Process diagnosis of deafness in children in the perception of familiar and managers

Processo de diagnóstico da surdez em crianças na percepção de familiares e gestores

Luciana Santos Gerosino da Silva¹, Claudia Giglio de Oliveira Gonçalves¹

ABSTRACT

Purpose: To analyze the perception of family and managers (education and health) on the process of diagnosis of deafness in children in a city in Paraná. Methods: The analysis of the material gathered in the focus groups and on the interviews was made based on the analysis of content of the thematic mode. The discussion of the data was organized based on the analysis of the subjects’ testimonies. Results: The thematic categories were: the early diagnosis and hearing health as a human right; and the necessity of adequate support and initial guidance; challenges in the inter-sector and inter-network relations. Conclusion: We have reached the conclusion that the repercussions of a late deafness diagnosis have influence in health and education aspects of the deaf children’s life. Early diagnosis and adequate support did not happen with the majority of the children. An inadequate inter-sector relation between Health and Education municipal authorities was verified.

Keywords: Public Health; Early Diagnosis; Speech, Language and Hearing Sciences; Hearing Loss; Deafness; Parents; Health Services

RESUMO

Objetivo: Analisar a percepção de familiares e gestores (educação e saúde) sobre o processo de diagnóstico da surdez em crianças de um município do Paraná. Métodos: A coleta de dados deu-se a partir da técnica de grupo focal formado por dez pais e por entrevista aberta individual com gestores. A análise do material extraído foi feita por meio do estudo do conteúdo na modalidade temática. A discussão dos dados foi organizada pela análise das falas dos sujeitos. Resultados: Foi possível extrair duas grandes categorias temáticas: frustração no processo de diagnóstico, acolhimento e orientação; dificuldades na relação intersetorial Saúde e Educação. Conclusão: Os desdobramentos da surdez diagnosticada tardivamente permearam os âmbitos relacionados à saúde e à educação das crianças com surdez. O diagnóstico precoce e o acolhimento adequado não ocorreu na maioria das crianças e verificou-se que a relação intersetorial (saúde e educação) é insatisfatória.

Descritores: Saúde Pública; Diagnóstico Precoce; Fonoaudiologia; Perda Auditiva; Surdez; Pais; Serviços de Saúde

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Authors’ contribution: LSGS principal researcher, development of research, schedule planning, survey of literature, collection and analysis of data, article writing, article submission and procedures; CGOG guiding, development of research, schedule planning, data analysis, correction of written article, approval of the final version.
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INTRODUCTION

A demographic survey conducted by the Brazilian Institute of Geography and Statistics\(^1\) found that 45,606,048 million people reported having at least one of the investigated deficiencies and this corresponds to 23.9% of the population. A hearing disorder was cited by 36.2% of the population, and of this percentage, 1.3% are in the 0-14 year-old age group. Among the affected population, children in the age groups below 15 years old have permanent hearing loss, and two thirds, about 41 million, live in developing countries\(^2\). In neonates, the incidence of hearing loss is 1.5 to 5.95 per 1,000 live births and the causes, often, could be prevented\(^3\).

Thus, hearing loss in children is considered a public health problem due to its high prevalence and also the multiple consequences that impede healthy child development.

It is known that sensory deprivation early in life can lead to difficulties in the acquisition of speech and language, interfering with the development process for thinking, intelligence, and reasoning, as well as the formation of the individual as a whole, even in the schooling process. These facts stress the need for early diagnosis and the creation of hearing screening programs for all children born in the country\(^4\).

The recognition of hearing impairment as a public health problem has spurred the creation of public health policies, aimed at minimizing their impact on people’s lives. Furthering the discussion about health care, based on principles of the Brazilian Unified Health System, such as universality, fairness, and integrity in health care for the population at risk for hearing impairment and deafness, the National Policy on Hearing Health Care (PNASA) was instituted in 2004\(^5\). The ordinance calls for the establishment of state systems, responsible for performing comprehensive actions for the promotion of programs for hearing loss prevention, diagnostic audiology, providing hearing aids, monitoring, and rehabilitation\(^6\).

