



Annual report 2019

Inclusion Europe

Ambitions. Rights.
Belonging.

European movement of people with
intellectual disabilities and their families.



Copyright © by Inclusion Europe
All rights reserved

Published by: Inclusion Europe

Coordinator: Josipa Friščić

Design: Josipa Friščić, Fanny Lamon

Writing and editing: Josipa Friščić, Fanny Lamon, Milan Šveřepa,
Angelika Hild, Giuseppe Martone

Contributors: Nina Vertot, Theresa Shearer, Mateja de Reya

Easy to read: Soufiane El Amrani



Inclusion Europe has been supported by the European Union. This publication reflects the views only of the author, the European Union cannot be held responsible for any use which may be made of the information contained therein.

Table of contents

A letter from the president	4-5
EPSA report	7-9
Topic of the year	10-11
Timeline	14-15
Highlights	16-31
Publications	32
2019 in numbers	33
Finances	34-35
About us	37-38
Our members	39-42
Easy to read dictionary	43-53

A letter from the president



Dear friends,

The public opinion about intellectual disabilities never ceases to astonish me. People with little or no experience of intellectual disability tend to see it as a pitiful condition, as something that does not seem to concern them much. "Away from my eyes, away from my mind" is thinking which also explains why people with intellectual disabilities have been institutionalized. The majority of people do not wish to be constantly reminded of the kind of minority which does not match with the idea of everything being fine.

Every parent expecting a child has probably heard, once or several times "No matter if it is a boy or a girl, as long as everything is fine!" I remember very well having heard it and how I grew to oppose it. This saying hit me especially after Markus was born, our second child and our first son with multiple and intellectual disabilities. **"As long as everything is fine!"** was the title of my first ever article on disabilities. I wrote it when Markus was three months old, 33 years ago. The article was published in a monthly Finnish magazine "Kaks plus" (Two plus), a magazine addressed to young families with babies.

It was the beginning of my public life. By writing the article I wanted to shout out to the world around me that everything actually can be fine even if the child has a disability, that there are more important things than just being fine. **A child was born, and that was important.** This child could not be sent back anywhere. Children like our Markus also have the right to their family, and the families with children of his kind, also had a right to exist.

Since this first article there have been many more articles published and also numerous tv-, radio-, and magazine interviews. There have been lectures in universities and vocational schools, and presentations in seminars, conferences and congresses. All of them about being a family with a disabled child. One thing somehow lead to another, and all these things just seemed to happen, without me ever planning any of it.

I found myself being “The father” speaking out loud of the situation of families with children with disabilities. I was once told that I have an ability to make my private into something public. With the stories based on my own experiences from my own family’s life I seemed to be able to give an easier to understand picture of the life of families with children with intellectual disabilities.

Ability or not, I still strongly believe, that there is a huge need for us to tell our stories. When people hear stories from someone’s real life, it truly makes a difference and it makes the difficult situation more real, more understandable. Stories of families are easier to relate with and these stories give the general public tools to deal with for them difficult issues. Giving a face to a life with intellectual disability makes it easier to understand to people with no experience of the subject.

In many European countries intellectual disability still is a stigma. Something hard to understand and to live with. Something people rather avoid than face with. Something that does not happen to me but to somebody else. Something strange and scary. Something to be put away from our eyes. Something to be institutionalized. This has to change and that is why we have an even bigger need to tell our stories. We must shout out to the world that a life with disabilities can be as full a life as any. We must make societies understand that people with intellectual disabilities have exactly the same rights as all others and their families have right to be just families. By telling our stories we make our private into something public.

Inclusion Europe is a perfect platform for our stories. Let’s use it. Let’s share our stories throughout our network and give Europe tools to understand intellectual disabilities.

Jyrki Pinomaa
President



A letter from the president



My name is Jyrki Pinomaa.
I am the president of **Inclusion Europe**.



Two of my children have **intellectual disabilities**:
Markus and Robin.

When Markus was three months old,
I wrote an article.

The article explained that
everything can be fine
even if a child has a disability.

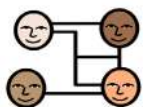
Today, I continue to speak out of
the situation of families with
children with disabilities.



Children with intellectual disabilities
have the right to their family.
And the families with children with disabilities
also have a right to exist.

I believe that
there is a need for us
to tell our stories.

In many European countries,
intellectual disability is
something hard to
understand and to live with.



Inclusion Europe is a
perfect platform for our stories.
Let's share our stories throughout our network.

Let's give Europe tools to understand intellectual
disabilities.

> Find explanations of the words marked in **bold** at the end of the report (pages 43-53)



EPSA report

What did we work on in 2019?



My name is László Bercse.

I live in Budapest, in Hungary.
I am the vice-president of Inclusion Europe.
I am also the chair of EPSA.

The European Platform of Self-Advocates (for short, EPSA) is made up of groups of self-advocates from different countries in Europe.

I want to tell you about what we worked on in 2019.



In February, Inclusion Europe held its directors meeting, in Budapest. It was a great honour to host this event.

The directors of Inclusion Europe's member organisations came to the meeting, from all around Europe.



We talked about the European Elections
We also talked about working together on the right to vote.

The European Elections

Thanks to Inclusion Europe and its members, many people with intellectual disabilities voted for the first time at the European Elections.

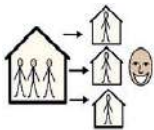
The right to vote got huge attention in the news and on social media.

> Find explanations of the words marked in **bold** at the end of the report (pages 43-53)

People could even watch our video about the right to vote in front of the European Parliament in Brussels, on the night of the elections.

Europe in Action conference in Vilnius

In June, we organised the Europe in Action conference. This year the conference was held in Vilnius, in Lithuania.



We talked about independent living and the right to be part of the community.

At the conference, I talked about the barriers to independent living in Hungary. I also talked about how self-advocates in Hungary work to break down these barriers.

General Assembly of EPSA



At EPSA General Assembly in Vilnius we elected a new chairperson because the mandate of Senada Halilčević came to an end.

I got elected as the new chair.
I was very happy to be elected.
We thank Senada for the good work she did.



At the General Assembly Oswald Föllerer got elected as the new member of the EPSA Steering Group. Welcome Oswald!

