



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 1/2023

Greetings from the President

The main event in the first semester of 2023 for FEPEDA has been the Webinar organized by FEPEDA to make 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.

There were about hundred participants from Europe to the Webinar and also some countries in the World (see more details in following pages).

The other main event was the 5th European Parliament of People with Disabilities held in Brussels in the hemicycle of the Parliament on May, 23rd, 2023. This Parliament gave the situation of people with disabilities in Europe in the various fields: inclusion, accessibility, education, employment...to make the members of Parliament aware about the needs of people with disabilities in view of the European elections of 2024.

I wish also to highlight that the last MC meeting, held in May 2023, was in Rome, organized by Italian organization which became again member of FEPEDA in 2022.

Some contacts have been taken with Countries which could become or become again member of FEPEDA

Many actions have been also done by FEPEDA on the last 6 months as showed in the following of this Newsletter.

FEPEDA thanks a lot the members for their involvement

I wish you a nice Summer and good holidays.

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André Cuenca, President of FEPEDA



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Webinar on FEPEDA Research results

The Webinar has been held on March, 3rd, 2023 on World Hearing Day, online.

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.

Neonatal hearing screening, access to hearing devices, access to early intervention, mainstreaming education have changed the approach to deafness. However, children and young people with a hearing disability and their families still have needs to which we must all, society, public administrations, companies, representative organizations..., provide an answer”.

This webinar has been possible thanks to Sari Paloposki, the Finnish member, manager of this project. She had the support of Petra, our previous secretary, for the questionnaire issuing and the exploitation of the results, and also Carmen de Lamo with the support of Natalia Beraza, from the Spanish organization, for the preparation of the presentation and the webinar. Many thanks to them and also to the FEPEDA members for their participation in this project and all the team who made this presentation possible and accessible: sign language interpreters, speech to text transcribers and audio-visual technical team.



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5th European Parliament of People with Disabilities

This event was organized in relation with EDF (European Disability Forum) and opened by speeches from the President of European Parliament and the President of EDF.

There were conferences from speakers and testimonies from people with disabilities who spoke about their experiences and shared the difficulties they meet in their daily lives: accessibility, discrimination, education, employment,

The President of FEPEDA, participated in this Parliament as member of French Delegation. FEPEDA made comments on the Manifesto which have been approved during this Parliament. The President of FIAPAS, the Spanish organization, member of FEPEDA, participated in Spanish Delegation, and also the President of FIADDA, the Italian organization, member of FEPEDA, as Head of the Italian organization.



From the left side to the right one: André Cuenca, President of FEPEDA – Antonio Cotura, President of FIADDA – Jose Luis Aedo Cuevas, President of FIADDA



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Previous FEPEDA meetings

A Bureau meeting was held on 23rd March, 2023. Members of the Bureau are:

André Cuencá as new President of FEPEDA
Sari Paloposki as Vice President
Carmen de Lamo as Vice President
Cosmin Brasov as Vice President
Franziska Geiser-Bedon as Treasurer

A Management Committee meeting was held on 5th and 6th of May, 2023, in Rome, Italy.



Members of FEPEDA and members of Italian Organization in Rome on May, 6th

Moreover the items usually reviewed in CA meeting, the specific topics have been presented and subject of exchange between the members:

- Financial support to families in Finland
- Erasmus experience by Bulgaria
- Multidisciplinary approach experience in care by Czech Republic



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Upcoming FEPEDA meetings

Bureau meeting virtually by Zoom will be held in September 2023

General Assembly and Management Committee meetings on October, 20 2023 in Sofia - Bulgaria

FEPEDA Projects

Family survey:

Webinar on March 3rd to present the results (see above).

FEPEDA external relations

European Disability Forum's Annual General Assembly was held in Brussels - Belgium, in May 22nd. A delegate of FEPEDA participated in this AGA.

FEPEDA continues its participation in the European Platform of Deafness.

FEPEDA continues its participation with [Global Coalition of Parents of Children who are deaf or hard-of hearing](#).

Students exchange

The idea is to give the possibility to young deaf or hearing-impaired people to participate and live in a foreign family for the whole or part of school year. The process is now defined. We need to motivate families interested in students exchange.



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Country News

Czech Republic

There were many **events** in our organization (Information Centre for Parents and Friends of Children with Hearing Impairment, IC) and our befriended organization CDS Tamtam that took place: several **theatre plays** (some with interpretation to Czech sign language), Zoo visits or open door day in Ostrava branch where 10 years anniversary was celebrated. The specialized library of IC was also a part of the Czech annual event of libraries **“The Night with Anderson”** on the occasion of H.Ch. Anderson’s birthday celebration. It is a sleepover in a library and reading activities to support literacy and interest in books in both deaf and hearing children. In May, we attended the conference **Future of Hearing Healthcare 2023** by Hearing Health Matters.



From the event “The Night with Anderson”

We also published an article **promoting the presentation of the FEPEDA family survey on our specialized online journal ldetskysluch.cz**. Our last two topics covered by our journal were **Child Psychology** (including an interview with a famous psychologist about Respectful parenting) and **My identity - who am I?** A very popular article was about a new book **Deaf Utopia by Nyle DiMarco**. Another one was an interview with **Klára Svobodová**, a Czech author and mother of a deaf girl and a hearing son. She is also very open about her tragic experience of losing her first daughter during childbirth, she breaks the taboo and encourages other parents to seek help, not to isolate themselves and talk about the loss. Amongst other articles, we also translated a piece



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about a musician who transforms his tinnitus into notes and we made an interview with a Swedish headmaster of a preschool and school for children with hearing loss.



