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OPPORTUNITIES**EDSA AGA 2024**

Dear EDSA members,

As we have already informed you, our next AGA will be held in Lisbon from 25 to 27 October 2024 and will be organised by PAIS 21.

Here is the link for registration:

[https://docs.google.com/forms/d/e/1FAIpQLSfd9QuogRv4lBq-t\\_QLKNhhf8elfrEWr7NrGNidqzjibRWZKQ](https://docs.google.com/forms/d/e/1FAIpQLSfd9QuogRv4lBq-t_QLKNhhf8elfrEWr7NrGNidqzjibRWZKQ)

In addition to the official AGA meeting, there will be a one-day seminar on the topic: Down syndrome and sports participation.

All members are welcome to send their input.

We look forward to hearing about successful sports projects and programmes, sports events and how people with Down syndrome participate in sport in your country. Special Olympics or inclusive sport? Which are your experiences?

If you have something interesting in mind for the others, please prepare: short speeches, short videos, presentations...

We can share all this among ourselves, learn from each other and bring new input back home.

Please write to [halder.cora@t-online.de](mailto:halder.cora@t-online.de), if you are considering a speech (10 minutes), so we can get the programme organised.

At the beginning of October, we will also send you a short questionnaire on the topic of sport. The results will be presented in Lisbon.

More information on the meeting and conference will follow shortly.

Kind regards

Cora

## EDSA MEMBER OF THE MONTH



### **The Swedish National Down Syndrome Association (Svenska Downföreningen)**

Founded in 2002, the Swedish National Down Syndrome Association has been dedicated to raising awareness about Down syndrome and advocating for full participation and self-determination. We offer individuals with Down syndrome and their families a platform to make their voices heard while creating opportunities for activities, meetings, and a sense of community. As a non-profit, nationwide organization, we are proud to have 18 local chapters across Sweden and around 4,000 members. There are four part-time employees at our national office that is situated in Stockholm, and all other work within the association is done on a voluntary basis.

### **Our Journey and Growth**

The association was established over 20 years ago by a group of passionate parents who recognized the need for a specific organization focused on individuals with Down syndrome and their families. Since then, we have expanded into a nationwide network, with 18 local branches across the country.

### **Our Vision**

We believe in the potential and equal value of all people. Our goal is to create a society where individuals with Down syndrome are equal citizens, with full participation, equality, and self-determination based on each person's unique abilities. With the right support from an informed and engaged community, people with Down syndrome can lead fulfilling lives and contribute to society.

### **Life for Children with Down Syndrome in Sweden**

In Sweden today, children with Down syndrome grow up in their families, attend preschool, and later, school, with access to the support they need.

### **Guiding Principles: Knowledge, Community, and Opportunity**

Our work centers around three main principles:

- **Knowledge:** We increase knowledge and awareness as well as share experiences of what it can be like to live with Down syndrome
- **Community:** We create meeting places for people who in various ways come in contact with Down syndrome.
- **Opportunities:** We engage in active dialogue and discussion to improve opportunities in society for people with Down syndrome.

## Major Campaigns

We lead two major awareness campaigns each year, both tied to global movements:

- **World Down Syndrome Day (March 21):** The UN-designated day to raise awareness about Down syndrome. In Sweden, we celebrate through the 'Rock Your Socks' campaign, where wearing mismatched socks symbolizes support for people with Down syndrome and promotes equality.
- **Down Syndrome Awareness Month (October):** In Sweden, this campaign is called 'Rocktober,' focusing on spreading knowledge and understanding of Down syndrome throughout the month.

## Support and Services for Families

When a child is born with Down syndrome in Sweden, the family is connected with local rehabilitation services, which provide a range of support from physiotherapy to speech therapy, special education, and psychological counselling. Families receive guidance on how to navigate the support system, ensuring their child's development and well-being. This partnership between families and services helps create the best possible environment for each child's growth.

## The Impact of the LSS Act

The introduction of the LSS Act in 1994 was pivotal in promoting equality and full participation for individuals with disabilities. Thanks to this law, people with Down syndrome now have better opportunities to live independently, form friendships, and engage in activities of their own choice, marking a significant step toward achieving equal rights and integration in society. Unfortunately, we are now witnessing a dismantling of the rights that people with Down syndrome gained in Sweden during the 1990s. Both the state and municipalities are focusing to save money rather than ensuring good living conditions for people with Down syndrome.

