

SUMMARY

01

NEWS FROM EDSA MEMBERS

03

NEWS FROM EDSA

05

INTERNATIONAL LABOUR ORGANIZATION

07

EDSA'S AGA MINUTES

NEWS FROM EDSA MEMBERS



DOWN SENDROMU DERNEĞİ (TURKEY)

DSD SELF-ADVOCACY GROUP "VOICE+1" WERE IN BUDAPEST FOR THE "IDEAS AGAINST POVERTY" PROJECT ON OCTOBER 14-18!

Turkey first self-advocacy group "VOICE+1" is working to become better self advocates.

This year they have focused on poverty and social exclusion. This subject is very challenging for the group. They are trained to have a clear understanding what poverty is and social exclusion and after that they have tried to figure out what they can do to help people who lives in poverty and socially excluded. As a part of that works, they have visited Budapest. They both experienced the City and participated in studies to prevent poverty.

The first day they have visited a restaurant where people with intellectual disabilities work and they are defined as a "sheltered workshop,". The second day they have presented what kind of work they have done about poverty and social exclusion in Turkey. The presentations were done by two members of "Voice+1", Barış Kelleci and İrem Arslan.

The third day, they have cooked for homeless people with other self-advocacy group from Hungary, Spain and Poland at Szimpla Garden. Than they have met and talked with them to understand their stituation in the country. After that, there was the most exciting part of the visit: all groups visited the Hungarian Parliament, and had a meeting chance with the Member of Parliament Mr. Gergely Tapolczai who is an person with hearing impairment.

Lastly, they have took an action to understand what it mean to be poor. Their task was trying to meet the three day meal needs of a family with eight members by spending only ten Euros. "Voice+1" self-advocacy group have prepared a list. They have tried to buy all the things in their list by 10 Euros. At the end of the activity the foods were send to the families who live in poverty.

Although the program is very busy, they can also have the chance to visit the City and they all liked Budapest. The next destination will be Krakow, Poland in February. Keep following "VOICE+1".



NEWS FROM EDSA

Kiev invited EDSA Experts



Conference on Job Inclusion

On the 5th and 6th December 2019 a conference was organized by the Ukrainian DS Association in Kiev. The focus was on Education and Employment of people with Down Syndrome. Besides the contributions from Ukraine, there were two guest speakers from the Netherlands.

With the financial support through the EDSA project “Invite an Expert” the DS Association in Kiev, as an EDSA-member, had invited Anna Contardi and Cora Halder as speakers to the conference.

Elena Bolshanina, the president of the Ukrainian DS Association welcomed about 100 parents and professionals to this two days conference. They received information about the best educational methods to prepare youngsters with DS for future work-live, about vocational training, how to organize the transition from school to work and how to enable the young people to be part of the “work force”.

Autonomy and vocational training

On the first day Anna Contardi gave a 4 hrs. workshop for parents in a parallel seminar, the topic was autonomy – how to make the child, the youngster as independent a possible. It was a very interactive meeting, with a lot of questions, practical advice and changing ideas. Parents were very pleased to have had the possibility to discuss topics with Anna.

On the second day, Anna presented how in Italy job preparation is organized, what kind of work possibilities are found on the Italian job market. A good example of successful job inclusion and a successful EU project is Valueable, which she introduced to the interested Ukrainian audience.



Anna Contardi from Italy during her presentation

Key qualifications

Cora Halder gave a talk about how children and youngsters can learn the job skills – (key qualifications) – they need for a successful employment on the open work market. The best place to learn these is an inclusive school. She explained how inclusive education can be organized and showed the advantages of mainstream schooling above special education.

In a second lecture she presented the job situation for adults with DS in Germany from the workshops for persons with an intellectual disability to supported employment and working on the first job market.

There is a development to more job inclusion, according the UN Convention on the Rights of Persons with Disabilities, which states that the right to work for persons with a disability includes the right to the opportunity to work in an open, inclusive and accessible labour market and work environment.



Cora Halder during her lecture

A vision for Ukrainian parents

For a country like Ukraine, where there is still a lot of rejection towards children with Down Syndrome, where proper education for these children only started 10 years ago, where school inclusion is in their infancy, it is a big jump to imagine how employment on the first market can be successfully realized. But as participants told us, they need such positive examples to have a vision, to have a direction, a goal to head for.



International
Labour
Organization

ILO Global Business and Disability Network

Persons with disabilities need new roadmap to join future world of work

Those with disabilities will face additional challenges in reaping the benefits of changes affecting the world of work, according to a new report. The publication also outlines a roadmap to help create a more equitable future of work.