Hear Our Voices conference in Graz

In September we organised the Hear Our Voices conference in Graz.



At the conference 150 self-advocates from 18 countries came to talk about how to be active in politics.

We also talked about what happened at the European Elections:

- Were they accessible?
- How can we make elections more accessible?

At the conference I said:

“People who are not allowed to vote, cannot have a say in our common choices.”



EPSA Steering Group meetings

EPSA is short for European Platform of Self-Advocates

With EPSA Steering Group we worked on organising Hear Our Voices and Europe in Action.

We gave feedback to Inclusion Europe about accessibility at events.

I want to thank all my colleagues and other self-advocates for the work they did in 2019. I wish them to keep up the good work in 2020!

Best regards,
László Bercse

Topic of the year: the European elections

2019 was the second year of implementation of our five-year strategy. "Elect", the topic of the year, focused on the European elections 2019. Inclusion Europe campaigned for the right to vote and participate in the European elections.



The elections to the European Parliament happened in May 2019. As Members of the European Parliament make decisions that influence the lives of all European (EU) citizens, Inclusion Europe wanted to make sure the elections had good results for people with intellectual disabilities. That is why Inclusion Europe prepared a manifesto on how to make the most of the European elections. **The manifesto called on people with intellectual disabilities, their families and all European citizens to:**

- Talk to the candidates in elections to make them aware of their opinions.
- Tell their friends, families, and colleagues why the European elections are important and that they should participate in them too.
- Cast their vote in the European elections to keep and strengthen their rights in Europe.

#ThisTimeWeAreVoting event at the European Parliament

Every adult should be allowed to vote without discrimination. People with disabilities can only use this right if voting procedures become accessible. Recent developments in different EU countries are encouraging. These are the three key takeaways from **Inclusion Europe's #ThisTimeWeAreVoting event in the European Parliament**, where we kicked off our election manifesto.

As the votes in European Elections 2019 were being counted, we could see our video of self-advocates talking about voting being played in front of the European Parliament in Brussels.

"These were elections like never before"

Regardless of the political results, these 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.

All of this and much more came about because of the great work the European inclusion movement has put into the campaigning:

- Talking to the candidates, producing easy-to-read materials about elections, helping the elections authorities when it came to accessibility.
- Explaining what the European Parliament is doing.
- Translating and adapting Inclusion Europe's manifesto.

The European elections were a great moment because of you!





Topic of the year: the European elections



2019 was the second year of our new strategy. We talked a lot about the **European elections**.

The European elections took place in May 2019. In the European elections we vote for the **MEPs**.



The MEPs make decisions that influence the lives of all European citizens.

Inclusion Europe prepared a **manifesto** to defend the right to vote and to participate in the European elections.



The manifesto called on people with **intellectual disabilities** and their families to:

- Talk to the candidates
- Organise and work with others
- Go and **vote**

The manifesto also called on candidates and parties standing for European elections to:



- Engage with people with intellectual disabilities.
- Provide **accessible** information.
- Deals with issues that are important to people with intellectual disabilities.

#ThisTimeWeAreVoting event at the European Parliament



Inclusion Europe had an event at the **European Parliament**. The event was in February 2019. During this event, we spoke about

> Find explanations of the words marked in **bold** at the end of the report (pages 43-53)



the **European Elections** and accessibility for people with **intellectual disabilities**.

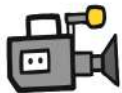
Everyone at the event agreed on 3 things:

1. Every person should be able to **vote**.
2. If we want people with intellectual disabilities to vote, we need to make it accessible for them.
3. The situation is getting better in many European countries.



Inclusion Europe did many interviews with **self-advocates**.

We asked them: "Why is voting important to you?". From these interviews, we created a video.



The video was played in the **European Parliament** in Brussels.

These **European elections** have been a great moment for the Inclusion movement.

Many people with **intellectual disabilities** voted in their country for the first time.

For the first time people under **guardianship** were able to **vote** in:

- Denmark
- France
- Germany
- Spain

This happened because a lot of people in the European inclusion movement worked hard to make our voices heard.

Timeline 2019

January

Launch of the “Elect” campaign that was all about the right to vote and to participate in the European elections.



March

Inclusion Europe contributed to several events and documents about the situation of deinstitutionalisation in the EU. These events were organised by the European Commission.



May

As the votes in European Elections 2019 were being counted on Sunday night, we could see our video of self-advocates talking about voting being played in front of the European Parliament in Brussels.



February

The directors of Inclusion Europe's member organisations met in Budapest, Hungary, to talk about the work they are doing in their respective countries and organisations, and how to cooperate for inclusion in Europe.



April

Joint seminar about social protection and the Social Pillar with EDF, EUD and EAPN, at the Annual Convention for Inclusive Growth organised by the European Commission.



June

Europe in Action conference in Vilnius gathered 239 participants from 40 countries. Speakers from 24 countries: self-advocates, family members + other activists and experts with a goal to provide new ideas on how to make inclusion happen everywhere.



July – August

Producing the easy-to-understand videos about the CRPD.

October

An exchange about online safety with MEPs and representatives of the European Economic and Social Committee (EESC) in Brussels, as part of the be.safe project.

December

Youth self-advocates and other representatives of the inclusion movement attended the European Day of Persons with Disabilities conference organised by the European Commission.



September

150 self-advocates from 18 countries, countless positive encounters and 7 main demands: this is the result of the Hear our Voices conference for self-advocates, which happened in Graz in September.

November

Seminar on political participation, held in the European Parliament. Self-advocates reflecting on their campaigning for the right to vote. The event was co-organised with several partner organisations.

Directors' meeting in Budapest

During the meeting the topics discussed were the European elections 2019, public procurement and “deinstitutionalisation”, employment and self-advocacy and Inclusion Europe’s work.



Public procurement and “deinstitutionalisation”

One issue that emerged during our discussions constitutes a major threat to the well-being of people with disabilities: the increased trend of basing public procurement of support services on costs as the main criteria. This often leads to the decline of service quality, or to the services disappearing altogether.

Another issue of concern is the “deinstitutionalisation” process in Hungary. There are 23,000 people living in institutions, according to ÉFOÉSZ. Hungary was granted a large sum of EU money dedicated to the process of deinstitutionalisation.



