



# Include

Special issue for the European Day of Persons with Disabilities 2019

- **How the new European Disability Strategy should support people with intellectual disabilities and their families**
- **Thibeau Bastien: Meet the successful Belgian sailor**



## Introduction

# What Inclusion Europe expects from the new EU disability strategy

The European Disability Strategy should:

1. Address the right to make decisions;
2. Establish clear targets on community living;
3. Address violence against women with intellectual disabilities;
4. Recognise the role of families in fulfilling the rights of their relatives with disabilities and supporting them across Europe.

Across these recommendations a particular attention should be paid to:

- Children with intellectual disabilities and their families;
- Women with intellectual disabilities;
- People with complex support needs and their families.

They are particularly likely to be discriminated against.

The strategy has a duty to address the specific issues they face.

## European Disability Strategy



# The strategy needs an easy-to-read version!

Find explanations for the words in **blue and bold** at the end.



The **European Disability Strategy** is an important text. It says what the **European Union** has to do to make sure people with disabilities in Europe get the same rights as everyone else.

We think that everyone should be able to read the European Disability Strategy.



This is why we want a version in easy-to-read of the European Disability Strategy.

This will make it possible for people with **intellectual disabilities** to read the strategy. Then they can learn more about their rights.

## Self-advocates' demands

# “Real jobs and real pay”, “accessible information” and much more

At the Hear our Voices conference, 150 self-advocates from 18 countries met in Graz, Austria. They wrote down demands for national and EU leaders.

This is what they want:

- The right to vote
- To be included
- To get accessible information
- To get real jobs and real pay
- To have the same opportunities
- The right to self-determination
- That all institutions are closed
- Punishment for the countries that are not respecting the Convention
- Money to invest in people, not in institutions
- Justice for all
- Respect! Talk to us directly.

► Read more about the conference here: [bit.ly/IEHoV19](https://bit.ly/IEHoV19)



Group picture from the conference



## Deinstitutionalisation

# Children with disabilities deserve a life outside of institutions



Inclusion Europe's  
director Milan  
Šveřepa

Today, children with disabilities represent the majority of children remaining in institutions.

"In a number of European States, children with disabilities are disproportionately more likely to be placed in institutional care than their non-disabled

peers and appear far less likely to benefit from efforts to affect a transition from institutional to family-based care," writes The Academic Network of European Disability Experts in their latest report.

### The heart of the problem

In many countries, the legal framework is geared towards institutionalised solutions, and funding at the national level continues to favour institutions rather than the alternatives. All the existing good practices and innovative services are essentially exceptions, out-of-the ordinary situations created despite the prevalent legal and funding environment.

Therein lies the main challenge in making the next step – to turn the cases that are currently the exceptions into the rules. For children with disabilities, this

means implementing structural changes at each key stage of their lives.

### Early support

Early intervention should start right after birth if possible. The support should be individualised, structured, provided on a long-term basis – not just for a few months but up until the child goes to school – and provided at home.

### Education

The policy of keeping children out of institutions and providing support at



an early age must be followed by quality education.

It is critical for children to go to school with other children from their neighbourhood, as it makes it possible for them to form important and lasting relationships.

### Employment

Children do not remain children forever.

Limiting their chances of success in adulthood by failing to help develop properly, by segregating them from society and by not providing proper education, sets them on a path towards unemployment, with no jobs (or only stereotypical, non-paid activities) and with life-long dependency on “care”.



### Institutionalisation later in life

In many countries, the drop in the number of institutionalised children is simply due to these children growing older, and being transferred to institutions for adults.

Institutionalisation can also happen later in adult life, when the parents or siblings who were providing support are unable to continue doing it – and community-based support is lacking. The actual placement in an institution, as well as the dread of it always hanging over the heads of the families, have devastating effects on all involved.

