



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 2/2024

Greetings from the President

Two main events on the second semester of 2024:

- FEPEDA Annual General Assembly
- Participation to EDPD: European Day of Disabled People

General Assembly meeting was held in Madrid - Spain in October 2024 (and online for members who couldn't travel).

There was a very good participation of FEPEDA member representatives from organisations of the various countries of Europe. There was a meeting with Spanish organisation (FIAPAS) members before the General Assembly meeting.

The meeting was very well organised by Spanish organisation providing an excellent welcome to members.

Exchanges between members highlighted the actions of the members for deaf and hearing-impaired children (see more details in the following pages).

The President of FEPEDA represented FEPEDA to EDPD (European Day of Persons with Disability in Brussel on November 28 and 29, 2024). This event was organised by the European Commission in collaboration with the European Disability Forum. The main objective was to address key challenges and opportunities for improving the lives of persons with disabilities across Europe: review and status of actions from 2021 to 2024 and definition of actions to be carried out for the period 2025 - 2031 (see more details in the following pages)

As you know, nothing can be taken for granted and we will need to stay mobilised in 2025. I would like, on behalf of FEPEDA, to thank 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 young people and their families in their countries and in Europe, with respect for the way of communication and the method of education they have chosen.

I wish you and your family a very happy new year.

André Cuenca, President of FEPEDA

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European Day of Persons with Disabilities November 28 and 29, 2024 Brussels - Belgium

The European Day of Persons with Disabilities (EDPD) was held in Brussel. The objective was to address key challenges and opportunities for improving the lives of persons with disabilities across Europe. FEPEDA's President, Andre Cuenca, actively participated in this important event, which underscored pressing issues and advanced new strategies for inclusion and equality.

Opening Session: A Call for Action

The event opened with discussions on the European political landscape, marked by the past European elections and the rise of political movements sceptical of the EU. The session highlighted growing inequalities and the need for initiatives promoting equality and inclusivity. Key recommendations included:

- Strengthening ties with the European Parliament to defend people the rights of persons with disabilities.
- Promoting societal inclusion over institutionalization.

During his intervention, Adam Kosa, Member of Parliament, who is a deaf person, explains that we need advocacy to have Sign Language recognised as a European language.

Panel 1: Strategy for Disability Rights

The first panel examined gaps in employment and quality of life for persons with disabilities. Key findings included:

- Employment rates for persons with disabilities stand at 50%, compared to 75% for others, with significant disparities for women and young people.
- Half of EU Member States have set quantified employment targets, with Eurostat monitoring progress.
- There is an urgent need to bridge the gap between strategy and implementation while aligning methods across Europe through peer reviews, such as Belgium's scheduled review in 2025.

The panel called for enhanced funding, measures to combat forced sterilization and violence against disabled women, and improved accessibility in technology and everyday items, including household appliances. It also emphasized independent living, electoral rights, and access to justice.

Panel 2: Advocating for Independent Living

A powerful testimony from a Portuguese woman with disabilities illustrated the transformative impact of community support and accessible housing. Key issues discussed included:

- The slow pace of social change and Europe's reluctance to shift away from institutionalization.
- The need for increased funding to facilitate deinstitutionalization.
- Independent living as a fundamental freedom requiring a reimagined support model.



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Access City Award: Showcasing Excellence in Accessibility

Celebrating its 15th anniversary, the Access City Award honoured cities excelling in accessibility:

- **1st Prize:** Vienna, Austria
- **2nd Prize:** Nuremberg, Germany (noted for transport)
- **3rd Prize:** Cartagena, Spain
- **Special Mention for Role Model on Built Environment and Transport:** Borås, Sweden
- **Special Mention for accessible sports infrastructure:** Nuremberg

The awards highlighted innovative use of digital technologies and underscored the universal relevance of accessibility as Europe's population ages.

Panel 3: Building Inclusive Cities

The final panel focused on creating accessible urban environments. Testimonies underscored challenges such as inaccessible public transport and facilities. Recommendations included:

- Involving persons with disabilities early in planning processes.
- Expanding accessibility to include private spheres and digital platforms.
- Promoting education and awareness to foster welcoming, inclusive cities.

Closing Reflections

The event concluded with a collective commitment to:

- Implement employment policies targeting young people with disabilities.
- Secure funding for independent living housing initiatives.
- Ensure practical implementation of disability strategies, emphasizing autonomy and social interaction.

Looking ahead, the next EDPD will spotlight innovations in one of Europe's most accessible cities, reinforcing the collective effort to build a more inclusive society."