Employment and self-advocacy: interesting examples

Our Danish member LEV shared the success of a programme they developed which helped 3,000 people to find work on the open labour market over the last 8 years.

We learned about how self-advocates at ÉFOÉSZ were involved in the monitoring of the CRPD in Hungary. They prepared a country review and met with CRPD Committee members to talk about the situation in Hungary.



Directors' meeting in Budapest

In February 2019 the directors of all the member organisations of **Inclusion Europe** met in Budapest.



We talked about these topics:
European elections in May 2019.

We made a document which explains why the European elections are important.

We want people with **intellectual disabilities** to have the right to vote in every European country.



Care people for persons with intellectual disabilities

Care people are people who come to your house and help you do different things.

The **European Union** gives money to pay these people in the European countries.

We need to make sure that people who move out of institutions can live a good life.



Work for people with intellectual disabilities

Our Danish member LEV told us about a project they did in the last 8 years.

With this project they found work for many people with intellectual disabilities.

> Find explanations of the words marked in **bold** at the end of the report (pages 43-53)

“Europe in Action”: Hundreds meet to discuss independent living



“To go wherever I want to go and to do whatever I want to do, without anyone’s approval” – “To decide where I can live, who I want to live with, how I spend my free time” – “To be able to meet new people” ...

These are just some of the answers provided by self-advocates when being asked “What does independent living mean to you?” at **Europe in Action conference 2019 in Vilnius**. **“Everyone can live by the river”** was the motto of the conference, which means that everyone has the right to be independent and to decide about their own life.

The aim of this year’s Europe in Action conference, which was hosted by our member Viltis, was to **provide new ideas on how to make inclusion happen everywhere, for everyone**.

With Lithuanian Minister of Social Security and Labour Linas Kukuraitis as a patron, “Europe in Action” saw speakers from a range of backgrounds including keynote speaker Elisabeta Moldovan who fought her way out of an institution, UN CRPD committee member Jonas Ruškus and Marco Miglioni from the European Commission’s Disability and Inclusion unit.

Summarising the conference outcomes, Inclusion Europe’s Secretary-General José Smits concluded: **“The aim is no less than to change society. But we can do it little by little and start with the people we know. What is the next small step you want to take?”**



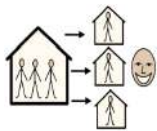
Europe in Action in Lithuania

The “Europe in Action” conference happened from 5-7 June.

For the conference, we went to Vilnius. Vilnius is the capital of Lithuania. The conference was about inclusion.

We talked about how we can make inclusion happen everywhere.

We also talked about **independent living**.



At the conference, we asked **self-advocates** what independent living means to them. This is what they said:

- “To go wherever I want and to do whatever I want, without anyone telling me what to do.”
- “To decide where I can live, who I want to live with, how I spend my free time.”
- “To be able to meet new people.”



They talked about different topics. For example:

- what the **UN CRPD** says about independent living
- how families can support people with **intellectual disabilities** to live independently
- what the situation is like in countries like Austria, Lithuania or Japan



At the end of the conference, José Smits from **Inclusion Europe** gave a summary: “What we must do is to change society. We cannot change everything now. But we can do some things now, and other things later. Can you think of one thing you would like to do right now?”

> Find explanations of the words marked in **bold** at the end of the report (pages 43-53)

“Hear our Voices” self-advocacy conference

150 self-advocates from 18 countries, countless positive encounters and 7 main demands: this is the result of the Hear our Voices self-advocacy conference which happened in Graz (Austria) in September.

Upon invitation of Lebenshilfe Graz and the mayor of the city of Graz, self-advocates had come to discuss the right to vote and to be elected, and more broadly about speaking up, under the motto **“My voice counts!”**.

Elisabeta Moldovan from Romania spoke about her experiences growing up in institutions, and how she now uses her voice to help move people to the community, and Manuel Lankmair presented his study on “Elections and Party Platforms – can we access and use them?”.

There was one new development which particularly drew participant’s attention – the fact that more and more self-advocates are presenting themselves as candidates for elections.

Xavier Orno from Spain was one of them: Alongside 12 other self-advocates, he ran for the Spanish municipal elections in May. At the conference, Xavier Orno talked about the knowledge he gained during his elections campaign, the support he received and the specific viewpoint people with disabilities can bring to party politics. He concluded: “I hope we can be an example for other self-advocates!”



Inclusion Europe’s vice-president and chair of EPSA, László Bercse stressed that self-advocates want to be involved in the decisions that concern them. **“We might need some support sometimes, but we are also able to help!”**



Former EPSA chair Senada Halilčević was very clear: **“When you exclude us from voting you are sending the message that we are not equal citizens!”**.

The conference conclusions reflected demands that self-advocates have been voicing for a long time, namely:

- voting rights for people under guardianship
- accessible information
- real jobs and fair pay
- self-determination and equal opportunities
- all institutions to be closed
- inclusion



Inclusion Europe will continue supporting self-advocates in their fight for this to come true everywhere in Europe. As another self-advocate said at the conference:

“If you dare to speak up, inclusion happens!”



“Hear our Voices” conference for self-advocates



From 18 to 20 September, 150 **self-advocates** coming from 18 countries met in Graz, Austria for the Hear our Voices conference.

The conference was organised by **Inclusion Europe** together with the organisation Lebenshilfe Austria, and upon invitation of the mayor of Graz.

The theme of the conference was “My voice counts!”.

Self-advocates talked about:

- the right to **vote**
- how to participate in **politics**.



One of the self-advocates who spoke at the conference was Elisabeta Moldovan from Romania. Elisabeta talked about her experience growing up in **institutions**.

At the conference there were some self-advocates who ran for elections themselves. One of them is Xavier Orno from Spain.



Xavier and some other self-advocates ran for the last local **elections** in Spain.

Xavier hopes that other self-advocates will follow his example and will run for elections in their countries.

Other self-advocates spoke at the conference: for example,

László Bercse, from Hungary.

> Find explanations of the words marked in **bold** at the end of the report (pages 43-53)



László is the Vice-President of Inclusion Europe and the **chair** of **EPSA**.

