



***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***

FEPEDA Newsletter 1/2021

Greetings from the President

On April 17th, 2021, FEPEDA hold a Management Committee. A new Bureau has been elected and I have been elected as new President.

First, I wish to warmly thank Sari Paloposki, from Finland, who had been FEPEDA President for three years and a half (6 months more than the scheduled mandate). Under her lead and with Management Committee members involvement, as it was also done in the past by her predecessors, FEPEDA did a big work to improve the quality of life and defend the rights of deaf and hearing-impaired children and their families.

I am honoured to have been nominated President of FEPEDA. I have been involved in FEPEDA for about 17 years and I am happy to continue to work in this organisation with this position. I am grateful to Management Committee members for the trust they gave to me. I am aware of the responsibilities of the President of such an organisation and I will work hard in order to be worthy of this trust.

For more than one year, the situation in Europe has been degraded by COVID and we know that people with disability are particularly weakened.

FEPEDA will continue to support and to help organisations and families in Europe facing with this crisis and, also after, when better days will be here. We know that we need to stay vigilant, and we must continuously work to defend the rights of the families.

I send to you my warmest greetings. Take care of you, your family and your friends.

André Cuenca, President of FEPEDA

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Previous FEPEDA meetings

The first Management Committee meeting this year was held on 17th of April, 2021. Due to the COVID19 pandemic, the meeting was held virtually by zoom.

In this meeting there were also elections for the Bureau. André Cuencá from France was unanimously elected as new President of FEPEDA following in this position Sari Paloposki from Finland. FEPEDA addressed a warm thank you to Sari and Petra Paloposki for their great work during the past years.

Members of the Bureau:

André Cuencá as new President of FEPEDA

Sari Paloposki as Vice President

Franziska Geiser-Bedon as Treasurer

Cosmin Brasov and Carmen de Lamo continue as Vice Presidents (elected in October 2020)



Upcoming FEPEDA meetings

Next Bureau meeting will be held on 28th July, 2021.

Next General Assembly and Management Committee meetings will be held 15th-16th October. (Depending on COVID-19 situation, the meeting will be held online or possible in Malmö or Paris.)

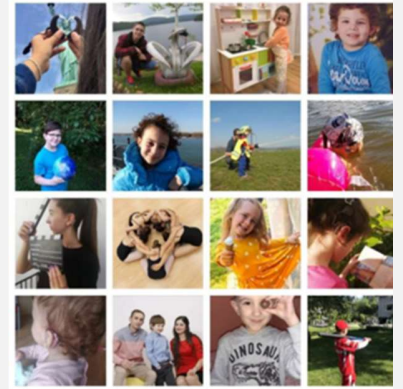


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FEPEDA Projects

Photo campaign:

FEPEDA Photo Campaign was originally launched in autumn 2020. The campaign has been successful amongst the families around Europe. We are happy to inform that the campaign is still ongoing and new children and young people are welcome to join. For more information, please contact the President.



Family survey:

FEPEDA carried out family survey in autumn 2020. The first results were presented at the Management Committee meeting in April. We are still processing the results deeper and an official report on the results is coming later this year. *FEPEDA warmly thanks everyone who has participated in this survey!*

FEPEDA QUESTIONNAIRE

2020

Advocacy and networking

FEPEDA was invited to closed round table discussion chaired by MEP Adam Kósa. The meeting took place in February 2021. FEPEDA was represented by Natalia Beraza from Spain.

European Disability Forum's General Assembly was held online in June, André Cuencá as representative of FEPEDA.

The European Platform of Deafness had its first meeting this year online in April. Sari Paloposki attended the meeting on behalf of FEPEDA.

The World Hearing Forum launched The World Report on Hearing on the World Hearing Day 3rd of March. The report is interesting and members are encouraged to use it in their own advocacy work.

On the World Hearing Day FEPEDA launched a press release as in many years before. This year the press release was drafted jointly with our international cooperation partner GPODHH.