The proposal is clear and in place. However, it is necessary to evaluate, in view of its participants, how it is implemented, and more specifically, what are the implications of an audiological diagnosis. There are two categories that participate directly in the diagnostic process: on the one hand, parents of deaf children who use the system, and, on the other hand, the managers who plan and evaluate the implementation process and execution of interventions arising from the policy.

In view of these considerations, this study aimed to analyze the perception of family members and education and health-care managers on the process of diagnosis of deafness in children in a city in Paraná state.

METHODS

This is a qualitative study. The research site was the Specialized Educational Service Center, located in the metropolitan region of Curitiba (PR), a benchmark for services for the hearing and visually impaired, making up a network of Special Education services for the Municipal Department of Education, using qualified teachers and a speech-language pathology professional.

The center is frequented by 100 students from various age groups, with 80 presenting visual disorders and 20 having hearing disorders. Of the 20 with hearing loss, 18 have profound sensorineural bilateral hearing loss (bilateral deafness), and two have severe to profound bilateral sensorineural hearing loss. The students who attend school regularly participate in programs that aim to develop skills which will facilitate the process of learning, language development, cognitive and perceptual processes, socialization, and autonomy.

Such programs include: early intervention and specialized educational services, acting through specific techniques for teaching and learning for blind students; bilingual education support, and teaching speech to the hearing and visually impaired; visual stimulation, soroban/mathematics; creation of special materials; crafts lessons; activities for daily living; orientation and mobility; physical education; computer classes; signing classes with a deaf instructor; a signing interpreter and family counseling.

The inclusion criteria for this study were that the subjects be parents and/or caregivers of children who began monitoring at the educational service center in 2004 (the year that the PNASA was established nationally). Excluded from the study were parents and/or caregivers of children who joined the center after this year.

Thus, the subjects eligible for this study were ten parents and/or caregivers (family members) of students with bilateral deafness, regardless of chronological age or time of diagnosis of deafness.

The criteria for the choice of the managers were based on position, availability, and accountability. Two managers participated – one representing the education sector who worked at the regional education center in a metropolitan area in north Paraná, and was responsible student with deafness, visual impairment, and physical neuromotor disabilities. Representing the health sector was a professional who held the position of coordinator of Child Health of the municipality.

Thus, the subjects comprised two groups: Group 1: Family - consisting of guardians of deaf students, and Group 2: Managers - representing and making up the Departments of Education and Health. Participants had the problem of deafness as a common point in their experiences, each with a unique view and perspective on the difficulties since diagnosis in behavior and schooling. It is noteworthy that there were eight children with deafness, belonging to eight families. However, participating as guardians were two fathers accompanied by their respective wives and a father without his wife, totaling ten subjects in Group 1 - Family.

As a facilitating artifice and a resource for maintaining confidentiality of the participants, they were represented by...
the initials for the group they belonged to (Group 1 (Family) - G1; Group 2 (Professionals) - G2, plus a code corresponding to the participant (G1 Family - F1; G2 Professional - G2). For coding to differentiate the individual (mother or father) an ordinal number (1) was added after the code that corresponds to the participant (e.g. F5 - mother; F5.1 - father).

The methodological approach used was the strategy of the focus group as it returns to a particular focal point, which is the issue at stake so that the group will discuss as many dimensions as possible, within an interactional process. In addition, we also used the feature of individual interviews with managers.

The focus group consisted of ten subjects (parents and/or caregivers) who had similar characteristics and social position, as recommended in the literature(6). Two meetings were held with all subjects, an hour and a half long, and on different dates in the month of February 2012, in a cozy atmosphere - the meeting room of the educational service center. The moderator-researcher led discussions, maintaining focus. Another researcher made the audio recording and took relevant notes. In order to make it possible to measure the parents’ knowledge regarding deafness, the starter question for the families of the focus groups was: “What was the process of diagnosis of deafness for your child like?” It is noteworthy that some parents did not participate in certain subjects and that is why their stories have not appeared in the quotes.