László said that it's important that people with **intellectual disabilities** can decide for themselves.



Senada Halilčević is the former chairman of EPSA.

Senada said:

"When people with intellectual disabilities are not allowed to vote, they don't feel part of society.



Self-advocates said which changes they want to see happening.

These are the same things they have said before:

- voting rights for people under **guardianship**
- **accessible** information
- **employment** for people with intellectual disabilities
- **deinstitutionalisation**
- inclusion

Final event of the “Be.Safe” project



The be.safe project, an initiative Inclusion Europe launched together with project partners from Czechia, North Macedonia, Poland and Portugal, aims to tackle this issue, by providing guidance on how to safely use the internet. The final event of the project took place in Brussels at the European Economic and Social Committee (EESC).

Self-advocates had been involved in different ways during the project, for example through training courses or in the development of materials. It was therefore also a self-advocate who gave his final assessment: Simon Lesur from Inclusion Europe's member "Papillons Blancs de Dunkerque" explained that he learned a lot when taking part in the project, and added that "the easy-to-read guide on how the police can help me when I became a victim of crime should be disseminated everywhere.

Director of Inclusion Europe, Milan Šveřepa pointed out how "hundreds of thousands of people with intellectual disabilities are still not allowed to access the internet, have their own e-mail addresses, use online platforms..." According to Inclusion Europe's director, **exclusion online is an "extension of the segregation they suffer in everyday life"**.

This assumption was backed by Ruth Shrimpling from Victim Support Europe, who presented the organisation's campaign **"Crime is crime. Even online."**: **"1 in 7 people become a victim of crime every year. But if we count crimes that are not reported, it is much, much more"** – and this of course also applies to the issue of cybercrime.



Crime happens online also



Be.Safe is a project which began in 2017 that teaches people with **intellectual disabilities** how to protect themselves against cybercrime.



Cybercrime is a crime that happens on the internet. For example, if someone tells you in an online chat that he will hurt you.

Inclusion Europe organised an event for the end of the Be.Safe project.

This event took place at the **European Economic and Social Committee**.

At the event, there was a video message by the **MEP** Elissavet Vozemberg.



Another speaker was Simon Lesur, a **self-advocate from** France.

Simon said that he learned a lot while taking part at the project.



The goal is to make the internet more safe for people with intellectual disabilities.

Advocacy training on women empowerment



“The UN CRPD states that countries must support women with disabilities. Women with intellectual disabilities need to get together and make their voices heard!” said Senada Halilčević at the Advocacy Training on women empowerment

Nearly 40 participants from 13 European countries had come to talk about the discrimination women with intellectual disabilities face, and how to tackle this issue.

One focus of the training was violence against women with intellectual disabilities, especially when it comes to women living in institutions. Inclusion Europe coordinated a project on this issue, with women in Croatia, Italy, Lithuania, Romania and the Netherlands being questioned about their experiences. At the training, participants learned about the many different types of violence that exist.

“It’s time for equality” was the message that the participants brought to the European Parliament when they met with the secretariat of the Committee on Women’s Rights and Gender Equality, as well as with members of the European Parliament.





Advocacy training: it's time for equality!



Inclusion Europe organised a training in Brussels between 4 and 6 December 2019.

The training was about the rights of women with **intellectual disabilities**.

Almost 40 people took part in the training. They came from different European countries.



We talked about **discrimination** of women with intellectual disabilities, especially women living in **institutions**.

We also talked about how they can fight for their rights.



During the last days of the training, participants met with some **MEPs**.

They talked with MEPs about the problems that women with intellectual disabilities have.



Our former vice-president Senada Halilčević said:

“Women with intellectual disabilities need to get together and make their voices heard!”

New tool to ensure EU funds invest in inclusion in the community

The European Expert group on the Transition from Institutional to Community-based Care (EEG) and Hope and homes for children have published a new tool to ensure EU funds are used for inclusion.

The “Checklist to ensure EU-funded measures contribute to independent living by developing and ensuring access to family-based and community-based services” aims to ensure many more EU citizens benefit from EU funding for inclusion and to prevent the misuse of EU funds.

The purpose of this checklist is to ensure EU funds in the 2021-2027 programming period contribute to independent living and inclusion in the community. More specifically, the checklist supports desk officers to check the consistency of the measures with the legal and policy frameworks in the fields of:

- **Transition** from institutional to family-based and community-based services for children, persons with disabilities, persons with mental health problems and elderly persons
- **Development** of quality family-based and community-based services
- **Prevention of separation** of children, including with disabilities, from their families
- **Prevention of segregation** and institutionalisation of children, persons with disabilities, persons with mental health problems, older people and homeless people, regardless of their residence status

Inclusion Europe is member of the EEG. Therefore, Milan Šveřepa said: “We encourage our members to use the checklist during this important period of negotiations between the EU and members states about the future EU budget. The checklist can help communicate what types of actions and services are needed to support the inclusion of people with intellectual disabilities. The checklist also highlights actions and types of services that contribute to segregation and should not receive funding.”



New tool to ensure EU funds invest in inclusion in the community



Inclusion Europe is a member of the EEG. The EEG is a group of people working on **institutions**.

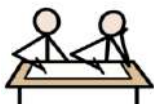
They want to make sure that people who live in institutions can move from institutions to the community.

For example, people with disabilities, children or homeless people who live in institutions.



Money of the **European Union** is sometimes used to create new institutions or to rebuild old institutions.

The EEG wants to stop this from happening. The EEG wants to make sure that the money of the European Union is used for community and family care.



For this reason, the EEG has worked together with “Hope and homes for children”. “Hope and homes for children” is an organisation that wants to close institutions for children.



The EEG and “Hope and homes for children” wrote a text.

This text tells people who work at the European Union how they can make sure that money of the European Union is used for community and family care.

Inclusion Europe's new board members



Several changes took place at Inclusion Europe's General Assembly and the General Meeting of the European Platform of Self-advocates:

At the conference, Senada Halilčević stepped down as EPSA chair – she had been in this position for ten years. Senada's successor is László Bercse from Hungary, who is now also one of Inclusion Europe's vice-presidents.

