trust in the health care system – inflect parents' accounts of their experiences.

In the United Kingdom, as in many other countries, some parents of deaf children come to appreciate that membership in the Deaf community can provide their child with a secure identity, a sense of belonging and possibilities for a fulfilling life (Blume 2010; Padden and Humphries 2005). This was not the case in the region of Ecuador in which we carried out this study, not even for parents whose children communicate principally in Ecuadorian Sign Language (LSE) or who are themselves deaf.

Nevertheless, and despite profound differences in the two countries' societies and cultures, there is one respect in which the Ecuadorian parents' accounts coincide with those of the British parents interviewed by Beazley and Moore. In both studies there was significant criticism of the lack of information provided by the professionals parents dealt with, and of the nature of the advice they received. It appears that from the parents' perspective that professional advice is typically directive and rarely goes beyond offering standard, usually technical, 'solutions'.

We can also distinguish two distinct clusters of experiences, reflecting Ecuador's extreme social stratification. On the one hand are parents who have access to not only the economic resources, but also the social resources needed to cope with hearing impairment: who can rely on their extended families and who have organised a peer-support group. On the other, there is a group lacking both economic and social resources. These are parents who are not only struggling financially, but whose extended family – itself possibly vulnerable and disadvantaged – may shun rather than support them. There is no sense here that diagnosis permits families to regain 'predictability and control in life' as suggested in the literature. The conditions in which some of our respondents live mean that they probably never had control or predictability in their lives.

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Notes

1. One respondent, recalling her grandson's diagnosis 11 years earlier, said 'I took him to the doctor. Back then doctors paid almost no attention to children with disabilities, so he was simply another deaf child, another deaf child who came to the doctor and that was it'.
2. See <http://www.discapacidadonline.com/mision-manuela-espejo-ayuda-personas-discapacidad.html>
3. Until 2014, the Instituto de Invidentes y Sordos del Azuay.
4. Ecuadorian Sign Language (LSE) was used in the two interviews at which one or more interviewees were deaf, with questions and answers voiced for transcription.
5. Centro de Protección para Discapacidades, which provides services for people with disabilities. Now part of the Ministry of Economic and Social Inclusion.
6. Instituto del Niño y la Familia, later changed to Instituto de la Niñez y la Familia and attached to the Ministry of Economic and Social Inclusion.

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