FCEI-conference is postponed until June 8-11, 2022. The conference will be held in Bad Ischl, Austria. We will keep you informed of any news.



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Global Coalition of Parents of Children who
are Deaf or Hard of Hearing



European Federation of Parents of
Hearing Impaired Children

FOR IMMEDIATE RELEASE

Millions of Children Worldwide Have Unaddressed Hearing Loss

According to the World Health Organisation (WHO), 34 million children worldwide have a disabling hearing loss. On **World Hearing Day**, 3 March 2021, a strong message about early identification and cost-effective interventions is being communicated by parent advocates with the Global Coalition of Parents of Children who are Deaf or Hard of Hearing (www.gpodhh.org) and the European Federation of Parents of Hearing Impaired Children (www.fepeda.eu).

In the spirit of the WHO's 2021 campaign, *Hearing Care for ALL! Screen, Rehabilitate, Communicate*, GPODHH and FEPEDA challenge national health care systems around the world to integrate people-centred ear and hearing care within universal health coverage. Both parent-led groups call for governments to integrate Universal Neonatal Hearing Screening (UNHS) Systems through adoption of the 1-3-6 UNHS Goals:

- screening by 1 month
- identification by 3 months
- entry into early intervention by 6 months of age

Early identification is only the starting point for improved child outcomes. The benefits of neonatal hearing screening will not be realised unless children receive ongoing, affordable services, and support. Every child with hearing loss deserves early identification of their hearing loss, timely early intervention to support spoken or sign language development, according to the choice of their parents, and properly fitted listening devices, when appropriate. Evidence indicates these are key factors for minimizing the impact of hearing loss on a child's development, educational attainment, and socio-emotional wellbeing.

In addition, GPODHH and FEPEDA emphasize the centrality of the family in each child's life. In order to prosper, children need an enabling environment for their families and caregivers. Research proves the most important predictor of a child's success is the meaningful and effective involvement of his/her family. Formalized, measurable family support mechanism must be included in UNHS protocols and practices—and in the thought-leadership of early hearing detection and intervention systems.

GPODHH and FEPEDA champion a world where no child, young person, or adult with hearing loss is left behind.

-end-

World Hearing Day

You can find the press release also on
FEPEDA website:

<https://fepeda.eu/celebrating-the-world-hearing-day-2021/>

More information on our Global partner
GPODHH: www.gpodhh.org



Country News

Bulgaria

The Association of Parents of hearing-Impaired Children realized a national sociological survey for the community of people with hearing impairment, funded by the project BG05M9OP001-2.011-0006 "Equal opportunities for children and youth with hearing impairment and their families."

The aim of the survey is, based on empirical data and analysis, to research the needs of people with hearing impairments and their families regarding the current state and opportunities for social integration through employment, access to continuing education, satisfaction with community services and accessibility to modern technologies in hearing aids in Bulgaria.

To find answers to these questions, APHIC in partnership with proven experts, turned to over 500 representatives of the target groups from all over Bulgaria.

We are pleased to present the main thematic units and summarized the results.

Hearing aids

- 85.5% of respondents or a family member with whom they are directly involved, have a hearing aid;
- 61.2% paid in full or in part for the hearing aid they needed
- 40.2% of the respondents answered that maternity hospitals and pediatricians do not have enough information about the audiological clinic and specialists, and do not provide timely and adequate such information to the parents.

Speech therapy

- 85.8% of the respondents used early hearing and speech rehabilitation, 34.6% of them had to pay extra or travel (to another towns) to receive it.
- The most frequently used specialists are hearing and speech rehabilitator (85.7%) and speech therapist (51.9%).
- According to 42.9% of the respondents, sign language has a place only as a supportive method in the process of rehabilitation of hearing and speech, in the opinion of therapist and parents

Education

-75.1% of the respondents' state there is a lack of trained specialists to support the process of integration and education of hearing-impaired students. According to 51.7%, there is not enough access to information about the taught material (subtitles, recordings, etc.). For 25.1% it needs sign translation, and for 47.1% - technologies to support the learning process.

