

## **EUROPEAN DOWN SYNDROME ASSOCIATION**

**July 2023** 

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# **URGENT! EDSA AGA 2023**

Dear EDSA members,

On the 26th of June I sent you the first information about the 2023 AGA, which will take place in Madrid from 27 to 29 October. This is the location:

## https://goo.gl/maps/egjgdxEzDRiMovoB9

As a second step, we are sending you this form, to ask you if you are coming to the AGA, with how many delegates from your association you will be attending, if anyone is interested in serving on the board (a new board needs to be elected). On the second page of the form there are a few general questions about participation in projects. <a href="https://forms.gle/48hqGH4aov773P467">https://forms.gle/48hqGH4aov773P467</a>

Can you please fill in the form and send it back as soon as possible? Thank you very much.

In the next weeks, we will send more details about the topic of the seminar day and how you can participate. We will also collect short presentations from the members about their work, projects etc.

The official registration form will be sent to you soon.

Any questions? You can write to me: <a href="mailto:halder.cora@t-online.de">halder.cora@t-online.de</a>

Best regards, have a nice weekend

Cora



## **NEWS FROM THE WORLD**

#### WHY DISABILITY-INCLUSIVE EMPLOYMENT BENEFITS ALL OF US

Simon Brown, June 2023 sightsavers.org

We continue to live in a world where people with disabilities are half as likely as people without disabilities to participate in labour markets, and twice as likely to be unemployed when they do get the opportunity to participate.

Global data analysis from the International Labour Organization backs this up, showing a 27% employment rate (relative to the adult population) for people with disabilities, compared to 56% for people without. People with disabilities are often channelled into precarious jobs that are deemed more 'appropriate' for them, or barely sustained out of work by minimal state safety net allowances. And yet, as I often argue, the consequence is a US\$6 trillion (£4.8 trillion) loss to the global economy. It doesn't make sense!

Although I previously worked in the development sector for 20 years, I'm still new to the area of disability-inclusive employment. But the last four years, since I've joined Sightsavers, have been really exciting, and I've seen how we can influence labour markets to be more inclusive of people with disabilities in decent employment. It's not that the system necessarily resists inclusion, it's that it doesn't know how to make it happen.

## An appetite for change

It's not universally so, but there are an awful lot of companies around the world who want to be more inclusive. Companies whose workforces increasingly expect to be inclusive; who have tried, struggled, and are asking for help, not criticism. And of course there are many, many millions of people with disabilities who aspire to decent, formal employment but lack the self-confidence to readiness to go after opportunities. They may have internalised societal messaging that roles more complex or technical than dressmaking or shoemaking should not be their aspiration.

Start to address the negative attitudes and the absence of a capacity-building function in labour market systems, and we begin to see how the system changes. We also see that this is one of the greatest opportunities of the current generation, and the next one.

#### Inclusion Works: what we learned

This potential for change was highlighted by the UK Aid Inclusion Works programme (part of the Inclusive Futures consortium initiative led by Sightsavers), which ended in 2023. The programme showed us how structured labour market analyses not only helped understand the gaps, but also identify sectors and industries offering the best opportunity for greater inclusion in workforces. The next step was to partner with pioneering companies that actually wanted to make it happen.

We learned that decent employment doesn't limit us to look at waged or selfemployment, but also can take us into agricultural supply chains (farming) and microentrepreneurs in retail networks.



We also learned how demonstrating a change in one context can lead to similar changes in others. I'm not for one moment suggesting we've reached the tipping point yet. We're far from it, but we start to sense that there can really be one!

Working with Accenture and its Skills to Succeed Learning Exchange helped us much better understand that there a lot of people with disabilities who just need access to a system of online learning to build their self-confidence. This can help people to apply for job opportunities and successfully navigate recruitment processes. The system costs us nothing, outside of providing cheap internet access to learners.

We also gained a greater understanding of the potential within private sector value chains by working with Diageo in Kenya on inclusive agricultural supply chains. Hundreds of farmers with disabilities are now enrolled in the Diageo supply chain, supported through a commercially viable network of farmer hubs that attract equal numbers of farmers with disabilities. This is beginning to be replicated in other African countries where Diageo has a business interest, and the value chains approach has taken us into retail network partnerships with other companies including Coca-Cola Beverages Africa and Unilever.