GENEVA (ILO News) – Five key objectives need to be met if people with disabilities are to benefit from the major trends shaping the new world of work, according to a new report.

There are estimated to be one billion people in the world with disabilities. They already face challenges that hamper their participation in the world of work and place them at greater risk of poverty and social exclusion. Across eight geographical regions, an average of 36 per cent of working age persons with disabilities are in employment, compared to 60 per cent of the general population.

As consumers, persons with disabilities represent more than US\$1.2 trillion in annual disposable income, and, as societies age, this market for goods and services is expected to increase, the study says.

[*Making the future of work inclusive of people with disabilities*](#), is a joint publication of the [*ILO Global Business and Disability Network*](#), Fundación ONCE and KPMG Spain. It was developed within the framework of Disability Hub Europe.

New megatrends are reshaping the world of work and have the potential to improve the quality of life and work, albeit coming with significant challenges, the report says. These trends are relate to technology, skills, cultural change, demographic shifts and climate change. If disadvantaged groups, including persons with disabilities, are to benefit from these transformations a new roadmap is needed, it adds.

“The consequences of [these trends is] unclear, but the rise in inequality and the effects on those more disadvantaged sectors of society, such as persons with disabilities, are a matter of concern....and a growing strategic risk,” the report advises.

The authors identify five key objectives necessary if persons with disabilities are to

be included in the future of work.

1. New forms of employment and employment relations must integrate disability inclusion;
2. Skills development and lifelong learning must be inclusive;
3. New infrastructure, products and services must follow the principles of Universal Design (meaning they can be accessed, understood and used by all);
4. Assistive technologies must be affordable and available; and
5. More measures to include persons with disabilities in growing and developing areas of the economy are needed.

In addition, social protection systems are an important complement to achieve a future of work inclusive of those with disabilities.

The report points out that an explicit reference to the need to ensure equal opportunities and treatment for persons with disabilities is included in the call for a human-centred approach to the future of work, outlined in the [ILO Centenary Declaration for the Future of Work](#), adopted by the ILO's member States in June 2019.

“Not enough companies are including disability in their work on diversity and inclusion, even though the benefits are increasingly proven,” said Shauna Olney Head of the ILO's Gender, Equality and Diversity Branch. “We know that people with disabilities are currently more likely to be in vulnerable employment and to be paid less. If we are to achieve the goal of a future of work that includes everyone, we need to urgently adopt the principles outlined in this roadmap.”

From: ilo.org

EDSA'S AGA MINUTES



EDSA Annual General Assembly 2019

Minutes of the meeting

Date and time

Friday, November 15 th, 2019, 16.00h - 19.00h

Sunday, November 17th, 2019, 09.00h - 12.00h

Venue: Albergo Etico, Via Pisanelli 39/41, Rome Italy

Present: representatives DS organizations from 25 countries and 30 associations, from Albania (Down Syndrome Albania Foundation), Austria(Down-Syndrom Österreich), Bosnia-Herzegovina (Zivot sa Down Sy), Croatia (Croatian Down Syndrome Association), Czech Republic (Down Syndrom CZ), Denmark (Landsforeningen Downs Syndrom), France (ARFT and Trisomie 21), Germany (Deutsches Down-Syndrom InfoCenter), Hungary (Alapitvány Hungary and Down Egyesület Hungary), Iceland (Downs-Syndrome Association of Iceland), Ireland (Down Syndrome Ireland), Italy (AIPD), Luxembourg (Trisomie 21), Malta (Down Syndrome Association Malta), Netherlands (Stichting Downsyndroom) Norway (Norwegian Network for Down Syndrome), Poland (JATEZ), Portugal (PAIS 21-Down Portugal), Russia (Downside Up), Slovenia (Drustvo Downow sindrom Slovenija), Spain (Down Espagna, Asnimo Mallorca), Sweden (Svenska Downföreningen), Switzerland (Associazione Progetto Avventuno, Association Romande Trisomie 21 and Insieme 21), Ukraine (Ukrainian Down Syndrome Association).

Excused: DS organizations from Kosovo, Great Britain (DownsED), Italy (CooDown), Slovakia, Turkey, Romania

Without excuse: Great Britain (DSA), Belgium, Cyprus, Greece, Spain (Fundació Catalana) Macedonia, Scotland.