- 32% of respondents said that they had to choose an out-of-residence school to receive additional support. 32% of parents were personally looking for specialists to visit the school to raise awareness of the teaching staff about the



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specifics of students with hearing impairment. 16.4% had to change the initially selected school due to problems with integration and the accessible environment for students with hearing impairments.

- 54.8% of the respondents indicate that higher education institutions do not have the necessary training to work with students with hearing impairments. According to 40% there is no access to information about the taught material (subtitles, recording).

- 37.1% need specialists to provide personal support to hearing-impaired students, and 32.8% would like more information campaigns on the specifics of disability, addressed to other students and faculty. According to 24.3%, there should be sign language interpretation in higher education.

- 57.4% of the respondents faced aggression and discrimination based on hearing impairment in the school they or a member of their hearing-impaired family attended.

Employment

- 65.6% of respondents believe that people with hearing impairments do not have equal access to employment. For 36.5.9% the state measures to promote the employment of people with hearing impairments are non-working, and according to 33.2% the proposed employment for people with hearing impairments is lower paid or short-term.

- 39.6% of the respondents used personal contacts to start work, and in 19.3% the performed work activity is less qualified compared to the possessed education and / or skills

Accessible environment

-23.2% of the respondents share that they had to temporarily or permanently change the place in which they lived to have better opportunities for rehabilitation and integration.

-53.1% of the respondents indicate as the biggest concern in the long run for them or for a member of their family with hearing impairment the impossibility to realize on the labor market. The list is supplemented by concerns about the lack of access and opportunity to receive quality education (46.3%), lack of access to adequate support and services (44.5%), lack of funds for rehabilitation and / or hearing aids (33, 1%).

Lithuania

Lithuanian Association of Families with Deaf and Hard of Hearing Children PAGAVA, taking into account the prevailing situation in the world due to the pandemic, from March 2021 started organizing remote monthly "Family Club" meetings for the members of PAGAVA. "Family Club" is a parents' meeting. Realizing that there is a great lack of communication for everyone at this difficult time, we decided that such meetings would be helpful for parents. During "Family Club" meetings, parents share their experience, useful information, and thus help make important decisions or solve arising problems.



Topics of the first meetings included deaf children education in mainstream schools, difficulties faced by children and how children can deal with them; advice and counseling for families on the choice of cochlear implants. The topic of the next meeting will cover cyber security in remote work and distance learning.



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"Family Club" meetings help PAGAVA staff better understand the needs of the members of the association and thus be able to provide families with necessary support and extend PAGAVA services.

Spain

FIAPAS INFORMATION FOR FEPEDA NEWSLETTER (January-May 2021)

FIAPAS ADDS NEW INTERFACE IN ENGLISH TO ITS VIRTUAL LIBRARY

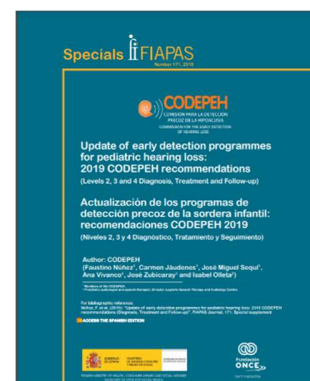


FIAPAS Virtual Library has a new interface in English in order to expand the scope and dissemination of publications and materials specialised in the field of hearing impairment, contained in it, while maintaining its responsive and accessible format.

The FIAPAS Virtual Library now allows you to select the browsing language. With the new format it is possible to access the bibliographic sheets of its publications and materials, translated into English. They indicate whether they are available in Spanish and/or English. In addition, when a publication is searched, the language of the publication is indicated. New publications and materials in English will be added progressively.

