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04. Inclusive Education

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Family, Education and Inclusion of Deaf Children with Cochlear Implants: first results.

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Introducción.

This contribution presents the progress of a doctoral research project that aims to respond to the needs and possibilities that families have to meet and provide educational support to a son or daughter who was born with profound deafness and who has undergone cochlear implantation. According to various researchers (Bruin, 2018; Holt, Beer, Kronenberger, Pisoni & Lalonde, 2012), cooperation between different educational agents is vital for the comprehensive development of minors, with the family being a first-order entity. There are few studies in this regard, hence the importance of recovering the experiences of families to develop an inclusive education.

We can say that we are living in a unique moment in terms of medical and technological advances in the world of deafness that minimize the consequences of this disability in a society that culturally still needs to open possibilities for diversities.

One of the most notable advances is that referred to hearing. One is the hearing aid, which is an electronic device that amplifies sound and is placed behind the ear or inside the ear and is used for those who have mild or medium hearing loss. Parallel to the advances in hearing aids, in the mid-20th century important achievements were made in another type of prosthesis, the so-called cochlear implants (CI), for people with profound bilateral hearing loss. According to the Spanish Confederation of Families of Deaf People (FIAPAS), this device is recognized by the scientific community as one of the historical advances of the last century, which has changed the lives of more than half a million people in the world (...), making it possible for deaf children to have better access to oral language at an early age and to the learning that derives from it.

Together with speech therapists, schools and health professionals, the involvement of parents with minors is considered a key to achieving the success of mentioned



rehabilitation (Juan, 2016; Santana & Moreno-Torres, 2012). As Schlesinger points out (in Lutterman, 2009), the best predictor of literacy for these children is found in the linguistic interaction between parents/guardians and children, which he called the elusive "X factor". This factor turned out to be of greater importance than social class, economic status of families or IQ.

On the other hand, article number 9 of the United Nations Convention on the Rights of Persons with Disabilities (UNESCO, 2006), defines "accessibility as a necessary condition for persons with disabilities to be able to enjoy the same goods and services on equal terms. And in its article 24, it explains that "disabled people can access inclusive, quality education, on an equal footing with others and in the communities in which they live", therefore promoting access to this type of resource or interventions becomes essential to ensure the rights of people with disabilities.

Within this framework, this research seeks to deepen the understanding of the role of normal-hearing families with deaf children with CI and, in this way, attend to the different experiences, strategies and trajectories that ensure inclusion. It focuses on studying family contexts of CI users for two reasons: on the one hand, it is an autoethnographic study, since the doctoral student is the mother of an implanted child and, on the other hand, although many of the strategies and experiences can be similar to that of minors with hearing aids, many of the family knowledge networks move through different spaces since the type of prosthesis generates differences in care, in programming, and in the resources around them.

Methodology, Methods, Research Instruments or Sources Used

The main objective of this study is to recover the voices of the families that have children in their care with CI, to collect information, analyze it and make proposals for action to improve the lives of these people.

This article presents some results obtained from the first two years of research. The information is collected under different aspects: (1) in which parents have known the diagnosis of their sons and daughters; (2) the type of information and training provided by the staff who care for the families and the guidance offered to them; (3) to know the main methods that families have used to find out, how they have felt, what their needs are, how they have dealt with this disability together with the rest of the family members, what kind of difficulties they encounter on a daily basis and if these families have received training in this regard; (4) What kind of strategies do families use to communicate and educate with these boys and girls before and after the implantation of these electronic devices, and what strategies have they developed together with the teaching professionals who have been with these minors during the school stage?

This research project has its methodological basis in auto-ethnography (Denzin and Lincoln, 2012), recovering a narrative biographical approach (Clandinin, 2013), and from the approaches of inclusive research (Nind, 2017) that assumes certain principles and responsibilities towards research and co-investigators, which generates "research committed to the fight against exclusion, committed to processes of change and socio-



educational improvement, participatory and collaborative with educational actors/agents and ethically committed" (Parrilla, 2013, p.7-8).

To this end, it is proposed to combine different techniques and strategies that allow us to approach the object of study, both from a panoramic dimension to the family reality of deaf children with CI in normal-hearing families, as well as a more specific approach to devices, practical experiences and their success strategies.

For this contribution, we take the first results of the autobiographical life story that will be woven with the collection of information with other families through an online questionnaire, all of this, as a first procedural phase of the project to propose a panoramic view of family experiences and thus give meaning to auto-ethnographic research.

Conclusions, Expected Outcomes or Findings

The analysis of the information obtained in this first stage of this research project reveals that despite the existence of bibliographic references on strategies to improve communication with people who have these electronic devices (Juan, 2016; Santana and Moreno, 2012), families barely use them, since only 25% state that they take advice from such information. It is detected that there is a lack of information and advice from health professionals and speech therapists who are experts in the field. If the parents do not have the resources, the will, the motivation and the emotional strength to know and put into practice these strategies, the opportunities to hear and speak of these minors are reduced.

We must highlight the lack of training by professionals in the educational world to address strategies with people with IC. Currently, initial university training lacks specific training on these issues that we have been developing to inclusively address the reality of people with these devices. The information analyzed shows that families with this group of minors perceive a lack of motivation and training on the part of their sons and daughters' teachers. The family-tutor relationship is essential for improving academic and communication results with children with CI, although sometimes this depends on the level and economic resources, availability of time and family involvement, according to each family and social context.

Finally, it should be noted that, for there to truly be educational inclusion, it is considered necessary to create work teams made up of health professionals, speech therapists, programmers, teachers, and families, and these are the link between all of them, with the objective of rowing in the same direction, to generate spaces that can meet the needs of these minors.

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