What we've learned about increasing technical IT skills through the Nairobi IT Bridge Academy (piloted by Inclusive Futures) is now something we're replicating in Nigeria and South Africa. This work is always done in collaboration with the private sector, to guarantee at least three to six-month internships to participants who graduate with an industry-recognised Cisco Systems accreditation.

Finally, we've learned we must ensure that there is a solution to that 'missing middle' (the absence of a capacity-building function) in labour rights. We've begun to address this by working with the ILO to establish functional, private sector led, national business and disability networks. These act as knowledge exchange opportunities for employers, supported by the expertise of the disability movement.

## The essential element: engagement

None of this work is possible without meaningful engagement with organisations of people with disabilities and private sector companies. One of the most powerful things I've learned over the past four years is that, in the words of Sally Nduta, CEO of the United Disabled Persons of Kenya: "We need to learn to start together, identify the challenges together and identify solutions together so that we are walking that journey together." When we get that right, change happens!

Interested in learning more or partnering with us on disability inclusive employment? Contact Simon by emailing <a href="mailto:sbrown@sightsavers.org">sbrown@sightsavers.org</a>



## **EDSA TALKS WITH HUNGARY**

We spoke with Katalin Gruiz, president of Down Alapítvány.

Interview made by Cora Halder, Edsa Board member





The situation in Hungary for people with DS or another disability is nowadays not as good as one would like it to be. In fact, many things were much better 10 or 20 years ago.

The reason for this is that the current government is not interested in supporting people in general (health care and education is on the floor), especially not the people with a disability who require additional support, invested work and money.

The political situation in Hungary at the moment is very difficult for Ngo's. Those who are involved in work with persons with a disability are also affected, and are exposed to autocracy.

Katalin is very sad about the present situation in Hungary. Sometimes it looks like that all the work has been for vain. The foundation is desperately trying to at least maintain what she has already achieved.

The whole report of the interview



# NEWS FROM THE PROJECTS WITH EDSA MEMBERS IN THE CONSORTIUM

#### THE VALUEABLE NETWORK

Empowering Persons with Down Syndrome in Croatia through Collaboration with Valueable Network: Interview with Dinka Vukovic

Interview made by Benedetta Galeazzi, Valueable Communication Office



Valueable Network keeps **expanding**: we are now present in **Croatia**, thanks to the new partnership with **Hrvatska zajednica za Down sindrom (HZDS)**! We had the pleasure of interviewing Dinka Vukovic, the President of HZDS, the Croatian Down Syndrome Association, and also the current **president** of European Down Syndrome Association (EDSA). Dinka shared her personal journey and her experience in advocating for persons with Down syndrome in Croatia and Europe. Our conversation has shed light on the benefits and challenges of the collaboration between HZDS and Valueable Network.

## A Journey of Empowerment:

Dinka's engagement with the disability field began when her son Philip was born with Down syndrome in 2000. Faced with limited information and support in Croatia, she took it upon herself to learn about intellectual disabilities and advocate for her son's rights. Through extensive research and collaboration with parents and experts, Dinka established HZDS in 2005, an umbrella organisation that brought together 4 associations from various counties in Croatia. By travelling abroad and getting inspiration from UK education centres and American pedagogical materials Dinka has been able to propose innovative solutions to the challenges faced in the quest to break down barriers for persons with Down syndrome in her home country. She actively engages with government officials, gives lectures in schools, and raises awareness amongst parents about the capabilities and potential of persons with disabilities. Her dedication led to significant achievements, including pushing for law changes and creating opportunities



for children with Down syndrome to attend regular schools. HZDS has now grown to encompass 8 associations in 9 counties and has become a member of EDSA and Down Syndrome International. Dinka's vision is to prepare young people with Down syndrome for **independence**. Clearly, having a meaningful job is a key step to achieve this objective.