Oswald Föllerer from our Austrian member "Selbstvertretungszentrum für Menschen mit Lernschwierigkeiten" became a member of the EPSA steering group.

Bryndís Snæbjörnsdóttir from our Icelandic member Landssamtökin Proskahjálp was elected to the board.

Helene Holand from Norway finished her involvement in the board, serving maximum years possible.



Inclusion Europe's new board members

At the Europe in Action conference, we also had the General meeting of EPSA.



At the meeting, Senada Halilčević left **EPSA**.

Senada had been the chair of EPSA for many years.

The new **chair** of EPSA is László Bercse from Hungary.



Thank you Senada for your great work, and welcome to László!

László is now also the vice-president of **Inclusion Europe**.



Oswald Föllerer from Austria became a new member of the EPSA steering group.



There is also a new board member: Bryndís Snæbjörnsdóttir from Iceland.



Helene Holand from Norway left the board. You can only be a board member for 12 years. Helene Holand had been a board member for 12 years.

Publications



Inclusion Europe made a **video** that talks about the UN CRPD. The video is easy-to-understand.

UN CRPD is short for “United Nations Convention on the Rights of Persons with Disabilities”.



Empower 2018: the paper was looking at the way the right to make decision was crucial to ensure one’s self-determination.

Elect 2019: we look at the right to make decision and how it reflects in political life. Also in French, German, Hungarian and Polish



Checklist to ensure EU-funded measures contribute to independent living by developing and ensuring access to family-based and community-based services

2019 in numbers



8,650

Facebook friends
(+10,7% increase from last year)



17

speeches, presentations
and contributions to
conferences



9,575

Twitter followers
(+19,6% increase from last year)



9

videos
+ new YouTube channel



10

events organised



10

different countries



88

articles



15

media articles about
Inclusion europe



2

new members

Inclusion Europe's finances in 2019

The annual financial audit was conducted in accordance with the required standards and terms of reference by examining the financial statements, with a balance sheet of € 493,177.64. The auditor confirmed that the financial statements present correctly Inclusion Europe's net worth and the association's financial position.

The 2019 financial result of Inclusion Europe was a small operating loss of € -268.

The income of Inclusion Europe is again based on 3 pillars:

- **Membership fees:** 19% of our income. This corresponds with the budget and shows that our members are aware of the

necessity to support Inclusion Europe activities by their regular contributions.

- **Running costs grant** from the European Union: This income represents almost 39% of our revenue.
- **Project income:** This item represents 39% of our revenue.

We would like to thank the European Commission, the Open Society Foundation and our members for their financial support!

Finance Committee: Theresa Shearer, Mateja de Reya, Jyrki Pinomaa

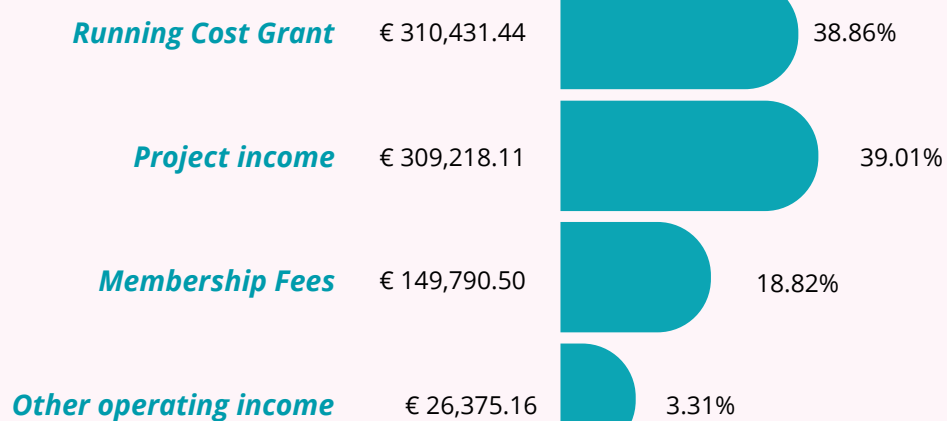
Our projects in 2019

Name of the project	Source of funding	Role of Inclusion Europe
Running costs grant	European Commission	Coordinator
ICLife (Inclusive Campus Life)	Erasmus+	Partner
Be.safe	Erasmus+	Partner
Life after violence Empowering women with intellectual disabilities	Open Society Foundations	Coordinator
My talents. For diversity.	Directorate-General for Justice	Coordinator
IE+	Erasmus+	Partner