The technique applied to the individual interview with the manager was chosen, keeping in mind, that what would be related would be the narrative practices and perceptions of the individuals involved and not content faithful to practice(7).

Therefore, open or in depth interviews were conducted, i.e., the informant was asked to talk about a certain subject and the investigator’s questions during the dialogue were made with the intention of deepening reflections(7).

The interviews were scheduled and occurred in the managers’ workplace in just one meeting, separately, on different dates. The recording was authorized by the participants and interspersed with the various social voices that could be perceived in the speech of a subject.

The information was organized with the aim to promote the joining of the data and meanings revealed in the reports of the subjects, establishing core senses.

Soon afterward, the integration of the content was done based on core senses of each group in an attempt to establish a basis between the meanings revealed in the quotes. After finding differences, convergences, and complements to the core senses, between the different groups, a comprehensive reading of the material was performed, in which the empirical study categories were selected.

- Second stage: categories were selected.
- Third stage: inferences were proposed and interpretations were made of the material, relating it with the theoretical framework and interpretation of results obtained with the aid of the adopted theoretical foundation.

Therefore, it was possible to understand the conditions that generated a given quote, be it a family member or a manager, marked by social memory (shared body-historical-cultural) and interspersed with the various social voices that could be perceived in the speech of a subject.

The study was approved by Ethics and Human Research of the Hospital de Clínicas, Federal University of Paraná, with CEP registration: 410ext043/2011-10 and all subjects signed

**Chart 1. Identification of Group 1 Subjects**

<table>
<thead>
<tr>
<th>Identification</th>
<th>Gender</th>
<th>Age (years)</th>
<th>Age of child</th>
<th>Education Level</th>
<th>Monthly income (# of minimum salaries)</th>
</tr>
</thead>
<tbody>
<tr>
<td>F1</td>
<td>Female</td>
<td>23</td>
<td>7</td>
<td>Primary - Incomplete</td>
<td>≤1</td>
</tr>
<tr>
<td>F2</td>
<td>Female</td>
<td>35</td>
<td>8</td>
<td>Primary - Incomplete</td>
<td>≤1</td>
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<tr>
<td>F3</td>
<td>Female</td>
<td>22</td>
<td>6</td>
<td>Primary - Complete</td>
<td>≤1</td>
</tr>
<tr>
<td>F4</td>
<td>Female</td>
<td>22</td>
<td>2</td>
<td>Primary - Incomplete</td>
<td>≤1</td>
</tr>
<tr>
<td>F5</td>
<td>Female</td>
<td>29</td>
<td>9</td>
<td>Primary - Incomplete</td>
<td>1 - 5</td>
</tr>
<tr>
<td>F5.1</td>
<td>Male</td>
<td>30</td>
<td></td>
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<td>1 - 5</td>
</tr>
<tr>
<td>F6</td>
<td>Female</td>
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<td></td>
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</tr>
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<td>37</td>
<td>11</td>
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The data were analyzed using Content Analysis in the form of Thematic Analysis, having as a background the reality shared by the subjects – deafness as a social problem. After transcription of the entire material, the analysis was designed from three possible steps and highlighted relations between the different sources(7). The steps followed are as follows:

- First step: the material was read and re-read during which the researcher had direct contact with the documents. Subsequently, the corpus was constituted, in which was determined the register units (keywords or phrases), context unit (defining the context of understanding the register units), the quotes and the categorization format.

- Second stage: categories were created expressions or meaningful words, according to which the content of speech was framed for each group.

- Third stage: inferences were proposed and interpretations were made of the material, relating it with the theoretical framework and interpretation of results obtained with the aid of the adopted theoretical foundation.

Therefore, it was possible to understand the conditions that generated a given quote, be it a family member or a manager, marked by social memory (shared body-historical-cultural) and interspersed with the various social voices that could be perceived in the speech of a subject.

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the Informed Consent Waiver, agreeing to their participation. Prior to submission of the project to the committee, authorization for the development of research was requested from the Bureau of Health & Bureau of Education, since the object of the study involved both sectors.