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EDPD Conference room



André CUENCA with members of European Platform of Deafness



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Previous FEPEDA meetings

A Bureau meeting was held on September 4, 2024: review of the Strategy Workshop results and Preparation of Next General Assembly and Management Committees meetings scheduled in October 2024 in Madrid

Since October 2024, members of FEPEDA Bureau are:

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

(* FEPEDA Constitution allows four Vice-Presidents in the Bureau

General Assembly (GA) meeting was held on October 19, 2024, in Madrid – Spain and online. It was preceded by a first **Management Committee (MC)** meeting on October 18 to prepare the GA and followed by a second MC meeting on October 19 to elect the Bureau.

The meetings were attended by 18 participants from 15 European countries. FEPEDA members met FIAPAS members (Spanish organisation). The Spanish association provided an excellent welcome to the participants and the two days meeting were very well organised.

In addition to the usual items to be dealt with at a GA meeting, such as finances, the budget, the annual report and the action plan, discussions took place on various subjects presented by the country representatives:

- Exchanges in multidisciplinary approach experience in care, based on early detection of postnatal hearing loss presented by Spain.
- Communication strategies and publishing by Czech Republic

Moreover:

- Presentation of Strategy Workshop results were presented to MC members and were accepted by them
- Action Plan, now based on Strategy Workshop results, was commented during GA meeting and approved with the changes

FEPEDA members had the pleasure to welcome the representant of Latvian organisation, for the first time in FEPEDA meetings.

The members representing the following countries were elected or re-elected: Austria, Bulgaria, Czech Republic Germany, Spain and Switzerland.



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At Bureau level, the current President was elected for one year more, the three Vice-Presidents and the treasurer were elected or re-elected for 3 years. The Swedish representative entered in the Bureau and was elected as the fourth Vice-President. The General Secretary, elected in GA 2023 for 3 years, kept this position



FEPEDA members in Madrid



FEPEDA members online



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Upcoming FEPEDA meetings

Bureau meeting virtually by Zoom will be held in January 2025

Management Committee meeting on April 11 and 12, 2025 in Vilnius – Lithuania

Bureau meeting virtually by Zoom will be held in September 2025

General Assembly meeting in October 2025 in Georgia or in Germany (To be defined)



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Country News

Austria

The Austrian parent's association 'Parents and Friends of Children who are Deaf or Hard of Hearing' has established a long and good cooperation with the Institute of Neurology of Senses and Language at the Hospital of St. John of God in Linz.

This year the institute together with our organisation held a family weekend for the third time, for families with deaf or hard of hearing children with additional disabilities.

We realised once again how important such offers are for these families, who often feel like they don't belong anywhere. The idea of the 3-days event is that the whole family - child, parents, siblings - can take part for free (funded by the Rotary Club). The schedule contained a special program for the children including individual childcare, a small family trip, a parents' seminar as well as guided and open exchange among the families.

The results of this supporting event are visualized in a poster, which was submitted to the FCEI (Family-Centred Early Intervention) Congress - and won the audience's vote. (see following page).



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Family Centered Early Intervention Program Linz, Austria



**PARENT-PARENT CONNECTIONS EMPOWER FAMILIES:
 A WEEKEND FOR FAMILIES WITH DHH CHILDREN WITH SPECIAL NEEDS**

OBJECTIVE: Strengthening families jointly: Families with children who are deaf or hard of hearing and have additional needs shall be encouraged in order to support their children in developing their potential and communication skills and to overcome isolation. The aim is to become powerful as a child in the family, in living together and in society. The framework program (professional childcare, group activities, evening program) is designed to help to catch a breath, to get to know each other and to relax – for some families it was the first holidays in the last five years

METHODS

Empower

- Donate and receive
- Experience and enjoy
- Intensify and connect

Generous invitation
 without any costs for the whole family (sponsoring)

Ensure safe care for affected children and their siblings – to free up space for parents

Leisure time activities for DHH children, siblings and the whole family (indoor and outdoor play activities, trip, hiking with alpacas, campfire, music, sports)

2 Workshop sections
 moderated focus discussion topics brought in by parents themselves

PARTICIPANTS 2022 - 2024

- 33 DHH children with additional needs
- 24 siblings
- 32 mothers, 29 fathers (29 came as couples)
- 1 grandmother

33 FAMILIES

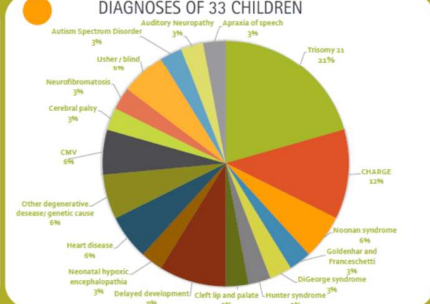
- 2022: 12
- 2023: 10
- 2024: 10

CAREGIVERS: around 22 each year

- 15 professionals (specialist in psychiatry and neurology, pediatrician, psychologist, interventionist, parent peer)
- 7 volunteers (students of medicine, interpreting and speech therapy; nurse, caregiver for the disabled, friend)

TOPICS IN DISCUSSIONS

- What does the diagnosis mean? Processing the diagnosis and finding out what is helpful
- Thoughts about future: kindergarden, school, integration process
- Support from outside the family: get and accept help (Do you get help from your family? Leaving the child in other hands / trusting. "Our family of origin can't cope with our situation")
- Being jealous of healthy children: "We have to cancel all sorts of things because of illness. How can I deal with comparisons with other children?"
- Involving siblings adequately
- Finding sources of strength in everyday life
- "Communicating with my child means: I am completely where my child is! I am in resonance with her!"