Financial report

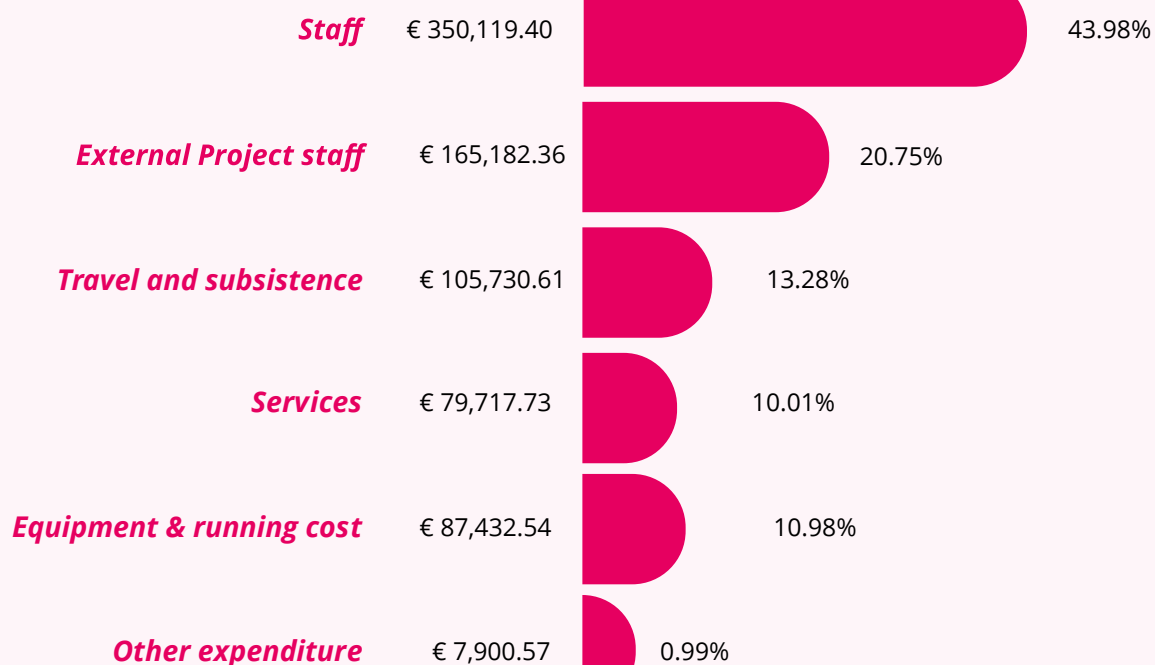
2019 - resume

Income



Total income € 795,815.21

Expenditure



Total expenditure € 796,083.21



Our income and expenses in 2019

Inclusion Europe managed its money well in 2019.

We received money from our members,
from the European Commission
and from the Open Society Foundation.

We spent money for different things:
For example, for the staff at Inclusion Europe;
Or for the conferences and events.

A professional came to check
how Inclusion Europe manages its money.
This professional is called “the auditor”.

The auditor said Inclusion Europe managed
money well in 2019.

> Find explanations of the words marked in **bold** at the end of the report (pages 43-53)

About us



Vision

We want a Europe where:

- people with intellectual disabilities enjoy equal rights and fully participate in all aspects of life
- family members of people with intellectual disabilities can be just that – family members
- the interests and concerns of people with intellectual disabilities and their families are considered in all policies affecting them

Mission

We fight for equal rights and full inclusion of people with intellectual disabilities and their families in all aspects of society.

Values

Respect
Solidarity
Inclusion

Strategy

In 2019 we talked a lot about Elections and the right to vote in the European elections.

We will have other topics in the next years:

2020: Educate – on inclusive education.

2021: Employ – on good jobs for everyone

2022: End segregation – on moving people out of institutions

Our team

The board

The board of Inclusion Europe is elected at the Annual General Assembly and is responsible for managing the affairs of Inclusion Europe.

As of the end of 2019



Jyrki Pinomaa
President
Finland



László Bercse
Vice-President
Hungary



Bryndís Snæbjörnsdóttir
Vice-president
Iceland



José Smits
Secretary-General
Netherlands



Gerhard Kowalski
Treasurer
France



Dana Migaliova
Lithuania



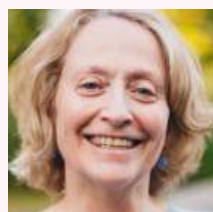
**Maria Antonia Fortuño
Cebamanos**
Spain



Mateja de Reya
Slovenia



Harry Roche
United Kingdom



Denise Roza
Russia



Theresa Shearer
Scotland



Andreas Zehetner
Austria

The Secretariat

Inclusion Europe's office
is in Brussels, Belgium

Contact:

Avenue des Arts 3,
1210 Brussels, Belgium
[secretariat@inclusion-
europe.org](mailto:secretariat@inclusion-europe.org)

Milan Šveřepa, Director

Helen Portal, Advocacy and policy officer

Josipa Friščić, Communication officer

Sandra Marques, Self-advocacy officer

Nina Vertot, Finance officer

Soufiane El Amrani, Easy-to-read and advocacy officer

Jacqueline Pareys, Office Assistant

Bárbara Marcondes, Policy Trainee

David Lysaght, Policy trainee

Fanny Lamon, Communication trainee

Our members

Inclusion Europe has 79 member organisations in 39 European countries. The European Platform of Self-Advocates has 18 members in 13 countries.



● Colored countries mark countries with an Inclusion Europe member.

List of members

Albania

Help The Life Association
www.helpthelife.org

Austria

Lebenshilfe Österreich
www.lebenshilfe.at

Lebenshilfe Wien
www.lebenshilfe.wien

Selbstvertretungszentrum
für Menschen mit
Lernschwierigkeiten
www.svz.wuk.at

Belarus

BelAPDiMI
www.belapdi.org

Belgium

Inclusion asbl
www.inclusion-asbl.be

Bosnia and Herzegovina

Association Sumero
www.sumero.ba

Bulgaria

BAPID – Bulgarian
Association for Persons
with Intellectual Disabilities
www.bapid.com

КАРИН ДОМ – Karin Dom
Foundation
www.karindom.org

National Association of
Resource Teachers –
Bulgaria
www.narubg.org

Croatia

Udruga za promicanje
inkluzije – Association for
Promoting Inclusion
www.inkluzija.hr

Udruga za samozastupanje
– Association for Self-
Advocacy
www.samozastupanje.hr

Hrvatski savez udruga
osoba s intelektualnim
teškoćama –
Croatian Association of
Societies of Persons with
Intellectual Disabilities
www.savezosit.hr

Cyprus

Pancyprian Parents
Association for People with
Mental Handicap

Czechia

SPMP (ČR): Společnost pro
podporu lidí s mentálním
postižením – Inclusion
Czech Republic
www.spmpr.cz

Sebeobhájci Praha

Rytmus
www.rytmus.org

Denmark

Landesforeningen LEV
www.lev.dk

Estonia

Vaimukad: Eesti
Vaimupuudega Inimeste
Tugiliit (EVPIT) –
Estonian Mentally
Disabled People Support
Organisation
www.vaimukad.ee

EVPIT Self-Advocacy Group

Faroe Island

Javni
www.javni.fo

Finland

Kehitysvammaisten
Tukiliitto r.y.
www.tukiliitto.fi

FDUV
www.fduv.fi

Steg för Steg
www.stegforsteg.fi

France

Association “Les Jeunes
Handicapés”
www.ajh.fr

Les Papillons Blancs de
Dunkerque
www.papillonsblancs-dunkerque.fr

Nous Aussi
www.nousaussi.org

UNAPEI
www.unapei.org

Germany

Bundesvereinigung
Lebenshilfe für Menschen
mit geistiger Behinderung
e.V.
www.lebenshilfe.de