RESULTS

Group 1 was composed of the families of children who are part of the educational service center. Seventy percent of families were females, with a mean age of 27.1 years. With respect to education and income, 70% had not completed primary education, with income below the poverty level and most (40%) were patients from the same health unit.

It is worth mentioning some information about the children belonging to the families described: most children (five children, 62.5%) were 6 to 10 years old, while three children (37.5%) were 1 to 6 years old, and 62.4% were male. Most patients had a diagnosis of profound bilateral sensorineural hearing loss, diagnosed between 0 and 3 years of age (62.5%), with idiopathic causes (62.5%) and 87.5% of the children were not subjected to OAE testing at birth. Currently, 37.5% do not use any type of hearing aid, while 37.5% use hearing aids bilaterally and 25% underwent a cochlear implant procedure.

Diagnoses considered late, with a mean age of 3.26 years in most children, could be observed in other studies. Only one child was in a special school, while the others were placed in regular classes in regular schools, in the process of acquisition of sign language, which suggests a movement of inclusion, the result of enacted policies in the area.

Group 2 was made up of local managers, statutory service providers in a management position. The health manager (G1) had nursing training and expertise in public health, working in the city for eight years. The education manager (G2) graduated in physical education, with experience in the area of inclusion (data provided during the interview).

Through the analysis of participants’ speech (quotes), it was possible to extract two major themes for discussion: 1 - Early diagnosis, hearing health as a right, the proper care and initial guidance as a necessity; 2 - Difficulties in interdisciplinary relationships between Health and Education.

Frustration with the process of diagnosis, care, and guidance

In their conversations, the families made it clear that there is a lack of care and supply of the initial guidance on deafness. The time of diagnosis is an emotional moment, and one which took parents by surprise, bringing feelings of guilt, insecurity, and denial, interspersed by an incessant search for other diagnoses.

Managers demonstrated that they realize the importance of early diagnosis of deafness and, contradictorily, the health manager stated that school is the most important place in raising children with hearing loss.

The managers who attended these children demonstrated a lack of knowledge about child development, which was evident and could be observed in participants’ statements.

The need for the test of neonatal OAE testing in the city was stated by the manager responsible. The delay in the release of exams, as well as difficulty in accessing health services could be seen in the reports.

In contrast to the delays reported by subjects in Group I, the health manager (G1) referred to the scheduling and carrying out of the basic hearing examination as “fast”.

The excerpts can be seen in Chart 2.

Difficulties in the areas – Health and Education

In this second central theme, families mentioned the lack of knowledge in primary care managers regarding the Department of Education offerings, for example, the existing Educational Service Center in the city, the site of this research, and the fact that they had access to the care center. The managers, in turn, portrayed the relationship between health and education sectors.

The excerpts can be seen in Chart 3.

DISCUSSION

Most subjects who made up the Family Group were females (70%). According to the literature, the mother is normally responsible for domestic services and the health of the child and, in the case of a child with disabilities, fathers rarely attend the centers, leaving all the responsibility to the mother figure, especially in families with low monthly income. In this study, three fathers participated actively and were sensitive and interested in all the consequences of late diagnosis in their children.

The families mostly had an incomplete primary education and monthly income of up to minimum wage, which in Paraná corresponds on average to 700 Brazilian Reals. In a study conducted in five hospitals in the city of Recife, in order to characterize the socioeconomic and demographic profile of mothers who participated in the hearing screening, it was found that, usually, mothers were older than 20, had an incomplete secondary education, and low family income. The authors cite the importance of knowing the profile of the intended population regarding policies and projects for local hearing care.

Some studies demonstrate that the lower the purchasing power, the more deaf children will have limitations and attribute this to the difficulty in access to rehabilitation services. Another study, showed that the prevalence of hearing loss decreases as family income increases.