EUROPEAN DOWN SYNDROME ASSOCIATION

Welcome and opening of the AGA

Pat Clarke welcomed the delegates in the premises of hotel Albergo Etico and thanks to the AIPD about organization of AGA and seminar in Rome. Pat Clarke then opened the assembly, welcoming those delegates who were attending an EDSA AGA for the first time and asked all delegates introduce

themselves and their associations.

Minutes AGA 2018

The minutes of the AGA 2018 were sent to all members before the meeting so that they could read again. There were no questions or comments on the minutes. Minutes AGA 2018 accepted.

President Report

Pat Clarke gave a short overview of the activities since last AGA:

- WDSO 2019 poster campaign "Leave no one behind! " - 23 members participated (idea and coordination done by Cora Halder).
- the program „Invite an expert“ continues
- Valueable project continues, status presented by Paola Vulterini from AIPD
- Questionnaire on Independent Living prepared by Anna Contardi and results shown on seminar
- Collecting Information on EDSA members prepared by Emanuela Zaimi
- EU project 848077 - GO-DS21 accepted by EU commission in November 2019
- T21 Research Society (T21RS) is a leader and EDSA is one of the partners; next step will be the project kick-off meeting in the beginning of 2020. when detailed information will be defined regarding EDSA tasks and involvement.

Pat informed that EDSA past checking of the EDF regarding membership.

Next EDF meeting will be in Zagreb (Croatia) from 9-10 May 2020, as Croatia is the Presidency of the Council of the EU during first half of the year 2020.

Treasurer Report

Isidro Moyano, the treasurer presented and explained the financial statements for the year 2018 and the preliminary financial statement for January - 13th November 2019.

Some facts from the EDSA accounts 2018/2019:

- EDSA pays yearly membership to EDF and DSi – part of the money is spent on website maintenance, for the secretariat and for the EDSA-newsletter
- the program „Invite an expert“ has been used once in 2018 (Downside Up Russia) and twice in 2019 (DS Kosovo, DS Ukrainian), traveling costs of experts were paid by EDSA according to the program rules
- in 2018 EDSA exceptionally had a deficit (-1.400,57 EUR) due to the several additional activities or situation:
 - participation on WDSO 2018 in UN - New York
 - WDSO Congress 2018 in Glasgow (support to the youngsters, · meeting)

· situation of the income of membership fees (some members are paying for more years at once, not per year or with delay etc.)

– on 31st December 2018 on EDSA account there was more than 34.000,00 Euros, and on the 13th November 2019 there was more than 37.000,00 Euros.

Isidro Moyano also presented an overview of EDSAs financial situation of the last 12 years (2008-2019). He prepared and presented overview of the money spent on the program „Invite an expert“ over the last 6 years (2013-2019).

All these reports can be reviewed in the restricted area for members on the EDSA website.

The financial report for the year 2018 was approved by the assembly.

Election of new Board members

Due to the resignation of Karianne Abrahamsson (Norway) and Denis Chauve (France) there are two vacancies on the Board. According to the Statue nomination for the new Board members were open until November 7th , 2019. Two nominations received, from France for Nathanael Raballand and from Austria for Monika Mazegger. Nominations accepted and approved by assembly. Nathanael Raballand and Monika Mazegger are new EDSA Board members.

Status - projects, activities

Paola Vulterini from AIPD presented project “On my own...at work” and Valuable network

(<http://www.valueablenetwork.eu>) created through the Erasmus+ project (2014-2017), results and next step through the new project.

During the first project group of disability associations, universities and hotels established Valuable network and prepared tools like **applications** for the trainees and workers with intellectual disabilities, then **videos** for a proper relationship between people with intellectual disabilities and their workmates and **e-learning** for managers of the hospitality sector like set of instruments aimed at certifying the efforts of the company towards work inclusion.

Valuable project was very successful, and EU Commission approved next step of the project, new project in period 2019-2022.

Between two projects Valuable team asked for the support from partners and EDSA approved support in amount of 4.000,00 Euro. As project has got new finance from EU, they offer to EDSA that that amount of money be used for one of the two options:

a) Paula from AIPD could have short course and explain how to prepare EU project for the associations, e.g. how to prepare project that include study visit

b) organize study visit to Rome and AIPD for all associations. Decision will be proposed by the Board very soon. During discussion Nathanael from Trisomie 21

(France) talked about project that he is involved in, about inclusion in the school and he could send project example as it is based on study visits.

EDSA newsletter

Associations agreed that newsletter is very useful and propose to continue with it. AIPD prepared status report. Report and newsletters are stored in the restricted area for members on the EDSA website.