WHAT FAMILIES TELL US:

It was good for us to share our experiences. Every time I think about the weekend, it brings a smile to my face!

8-year-old sibling Elias: Mom, I feel better now! Now I know I'm not alone. So many children have a brother or sister with a disability!

I am taking a new perspective on our lives with me. I wish I could keep this awareness!

It was so nice in this group, we didn't feel alone and this cohesion, this "we are the same", I am not alone with my worries, fears, ... still gives me such a strengthening feeling

If it hadn't been for the family weekend, I wouldn't have dared to discuss it with the doctors like that.

What can I take home? Strength and self-confidence! Also many new acquaintances!

I take with me a more positive view of my child – to look much more often at what I enjoy about my child

RESULTS (qualitative):

Self-efficacy triggered / increased

- New members at the parents' association
- New parent groups with the same challenges in the family e.g. Trisomy 21, CHARGE have been formed
- More active participation in FLIP offers online and in presence e.g. FLIP group meeting, parent meetings, desire for more special guided groups e.g. parent group Trisomy 21

CONCLUSION:

"The impulses and inputs were great, a big support. They will trigger and help a lot in our minds again" – a parent's thought that encourages our team to offer this weekend for different families again. Preliminary results of this highly specialized support show outstanding benefits for parents and particularly profound and long-lasting efficacy.

Contact: Marlene Aigner, Doris Binder, Johannes Fellinger, Johannes Hofer, Daiva Müllegerger-Treciokaite | doris.binder@bblinz.at | Institute for Neurology of Senses and Language, Hospital of St. John of God, Linz, Austria

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Bulgaria

In September, the Association of Parents of Hearing-Impaired Children organized an international youth exchange with the support of the Erasmus+ program.

Hearing impaired youth from Lithuania, Poland, Spain, Georgia, North Macedonia and Bulgaria gathered in Sinemorets (Bulgaria) to discuss important topics such as human rights, social inclusion and social dialogue, which are core values of the European identity. During the exchange, participants talked about European and local policies for people with disabilities and their implementation in the different partner countries. They shared good practices and the role of advocacy and empowerment of deaf and hard-of-hearing young people.

The program included various workshops, games and presentations, which were combined with tours of historical sites in the region such as Ahtopol, Tsarevo and Sozopol. The youth also had the opportunity to explore the mystical Strandzha by boat on the Veleka River. At the national evening, the participants presented Bulgaria with folk costumes and dances, and the guests took their first steps in the Bulgarian horo. The partners from other countries also presented their cultures with interesting and delicious presentations.

All participants expressed gratitude for the shared moments and the new friendships they created during the exchange.





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Czech Republic

We have written an article about the Rotary club and the possibility to apply for exchange visits and how it all works (cooperation with FEPEDA). We have prepared an issue of our printed journal about psychotherapy and mental health of deaf children and another one about the methods of communication development. There were summer camps, an annual garden party for families in September and other important events organized.



Annual garden party for families

In the **social work area**, there has been an increase in the allowance for care. An increase of the financial humanitarian benefit for Ukrainian refugees with disabilities was also approved (with effect from the beginning of next year). The challenges of social work department of CDS Tamtam are certainly finding the possibilities of solving the situations of clients who, due to a sudden situation, especially concerning their health, find themselves short-term without a source of income and/or of housing availability. On the other hand, there are also some joyful topics such as arranging judicial interpreters for wedding interpreting.



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Regarding our **early aid intervention** of CDS Tamtam we continue to focus on interdisciplinary cooperation and we have held several interdisciplinary meetings for families where both experts and parents did participate. Then there is a challenge of financial founding. The state subsidy is distributed in two ways. The first is for a large group of providers with regional scope and the second for a group of services with nationwide scope, where we also belong. This year, negotiations are underway on which types of social services should be national and which regional, and this also applies to us. Also, there is a risk that many deaf people would lose a lot of interpreting services in case a new law is approved (limitation of all state services would mean that regional services will not be adequate in some places).

Our **psychologist** has started working full time and has a new office with new tools and equipment including two sandpits. We are happy that there is no limit of consultations or psychotherapy sessions for deaf children, their parents and deaf adults.