Deaf children belonging to the aforementioned families are, mostly, male and between the ages of 6 to 9. All children have profound bilateral sensorineural hearing loss with 62.5% being of unknown causes. The diagnosis was considered late, at
a mean age of 3.26 years in most children, which can be seen in other studies\(^\text{(12)}\) and only one child is in special school, while others are placed in regular classes in regular schools and are in the process of acquiring sign language suggesting a movement of inclusion, the result of policies enacted in the area.

In relation to the method used by health managers, such
as a lack of explanation to the families in this study upon the diagnosis of deafness, another study, in order to investigate the experience of ten mothers who were doubtful with regards to the diagnosis of deafness and the subsequent referral for treatment. The study also showed data regarding the mothers' perception about the way the diagnosis was framed and explained\(^{(13)}\). The authors concluded that communication with deaf families needs to take into consideration the social, cultural, and emotional needs of the parents.

Therefore, the importance of the health care professional who makes the diagnosis of deafness for the family, which often despairs and loses itself in the health system without sufficient information and explanations, is evident. This fact was observed in this study and it is noteworthy that it was a local reality and cannot be generalized to other locations.

It is known that in the process of hearing assessment there is the moment of communication to parents when they are passed on information about the existence of some hearing impairment, the characteristics of this impairment, and guidance regarding actions to be taken and subsequent referrals\(^{(14)}\). It is in this moment of weakness that care and listening should do more present, establishing a bond of trust between managers and caregivers.

In their statements, the family members reported “shock” when hearing the news of their child’s deafness. It is known that the diagnosis should be given appropriately, avoiding the feeling of abandonment in the family. This will lead to decision making and rehabilitative interventions, which provide for the best child development\(^{(16)}\).

<table>
<thead>
<tr>
<th>Chart 3. Quotes from statements of subjects referent to Category 2</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Category 2</strong></td>
</tr>
<tr>
<td>Difficulties in intersectoral relationships – Heath and Education</td>
</tr>
<tr>
<td>“ [...] If you have a health service center here that has early stimulation for both deafness and for visual impairment, which starts from 4 months of age, the reason this child has now come at the age of two and was not referred earlier, at 4 months old, to do this stimulation? So there is a flaw! Where is the flaw? In the pathways and procedures … and that reflects on the child’s education in school … “ (F5)</td>
</tr>
<tr>
<td>“ [...] And my boyfriend’s mom is a teacher of X and is part of the association of parents and teachers and the director knows about here, oh we got there he had called her and she had already prepared all the material […]” (F4)</td>
</tr>
<tr>
<td>“He was a teacher there for the project.” (F2)</td>
</tr>
<tr>
<td>“It was a lady from church. When I returned to the clinic with my daughter already having implants nobody guided me for anything.” (F3)</td>
</tr>
<tr>
<td>“[...] I went to municipal schools after I discovered that he was deaf, walked, walked, walked, and nothing. So the director of a school that I do not remember, took a paper and wrote the address of the headquarters here and that is why we came here. It was pretty fast, what took a long time was to discover that he was deaf […]” (F1)</td>
</tr>
<tr>
<td>“And when I went there looking for daycare in a regional normal nursery, then she was about 2 years old, and a woman said that it was difficult to get a place there, and then I said she was deaf and the woman there said I was to look for this health service center. It was the social worker who informed me that at the same time, and she called and set it up. But before that I had never heard of this service center.” (F6)</td>
</tr>
<tr>
<td>“And our relationship with education is that we have a good partnership with the coordinator who is a psychologist, when she needs to consult us, we make it so. We have a reference in pediatrics with UB in Alto Macarana who is Dr X, excellent professional. And when the child has a hearing problem she makes an assessment and forwards it to the high complexity area. So special education will have this easy access, connecting directly with coordination and scheduling.” (G1)</td>
</tr>
<tr>
<td>“There is no evident integration between the areas of education and health. Of course we end up doing some referrals, when necessary, so that health will support us.” (G2)</td>
</tr>
</tbody>
</table>
By having the first contact with the child after birth, the pediatrician becomes co-responsible for identifying children with suspected hearing impairment and must take into account the medical history and complaints brought by mothers. It was found that this was not the reality experienced by the subjects of this study.