► *This article is a shortened version. The full article in English, Czech, French, German, Italian & Spanish and an easy-to-read version (in English) are available at [bit.ly/Deinstitutionalisation](https://bit.ly/Deinstitutionalisation)*

## Sports

# “Sailing is different in every country”

Thibeau Bastien, a 22-year-old sportsman from Belgium, has, together with his “sailing buddy” Matthias, achieved an impressive track record in sailing. After joining Unified sailing Belgium in 2013, he became European champion in 2015 and in 2017, won gold at the Special Olympics World Games in 2015 in Los Angeles and in 2019 in Abu Dhabi. He takes special pleasure in tying sailing knots. The Belgium Sailing Association elected Thibeau “Yachtman of the Year” in 2015. He will be the “face” of the campaign for the National Games of Special Olympics Belgium in 2020.



Thibeau Bastien

**You are very much into sailing. Can you tell me how you got interested in this sport?**

I've been sailing with my parents since I was still a baby. We have a boat and they took me along their trips from a very early age.

**How did you decide that you wanted to take part in competitions?**

Unified Sailing contacted my school asking if they knew students who were good at swimming. So my teachers pointed me out. Together with my parents, I went a few times to get introduced to Unified Sailing. I liked it very much, so I enrolled. From that day I have been sailing almost every weekend.

I started sailing competitions in the Netherlands at their National Games of Special Olympics, because there was not yet a competition in Belgium. Later on, I got to know my buddy, Matthias Van der Auwelaer. We sailed together for the first time in October 2014 at the Dutch Unified Sailing National Championships.

### Who does what when Matthias and you sail together?

Matthias is in charge of the sailing tactics. He controls the sails and gives me navigation orders. I am the navigator.

### Your duo has won a lot of important prizes. Is there any

### race that you remember more than others?

That would be the second last race in Abu Dhabi. We were very close with another team. Matthias decided to tack because the other boat was catching up. So I pushed the stir the other way. The other boat was so close, it hit us at the back. It all happened in my back, I did not see it coming. It was a bit of a scare. Also, sailing is different in every country. In Switzerland, for example, you can go sailing at 1800m altitude surrounded by mountains – this is simply great. I also love sailing in Mallorca. The sea is so blue there.



Thibeau Bastien sailing





## Right to vote/ Legal capacity

“These elections were different from any other election”



Inclusion Europe video shown on the Esplanade in front of the European Parliament at the European elections night

The European elections 2019 were a great moment in the history of the inclusion movement. With voters with intellectual disabilities participating for the first time in several countries and with great public visibility, this was an occasion to enjoy.

Voters in Denmark, France, Germany and Spain who were previously excluded by guardianship laws took part in the elections for the first time. And judging by the many posts on social media, they made the most of the opportunity. This work must continue to ensure in the next European elections, there are no more EU members states denying people with intellectual disabilities their right to vote.

► Find an easy-to-read version of this article at [bit.ly/ElectionsETR](https://bit.ly/ElectionsETR)

## 5 reasons why people with intellectual disabilities should get the right to vote

### People with intellectual disabilities can make their own choices

**We make choices all the time – some of them are good, some of them are bad. People who don't have disabilities do** not need to justify their choices. No one asks them whether they were made on a rational or emotional basis. We should therefore **not demand higher standards from people with intellectual disabilities** make their own choices, provided they get the right support:

### We can support people with intellectual disabilities in making decisions

People with intellectual disabilities have the right to be accommodated so they are in a position to make independent decisions. This includes providing **information** (for example party programmes, election manifestos ...) in **easy-to-read language**, communicating in an understandable manner or providing assistance during voting.

### Everyone's voting decision is influenced

Election campaigns are about politicians and parties trying to convince citizens to vote for them. **Influencing is one of the main tools of political persuasion**, and it is certainly not restricted to people with intellectual disabilities. Misleading or false information can be a serious problem for everyone, but eliminating the electoral rights of some citizens is not the solution.