Theater performance with Czech sign language interpretation



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Finland

The Finnish Association of Parents of Deaf and Hard of Hearing Children (KLVV) organized a campaign in November emphasizing the importance of peer support in the lives of hearing-impaired children and their families. The campaign encouraged parents to reflect on what peer support is, the benefits it offers to the whole family, and how and where it can be accessed.

As part of the campaign, we conducted a survey among families who have participated in KLVV's peer support events. The results highlight that, from the parents' perspective, sharing information and experiences with other families in similar situations is particularly meaningful. Parents feel that other families with hearing-impaired children better understand their circumstances and can relate to their experiences. For hearing-impaired children and youth, peer support especially strengthens self-confidence, courage, and identity. More information about the campaign and survey results is available on our website: klvl.fi/vertaistukea.

In other news, significant changes are on the horizon for Finland's education system. The Basic Education Act and national curriculum guidelines will be reformed, requiring schools to update their local curricula by August 1, 2025. The Finnish National Agency for Education is preparing the reforms, which have included extensive consultations and a public feedback process. The goals of the reform are to ensure adequate support for all students while reducing the administrative burden on teaching staff. The new support measures aim to be nationally consistent, clear, and versatile. The legislative proposal has received a significant amount of feedback, with KLVV also submitting its statement alongside other organizations in the hearing-impaired community.

We hope that these reforms will also lead to better recognition of the needs of hearing-impaired children and their families!



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Lithuania

International Conference "I'm not Deaf to Love. Inclusive Education: How to Ensure the Well-Being of Children with Hearing Impairments and their Families".

Lithuanian Association of Families with Deaf and Hearing-Impaired Children PAGAVA celebrates its 30th anniversary this year. On October 11, an international conference was held to mark the occasion. The event took place at the Parliament of the Republic of Lithuania and brought together parents of hearing-impaired children, educators, government representatives and international guests. During the conference, the achievements, challenges and future plans of the organisation were discussed. In its three decades of activity, PAGAVA has provided necessary support and advocacy services to families and children, initiated universal newborn hearing screening for early detection of hearing impairment, and helped ensure that deaf children can study in secondary and higher education institutions. Parents have been provided with trainings and psychological counselling, and summer camps and other activities have been organised for deaf children and their families. The organisation has made significant progress in obtaining government reimbursement for hearing aids, enabling families to choose quality devices for their children.

However, challenges remain. Implementing inclusion in education requires strengthening schools and teachers to ensure that inclusive education for children with hearing impairment is successful and smooth. Families living in rural areas face a shortage of specialists such as audiologists and speech therapists, and transport services are often not available. There is also a lack of effective early intervention system and psychological support for families. Insufficient reimbursement for hearing aids prevents access to the most advanced devices for all children.

PAGAVA continues its efforts to strengthen the family support system, raise public awareness of childhood deafness and involve more institutions in the decision-making process. The anniversary event featured inspiring stories, insights into different experiences and an emphasis on community unity. The celebratory atmosphere underlined the determination and consistent efforts of community members to create a better environment for children with hearing impairment and their families.





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PAGAVA volunteer team



Rima Sitavičienė with the First Lady of Lithuania
Diana Nausėdienė



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Romania

From July 13–19, 2024, the associations “Asculta Viata”, “Koala” and “Fundatia Farmecul Vietii” proudly continued their tradition of organizing the annual summer camp for children with hearing impairments and their parents at the Bivolarie School in Vicovul de Sus, Romania. This year’s camp made possible through the support of “Fundatia Farmecul Vietii”, was notable for its inclusive approach, bringing together 53 children with diverse hearing abilities—ranging from varying levels of hearing impairment to fully developed functional hearing.

The camp emphasized bilingualism as a central theme, encouraging its adoption and practice. Participants represented a broad spectrum of language users, including children who communicated exclusively in Romanian, exclusively in Romanian Sign Language (RSL), or bilingually. This blend of RSL users and non-users created a unique environment of inclusion and mutual learning.

The camp was supported by a dedicated team of more than 20 professionals, including educators, RSL interpreters, speech pathologists, and doctors, who ensured a meaningful and engaging experience for all. Additionally, a professional film crew documented the week, producing a documentary that will soon be available to the public, to highlight the challenges and triumphs of children with hearing impairments.

Children participated in a variety of activities, such as glass painting, pastry making, gardening, hiking trips, and caricature workshops, which received enthusiastic feedback, earning a 4.87 out of 5 satisfaction rating. To further empower families, seminars addressed topics such as therapeutic options for children with hearing impairments, bilingualism, and the use of sign language, broadening awareness of resources and strategies to support children’s development.

Together, we remain committed to this valuable tradition and to supporting children with hearing impairments and their families for many years to come.





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Happy New Year