

Fédération Européenne des Parents d'Enfants Déficients Auditifs European Federation of Parents of Hearing Impaired Children Europäischer Verband der Eltern Hörgeschädigter Kinder Federación Europea de Padres de Niños con Discapacidad Auditiva

On the World Hearing Day

FEPEDA MAKES PUBLIC THE RESULTS OF THE RESEARCH ON THE NEEDS OF FAMILIES OF DEAF AND HARD-OF-HEARING CHILDREN IN EUROPE

(3rd March, 2023).- On the World Hearing Day, the European Federation of Parents of Children with a Hearing Disability (FEPEDA) has made public the main results of its Research on the needs of families of deaf and hard-of-hearing children in Europe in which 1.273 families from 26 European countries have participated.

The comparison of the results with previous researches carried out by FEPEDA shows the evolution in the situation of deaf and hard-of-hearing children and young people across Europe in the last 20 years.

This morning, the European Federation of Parents of Children with a Hearing Disability (FEPEDA) held a public event in which, in front of almost a hundred attendees, it presented the main results of the research carried out during 2020 and 2021.

As FEPEDA's President, André Cuenca, has underlined "neonatal hearing screening, access to hearing devices, access to early intervention, mainstreaming education have changed the approach to deafness", however, André Cuenca continues "children and young people with a hearing disability and their families still have needs to which we must all, society, public administrations, companies, representative organisations..., provide an answer".

Sari Paloposki, FEPEDA's Vice-President and project manager of this Survey, has made the presentation of the results, making a call for:

- Ensuring the participation of parents' associations in neonatal hearing screening and early intervention programmes
- Better access to free hearing devices.
- More social, emotional and financial support for families with deaf and hard-ofhearing children.
- Better education for deaf and hard-of-hearing children. Updated and specialised training for teachers. Assistive products and services at school. Accessible materials and teaching strategies in digital education.
- More resources to assure accessibility to information and communication.
- Better employment opportunities.
- Better public awareness about deafness in children.

The event was fully accessible for deaf and hard-of-hearing people and counted on the participation of people most of the European countries, Australia, India, Uganda, Kenya... Participants were people with a hearing disability, families of deaf and hard-oh-hearing children, representatives of administrations and public authorities, as well as professionals involved in the care of children with a hearing disability (Universities, schools, health and hearing centres, family organisations, early childhood intervention programmes...).



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MAIN RESULTS

Profile of the sample

 Almost the whole sample had bilateral hearing loss. Most children had a severe or profound hearing loss (79%), but there were as well children with mild and moderate hearing loss.

Diagnosis of hearing loss

• The neonatal hearing screening test diagnosed most children (60%). Amongst children from 0 to 6 years, this percentage increased up to 73%. In 2013, only 35% of diagnosed children were tested at birth.

Access to hearing devices

• The majority of children (97%) used hearing devices (hearing aids or hearing implants). The use of cochlear implant has increased from 13% in 2000 to 56% in 2020

Means of communication

- Spoken language was the most used mean of communication (70%). Amongst them, 4% also used cued speech and 7% also used sign supported language (communication augmentative system). These percentage has increased from 47% in 2000 and 62% in 2013.
- 15% of children were bilingual (spoken language / sign language) and 11% of children communicated in sign language.

Education

- Most children were in mainstream schools (75%). In the last 20 years this percentage
 has experienced a huge evolution: from 44.5% in 2000, passing by 56% in 2013 to 75%
 in 2020.
- Most children between 7 and 17 were in the right class according to their age.
 Specifically, 87% of children between 7 and 11 years and 83% of those between 12 and 17 years.
- 72% of children studied another spoken language (foreign or/and official language).
- 19% of children expressed they had been bullied at school because of their hearing loss.
 Analysing the data by ages, 14% of children between 7 and 11 years were bullied. Result increased up to 22% in the group of children between 12 and 17 years.

Parent's perception on education

- 77% of parents were satisfied or very satisfied with the choices they had made regarding their child's education.
- Only 46% of families considered that deaf and hard-of-hearing children are educated at the same level as hearing children.
- Families expressed their concern about the quality of education their children received and about the opportunities they will have in relation to further education and employment.



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Information at diagnosis

- An important percentage of families did not receive information at the moment of diagnosis (37%).
- 33% of parents considered the information was confusing, unhelpful or insufficient.
- 65% of parents were encouraged to contact other families of deaf and hard-of-hearing children.
- Only 55% of parents considered the quality of professional support excellent or good.

<u>Parent's perception on the support by parents, parent's associations and professionals</u>

- 68% of parents were in contact with other parents of deaf and hard-of hearing children and 93% of the whole sample considered this contact useful.
- 63% of parents had regular contacts with their local association of parents and 67% of them expressed their satisfaction with the emotional support they received from other parents.
- 41% of parents were satisfied or very satisfied with the emotional support provided by professionals and 36% of them were unsatisfied with this support.

Parent's perception on the financial support

- Hearing implants and hearing aids were mostly financed by public administrations, as well as medical costs and support resources for school (FM systems and sign language interpreters). However, there were many cases where these and other technical devices must have been financed by the families themselves.
- 45% of families were unsatisfied with the level of the financial support.

Parent's perception on social inclusion

- 68% of families were unsatisfied or very unsatisfied with the level of **public awareness** in relation to deafness.
- 58% of families were unsatisfied or very unsatisfied with the level of accessibility for deaf and hard-of-hearing people in **public transport and in public offices**.
- In relation to the accessibility to **healthcare facilities** for deaf and hard-of-hearing people, 56% of families were unsatisfied or very unsatisfied.
- 40% of families were unsatisfied with the **quantity of subtitling** in on television and 35% with the **quality of the existing subtitling**.
- 33% of families whose children used sign language were unsatisfied with the level of access to sign language interpreters.