Introduction of the new members:

Association Romande Trisomie 21 (ART21), Down Syndrome Association Malta

Representatives of two new EDSA members, Association Romande Trisomie 21 (ART21) and Down Syndrome Association Malta introduced their associations. They showed power point presentations, magazines about their organizations, explaining the objectives and activities. It was very interesting to hear what is going on in the other countries. Questions and discussions took part after presentations.

The presentations are added to the restricted area for members on EDSAs website.

Collecting Information on EDSA members

Emanuela Zaimi from Albania prepared questions for the associations to collect information about status of the associations, their expectations and needs from EDSA. As input from associations came only shortly before the AGA, Emanuela showed just part of the results. She will continue to analyze and send results. Results will be analyzed on the Board to prepare new proposals and actions for the next steps and plans of EDSA work.

Invite an expert

Cora Halder and Anna Contardi explained how the program „Invite an expert“ functions. There were lots of questions and remarks. Basically, the idea is to share knowledge among each other. If an EDSA member is

planning a conference, a seminar etc. the association can invite out of a pool of experts, inside of EDSA, one person to speak at that event. EDSA will pay for travel costs, the lecturer will not ask an honorary. The inviting association has to come up for hotel costs.

In case if member wants to invite a person not directly connected to EDSA, but still an expert in DS-issues, travel costs might be paid as well. This has to be discussed with the Board. Lecturer outside the EDSA could ask for an honorary and that cost has to be paid by association.

Anna and Cora encouraged members to take more opportunities of the program.

During the discussion some associations mentioned how hard it is to find experts in some areas and asked for the proposal, e.g. France Trisomie 21 experts for self-advocacy.

Website <http://www.edsa.eu>

Cora explained how to get into the restricted area of the website. As the internet connection from the meeting place was not very stable, we could not show this procedure.

First step for the member to come to the restricted area is to ask for the password. The association has to send an email to the webmaster for this: (halgrade@t-online.de) and he will send it.

In the restricted area there are presentations from the AGAs and seminars and documents from the AGAs.

To make the website interesting and informative members are asked to send in news from their association, articles (in good English) photos (good quality). There will be a regular mail to ask for input from the associations.

The colleagues from AIPD who are in charge of the EDSA Newsletter are also happy with interesting contributions.

Family Exchange Program

Tania Mikhailenko (from Ukraine) explained how the family exchange program works. It is a possibility to visit and stay with families, who have a child with Down Syndrome in another country. Families who wish to use this program must be registered, their DS-association will be asked if the family is a member.

It seems that the registration not always functions properly. Fulya Ekmen (from Turkey), who is in charge with the family program but could not attend the AGA, will be asked to resolve the problem.

EDSA's forthcoming activities

AGA 2020

Pat Clarke informed that the next AGA will be held in Lugano, probably in September/October 2020. David and Monika Iduni of Associazione Progetto Avventuno will prepare the meeting. The topic of the seminar will be „Early intervention“. It was discussed, if this topic could be combined with another

issue (medical, aging,...). It was decided that Early Intervention is such a manifold and important issue that we need the whole day. Another suggestion was to offer workshops with different topics, not only lectures all day long. Proposals for experts in this field, who are willing to speak at our seminar, are welcome.

Health/mental health and/or aging might be topics for a next AGA seminar in 2021.

Next Board elections

Pat made clear that at the next AGA in 2020 board elections are on the agenda. He himself will not candidate any longer. Some other board members will also resign. People who want to run for a position on the board are welcome.

World Down Syndrome Day 2020

It was decided that there will be again a poster campaign for WDS like in former years. It is something all like and want to go on with. Cora will organize this. A flash mob is wished again as well. Anna Contardi said AIPD will prepare this.

The slogan of WDS 2020 will be: #We decide!#

It was decided that EDSA will not take part in actions on 21 March 2020 in Brussels. Cooperation with LIF is not so clear. Also, the Members of the European Parliament (MEPs) are not settled then with their whole roles.

EDSA plans to prepare another visit to the parliament in September/October 2020. The Board will develop a program for this visit but is happy for ideas from members.

Proposal for the European DS Congress in Bosnia and Herzegovina

May 2020

Maida Agic from association Zivot sa Down sy from Bosnia and Herzegovina informed that this association has a plan to organize 2nd European Congress on DS in Sarajevo in May 2020. The association has the resources to cover the cost of travel, accommodation and food to the lecturers.

The association asked for the support from EDSA in a few things:

- formal decision to support congress
- send information about congress to the members
- get information about members interest to participate on congress
- support in the preparation of the areas that congress will cover
- support in proposal for the lecturers
- could association use for one or two lectures program „Invite an expert“.