#### The Impact of the Valueable Network:

Dinka highlighted the transformative impact of the collaboration between HZDS and Valueable Network. Her association has greatly benefited from the expertise and support provided by Valueable Network coordinators Paola Vulterini and Giorgia Scivola. Dinka has emphasised that "Valueable Network gives HZDS the strength to showcase successful labour inclusion initiatives from other countries". In turn, this can inspire Croatian businesses to follow suit and bolster HZDS's requests when advocating government ministers to implement new inclusive policies. In February 2023 HZDS hosted the Valueable Network Coordination meeting in Zagreb, where representatives of partner organisations from 7 different EU countries met to discuss the future of the project. The 2-days meeting was a great success and we are excited to announce the upcoming launch of a new course on Health and Safety at Work.

### **Overcoming Challenges:**

Despite the progress made, Dinka acknowledged the challenges encountered in implementing the Valueable Network project objectives in Croatia. Finding motivated individuals to actively contribute to the project and ensuring timely completion of deadlines remains a hurdle. Another obstacle lies in finding suitable companies willing to employ young individuals with Down syndrome who may require additional support and training in the workplace. Nonetheless, HZDS shows businesses in the hospitality sector that employing persons with intellectual disabilities is not only possible but beneficial by **leveraging the Valueable experiences**. Dinka also expressed her view on the role of EDSA in fostering positive impact. She emphasised the importance of EDSA as a platform for different organisations across Europe to share best practices, learn from one another, and collectively **drive change in policies and social attitudes**. Dinka highlighted the need to encourage more active participation from individuals with disabilities in advocacy efforts. We must acknowledge the valuable opportunities Europe offers and continue to push for a more inclusive and **empowered society for all, not just some.** 



## **NEWS FROM EDSA MEMBERS**



DOWN'S SYNDROME ASSOCIATION (United Kingdom)



DSActive is a healthy lifestyle programme run by the Down's Syndrome Association.

Its aim is to provide as many opportunities as possible for people who have Down's syndrome to lead active and healthy lives.

They started in 2006 by offering a football session for people who have Down's syndrome with Fulham FC Foundation.

Since then, they have grown into a national programme offering many different sports and activities. They offer expert training to coaches, run festivals to celebrate the achievements of our athletes and support people who have Down's syndrome to achieve coaching qualifications.

## Find out more about DSACTIVE





#### TURKIYE DOWN SYNDROME ASSOCIATION



Türkiye Down Syndrome Association made closures of two important projects about promoting sports for people with Down Syndrome.

#### Handball +1:

It is a start-up project to create a handball league for the children with Down syndrome between the ages of 8-12 in Türkiye. The aim is to use handball to create a motivating environment to support social and physical development of children with Down syndrome.

## 1 in Sports at School:

It is another start up project designed to create a guide on the principles of inclusive sport activities in schools for students with and without disabilities and to ensure benefits for the Students Without Disabilities at sports schools who will become sports trainers. In that project these students learn how to communicate with students with intellectual disabilities and how to adapt activities for them.





## **EU AWARDS**

SALTO AWARDS 2023: APPLICAYIONS OPEN!!



Applications are now open for the Salto Awards 2023 for quality projects funded by the Erasmus+ and European Solidarity Corps programmes in the fields of youth, education or training from Programme and Partner Countries. The initiative, promoted by the European Commission, aims to recognise the value of projects that can inspire young people, policy-makers and potential Erasmus+ or European Solidarity Corps candidates.

### The 2023 award categories are:

- -Digital Transformation
- -Environment and fight against climate change
- -Inclusion and diversity
- -Participation in democratic life
- -Solidarity and Volunteering
- -Special mention: Skills development

## Who can nominate projects:

- -Members/project participants: people who have participated in or carried out projects relevant to the category.
- -Organisations: organisations, movements and groups that have conducted projects on relevant topics.
- -Public institutions and stakeholders: local authorities, youth centres, schools, universities or other decision-makers who have been involved in projects.
- -National Erasmus+ Agencies and European Solidarity Corps.



#### What the SALTO Awards offer:

- -A prize of 700 euros for the winning project in each category;
- -Your project presented in the SALTO Awards winners' promotion and as best practice on SALTO communication channels and during events;
- -An invitation to the "Youth Participation in Democratic Life" event and award ceremony in October 2023 in Lublin, Poland, the European Youth Capital!

Deadline: 16 August 2023, (23:59 CEST).

**Read more** 



## **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**

phone: 0039 06 3723909 e-mail: internazionale@aipd.it

### THE STAFF

Carlotta Leonori Paola Vulterini

