

# Annual report 2018 Inclusion Europe

Ambitions. Rights. Belonging.

European movement of people with intellectual disabilities and their families



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# Jyrki Pinomaa explains how he became Inclusion Europe's president



My name is Jyrki Pinomaa.

I am the new president of Inclusion Europe.

I have four children.



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

I know that sometimes it can be hard for family members of people with intellectual disabilities.

You need to fight a lot to get the support you need.

My wife Marianne and I got in touch with other families with children with intellectual disabilities.

I started to work for people with disabilities and their families.



Many years later, I became president of Inclusion Finland and a board member of **Inclusion Europe**.



And now I am the new president!

I am very happy about that.

I am grateful to my wife and to my four children.

They have always supported me.



I am also grateful to Maureen Piggot.

Maureen Piggot was the president before me.

She did a lot of great work for people with intellectual disabilities and their families in Europe.

And I am grateful to our members. We are strong because of you.



We celebrated our 30th birthday in 2018.

And I think we have achieved a lot!

# "Celebrating Inclusion Europe's 30th anniversary has shown me how far we have come"



Dear friends,

My presidency of Inclusion Europe started at the General Assembly in Birmingham last June. I wish to thank you all for this great opportunity to be at your service and for the trust in me when you elected me as your president.

I also wish to express my deepest gratitude and respect to Maureen Piggott, my predecessor. There are no words big enough to describe the valuable work and the endless energy Maureen has given to our movement. She left me big shoes to step into, but also a well-paved road. Thank you, Maureen!

My road to this presidency started – without me then knowing it – in 1986 on November 1st at around 2am, when my wife Marianne gave birth to our second son Markus. A few months later Markus was diagnosed with physical and intellectual disabilities. Almost five years later, in August 1991, our three months old fourth child Robin was diagnosed with the same disabilities. We already had found peer families and become members of Inclusion Finland's local chapter in our municipality. We had become part of an international movement but back then there were much more important issues to deal with.

Luckily, no one could foresee the challenges we would face as a family with two children with multiple disabilities. In the very beginning we lived in a naive belief that all the help and support we would need would just flow in our direction. This, however, was not the case, not even in my home country Finland, which is well known for its Nordic welfare system.

On the contrary: You had to know the legislation and know what you were entitled to. Then ask for it by filling out numerous forms and attach to them medical certificates proving your case. Not only once, this was repeated yearly, as if our sons would suddenly grow out of their disabilities. So, we began our fight for the rights of our two sons with intellectual

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**Jyrki Pinomaa** President

disabilities. And at the same time for the rights of other children with intellectual disabilities and their families. When organising helps your family, you also help others.

After some twenty years on this road of protecting the rights of people with disabilities and their families in Finland, I found myself as president of Inclusion Finland and board member of Inclusion Europe. All this was possible because of the invaluable support from my wife Marianne and my children Rasmus, Markus, Martina and Robin.

I believe many people in our movement can relate to my story of fighting for the rights of people with intellectual disabilities and their families. There are as many stories to be told as there are people. All these stories connect us and encourage us to carry on.

At Inclusion Europe we work drawing upon the robust basis that is the UNCRPD. We work together with our members through projects, focus meetings, working groups, trainings, committees and conferences. People with intellectual disabilities and family members are always included in our work. We learn from each other and share good practices. All this makes us the strong movement that we are today.

Celebrating Inclusion Europe's 30th anniversary in 2018 with our members, friends and supporters has shown me how far we have come, how much we have achieved already.

We are strong because of you, our member organisations. Thank you!

Jyrki Pinomaa President

# Senada Halilčević: "Important things that happened in 2018"



My name is Senada Halilčević.

I am the vice-president of Inclusion Europe.

I am also the chair of EPSA.

EPSA is the European Platform of Self-Advocates.

I want to tell you about things that were important in 2018.

#### **World Congress of Inclusion International**



The **World Congress** was held in Birmingham in the United Kingdom.

The congress was organised by **Inclusion International** together with Inclusion Europe and Mencap.

Mencap is Inclusion Europe's member in the United Kingdom.

Many **self-advocates** from all around the world came to the congress.

They told the world that they have the same **human rights** as everyone else.