The association Zivot sa Down sy will send more information and official request towards EDSA.

News from the member organizations:

In the next session of the AGA EDSA members had the possibility to share an interesting project, a publication or anything else from their association with others. Following presentations:

Isidro Moyano presented a ppt about the family holidays for the members of the Czech DS Association. Summer and winter camps have been organized for 20 years and many families participate. The program is full of activities and courses, so it is a combination of work and leisure. Children e.g. have math education, which has been done during all these years by a Dutch lady Netty Engels. She has a daughter with DS and has developed her own math-method (after the Feuerstein method)

which has been very successful in the Czech Rep. All material has been translated into Czech language.

Netty died just some months ago. This is a big loss for the Czech association, as they were friends and workmates with Netty and her family for 20 years. Presentation is stored in the restricted area of EDSA website.

Dinka Vukovic spoke positive words about the benefits of being a member of EDSA. Her organization in Croatia has learned so much from the others, especially from the AIPD.

She also mentioned the meaning of being partner in EU projects. DS Croatia took part in several projects and Dinka presented some slides about the latest project which is still running. Topic is the preparation of youngsters with DS for the open job market, a project together with the Portuguese and Italian DS-organizations and the Santarem university (<http://t21.ese.ipsantarem.pt/> <https://www.facebook.com/t21community/>).

One of the project results is two years course at Santarem university (Instituto Politecnico de Santarem) called “Literacia Digital para o Mercado de Trabalho” <https://www.facebook.com/literaciadigitalpmt/> , <http://w3.ese.ipsantarem.pt/literaciadigital/> for the persons with intellectual

disabilities. Course is based on 13th years’ experience of similar course for the preparation for the labour market in Spain “Programa Universitario Promentor” at Universidad Autónoma de Madrid in cooperation with Fundación Prodis, <https://www.fundacionprodis.org/programas-servicios/promentor/> .

Six youngsters from Croatia participate and some of them are now doing internships as a follow up of the project.

Tiziana Nardini who is representing the Luxembourg organization came up with 2 projects:

1. Medical: after years of medical support from the french Le Jeune Foundation – as there were no doctors with knowledge about DS in Luxembourg – the situation has changed in the last years. A team of three

medical doctors has been in contact with LJF, visited the French center couple of times for further education. Two doctors are now specialist for children with DS, one is specialized in the treatment of adults with DS.

Luxembourg uses the medical guidelines from France. Other medical staff like nurses are now also making working visits at the LJF and are dedicated to use their knowledge for persons with DS in Luxembourg.

Emanuel Zaimi mentioned, that she is a member in „Global Down Syndrome Foundation“, they also have medical guidelines.

<https://www.globaldownsyndrome.org/become-a-member/>

2. Business: The DS organization bought space in a municipality building, which will be used for seniors to live independently, but in a structured environment. Part of this will be a café/restaurant, this will be owned and run by the DS Association. Project will be partly financed with state support and the restaurant will open its doors in March 2021.

Jilian Ott from French part of Switzerland showed a video from the Canadian DS Ass. It's about language recognizing research study „Project Understood“ by Google together with the Canadian DS Ass. Voice

technology is becoming a more important tool in day-to-day life that can help to make independent living more accessible. The problem is that currently, the technology doesn't always understand people with Down syndrome. Project Understood collect voice samples of people with Down Syndrome. More on EDSA website: <http://www.edsa.eu/promisingtechnology-for-people-with-down-syndrome-project-understood/> and <https://projectunderstood.ca>

Randi Ødegaard showed the new website of Norsk DS Network, called oppsiden.no NDSN has a paid professional who is collecting global news for this site. This part is available for everyone. In the member part of the new website (everyone can log in with password) you can take part in the chats, blocks

etc. The new website is frequently visited and the number of members of the NDSN increased with 20% since it is online. This is good for the organization, because the more members an organization has, the more money it gets from state.

Between the presentations of the members there was a short talk of **Mr. Antonio Pelosi**, the owner of the remarkable hotel, where we met, the Albergo Etico Roma, <https://www.albergoeticoroma.it> In this hotel people with a disability are working with a regular work contract and a regular salary.

Finally, several participants confirmed that the meeting had been very valuable and informative for them. They thanked the Board and AIPD for the organization.

At 12.00h the AGA was closed.

Pat Clarke, President Cora Halder, Operative Secretary

Dinka Vukovic, Secretary Gen

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!

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