

EUROPEAN DOWN SYNDROME ASSOCIATION

November 2023

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EDSA WEBINAR



SEX EDUCATION - identity-friendship-love-sexuality

Date: Wednesday,15 November 2023 17.00 hr

Speaker: Julia Gottfried, PEp Praxis für Entwicklungspädagogik, Mainz, Germany Translation: Croatian, Czech, French, German, Turkish, Ukrainian and Italian

Registration: https://us06web.zoom.us/webinar/register/1216986749417/WN_tiWiE2i https://us06web.zoom.us/webinar/register/1216986749417/WN_tiWiE2i https://us06web.zoom.us/webinar/register/1216986749417/WN_tiWiE2i https://us06web.zoom.us/webinar/register/1216986749417/WN_tiWiE2i <a href="https://us06web.zoom.us/webinar/register/1216986749417/WN_tiWiE2i <a href="https://us06web.zoom.us/webinar/register/1216986749417/WN_tiWiE2i https://us06web.zoom.us/webinar/register/ https://us06web.zoom.us/webinar/register/ <a href="https://us06web.zoom.us06web.zoo

In this session, Julia Gottfried provides an insight look into her work with young people in the area of sexual education. For many years she has been successful offering workshops in the areas of identity, friendship, love and sexuality through **infobox-liebe**. When working with parents and professionals, she repeatedly emphasizes: "It's less about genital sexuality than about the path and the education it takes to live and experience love in all its facets in a self-determined way."

Biography



Julia Gottfried was lucky to be employed by the well-known PEp — Practice for Development Education in Mainz (Germany) right from the beginning of her studies in 2009.

Since 2013 she has been advising, informing and accompanying parents, young people and romantic couples with DS on their very personal path to sexual education.

She regularly writes about her experiences in a column of the German magazine "Living with Down-Syndrome". She has been the owner of **infobox-liebe** since 2019 and travels all over Germany to pass on her



knowledge, enthusiasm, and thoughts on this topic to schools, parent associations and all other multipliers.

Infobox-Liebe / Infobox Love

emotional love life.

Infobox-Liebe / Infobox Love is an offer for sexual education lectures infobox-liebe offers in-house specialist lectures that remove taboos and at the same time show new, safe and socially acceptable ways for people with an intellectual developmental disorder to appropriately shape friendship, love and sexuality and

integrate them into their lives. All lectures are based on current scientific knowledge and aim to provide practical information and concrete approaches. Especially people with an intellectual disability depend on us professionals to lead a fulfilled, social and



BOX LIEBE



GOOD NEWS

Never before have so many people with Down Syndorme travelled around Europe for an internship abroad.

In the first three weeks of November as many as 14 people with Down Syndrome from Portugal, Italy, Spain, Germany, Croatia, Hungary and Turkey are doing their internship at Valueable network hotels (Axis Hoteis - Portugal and NH - Italy) and at the Inout hostel in Barcelona.

Follow the social media of Valueable, the associations and the hotels!

A more detailed article will be included in the next issue of the EDSA Newsletter.



HZDS (Croatia) 29 Oct-18 Nov to Axis Porto (PT)
Down Alapitvany (Hungary) 28 Oct-17 Nov to Axis Porto (PT)
TDSD (Turkey) 5 – 23 Nov to NH Villanova, Bologna (IT)
HAA (Germany) 5-24 Nov to NH Collection, Genova Marina (IT)
APPT21 (Portugal) 6-24 Nov to NH Siena (IT)
AIPD (Italy) 6-27 Nov to Inout Hostel, Barcelona (ES)



NEWS FROM THE WORLD

WDSC 2024



World Down Syndrome Congress 2024 Brisbane, Australia

The event is only 10 months away and preparations are well under way to deliver an educational and informative World Down Syndrome Congress 2024 in Brisbane, Australia from 9-12 July 2024 that will bring together families, leading international experts and advocates in a broad range of fields, as well as the opportunity to experience Australia with its unique environment.

We will also have an exciting social program to bring you the best of Australian music, culture and cuisine.

To find out more about the Congress, go to www.wdsc2024.org.au

Can you share this information?

We would really appreciate it if you could share some information on the Congress with your members and contacts. We have included information below, and also encourage you to follow our World Down Syndrome Congress Facebook page to stay up to date (and to share content from there with your Facebook followers).