The unpreparedness of public health managers in relation to deafness, as well as the lack of public auditory health efforts in primary care, facts observed in parental reports, suggests a lack of efficiency in training and guidance to managers, as suggested in PNASA⁵.

We know the linguistic, communicative, cognitive, social, and emotional benefits provided by early diagnosis and, before that, its importance in routine health professionals(¹⁷). Therefore, promotional actions can become an effective means in the process of early detection and appropriate referrals, from an interdisciplinary and multidisciplinary perspective.

In the data collected, early diagnosis for proper child development and rehabilitative interventions, was stated as necessary by all individuals (family and managers), even by those who did not have access to adequate information nor the means of diagnosis at birth, such as with neonatal OAE testing.

The municipality in question has only one speech therapist working in health care, 27 family health teams, and has no family primary care center (FPCC). And it is there, in primary health care, where interventions in hearing care should be initiated with health care professionals who strengthen integrity in the area.

The insertion of a professional speech-language pathologist in primary care could be a way to minimize imperfections in the promotion, protection, and rehabilitation of hearing health as well as access to diagnostic tests(¹⁸) and it would be possible through the creation of a municipal FPCC, with an interdisciplinary team including a professional speech-language pathologist to enable the strategies in primary health care, but also to strengthen intersectoral relations, strengthening that adds value to the PNASA. Likewise, the managers that make up the Hearing Health Care Services team could, using available information, train teams in primary care to identify the evolution of healthy language in children and develop strategies to see if there is something at odds with the normal hearing development, thereby avoiding late diagnosis.

It was possible to see the ignorance of some managers who attended families on the development of language, because they considered it normal for a child to talk after 2 years of age or older, and therefore did not hear complaints brought by the parents and, therefore, did not request diagnostic tests.

According to literature data, the first words spoken by a child in normal language development will be in the eighth month of life(¹⁹), but have communicative behaviors from three months, with the presence of a smile, focused looks, and babbling. Given these elements, it is necessary to refer children under the age of 2 for audiological evaluation.

However, what we see in recent national polls is a late diagnosis of profound hearing loss, with discovery at an average age of 4 years and 6 months in a study of the Southeast region of Brazil(²²). In a city in the Northeast region, a study shows a diagnosis age of 1 year and 2 months(²⁰), and yet another study shows diagnosis with a mean age of 5.46 years, the city of São Paulo(²¹). The international literature (U.S.) points to an early diagnosis at 2 months of life, accomplished through universal hearing screening and early intervention at 6 months of age(²²).

In this study, the results on diagnoses of sensorineural hearing loss and the average age of these diagnoses, although not via quantitative research with an extensive population sample, were distant from the international literature, and in turn, approached the data pointed to in other Brazilian studies.

For these children, these facts made it difficult to choose a school, a linguistic format, a means of hearing aid fitting, thereby causing delays and major hurdles in language development.

In contrast, the local health manager (G1) talked about the progress of the current administration, in relation to the completion of the OAE test (via outsourcing services) since 2010. However, PNASA was implemented in 2004, i.e., early diagnosis in the municipality began only six years after implementation of the national hearing health policy.

In the majority (62.5%) of the children who participated in this research, in the age group of 6-10, only one child, born in 2010, could have benefited from the OAE test when he was born in the maternity ward, but, this did not happen and his diagnosis was only confirmed at 2 years of age.

As already discussed, the early diagnosis of deafness should happen prior to entering pre-school, normally between the ages of 4 and 6. Also, according to the Brazilian Law of Guidelines and Groundwork for Education, early childhood education occurs in daycare until 4 years of age, however, according to IBGE(³¹), Brazilian children enter school starting at 3 years of age, an advanced age considering deafness diagnosis. However, it is noteworthy that otoacoustic emissions testing became mandatory in the state of Paraná, through state legislation, on December 22, 2004(²⁵).

Another fact reported by parents was the wait for scheduling audiological diagnostic tests, such as audiometry, auditory evoked potential, and otoacoustic emissions, as well as access to rehabilitation resources, such as hearing aids and cochlear implants (CI), which are guaranteed by PNASA(⁵).

