



***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 1/2025

Greetings from the President

One of the main events on the this first semester of 2025 was the Global Disability Summit held in Berlin – Germany on April 2 and 3. The President of FEPEDA attended this Summit and represented FEPEDA.

The other events were:

- The reception for the new year of Disability Intergroup Members of the Parliament on January 29. The President of FEPEDA attended this reception and met some Members of the Parliament. A letter was sent before this reception to all Disability Intergroup Members to give them information on FEPEDA and to make them aware of the necessity to defend the rights of the deaf and hard-of-hearing children and young people and their families
- The EDF AGA meeting (European Disability Forum Annual General Assembly) in Vilnius – Lithuania on June 21 and 22. FEPEDA, member of EDF, sent a delegate to this AGA meeting

With the participation to these events and the daily work, FEPEDA did a lot of advocacy work, through to ensure that the rights of children and young people and their families will be considered and improved.

Another important event for FEPEDA was the Management Committee (MC) meeting held in Vilnius on April 11 and 12 in Vilnius.

We are working to ensure that more associations from various European countries become members of FEPEDA. At a time when the rights of people with disabilities are becoming less a priority in Europe, it is important to strengthen FEPEDA. The more numerous we are, the stronger we will be.

So, FEPEDA thanks a lot the members for their involvement to defend the rights and to improve the quality of life of deaf and hard of hearing children and their families, with respect for the way of communication and the method of education they have chosen.

I wish to all of you a very nice Summer.

André Cuenca, President of FEPEDA

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European Disability Forum (EDF) Annual General Assembly (AGA) meeting

EDF AGA meeting was held on June 21 and 22, 2025 in Vilnius - Lithuania. FEPEDA attended as full member. The delegate was the President of FEPEDA. The main topics were:

- Conference on self-determination of persons with disabilities
- Advocacy on preparation of European funds
- Advocacy in progress on priorities for the next 5 years
- Adoption by the Forum of Annual Report, Action Plan, Financial year 2024 and budget 2026
- Focus on the European Disability Card
- Situation of persons with disability in Lithuania by the Lithuanian Disability Forum
- Women's Committee

A representative of PAGAVA, the Lithuanian organisation of parents of deaf and hard-of-hearing children, member of FEPEDA, could attend the AGA meeting as observer.



FEPEDA delegate to EDF
with PAGAVA representative



FEPEDA delegate to EDF
with PAGAVA representative and FIADDA
representatives (President on the right and
Vice-President on the left)

(*) FIADDA is the Italian organisation of parents of deaf and hard-of-hearing children, member of FEPEDA



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Third Global Disability Summit in Berlin, April 2 and 3, 2025

- Organised by DIA (Disability International Alliance), Germany and Jordan
- Participation of André CUENCA representing FEPEDA
- 4,500 participants from 100 countries. The Summit resulted in 800 new commitments from governments, development actors, private sector, and civil society. The Summit resulted in 800 new commitments from governments.





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Previous FEPEDA meetings

Two Bureau meetings were held by videoconference:

- On January 16, 2025: ordinary Bureau meeting
- On June 5, 2025, to work on:
 - the benefits for an organisation to become member of FEPEDA
 - on the FEPEDA communication plan

Members of the Bureau are:

- André Cuenca as President of FEPEDA
- Antoanetta Yarichkova as General Secretary
- Sari Paloposki as Vice President
- Juan Diego Garcia Gallardo as Vice President
- Cosmin Brasov as Vice President
- Daniel Lakso as Vice President
- Franziska Geiser-Bedon as Treasurer



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FEPEDA Management Committee (MC) meeting was held on April 11 and 12, 2025 in Vilnius - Lithuania.

The FEPEDA Management Committee (MC) meeting was held on 11 and 11 April 2024 in Vilnius, Lithuania.

14 members attended the meeting plus one assistant. One member sent apologies before the meeting as he was busy with another meeting.

This meeting was hosted by the Lithuanian organisation (PAGAVA). The organisation was very good, and the welcome of members was excellent.

In addition of the members of Management Committee, some members of PAGAVA attended the meeting on April 12. The Swedish organisation (DHB) attended online on April 12 in the afternoon.

The meeting was marked by a lot of exchanges between members and the main items were:

- Presentation by each member of her/his organisation and the current projects and actions during the meeting with DHB.
- Exchanges to improve communication plan
- Preparation of two Webinars (one in 2025 and one in 2026)
- Report of EDPD (European Day of Persons with Disabilities) held on November 29 and 30 in Brussels where FEPEDA was represented
- Report of GDS (Global Disability Summit) held on April 2 and 3 in Berlin where FEPEDA was represented
- Report of meetings with European Platform of Deafness
- Preparation of the next EDF AGA (European Disability Forum Annual General Assembly) in June 21 and 22, 2025 in Vilnius where FEPEDA will send a delegate
- Preparation of FCEI (Family Centred Early Intervention) conference scheduled on June 2026 (10 to 12) in Bad Ischl – Austria: call for papers and for participation
- Review of existing organisations in Europe which could become member of FEPEDA and definition of relevant action plan to contact them
- Review of the document prepared by FIAPAS (the Spanish organisation) in the name of FEPEDA to reply to call for inputs for the Rapporteur on the rights of persons with disabilities
- Review of information from each country: questionnaire prepared by the member of Czech Republic organisation. Each organisation will fill in this questionnaire
- Review of Action Plan for the next years

Many thanks to the members for their active participation in this MC meeting and to PAGAVA, the Lithuanian organisation for hosting the meeting.