► *Read the other 2 reasons and an easy-to-read version of this article at [bit.ly/ElectionsETR](https://bit.ly/ElectionsETR) and [bit.ly/IE5reasonsVoting](https://bit.ly/IE5reasonsVoting)*

► *Find out more on how to make elections accessible: [bit.ly/AccessibleElections](https://bit.ly/AccessibleElections)*

## The family perspective

# “An inclusive school needs to provide learning opportunities for everyone”

*Jeanne Nicklas-Faust is federal manager of Inclusion Europe's German member Lebenshilfe, and a medical doctor. She has a daughter with complex support needs. We asked her about the support the family received, as well as the challenges they encountered while raising their daughter.*



### What was the situation like when your daughter was born?

Our daughter Eva was our second child, her older sister was nearly three years old at the time. The disability only manifested itself during the first year. When Eva was one year old, she started having severe epileptic attacks. Until the age of 6, she was in and out of

hospital. During this time, we had dinner together at the hospital so we could be together as a family at least once per day.

### How did your surroundings react to your daughter's disability? What support was available?

We live far away from our families, so we received a lot of support from friends. But others also turned away from us. My husband and I took turns working part time, and we had a caretaker look after Eva for a few hours per week. In the beginning, we needed to pay for the care out of our own pockets. Later on, we received a state allowance for this. My colleagues supported me by taking on my evening shifts. But we would have been grateful to receive more support with our older daughter during this period, and also just general practical support.

### **Did your daughter attend an inclusive school?**

The school was a specialised school with a focus on supported communication. We knew that our daughter would not be able to speak, so we thought that the most important thing for her would be to learn to communicate in different ways. The kind of support needed for this unfortunately was not available at any other school. From the age of 5 onwards, she learned a type of sign language – only when she turned 14, she understood that she could communicate that way. Very knowledgeable teachers made this possible.

### **What needs to be done so a school can be truly inclusive?**

It needs to take its educational mission seriously and provide learning opportunities for everyone. I would like to take Eva's flatmate as an example, who also has complex support needs. He attended a school where students with and without disabilities were learning together. Because of this, he still has a diverse group of friends. But he did not learn to communicate, even though I think this would have been even easier for him than it was for my

daughter. Inclusion must be done well, with the right support for every student.

### **Your daughter is an adult now. How has your life changed since?**

Eva moved out even earlier than her sister! She lives with two flatmates now and has assistants coming to the house once she is at home. In the absence of an offer for vocational training or from a "regular" sheltered workshop, Eva is working in a small workshop, with six other people with disabilities. We spend every second weekend and the holidays together, since we like spending time together. After Eva moved out, I got some time to relax. We as a couple also started doing sports since our children moved out.

### **How are you supporting your daughter in leading an independent life?**

I think that having personal assistants available is very important. In the case of Eva, we encourage them to make use of her ability to communicate in sign language, so she can make decisions herself. We are also trying to enable her to make new experiences. For example, she



takes music classes and goes on group trips during holidays where she gets to know new people with and without disabilities.

**What needs to change in politics and society so parents of children with intellectual disabilities are not excluded anymore? Which role does the European Union have?**

Parents need extensive support so they can organise their family life: It is not easy for all families to balance childcare and other care duties, work life and the individual needs of every family member. Children with disabilities need tailored and reliable support

e.g. in day-care, at school and during their leisure time.

New models of work, for example with time accounts instead of fixed working hours, as well as mobile working, can help. It would also be important to get additional support in everyday life and in the case of emergencies. Every European directive dealing with issues such as jobs and employment should consider the needs and situation of families with children with disabilities. Moreover, the EU should fund projects to improve and/or test support systems.

## People with complex support needs



# Manuel Lankmair on political participation and accessibility

Find explanations for the words in **blue and bold** at the end.



Manuel Lankmair works at Lebenshilfe Hartberg.

Lebenshilfe Hartberg is a part of our member Lebenshilfe Austria.

Manuel Lankmair has **complex support needs**.

We did an interview with Manuel.

## Manuel, what is your job at Lebenshilfe Austria?

**lebenshilfe**  
Österreich

I am working in advocacy with my colleagues.

