

INDEX

01 EDSA SEMINARY ABOUT SELF ADVOCACY

05 EDSA MEMBER OF THE MONTH

06 NEWS FROM EU

08 EU COMMISSION FUNDING OPPORTUNITIES

## EDSA SEMINARY ABOUT “SELF ADVOCACY”

28 October 2023 in Madrid

A full day seminar took place on Saturday 28 October. As always, the AGA is combined with a conference around a specific theme. This year the topic was: Self-Advocacy.



### 1. State of the art about Self-Advocacy in Europe

To introduce the topic José showed the results of a small survey among EDSA members and members of Down España: State of the art about Self-Advocacy.

Although most associations are aware that Self-Advocacy is an important issue, there was a lack of implementation almost everywhere. Only a few associations have people with Down syndrome on their boards, only a few associations regularly discuss projects, activities with young adults or listen to their ideas and suggestions.

Through the “Mentimeter” platform José gathered answers from all attendees on following questions: What should be the way in the strategy of your organisation in participation; What should be the level of participation of people with DS in this strategy?; What would be the ideal situation of Self-Advocacy? How is the reality?

Conclusion: there is still a long way to go to reach the ideal situation!

José handed out a new publication of Down España: Guide to the promotion of accessible governance

### 2. WDSO 2023 poster campaign “With Us Not For Us”

Cora said some words about the poster campaign of the last WDSO. The theme was „With Us Not For Us“ and thus deals with the same topic as the Self-Advocacy seminar. Even though it was initially difficult to find examples – very few of the EDSA member associations had any indication on their websites that people with DS are on their board

or that for example they co-operate closely with them in an advisory board. But then there were an astonishing 24 contributions and so it turned out that something is happening here and there in the direction of Self-Advocacy, but still far too little! All posters were presented again and Cora explained what was shown in the pictures.

### **3. Initiatives of Down España in the field of inclusive governance and self-advocacy**

The main speaker of the seminar was **Prof. Pep Ruf i Aixàs**. He is a Pedagogue and the Coordinator of the Independent Living Network of Down España, technical director in the Foundation Catalan Syndrome de Down (fcsd) as well as Professor of social education at University of Barcelona (UB) and Universitat Oberta of Catalunya (UOC). He introduced the National Network of Independent Living. His presentation gives a good overview of the proposals, the objectives of services of the network.

Some interesting issues Pep Ruf talked about:

#### **– promoting self determination**

Many people with DS are not aware of their rights, are not aware that they have the right to make own decisions. Neither do they know that they have also collected rights, as part of a group, of society. They live with parents, because they cannot change the situation, they are suffering of social exclusion. We have to teach them about their rights, we have to promote self-determination.

#### **– Improving the quality of life**

To have a lot of practical skills, to have autonomy is not a measure of independent living or of quality of life. We have personal assistance to overcome certain problems here. The real measure is the quality of life of the person, that means how far is he on the way to real independent living? It means much more as just practical skills.

– the different services, offered by the network like training courses, learning homes, shared housing, personal support services, self advocacy groups and inclusive leisure services

#### **– His opinion about housing**

housing groups are artificial groups. It is not what the person chooses himself! Housing projects are run by organisations, paid by organisations. It is not the person with DS who pays, decides. Inclusive projects where for example students and people with ID/DS live together are also artificial. This is not real independent living.

The natural situation is: People with DS choose for themselves whether they want to live alone or with a friend. All that is needed is suitable accommodation, assistance and money. A place in a residential facility costs the state around 3000 euros. This is more than enough to pay for a personalised solution.

In Catalonia, the region where Prof Ruf works there are about 1500 persons with ID/DS living on their own, alone. Most of them prefer to live by themselves, also because they have no such close friends they want to live with. Normally they get 10 hours weekly personal assistance, which is sufficient for most of them.

– **cognitive assistance** – an interesting term – this is the kind of assistance that most of our people with DS need, someone who explains situations, changes, mediate in difficult situations, planing, coaching and giving support in making decisions.

– **Inclusive leisure services** are important as well, then leisure time is more as just going out for a walk, to a shop or in the cinema. It also means being part of the community.

– Pep Ruf gave a definition of Accessible Governance and the strategies to promote this. There is a lot of work ahead! The latest publications of Down España deals with this issue and is called the „Guide to the promotion of accessible governance“. To make participation in governing bodies successful a lot of changes and adaptations are necessary.

At the end of his speech stood the final remark of Pep Ruf: We have to move from organisations for people with Down syndrome to organisations of people with Down syndrome!

There were many questions to Pep Ruf and the interesting discussion could have gone on for a long time but we had to stick to the time schedule, as the next presenters were waiting.