Der Rat behinderter
Menschen der
Bundesvereinigung
Lebenshilfe

Lebenshilfe Schleswig-
Holstein
www.lebenshilfe-sh.de

Greece

POSGAMEA – Panhellenic
Federation of Parents and
Guardians of Disabled
People
www.posgamea.gr

Hungary

ÉFOÉSZ – Értelmi
Fogyatekosok Országos
Érdekvedelmi Szövetsége
www.efoesz.hu

ÉFOÉSZ Self-Advocacy
Group
www.efoesz.hu

Iceland

Landssamtökin
Þroskahjálpi
www.throskahjalp.is

Ireland

Inclusion Ireland
www.inclusionireland.ie

Israel

AKIM Israel
www.akim.org.il

Italy

Anffas Italy
www.anffas.net

Latvia

Rupju Berns
www.rupjuberns.lv

Martin RULLIS
Latvian Self-Advocacy
Movement

Lithuania

VILTIS – Lithuanian Welfare
Society for Persons with
Mental Disability
www.viltis.lt

Luxembourg

APEMH
www.apemh.lu

Ligue HMC
www.ligue-hmc.lu

Malta

INSPIRE – The Foundation
for Inclusion
www.inspire.org.mt

Malta Federation of
Organisations of Persons
with Disability (MFOPD)
www.mfopd.org

Movement in Favour
of Rights for Persons
with Disability – Down
Syndrome Association

National Parents' Society of
Persons with Disability
www.npspd.org

Netherlands

Inclusie Nederland
www.inclusienederland.nl

Vereniging LFB
www.lfb.nu

Ieder(in)
www.iederin.nl

North Macedonia

Republic Center for
Helping Persons with
Mental Handicap
www.poraka.org.mk

Centre for Helping Persons
with Mental Handicap
(Poraka Negotino)
www.porakanegotino.org.mk

Norway

NFU – Norsk Forbund for
Utviklingshemmede
www.nfunorge.org

NFU Self-Advocacy Group

Poland

PSONI: Polskie
Stowarzyszenie
na rzecz Osób z
Niepełnosprawnością
Intelektualną –
Polish Association for
Persons with Intellectual
Disability
www.psoni.org.pl

Portugal

FENACERCI
www.fenacerci.pt

Romania

Ceva de Spus
www.cevadespus.ro

Pentru Voi
www.pentruvoi.ro

Federatia Incluziune

Russia

Перспектива
Perspektiva
www.perspektiva-inva.ru

Scotland (UK)

ENABLE SCOTLAND
www.enable.org.uk

ENABLE ACE COMMITTEE
www.enable.org.uk

Serbia

SAPI – Serbian Association
for Promoting Inclusion
www.sapi.rs

Serbian association for
self-advocacy
www.sapi.rs

Slovakia

ZPMPVSR: Združenie
na pomoc ľuďom s
mentálnym postihnutím v
SR –
Association for help to the
Mentally Disabled Persons
in Slovakia
www.zpmpvsvr.sk

Slovenia

ZVEZA SOŽITJE – The
Slovenian Association for
Persons with Intellectual
Disabilities
www.zveza-sozitie.si

Center for training, work
and protection
Dolfka Boštjančič, Draga

Spain

Plena Inclusión
www.plenainclusion.org

Som Fundació Catalana
Tutelar
www.somfundacio.org

Plena inclusion
GADIR self-advocacy group
www.plenainclusion.org

Sweden

FUB
www.fub.se

Inre Ringen Sverige
www.fub.se/inre-ringen

Switzerland

INSIEME
www.insieme.ch

European organisations

ECCE – European
Cooperation in
Anthroposophical Curative
Education and Social
Therapy
www.ecce.eu

Down Syndrome Education
International
www.dseinternational.org

Special Olympics Europe
Euroasia
www.specialolympics.eu



Easy-to-read dictionary

Here you can find all the explanations of the words that are marked in **bold** in the report.



Abuse

Abuse is when someone treats you badly. This can be that the person shouts at you. This can also be that the person hurts you or is violent in another way.



Accessible

Something that is easy to use for people with disabilities.

Such as:

- Ramps to get into a building.
- Information in **easy-to-read**.
- Information in sign language.

Accessibility Act

The Accessibility Act is a law made by the **European Union**.

Every country in the European Union must respect the Accessibility Act.

The Accessibility Act says what companies need to do to make their products and services more **accessible**.

For example:

- smartphones,
- computers,
- e-books,
- ticketing machines
- travels by bus or train.



Easy-to-read

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

It is important to use simple words and sentences.

If there are words that are difficult to understand, an explanation is provided.

The text needs to be clear to see, for example, black writing on a white background is good.

It needs to be well-spaced.

Easy-to-read often uses pictures to explain what the text talks about.

Someone with an intellectual disability needs to check the information is easy to 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.



Elections

An election is when people can decide about who should speak for them and make choices for them.

Elections happen in different areas.

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

EPSA

See **European Platform of Self-Advocates**

European Commission



The European Commission works with the **European Parliament** and the EU member states.

The European Commission suggests laws for the European Parliament and the **Council of the European Union** to discuss.

It also makes sure that the laws that have been decided upon are being followed by the member states.

European Day of Persons with Disabilities

The European Day of Persons with Disabilities is a big event that takes place every year.

Many people with disabilities come to the event. They talk with **politicians** and other important people.

They talk about things such as **accessibility** and the rights of people with disabilities.



European elections

The European elections are the elections to the **European Parliament**.

When you **vote** at the European elections, you can have a say on who the new **MEPs** will be.

The MEPs speak for all the people who live in the **European Union**.

The European elections take place every 5 years. The last elections happened in 2019.



European Parliament

The European Parliament is a place where important decisions of the **European Union** are made.

For example: laws and budgets.

The Members of the European Parliament (in short, MEPs) make these decisions and represent all the people who live in the European Union.

Every five years, the people who live in the European Union vote for their country's MEPs.



European Platform of Self-Advocates

The European Platform of Self-Advocates (for short, EPSA) is made up of groups of **self-advocates** from different countries in Europe.

EPSA has spoken for self-advocacy organisations in Europe since the year 2000.

EPSA meets at least once every year.



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.

The EU makes laws on many important things for the people who live in these countries.