Advocacy means to tell **politicians** what they should do better.

I have been **elected** by my colleagues to speak for them.

**As a self-advocate, you know a lot about accessibility.**

**What are the most important things you can do to make a meeting accessible for people with complex support needs?**

There are 4 things:



- Texts in **easy-to-read**
- Accessibility for wheelchair users, for example, ramps
- Images in Power Point presentations and not just text
- Texts should be sent around before the conference, so people can prepare

**Have you been to any conference that was a very good example for accessibility?**



There was a meeting of the self-advocates' council in Salzburg in Austria.

It was very accessible!

It happened in spring this year.

About 20 self-advocates  
meet four times a year  
to discuss their issues.

This was the first time  
I took part in this meeting.



### What needs to change so we can make events more accessible?

Organisers should speak with the people responsible for the venue.

There should be a checklist  
to make sure things are accessible.

For example, having ramps  
so wheelchair users  
can access the stage.

► This is a short version of the interview.

Read the full version here: <http://bit.ly/ManuelLankmair>



## Explanations

### Complex support needs

Complex support needs are when a person with disabilities needs help in different and complicated ways.

### Easy-to-read

Easy to read is information that is written in a simple way so that people with intellectual disabilities can understand.



Easy-to-read documents often have this logo, so it is easier to find them.

There are rules on how easy-to-read should be done.

You can read the European standards of easy-to-read information here:

[www.easy-to-read.eu](http://www.easy-to-read.eu)

### Election

Elections decide who should speak for us and make choices for us.

Elections happen in different areas.



For example, in your town or city  
when you can elect a new mayor.  
Or in your country  
when you can elect a new president.



## European Disability Strategy

The European Disability Strategy  
is an important text.

It says what the European Union  
has to do to make sure  
people with disabilities in Europe  
get the same rights as everyone else.

## European Union



The European Union (in short, EU)  
is a group of 28 countries.

We call these countries  
“member states”.

They have joined together  
to be stronger politically and economically.

The EU makes laws  
in different areas.

Some of these laws  
make things easier  
for people with disabilities.

## Intellectual disabilities

If you have an intellectual disability, it is more difficult for you to understand information and learn new skills than it is for other people.

People with intellectual disabilities often need support in learning or at work.

There are things that can make life easier for people with intellectual disabilities.

For example, information in easy-to-read language.

## Politician

Someone who helps run the country or part of the country.

Or someone who would like to do this.

Politicians, for example, are

- mayors
- ministers
- candidates in the elections

## Self-advocacy



Self-advocacy is when people with intellectual disabilities speak up for themselves.

These people are called self-advocates.

# SAVE THE DATE!

Europe in Action 2020:  
**Quality education for all**  
**Inclusive education – a lifetime approach**  
**27 - 29 May 2020, Vienna/Austria**



## What to expect?

### Education throughout the Life Span

- Parents – teachers – attitudes
- Diversity
- Individualization and capability approach
- Digitalization and lifelong competences

### Co-Creation, dialog including various perspectives & thinking out of the box with

- Students with and without disabilities
- Teachers and staff from schools & universities
- Family members

### Stakeholders involved

- Policy makers (politicians & administrators)
- Headmasters, teachers, trainers & supervisors
- Family members
- Students
- Communities

### Workshops

National Case studies and examples

- Political framework
- Educational concepts
- Structure & financing

### Walkshops

- Visiting schools, educational institutions & universities





**Ambitions. Rights. Belonging.**



**Website:** [inclusion-europe.eu](http://inclusion-europe.eu)



**Email:** [secretariat@inclusion-europe.org](mailto:secretariat@inclusion-europe.org)



**Telephone:** +32 25 02 28 15



**Address:** Avenue des Arts 3, 1210 Brussels, Belgium



**Facebook:** [facebook.com/inclusion europe](https://facebook.com/inclusion europe)



**Twitter:** [twitter.com/InclusionEurope](https://twitter.com/InclusionEurope)



Supported by the European Union