## Current Projects and Collaborations

The association have project groups working on key areas such as prenatal testing, self-advocacy, and communication. International collaboration is also central to our mission, and we work closely with organizations like the European Down Syndrome Association (EDSA) and Down Syndrome International (DSI).

## Statistics

Approximately 90 babies with Down syndrome are born each year in Sweden, and there are an estimated 5,000-10,000 individuals with Down syndrome living in the country today. Our organization continues to focus on supporting new parents, providing networking opportunities, organizing seminars and arranging summer camps for families with babies aged 0-2 years. By offering these resources and fostering a community, we aim to ensure that individuals with Down syndrome and their families are supported, empowered, and fully integrated into society.



## NEWS FROM THE PROJECT WITH EDSA MEMBERS IN THE CONSORTIUM

### ALL LIVING INDEPENDENTLY (ALI)

Erasmus+ Project: All Living Independently (ALI). Independent living trials for 10 young adults with Down syndrome: a meeting in Potenza (Italy)

From September 27th to 30th, 10 young adults from Luxembourg, the Czech Republic, Croatia, and Italy met in Potenza, hosted by the local chapter of the Italian Association of People with Down Syndrome ETS APS (AIPD), to participate in a shared experience focused on developing autonomy in managing daily life.

The project, "All Living Independently (ALI)," funded by the European Erasmus+ program and coordinated by AIPD Potenza, involved the participation of EDSA, Down Syndrome CZ, and Trisomie 21 Lëtzebuerg asbl. The goal was to establish common practices to foster personal and social autonomy for people with Down syndrome.

The event in Potenza, which also included a group from the Croatian association Hrvatska zajednica za Down sindrom (HZDS), served as an opportunity to assess the effectiveness of these practices. The aim is to later present this methodology to a broader audience, including through e-learning resources which will be available on the EDSA website after the next AGA.

According to all participants, **the 3-day experience has been fully positive**, the **atmosphere** was warm and friendly.

For all people with DS who took part in the meeting it has been a very good opportunity to **experience independent living skills**, within a group.

The youngsters met on Friday 27th September afternoon through a game: they shared their hobbies, life expectations, and preferences related to food, sports, and more. Based on this information, participants were divided into small groups, giving each one the opportunity to actively participate in the activities. Participants with DS were also requested to think about management of the various meals, from planning the food to be eaten, to go shopping, to set the table and to clean it. And so the participants with Down Syndrome, after choosing what to eat based on some local recipes, went grocery shopping, planned the preparation of various meals, set the table, and handled the cleaning in a spirit of conviviality and active participation. The "sarcinedda" workshop, held at the "Insieme" Association, gave the participants with Down Syndrome the opportunity to create a souvenir gadget from their experience in Potenza, featuring typical images of the Basilicata region

They also had to share the rooms and bathrooms, since they were accommodated in just two flats to allow for greater proximity and interchange (Luxembourg with Czech Republic and Croatia with Italy).

One of the "best" moments of the event has been the Sunday lunch in Matera, where youngsters of different countries enjoyed their time together without any mediations.

#### Particularly appreciated:

- The [recipe book](#) which was created for the event and used to plan the meals
- The gadget (sarcinedda) which was created along a joint workshop.

- The typical dish brought to Potenza by each team, to be shared with the others.
- “Peperoni cruschi (dry red peppers)”: food gadget, donated by AIPD Potenza to foreign teams.

NB: some days before Potenza, a preliminary online meeting was held, where all participants met for the first time and introduced themselves

Another online meeting among all participants will be organised in November, to recall their experience together by reviewing a selection of photos and toasting their friendship.



Co-funded by  
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## GOOD RESOURCES FOR EDSA MEMBERS



### **Understanding and supporting children in toilet training**

Toilet training is a significant developmental milestone for children, yet many, including those with intellectual or developmental disabilities, face challenges when it comes to bowel movements. This reluctance can stem from various factors, including fears, discomfort, and sensory sensitivities. Understanding these elements can help caregivers support children through this process.