It is noteworthy that there is no scientific data, or institution, to provide such information, but according to the statements of the subjects, the wait was at least one year, and a maximum of three years, to release diagnostic tests and also to provide hearing aids. Still, some parents considered there experience to be fast, while others sought additional networks or even went to another state (São Paulo).

In another study, based on data from the medical records of 22 deaf children in a city in the Northeast region, access to
hearing aids was available when the children were 3.6 years old on average[20], and Sao Paulo, with 166 records, initiated the use of hearing aids with approximately 7 years of age[21]. In this study, eight children, 37.5% were using hearing aids and 25% had received cochlear implants. However, three children (37.5%) were still awaiting the purchase of hearing aids, and it is noteworthy that, according to information provided by the mothers, the wait is more than two years.

These facts can be attributed to the difficulty in accessing the services available, as they are located in other municipalities and not where the users reside, but also a demand that surpasses available human resources, causing a long waiting period, regardless of the values put forth by PNASA[22] and the Sign Language Act, Law No. 10.436, established in 2002, which ensures priority service at all levels of complexity for students enrolled in the primary education school systems.

In the case of the local municipality in this study, the metropolitan region of Curitiba-PR, the actual service for diagnostic audiological exams and hearing aid fitting occurs in another municipality, responsible for 2nd Health Region of which Curitiba is also part.

Visible are the difficulties faced by families in the municipality studied in this research. It is common to see families “competing” for vacancies in the booking of diagnostic tests and the acquisition of hearing aids with other municipalities, all belonging to the same Health Region.

It is necessary to expand the service network of hearing health services, from diagnostic test access to a means of rehabilitation, from the deployment of a hearing health service in a municipality, or by means of a complementary network and agreements with other clinics near the residences of families.

The health care manager (G1) attributed these difficulties to a lack of investment, reflecting a widespread problem in our country, as well as the inadequacy of subsidies from the state, insufficient to meet local demands, resulting in the difficulties reported by the subjects in Group 1.

However, according to Law 8080/90, it is up to the Municipal and the Federal governments to execute and manage public health services, whether outsourced or not, and up to the State and Federal Governments to monitor, control, and evaluate the national health care systems networks, as well as technical and financial support to municipalities, among other duties.

It is necessary to improve the organization of the protocol for hearing aids in the national healthcare system, which seeks to provide comprehensive and effective care. For this to be possible, there must be intersectoral connections between health surveillance and health assistance networks, which would provide communication between the reference and counter-reference services, strengthening the overall completeness[23].

In this sense, a joint vision of a single system that works holistically and provides services that meet the needs of users is required.

Intersectoral action is essential when seeking comprehensive care and when it launches focused on the important consequences that a late diagnosis of deafness entails[24].

The lack of this joint system could be observed in the statements of parents who said that there is “a failure of the pathways for care and it reflects on the child’s education.” These “pathways” can be understood as a lack of communication between health services and education services.

Based on the Basic Operational Norm No. 01/93, which refers to a “unified”, health system, saying, “it must be understood as a set of doctrinal or organizational elements.” Therefore, health managers, especially speech-language pathologists, should be seen as linked to a set of services, recognizing the unified concept of the system, and not to any network fragmentation. It is necessary that, in addition to knowledge of the region, there be a vision of a network system that seeks a communication strategy between services of all the complexities belonging to the national health care service.

For this to be possible, even the health services need to be sensitive to the demands and know the available institutions and their competence at different levels[25], but also to provide quality treatment through humanized practices, focused on the concept of health as a right of citizenship[26].

It is this knowledge and network action that will make a difference and, from it, the consequences would be minimized, children would be diagnosed early, and arrive early to rehabilitation centers.

When parents referred to the pathways of access to the health services center, the absence of such coordination was evident. Parents mentioned that such information was transmitted by others (teachers, friends) and not by the Primary Care managers, at the time of diagnosis.