The EU makes laws in different areas. Some examples are:

- Laws to protect the environment.
- Laws for farmers.
- Laws to protect consumers.

A consumer is someone who buys things.

Guardianship

Guardianship allows some people to make life choices for others.

The person who makes choices for you is your guardian.

Your guardian can decide things for you, like where you live.

Sometimes, people under guardianship are not allowed to **vote**, get married, or take care of their kids.



Human rights

Human Rights are the rights that every person should have.

For example, the right to live.

Or the right to speak your mind.



Inclusion Europe

Inclusion Europe is an organisation for people with **intellectual disabilities** and their families.

We fight for their equal rights and inclusion in Europe.
We also want to make a difference to policies in Europe.

We started in 1988.

We have 74 members in 39 European countries.



Inclusive education

Inclusive education means that children with **intellectual disabilities** can learn together with other children without disabilities.



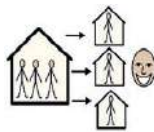
Inclusion International

Inclusion International is an organisation for people with **intellectual disabilities** and their families. It fights for their equal rights and inclusion in all aspects of life.

It started over 50 years ago.

It has 200 members in 115 countries all over the world.

Inclusion International is based in London in the UK.



Independent living

Independent living means that people with **intellectual disabilities** live in the community and have support to do what they want.

They also can:

- Choose with whom and where to live.
- Decide how they want to spend their time.
- Have the same experiences as all other people.



Institutions

Institutions are places where people with **intellectual disabilities** live with other people with intellectual disabilities.

They live apart from other people. This is what we call "separate".

Sometimes this happens against their will.

The people who live in institutions must follow the rules of the institution and cannot decide for themselves.

Intellectual disability

Intellectual disability means being less able than others to understand information and to use new skills.

This makes it more difficult to manage some parts of life.

Intellectual disability often starts before you are an adult.

It affects you for your whole life.

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

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

Legal capacity

Capacity is when you can make a decision or choice at one moment.

There are laws about how to decide if someone has capacity.

Then it is called legal capacity.

Legal capacity means that people with **intellectual disabilities** can do things on their own.

This is what they can do:

- Make choices about their lives.
- Get married, start a family and raise children.
- Sign contracts (also working contracts).
- Have a bank account.

- Control their money and property.
- Make decisions about their health.
- Take part in **politics** and have the right to **vote**.

Living independently

See **Independent living**



Manifesto

A manifesto is a text that explains the goals of a person or an organisation.

It is often made before an election by a person or organisation that wants to be elected.

Some manifestos are also done organisations to tell the candidates for the elections about what they think is important.

Everyone can read a manifesto.

Member of the European Parliament (MEP)

See **European Parliament**

OPEN SOCIETY
FOUNDATIONS

Open Society Foundations

The Open Society Foundations is an organisation.

They work to support **human rights** in different countries.

They support people with disabilities and others so they can make their voices heard.



Politician

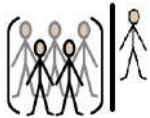
Someone helps run the country or part of the country. Or someone who would like to do this.

Politicians, for example, are

- mayors
- ministers
- candidates in the **elections**

Politics

Running the country, or part of the country.



Segregation

Segregation is when someone is set apart from others for an unfair reason.

For example, because of their disability.



Self-advocacy

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



Social media

Social media is websites and apps that let you create and share content.

For example, photos, videos and information.

Apps is short for applications.

These are tools that let you use social media on a mobile phone or tablet.



UN CRPD

The **United Nations** Convention on the Rights of Persons with Disabilities (in short, UN CRPD) is an important document.

It tries to make sure that the rights of people with disabilities are respected.

UN CRPD Committee

The **United Nations** Committee on the Rights of Persons with Disabilities (in short, the UN CRPD Committee) is a group of people that check what countries do to make sure the rights of persons with disabilities are respected.



United Nations

The United Nations is an international organisation.

They are at different places:
In New York, in the United States of America. And in Geneva, in Switzerland.

They work for peace and security everywhere in the world.



Vote

Voting means choosing the **politicians** who represent us and make decisions for us.



World Congress

The World Congress is organised by **Inclusion International** once every four years. It is a big event for **self-advocates**, their families and for people who work with people with **intellectual disabilities**.

Work-life balance directive

Work-life balance means having time to do things outside of work.

The **European Union** has done a law about it.

It is called the work-life balance directive. This law is very important.

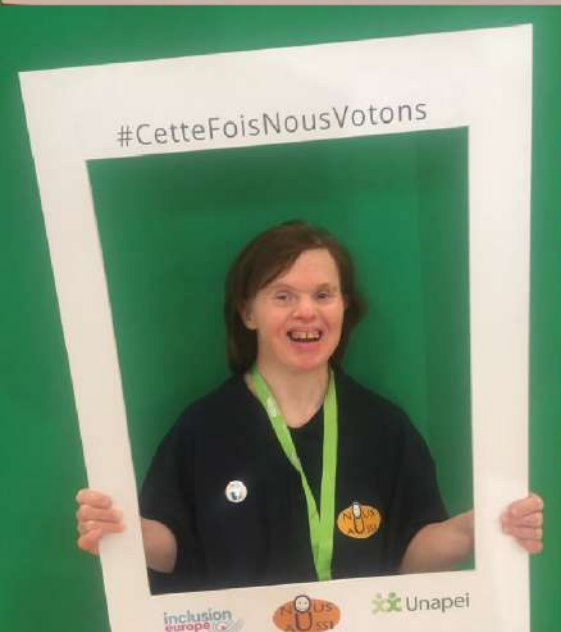
Family members of people with **intellectual disabilities** often find it difficult to find the time to support them.

With the new law,
they would be able to get more time off work
to support their family members.

The law is also important
for parents with intellectual disabilities.

They also need to have more time
for their children.

#ThisTimeWeAreVoting



Inclusion Europe
www.inclusion-europe.eu

Avenue des Arts 3
1210 Brussels
Belgium
T. +32 25 02 28 15
secretariat@inclusion-europe.org

Find us on
facebook.com/inclusion-europe
twitter.com/inclusion-europe
linkedin.com/inclusion-europe
youtube.com/inclusion-europe



This publication is funded by
the European Union.