<https://bibliotecafiapas.es/en/>

<https://bibliotecafiapas.es/genero/codepeh-documents-in-english/>



OTOTOXIC DRUGS, ONE OF THE MOST COMMON CAUSES OF DEAFNESS

The project "Prevention and early diagnosis of deafness due to ototoxicity" is the name of this work that concludes a scientific review on the early detection, prophylaxis, monitoring and treatment of ototoxicity in the paediatric population, carried out by the Spanish Commission for Early Detection of Child Deafness (CODEPEH), composed by the Spanish Society of ENT doctors, Spanish Association of Paediatricians and FIAPAS.

Ototoxic drugs represent one of the main causes of deafness that can be prevented and/or minimised. As in the case of any other type of deafness, early detection and appropriate treatment can avoid the consequences associated with it. Once this scientific review work has been completed, it has been translated into a [Recommendations Document](#), which will be soon translated into English.





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COVID-19 AND HEARING ACCESSIBILITY

In the case of the outbreaks of coronavirus, as an alternative to face-to-face attention, new ways of attending to citizens have arisen through video calls or applications which, despite their great usefulness, can be a major limitation for people with deafness, if they do not provide accessibility to hearing and communication.

CÓMO HABLAR CON UNA PERSONA CON SORDERA
Pautas generales para apoyar la comunicación en el entorno sanitario

Os recordamos unas pautas sencillas que facilitan y apoyan la comunicación con una persona con sordera y que pueden ser muy útiles para los profesionales (de la Sanidad, la seguridad, de emergencias...) que tienen que relacionarse con la ciudadanía en este momento de emergencia sanitaria.

- Tened en cuenta también que con las mascarillas puestas no es posible para la persona sorda leer los labios de quien le habla y la escucha es menos nítida e inteligible, por lo que se añaden dificultades y es más importante aún que os aseguréis de que la persona sorda está entendiendo el mensaje.
- En caso de hospitalización, cuando sea posible, hay que facilitar a la persona sorda el uso de su prótesis auditiva y proveerle de pilas para su funcionamiento.
- Prestar atención a las indicaciones facultativas en relación con las personas que portan un implante auditivo (coclear o de otro tipo).

DURANTE LA INTERACCIÓN...

NO LE HABLES NUNCA SIN QUE TE ESTÉ MIRANDO.

HÁBLALE DE FRENTE Y CON EL ROSTRO BIEN ILUMINADO.

SITUÁTE A SU ALTURA CON ESPECIAL CUIDADO SI ESTÁS ANTE UNA PERSONA QUE NO SE ENCUENTRA EN PIE O SI SE TRATA DE UN NIÑO/A.

In addition, the installation of screens, the use of masks and the physical safety distance, combined with the ambient noise of crowded spaces, hinder lip-reading, hearing and speech intelligibility.

For this reason, during these months, FIAPAS has carried out numerous political and social advocacy actions to remind people of the need for **telephone services related to health care and public safety to be accessible** to all people, **incorporating the possibility of chats, instant messaging and video calls that allow communication in real time, using voice, text, subtitles and images.**

FIAPAS also stressed the need for **hearing support devices**, such as the magnetic loop, which are essential to enable communication and access to information for people with a hearing disability who use hearing aids.

<http://fiapas.es/actualidad-y-agenda/nota-de-prensa/urge-incorporar-soluciones-accesibles-para-la-comunicacion-no>

HEARING ACCESSIBILITY IN UNIVERSITY ENTRANCE EXAMS

It also called on educational administrations and universities to **reinforce measures of hearing accessibility and access to information and communication** for deaf students in the university entrance exams, given the barriers generated by the necessary prevention measures against COVID-19.

Deaf and hard-of-hearing students with hearing aids or hearing implants also require the use of **individual FM equipment or the possible installation of a magnetic loop in the space** where the exam takes place (adapting part of it), in order to be able to receive directly, through their hearing aids, the voice of those who transmit the access indications, the instructions for carrying out the test or the communication of incidents, from those who are in charge of monitoring its progress.