Would your organisation like to participate?

There are also numerous opportunities for organisations to sponsor or exhibit at WDSC2024. You can find more information and our sponsorship and exhibition prospectus on the website here.

You may also like to submit an Abstract to present or perform at the Congress – you can find more information about that here.

Any questions?

If you have any questions, please contact info@wdsc2024.org.au or email Liz Willis at Liz.Willis@downsyndrome.org.au.

We look forward to seeing you in Brisbane next year.



NEWS FROM EDSA BOARD

ANNUAL GENERAL ASSEMBLY (AGA) OF EDSA 2023 IN MADRID



From 27 to 29 October 2023 the Annual General Assembly (AGA) of EDSA took place in Madrid. After 3 years of online meetings, this was the first time after the pandemic that we could meet again in presence.

It was a very nice meeting with 37 participants from 21 different European countries representing 25 EDSA member organizations. Further participants (from Romania and Ukraine) were present online.

The AGA took place in the premises of the Fundacion Aprocor, which works for the inclusion of people with disabilities. José Gutiérrez from Down España and also our EDSA Board member was responsible for the organization of the event and we thank him very much for all his work.

We could welcome a new member: Down Syndrome Association from Georgia. The association had recently submitted all the necessary papers for membership. Now two representatives from Georgia came to Madrid and could present the association, their work and tell us about the situation in their country.

We were also very pleased to welcome two representatives from DS Ukraine. Even though the situation in their country is still terrible, it was good to hear that DS Ukraine continues to do its best to support people with DS and their families. EDSA will continue to try to support the association as much as possible.

During the AGA the reports of EDSA's president, the treasurer and the operational secretary were presented. Also the reports from DS Turkey about the social media activities and AIPD Italy presented the report about EDSA's newsletter and their support by handling EU-projects.

Dinka Vukovic presented EDSAs agenda for the next few years, especially a better communication and exchange with and among members is in focus. For example, a new format is to be started, in addition to four webinars per year, another four online meetings are planned where an exchange will take place on a specific topic with the interested EDSA members.





Election of EDSA Board 2023-2026

The main item on the agenda was the election of a new board. Before the election, all board members were asked whether they wanted to keep their position or not and all EDSA members were asked whether they wanted to nominate candidates for the work in the board.

As there were as many interested candidates as there were board seats, a list with a proposal could be compiled before the AGA and presented to the participants during the meeting. This proposal was approved and we are happy to have again a dedicated, competent group of people who have committed to be active for EDSA for the next 3 years.



From left to right: Cora Halder, Jillian Reichenbach Ott, Nathanaël Raballand, Isidro Moyano, Dinka Vukovic, Monika Mazegger, Jacqueline London, Joeanna Xerri, Michaela Hilgner, Veronique Garrett, Carlotta Leonori, José Gutiérrez, Fulya Ekmen Board members not on the photo: Pat Clarke, Carol Boys, Frank Buckley, Maida Agic, Valerija Buzan

At each AGA time is allocated for the latest news from the scientific community. As before, Jacqueline London – who works as a scientist and will serve as a senior board observer for EDSA – presented results from recent studies and shared up-to-date information with attendees.

During AGA member associations have the opportunity to present their association, an activity or an interesting project. There were presentations from Georgia, Sweden, Ukraine, Norway, Romania, Malta and Portugal.

At the end of the first day, a visit to an inclusive rugby club was on the agenda. The participants even had the opportunity to participate in the training. Afterwards, our host Down España invited us for a snack and a drink in a typical rugby pub. During the breaks and the joint activities there was time to exchange experiences, to pass on information and to deepen the private contacts.

All in all, this was a very successful annual meeting, which inspired and motivated us to continue the work for people with DS all over Europe.

Text: Cora Halder Photos: Michaela Hilgner



EU COMMISSION FUNDING OPPORTUNITIES



RIGHTS OF THE CHILD AND CHILDREN'S PARTICIPATION

Programme

Citizens, Equality, Rights and Values Programme (CERV)

Call

Rights of the child and children's participation (CERV-2024-CHILD)

Deadline date

26 March 2024 17:00:00 Brussels time

This call for proposals aims at responding to children's current needs and challenges in the EU. This call pays specific attention to the rights of children with specific needs and vulnerabilities, including those who fled the Russian aggression against Ukraine.