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MC members during the meeting



MC members in Vilnius



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Upcoming FEPEDA meetings

Bureau meeting online in September 2025

Management Committee meetings on October 24 and 25, 2025 in Toulouse – France

General Assembly meeting on October 25, 2025, in Toulouse – France



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Country News

Czech Republic

News from the Czech Republic

In early intervention service we keep developing interdisciplinary cooperation, especially with phoniatrists, but also with other experts, in the form of regular meetings in regions, where we travel to visit clients. As part of our consulting work with clients, we standardize information and practical demonstrations of visual communication tools that help parents adopt a new way of communicating with their children, especially in the first period after a hearing loss is detected. We are planning to participate in the EURLYAD conference, which was held two years ago in Prague and will be held in Lisbon this September.

Methodological work is also underway on quality standards and methodological guidelines for the service. We currently also have significant experience (as a part of social activation service) with a family conference in the case of three children, where approximately 6 institutions are involved. Two of our colleagues will participate in training in Peter Limbrick's TAC (The Team Around the Child) method, which is hosted in the Czech Republic.

The amount of the humanitarian benefit for persons from Ukraine granted temporary protection will be increased. In the case of children with disabilities, it will be 11,835 CZK (474 euro) from the current 5,235 CZK (209 euro). The current amount of the humanitarian benefit for disabled adults is 7,290 CZK (292 euro) and will be 11,690 CZK (468 euro).

Our full time psychologist has a full capacity of the clients. She has started the "Play Therapy Training" which is very useful for deaf children and all children who do not speak.

Our organization launched a campaign on social media on the occasion of World Hearing Day. Four persons made reels about how they are taking care of their hearing or their child's hearing.

We are also preparing a family camp and other events. In March there was a traditional reading event for children with a sleepover called Night with Andersen. The event was lead by a deaf role model and it was translated to Czech sign language. **I would like to invite you all to participate in this international event in your country. Here is the info: <https://www.nocsandersenem.cz/en/>**

This year we celebrate our 35 years anniversary and we will hold a conference on this occasion.



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Spain

FIAPAS' commitment to hearing loss detection: New CODEPEH Recommendations on Postnatal Hearing Loss Detection in Children

In line with its 2024 campaign "[Let Everyone Hear It](#)", the Spanish Confederation of Families of deaf people (FIAPAS), in collaboration with the Spanish Commission for the Early Detection of Hearing Loss (CODEPEH), has released a new scientific report focusing on the early detection of postnatal hearing loss in paediatric populations.

The report highlights the potential of school-based hearing screening programmes as a viable and effective approach for identifying hearing loss that develops after the newborn stage. It proposes the use of tele-audiology as an innovative solution—enhanced by artificial intelligence—to increase both the efficiency and accuracy of detection systems.

These emerging techniques bring multiple advantages:

- ✓ Greater availability,
- ✓ Simplicity of use,
- ✓ Improved precision in hearing assessments,
- ✓ And the ability to carry out screenings remotely and independently, reducing the reliance on specialised personnel.

All findings and recommendations have been compiled into a new [CODEPEH Position Paper](#), accompanied by **public information materials** (a [leaflet](#) and [flyer](#)). These resources are designed to help **health and education professionals, as well as families**, recognise **key warning signs** and understand the **importance of timely detection, diagnosis, and intervention** for postnatal hearing loss.

This initiative aligns with the [2024 FIAPAS Manifesto](#), which calls for:

- Improved public health strategies for hearing loss prevention and care,
- Greater support for families,
- And stronger investment in technology and early intervention.



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EARLY DETECTION OF POSTNATAL HEARING LOSS in paediatric age groups





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Finland

The NGO sector has experienced quite a bit of turbulence this year. State subsidies for social and health organizations, known as STEA grants — which also serve as the main source of funding for the Finnish Association of Parents of Deaf and Hard of Hearing Children (KLVV) — were reduced at the beginning of 2025. This year, organizations received nearly €80 million less in grants than before, with the total amount decreasing from €384 million to €304 million.

Although the cuts have not yet directly affected KLVV's operations, they are set to continue next year and are then expected to impact KLVV as well. At present, organizations face uncertainty regarding the 2026 grants, which is causing concern both within the organizations and among the people they support. We have prepared carefully for this situation to ensure that support for families of deaf and hard of hearing children can be maintained as effectively and efficiently as possible.

The situation in Finland is especially concerning because the position of people in vulnerable situations in Finland has already deteriorated. The center-right government led by Petteri Orpo, which took office in June 2023, has implemented significant cuts to social security — particularly to unemployment benefits, student support, and housing allowances — further undermining the livelihood of low-income individuals.

Despite some uncertainty, KLVV's operation in 2025 has progressed with determination and a positive spirit! Our courses, camps, and events have filled up quickly, with some people even left on the waiting list. At the moment, we are preparing for our traditional Summer Days, taking place 27–29 June in Piispala, Kannonkoski. We expect around 20 families of deaf and hard of hearing children to join us there. We are also filming a new presentation video of KLVV, which we look forward to sharing with everyone!



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Have a nice Summer