#### **4. Self-Advocates training of Trisomie 21 France**

Nathanaël Raballand of Trisomie21 France together with his son Melchior (with DS) and Marie Laure.... had prepared a presentation about the Self-Advocates training of his organisation. At the same time there were two young adults from France connected online: Fanny, Antoine (and Vincent but connection did not function) There was an interesting talk, with all about what it means to be a self advocate, how they were trained to be a self advocate. Melchior asked questions and Fanny and Antoine answered.

Two videos showed how the training to learn to be a self advocate is organised. Some of them become then trainers themselves and teach the next persons with DS so that they all learn how to make their voice heard. In many cities in France there have been such trainings.

#### **5. “Reporteros Cañeros” of Down España**

After lunch José had invited a young lady Cristina, who works at Down España in different department since 18 years. In an interview with José she explained her role in Down España. She is also one of the „Reporteros Cañeros“, which means that she prepares questions to a certain current topic and then goes out in the street or in a shopping mall with her microphone and interviews passers-by. This can be seen live on a special TV-Channel. Christina has a humorous way of talking about her work. It was very nice to listen to her.

Some of the interviews were shown in a video. Besides Christina there is a young man with DS who also works as a reporter. <https://youtube.com/playlist?list=PLtNX3F-LGSoUxyBAzc-6rDjWgRZmCtpIE>

#### **6. Self-Advocacy program “My Voice My Society” of Türkiye Down syndrome Association**

Another contribution to self-advocacy came from the Türkiye Down syndrome Association. Fulya showed a good structured, informative presentation about the program “My Voice My Society“, which started 2017. One objective is empowering people with intellectual disabilities as citizens. And the second objective is empowering people who will guide people with intellectual disabilities as facilitators. The first self-advocate group called themselves Voice + 1 and has been very active right from the start.

Türkiye Down Syndrome Association is co-founder of a Network for the Rights of Children with Disabilities. They have trained facilitators in 17 NGO’s in the network. 12 NGO’s established their self-advocacy groups u.a. with children and youngsters with different disabilities.

Self Advocates achieve:

- They know and are aware about rights and asking for them.

- They develop self-confidence.
- They learn that their views are valued.
- Behaviour problems decrease.

It is not only about learning rights it is also about accepting oneself as a valuable person and realising one's value to the world.

### **7.–11. Five contributions were short videos from different associations**

– First we saw a film about the my voice self advocate group of DSA (**Down syndrome Association from the UK**), which shows the activities of this group.

– The video from **Romania of Aldo Cet** gives information about an EU project „Sustainable Service in DS“. It promotes an active model of people's involvement into the global call for action based on the quality of life model instead of the assistive model which is currently used in educational and social environments for people with Down syndrome. In 2 further short films some activities from the project were shown, already during the AGA.

– **DownSideUp from Moscow** send a video about two young people with DS explaining how a good early intervention pays off. That's how they got a good start in life as adults and it helped them to become independent.

– The contribution from **AIPD in Italy**, was a video made for the WSD 2023 about the rights of people with DS: the right to vote, to have a job, to fall in love, to choose a boy/girlfriend, to choose where and with whom to live! For this occasion a dance was trained by many DS groups all over Italy and was shown on the streets in many cities on 21 March (“Tutti in Piazza”: “All in the streets”)

– **DS Ireland** sent a short statement of a young woman with DS about self advocacy.

### **12. Contribution from Sweden**

Veronica Hallberg explained that even though they had tried to integrate a person with DS in the board of the Swedish DS association, they failed. It just did not function. She was very sad about this but other attendees mentioned that they had the same experience.

The discussion went about what to do, to make such a cooperation with persons with DS successful?

One answer is: they should be well prepared for this task. It is hard work for us to teach them about this role.

### **13. Contribution from Portugal**

Pais 21 Portugal presented their organisation, their vision and mission, values and projects. One of the projects is Autonomia 21 with the goal to find an occupation of the 18+ years old young adults who finished school. More self determination, going academic learning, possibility to try new things. The program Saber em Movimento started with 6 youngsters September 2022 with internships etc.

And was successful – several young adults found jobs after the training time.

[Here all the presentation](#)

## EDSA MEMBER OF THE MONTH

### UKRAINIAN DOWN SYNDROME ORGANIZATION



Ukrainian Down Syndrome Organization (UDSO) is the community of parents, families with Down Syndrome person among. 2023 is the year when it has twentieth anniversary. UDSO representatives joined EDSA annual meeting in Madrid. There was a presentation about today reality in Ukraine and UDSO activities in war conditions. It's the recognition for every one that Russia aggression is still going on in Europe in the 21-st century and civilians are suffering. They've reminded a big support of EDSA members, ordinary Europeans to Ukrainian families with children and adults with Down Syndrome. In spite of all challenges our colleagues from Ukraine have plans to develop, implement projects and are in contact with families.