This call focuses on implementation of the actions and recommendations at the EU, national and local level established in the relevant strands of the EU Strategy on the rights of the child. Projects can be national or transnational. Transnational projects are particularly encouraged.

Expected Impact:

- Making children aware of their right to participate and have their voices heard;
- Making child participation mechanisms inclusive and systemic;
- Implementing actions and recommendations of the EU Strategy on the rights of the child;
- Improving capacity building, the exchange of good practice, training on the rights and needs of children;
- Defining guidelines and guidance and improving data collection;
- improving allocation, planning and monitoring of resources and funds on promotion and protection of the rights of the child;
- Raising awareness of, and investing in capacity building;
- Providing adequate support to children with specific vulnerabilities.

Read more



GOOD RESOURCES FOR EDSA MEMBERS

INCLUSION EUROPE



Easy to understand videos about the European Disability Strategy and Deinstitutionalisation

Inclusion Europe produced three easy to understand videos about the European Disability Strategy and the role of the European Union in deinstitutionalisation.

European Disability Strategy

Persons with disabilities face considerable barriers in access to healthcare, education, employment, recreation activities, as well as participation in political life. The employment rate of people with disabilities stands at 50.8%, compared to 75% for people without disabilities and 28.4% of people with disabilities in the European Union are at risk of poverty or social exclusion. In March 2021, the European Commission adopted the Strategy for the Rights of Persons with Disabilities 2021-2030. The strategy called for an inclusive society in which the rights of people living with disabilities are protected and where there is no discrimination.

Read the easy-to-read transcript of the video about the European Disability Strategy.

Watch the easy to understand video about the European Disability Strategy.

Infographic – Elements and goals of the European Disability Strategy (1)

Deinstitutionalisation

The United Nations Convention on the Rights of Persons with Disabilities says that every person with disability has the right to live independently and to be included in community. Without independent living, persons with disabilities are unable to exercise many other Convention rights, such as education, work and employment, health or participation in political and public life. There are an estimated 87 million people with disabilities in the European Union of which 1,5 million still live in institutions. To end segregation of people with disabilities in institutions, there is a process called deinstitutionalisation which means supporting people to move out of institutions, to have their own home and support.



Deinstitutionalisation enables persons with disabilities to live independently, make their own decisions, be part of the community and, enjoy their rights as others. There are two ways to end institutionalisation. By establishing independent living and communitybased services.

Read the easy-to-read transcript of the video about deinstitutionalisation.

Watch the easy to understand video about the deinstitutionalisation.

Deinstitutionalisation – Infographic (1)

Role of the European Union in deinstitutionalisation

The European Union has improved lives of many people with disabilities by helping to end segregation and institutionalisation. For example, with EU funds, the European Social Pillar, or the European Disability Rights Strategy. Independent living is central to the European Disability Strategy, which is EU's main tool to implement the UN Convention. Likewise, it is central to the European Pillar of Social Rights, which promotes accessibility and independence in education, work, housing, as well as personcentred care. The EU's directive on Work Life Balance, supports people who care for relatives with disabilities and the European Structural and Investment funds are a driving force in helping people out of institutions. For instance, by supporting community-based services. Inclusion Europe is member of The European Expert Group on the transition from institutional to community-based care, which is often called the EEG. The EEG makes reports, guidelines, and trainings about how to use public money to provide better support for people with disabilities. Despite all the work for deinstitutionalisation, the number of people in institutions in the EU has not changed over the past 10 years. People with intellectual disabilities and people with complex support needs are most likely to still live in institutions in many countries.

Read the easy-to-read transcript of the video about the role of the European Union in deinstitutionalisation.

Watch the easy to understand video about the role of the European Union in deinstitutionalisation.

Role of the European Union in deinstitutionalisation-Infographic

Written by Josipa Friscic Communication Officer of Inclusion Europe



MAKE THIS NEWSLETTER REALLY YOURS!

Have you got any news that we could publish in EDSA newsletter? Please send us any information you would like to announce and we shall be happy to disseminate it all over Europe!

CONTACTS

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THE STAFF

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