The EarlyBrain's toolkit "Marta Against the Toilet" will provide theoretical and practical information for children, parents and caregivers.

### **Understanding the Challenges**

#### **Cognitive Inflexibility**

Children's cognitive flexibility is still maturing during early childhood. In the in-between years, inflexibility may manifest itself in the form of resistance to change, in particular for children with neurodevelopmental and behavioural conditions. One common example of this resistance occurs during the transition from diapers to the toilet. Children may struggle with the new sensations and routines associated with toileting, leading to anxiety and refusal to use the toilet.

#### **Tactile Hypersensitivity**

Many children experience tactile hypersensitivity, where certain textures or sensations become overwhelming. It is a common symptom in several neurodevelopmental and sensory processing conditions. The feeling of the toilet seat, the coldness of the porcelain, or the sensation of sitting can be uncomfortable for some. This discomfort can deter them from using the toilet, as they may associate it with negative physical sensations.

#### **Anxiety and Phobia**

Toilet anxiety, or phobia, is common among children. It can be triggered by various factors, including a traumatic experience with constipation or fear of falling into the toilet. Children may also develop anxiety in unfamiliar environments, such as public restrooms, where sounds and smells can be overwhelming. This anxiety can lead to avoidance behaviours, such as withholding bowel movements, which can exacerbate the problem.

#### **Intentional Withholding**

Urinary retention often occurs alongside stool withholding, creating a cycle of discomfort. When children withhold stool due to fear or pain from previous experiences, they may also experience urinary retention. This can lead to further complications, including constipation, as the stool hardens the longer it remains in the colon.

## **Behavioural Approaches**

### **Behaviour Modification: Token Economy**

Implementing a token economy can be an effective strategy for encouraging positive toileting behaviour. This approach involves rewarding children with tokens for successful attempts to use the toilet, which can later be exchanged for a larger reward. This method reinforces positive behaviour and helps children feel a sense of accomplishment.

### **Optimal Diet**

A well-balanced diet is crucial in preventing constipation, which is often a significant factor in toilet refusal. Ensuring that children consume a diet rich in fibre —fruits, vegetables, and whole grains— can promote regular bowel movements. Adequate hydration is also essential to soften stool and ease the process of using the toilet.

## **Developmental Considerations**

### **Evolution of Toilet Training Skills**

Toilet training is an evolutive process that varies significantly among children. Factors such as developmental readiness, personality, and environmental influences play a crucial role in how and when a child learns to use the toilet. Understanding that each child develops at their own pace can help parents and caregivers approach the situation with patience and empathy.

### **Anticipation and Routine**

Establishing a consistent routine can help children anticipate toilet use, reducing anxiety. Regularly scheduled toilet times can create a sense of normalcy and expectation, making the experience less intimidating. Incorporating enjoyable activities during toilet time, such as reading or playing with toys, can also help ease the anxiety associated with using the toilet.

## **Conclusion**

Addressing the challenges children with developmental issues may face when transitioning to toilet use requires a multifaceted approach. By understanding the underlying fears, sensory sensitivities, and the importance of routine, caregivers can create a supportive environment that encourages children to overcome their reluctance to use the toilet. Patience, empathy, and appropriate behavioural strategies can significantly ease this transition, fostering a positive experience for both children and their caregivers.

The EarlyBrain Consortium is developing toolkits, encompassing stories and training materials for parents and caregivers to support children. The first story “Marta Against the Toilet” will be available on [the project’s website](#) and will provide theoretical and practical information, as well as a tale for children to enjoy and learn about the challenges and how to overcome them.

*article published by European Association of Service providers for Persons with Disabilities*



## PRIVATE FUNDING OPPORTUNITIES



Inspired by the life and legacy of Gene Roddenberry, The Roddenberry Foundation (TRF) supports innovative thinking, original ideas, and extraordinary people who can change the world. Through four core programs they cast a wide net to uncover and support these great, often untested ideas and the individuals and organizations whose vision and leadership have the potential to bring them to fruition.



The Roddenberry Catalyst Fund is awarded to early-stage ideas and projects that have the potential to radically reframe existing problems, surface untapped innovations, and disrupt how and by whom we make the world a better place.

[Learn More About Catalyst](#)

## 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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