[Read the whole article here](#)



## NEWS FROM EU

### EUROPEAN DISABILITY CARD

#### European Disability Card and European Parking card for persons with disabilities



To make sure persons with disabilities can move freely around the EU, the Commission has proposed the creation of:

- a new European disability card
- an improved European parking card for persons with disabilities

#### What are these cards?

##### European disability card

The card will serve as a **proof of disability status** across all EU countries.

It will grant cardholders equal access to **special conditions and preferential treatments** anywhere in the EU.

The special conditions apply when using public transport, attending cultural events and visiting museums, leisure and sports centres, amusement parks, and more.

They can take the form of, among others:

- free entry
- reduced tariffs
- priority access
- personal assistance
- mobility aids

The European card will **complement national disability cards**, which will continue to be awarded by national authorities, based on their own criteria.

##### European parking card for persons with disabilities

The improved version of this card will guarantee use of parking spaces and facilities reserved for persons with disabilities in all EU countries.

**It will replace national parking cards.**

**When will the cards be available?**

On 6 September 2023, the Commission made [a proposal to create these 2 cards](#).

This will now be negotiated by the EU Council and the European Parliament, and a legal act will be passed, requiring EU governments to implement the cards for their nationals within 2,5 years.

### **What is in the proposal?**

The proposal sets the rules for both cards, concerning:

- the **physical format**
- the process for agreeing on the **digital format**
- the conditions, rules, and procedures for **issuing or withdrawing** cards
- accompanying **information** to be provided on the special conditions and preferential treatments

All of the above must be accessible for persons with disabilities.

### **Background**

This initiative is built on the experience of the ongoing [EU disability card pilot project](#) in 8 EU countries and based on [Council Recommendation 98/376](#).

A [public consultation](#) on the European disability card initiative was held in February-May 2023.

The proposal for the 2 cards delivers on a commitment made by the Commission in the EU's [Strategy for the Rights of Persons with Disabilities 2021-2030](#).

INCLUSION EUROPE MADE AN EXPLANATION OF THE DISABILITY CARD IN EASY READING  
[HERE THE LINK TO READ IT](#)

## EU COMMISSION FUNDING OPPORTUNITIES



### ERASMUS+ PROGRAMME GUIDE 2024

This Programme Guide is a tool for anybody who would like to have a thorough knowledge of what the Erasmus+ Programme is about. This document is mainly addressed to those who wish to be:

- participating organisations: meaning those organisations, institutions, bodies organising activities supported by the Programme;
- participants: meaning those individuals (students, trainees, apprentices, pupils, adult learners, young people, volunteers, or professors, teachers, trainers, youth workers, professionals in the field of education, training, youth and sport, etc.) involved in activities organised by the participating organisations.

Every year, thousands of projects are submitted by organisations across Europe in order to receive financial support from the Erasmus+ Programme; for this reason, the Commission has set up a transparent evaluation process that aims at providing grants for the best projects:

- for most Actions, all the rules and conditions for receiving a grant from the Programme are specified in this Programme Guide;
- for some other Actions, which are only mentioned in this Programme Guide, the rules and conditions for receiving a grant are described in specific calls for proposals published by or on behalf of the European Commission.

When planning an application, potential participating organisations can also be inspired and informed by other reference documents; some of these documents are listed in Annex IV of this Guide.

### **How to read the Programme Guide**

The Programme Guide has four main parts:

- Part A offers a general overview of the Programme. It gives information about the objectives, priorities and main features of the Programme, the participating countries, the implementing structures and the overall budget available. This section is addressed to those who wish to have a general overview of the scope and the structure of the Programme.
- Part B provides specific information about the Actions of the Programme that are covered by this Guide. This section is mainly addressed to those who are interested in knowing more in detail which types of projects are supported by the Programme.
- Part C gives detailed information on procedures for grant application and selection of projects, as well as the financial and administrative provisions linked



to the award of an Erasmus+ grant. This section is addressed to all those who intend to submit a project proposal under the framework of the Erasmus+ Programme.

- Part D provides a glossary of useful terms.

[Download the Erasmus+ programme guide 2024](#)

## 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

e-mail: [internazionale@aipd.it](mailto:internazionale@aipd.it)

### THE STAFF

Carlotta Leonori

Paola Vulterini