Likewise, teachers present during the test must be informed of the presence of deaf pupils and facilitate the use of the above-mentioned hearing support devices and follow communication support guidelines, also providing the necessary information in writing so that they can take the test under equal conditions and opportunities as any other student.

<http://fiapas.es/actualidad-y-agenda/nota-de-prensa/protocolo-covid-19-y-prueba-de-acceso-la-universidad-debe>



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PREVENTING HEARING LOSS AMONG YOUNG PEOPLE

On International Noise Awareness Day, FIAPAS recalled that, according to the World Health Organisation (WHO), **50% of adolescents and young people between the ages of 12 and 35 are at risk of hearing loss due to overexposure to noise in recreational contexts.**

In addition, since the **current COVID-19 pandemic**, there has been an undeniable increase in the use of **headphones or audio players and other electronic devices** (such as mobile phones and/or tablets) due to teleworking, online classes and increased hours spent playing video games or chatting online with friends and family.

Prolonged exposure to loud sound sources and noise, abusing the use of headphones with excessive volume, which in many cases exceeds 70 dB, especially when it comes to music, or working in noisy work environments, without adequate protective measures, among other possible circumstances, **can cause irreversible damage to hearing**, causing deafness in young people and bringing forward the age at which hearing loss may appear in the future **due to progressive and premature deterioration**. It should also be borne in mind that other problems associated with deafness such as whistling, or tinnitus may occur.

FIAPAS therefore demanded that the administrations regulating these products and leisure consumption environments, as well as in the workplace, adopt the necessary preventive measures in this regard. And it recommended that young people:

- Reduce the volume at which they listen to music, with or without headphones.
- Take breaks during prolonged use of headphones.
- Use hearing protection when exposed to loud noise in all types of environments (leisure, work, etc.).
- Check the safety measures on electronic equipment, video games, etc. to control the volume and make use of them.
- In the event of any suspicion or warning signs of hearing loss or any other type of hearing ailment, consult a medical professional to check the state of your hearing.

<http://fiapas.es/actualidad-y-agenda/nota-de-prensa/prevenir-la-perdida-de-audicion-entre-los-jovenes>

SPAIN. NEW REGULATION ON COMMUNITY FACE COVERINGS

Last February, the Ministry of Consumer Affairs approved the Order regulating the information and marketing requirements for hygienic masks, including transparent masks that allow lip-reading.

Aware of the need for transparent masks to facilitate access to information and communication for deaf people, while at the same time providing the necessary safety guarantees, FIAPAS has participated in the different phases of the drafting of this Order and provided updated information to all interested stakeholders.

In addition to the general requirements for all hygienic face masks, transparent ones shall have to comply additional requirements such as clear vision without fogging, ensuring that the product does not obstruct breathing, and the label shall indicate whether there is a speech-distorting effect. In addition, it shall refer to the particularity of those materials which do not facilitate the passage of inhaled or exhaled air. Only masks tested by an accredited laboratory may be marketed as hygienic masks or community face coverings.

<http://www.fiapas.es/recursos-de-ayuda-y-orientacion#mascarillas>



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Switzerland

For more equal opportunities and inclusion of hearing-impaired children.

Four organizations advocating concerns of hearing-impaired people in Switzerland, The A Capella Foundation, Sonos, pro audito schweiz and the SVEHK, have long been campaigning for the use of transparent masks. Transparent masks, or masks with viewing windows enable children with hearing impairments to participate in social life again in times of the coronavirus. This type of mask makes lip reading and better communication possible. Exclusions- specifically during school breaks- can be avoided.

«For clear communication»

Transparent masks type II made in Swiss production, are now available and are also exported to the rest of Europe.

The Swiss Association of the hearing impaired, Sonos, together with Flawa Consumer GmbH, have developed a type II medical protective mask with a transparent window. The mask is tested and CE certified.

For more information about the **MaXsmile medical face mask** please visit the website <https://www.flawa-masken.ch/en/typii>.



Image: Flawa – Medical face mask transparent type II MaXsmile



Enjoy the summer!