Our team watching the FEPEDA survey presentation

And what about **the social services** of our befriended organization Tamtam? The support from our side is more and more complex (regarding the area of relationship issues, school facilities, hearing rehabilitation, financial situation, housing situation...and the need for cooperation with other institutions and a multidisciplinary approach).

We have continuous feedback from the families about the necessity of our services and lately, we registered even higher interest in our services.



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Sweden

Youth with Language Disorder

DHB has during the last years lead the process to start an organization for young people with language disorder. The project was successful and now there is a national youth organization called “Unga Med Språkstörning” (UMS) in translation “Youth With Language disorder”. The project was funded by the Swedish Inheritance Fund. Part of the project was to make a film about the young people active in the process. The film is called “Finally!” as was the project name. You can watch it here: <https://youtu.be/cuQjly-bKeM>

Gå med i UMS!

“För mig är vänner och en aktiv fritid viktigt, det har jag fått via UMS.”
Wilma

“Jag gillar att kunna påverka och driva viktiga frågor för oss”
Albert

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Unga Med Språkstörning

Activities in the districts

All year round activities are going on in different parts of our country, organized by the regional districts (we have six regional districts and two national districts – one for families with language disorder and one for families with multiple disabilities). Many of the activities focus on bringing families together, exchanges of



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experiences and best practices, learning sign language and image support. In our western - the area around Gothenburg - annually in August a big summer camp attracts many families.

Here are some examples of activities organized by the districts during 2023:

- Downhill skiing
- District congress with family activities
- Sign language courses for families but also separately for women/mothers and men/fathers
- Weekend at an amusement park
- Summer camp
- Special meetings for families with children with deafness, hearing disorder and language disorder
- Circus school
- Swimming school
- Riding school

Between two worlds



2022-2025 DHB is running a new project funded by the Swedish Inheritance Fund. The project is called "Between two worlds" and explores the situation for young people with hearing disorders living between the hearing and the deaf world. Between the spoken language and sign language.

In the project there are focus-groups with people from the target group and professionals. Experiences and stories are collected and these will be used to produce a book, films, brochures and material for audiologists. The project will not give any solutions or methods but will collect and spread information to strengthen the target group, give relatives and professionals a greater understanding of the situation for the target group and improve the relation between the audiologists and the target group.



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Germany



Family conference in Duderstadt 2023

From 18-21 May 2023, the German Parents Association of Deaf Children (Bundeselternverband gehörloser Kinder e.V.) celebrated its 60th anniversary with a large conference for families with children with hearing disabilities. "Diverse · Digital · Strong" was the slogan of the presentations, workshops, the market place and the festive evening.

The programme began with a review of the history of the association. Katja Belz and Susan Pufhan were invited, who, with their former work on the board as a hearing-deaf team, brought the association to its current prominence and laid the foundation for the family conference in its present form. They reported on their pioneering and networking work at that time for the recognition of bilingual education with German sign language and German as well as the development of a strong self-advocacy of the parents. Other programme contents dealt with the role of deaf actors, especially children in film productions. Filmmaker Tobias Lehmann, actress Anne Zander and young up-and-coming actor Leif-Erik Werk showed ways to enter this profession as a deaf person and presented their commitment to a diverse film landscape. Psychologist Sophie Terhorst addressed the topic "Language deprivation and the psychological effects". She reported on new research findings that clearly identify the consequences of language deprivation and pointed out strategies to counteract this dramatic development. At the general meeting, the new BGK board presented its work of the first joint year and, together with the project presentations of some member associations, gave an outlook on the activities in the following year. The lecture by Stefan Goldschmidt on the "Culture of Deaf People" was rich in sign language wit and poetry and a successful prelude to the later workshop "How can I convey Deaf Culture to our children?". At workshop time, topics such as non-violent communication in the family with Sophie Terhorst or "Deaf Didactics" with Ege Karar and Bastian Staudt from the RTWH Aachen were also worked on. The latter was a novelty, up to now the Deaf Didaktiks working group has addressed teachers. In the workshop it became clear that families in particular are concerned with the learning behaviour of children and would like to be involved in the development work of a visual pedagogy, by means of Deaf Didactics in Germany. The "Market place of Opportunities" offered parents a lively exchange and lots of new information and suggestions. Here, providers of Sign Language courses, legal advice, new bilingual learning material, the Deutsche Gehörlosensjugend e.V. (German Youth of the Deaf), Biling e.V. and online telephone or written interpreting services presented themselves. Other highlights for the families were a sports tournament with mixed teams of children and parents, where participants competed in football, handball and volleyball, as well as the entertaining 60th anniversary celebration evening with touching and funny poetic contributions by big and small artists.

The conference was accompanied by a lively children's programme. In four children's groups, young adults with and without their own hearing impairment created an inspiring programme for the children with hearing impairment and their siblings. The children experienced encouragement and participation through targeted offers in group games, creative activities, sports, excursions, age-appropriate workshops and joint project work. The conference was barrier-free with sign language and spoken language and the support of sign language interpreters and communication assistants. Not only the lectures of deaf and hearing speakers were accessible to all, but also during the coffee breaks a lively exchange between deaf and hearing parents was possible without any obstacles. The conference was fully booked with 60 families. After the start of registration at the beginning



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of the year, far more families were interested in the conference than there were places available. The conference offers were well received and the feedback from the participants was very positive. They were able to network, received suggestions and knowledge as well as new courage and strength to work intensively for the best promotion and support of their deaf and hard of hearing children. The Bundeselternverband gehörloser Kinder e.V. (Federal Association of Parents of Deaf Children) will therefore continue this nice tradition and will also offer a family conference in 2024.





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Have a nice Summer!