The same findings also could be seen in a survey conducted in Salvador (BA), based on interviews with 30 users in speech therapy by the national health service in 2006, i.e., even after six years and in regions with different realities, the results converged when most of the participants reported having access to the service via orientation from people in their social network and not health professionals[26].

Thus, we return to the point at which the categories of this research approached and recognize the Primary Care site for guidance and referrals to educational centers, and respecting the flow mechanisms operating settings. The idea of networking actions and health services has been redefined as a chain of progressive care, which ensures the completeness and resolution processes of health care and sees comprehensiveness as main organizational support management for health actions[27]. Health (G1) and education (G2) managers, in turn, cited the attempt to close relationships between the departments, something that is informally experienced and restricted to the viability of health for scheduling exams and supplementary consultations for children who have enrolled in school, and the possible creation of a committee (G2).

The Living Without Limits Plan[27] emphasizes the need for
intersectoral communicability and prioritizes, among other goals that focus on health, inclusion and quality of life for people with disabilities, through actions based on a Care Network for People with Disabilities. Points to be considered important are the development of intersectoral action for health promotion and prevention, dissemination of information about available services in the network, attending the demand and welfare of network flows, the building of indicators for monitoring and evaluating services, as well as, the solvability of health care, among other measures\(^{27}\). The state of Paraná announced its adherence to the plan in August 2012 and, subsequently, the difficulties presented by the parents in this study are likely to be minimized or even solved, to the extent that management exercises what was determined in that the decree.

It is noteworthy that the interviews with managers (G1 and G2) happened prior to the date the state joined the National Plan, which may explain the fact that management did not mention any movement in relation to the deployment of the network in the region.

However, the mere facilitation in setting appointments, something which is already guaranteed and seen as a priority by the policies and laws mentioned above, should not be the only means of communication between the sectors of education and health. State and municipal departments should ensure assistance in joint, not fragmented, coordination with specific actions and sectoral policies. Thus, the complexity of hearing deficiencies, recognized from the demands presented, requires actions of the Health System in various levels of care\(^{23}\).

Some authors report that many of intersectoral measures take place informally, without prior planning, with actions established by only one sector, contrary to the ideals of intersectorality. Therefore, it is necessary to have constant dialogue between the sectors through linkages of co-responsibility and co-management, to have planned and scheduled special activities where there is sharing of management and coordination of knowledge and actions among the institutions involved\(^{28}\).

It is necessary to reflect on this new challenge of preparing proposals involving the vision of integration, including intersectoral actions in the areas of education and health, based on the Federal Constitution (1988), which provides for governmental skills and commitments\(^{29}\).

Other authors\(^{29}\) also discuss the areas of competence of some cross-sectoral policies, with full attention on different life cycles, attaching the active participation of health and education to the promotion and protection of health, habilitation, rehabilitation, information services, and guidance.

And so, weaving our approaches in the field of comprehensiveness with the ramifications of deafness, one of the possible paths would be the reorganization of health institutions with regard to the possibilities of integrating political projects and organizational practices geared to teaching, research, and operation of services, all at the local level\(^{25}\).

Also, the importance of the care that should be health managers is stressed, to enable support for families and the possibility of an early diagnosis, and appropriate referrals after the conclusion of the hearing of a child.

Therefore, this study, even though it reflected a local reality, provided contributions to possible reflections as to the fact that the experiences expressed by families may also be common to other subjects and that changes in attention networks are needed.

**CONCLUSION**

The results in this study showed that care was unsatisfactory and that the guidelines after the initial diagnosis of deafness were not adequate. The principle of integration was not comprehensively addressed since the waiting period for the release of diagnostic tests and means of auditory rehabilitation was more than one year, becoming a damaging factor on early intervention and consequently the development of children. There is not, in the local municipality of the study, a satisfactory sectoral relationship (health and education), or networking operations in health care, since those responsible for children with deafness were mostly sent to the service center by other people and not through the national health service soon after diagnosis.

It is noteworthy that these conclusions refer to a local reality and should not be generalized.

**REFERENCES**