Self-advocates said that these things are important:

- the right to live independently and be included in the community
- the law should be treat people with disabilities the same as everyone else
- the right to inclusive education
- the right to live without violence

EPSA held its General Meeting at the World Congress.

We talked about the work we did and many other topics.



One topic was especially important: the right to **vote**.

Many people with **intellectual disabilities** in Europe cannot vote because they do not get **legal capacity**.

This is against our rights.

It must change.



At the World Congress, Inclusion Europe celebrated its 30th birthday.

Inclusion Europe has done a lot for people with intellectual disabilities and their families.

Happy 30th birthday!



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#### The work we did

There was a leadership training on the right to vote and the **European elections**.

The training was held in September in Brussels.

Many self-advocates took part.

The EPSA steering group met regularly.



We talked a lot about Hear our voices, a conference for self-advocates.

In 2019, it will be held in September in Graz, Austria.

The topic will be taking part in **politics** and the right to **vote**.



In 2018 Inclusion Europe worked on a project about violence against women.

The project will continue in 2019.

The results will be presented at the Hear our voices conference.



I participated at a conference in Vienna in Austria, organised by the Fundamental Rights Agency.

The Fundamental Rights Agency works to protect **human rights** in the **European Union**.



I presented the work of Inclusion Europe and **EPSA**.

I also explained what still needs to be done so we can fully take part in society.

#### What is important in 2019

In 2019, we will continue to fight for the rights of people with intellectual disabilities in Europe.



For me, two things are very important: the right to live independently and to be included in the community.

Also, the law should treat us the same as everyone else.

These rights are written in the **UN CRPD**.

Nearly all European countries have signed the UN CRPD.

So people with intellectual disabilities in Europe must get these rights!

Warm regards,

HALILCEVIC

Senada Halilčević

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# What Inclusion Europe did in 2018

Lots of things happened in 2018!

And we are happy about these things:



- Many self-advocates spoke at events.
   For example, they spoke at the European Parliament, the European Day of Persons with Disabilities and at the UN CRPD Committee.
- More and more organisations are using easy-to-read.
   For example, the European Commission.



• We are also using easy-to-read more.

Nearly all the texts on our website have easy-to-read versions.

We also use easy-to-read more for the meetings of our board.

We did some easy-to-understand videos.
 For example, about the **United Nations**.
 <u>Here</u> you can watch the video

> Find explanations of the words marked in **bold** at the end of the report (pages 43-55)

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We worked well with our members.
We organised meetings for our members.
For example, about accessibility and easy-to-read.
We also spoke at events organised by our members.
We got 4 new members last year: welcome!



 We wrote a lot of texts on different laws.
 We wrote these texts to make sure that people with **intellectual disabilities** and their families are being heard.

For example, we wrote about the **Work-Life Balance Directive**. And the European **Accessibility Act**.

We want to thank everyone who helped us with our work in 2018!

We are looking forward to 2019.

# Ambitions. Rights. Belonging.

2018 was a year of celebrating the ambitions and achievements of our movement, a year of progress in ensuring the rights of people with intellectual disabilities and their families are respected – a year that once again showed the value of belonging to a wide community of organisations and people.

#### Self-advocates speaking up

We were happy to see self-advocates voicing their opinions at a number of large events: They spoke at the European Parliament and the European Day of Persons with Disabilities and delivered statements to the UN Committee on the Rights of Persons with Disabilities (UN CRPD Committee) in Geneva – with the support of our Swiss member Insieme.

Thanks in part to our joint intervention with Inclusion International on Articles 4.3 and 33.3 on the "Participation of persons with disabilities in the implementation and monitoring of the Convention", these articles now reflect the views of people with intellectual disabilities and their families.

The increased presence of self-advocates and our advocacy efforts certainly played a role in convincing 50 MEPs to ask for the topic of guardianship to be discussed in the European Parliament.

#### Easy-to-read: extending usage

Easy-to-read is becoming more and more widespread, with the European Commission, as well as several EU-level disability organisations, increasingly using it. For our part, we produced easy-to-read versions of nearly all our articles, prepared explainers with easy-to-read versions on important EU initiatives, and started a series of easy-to-understand videos on subjects such as the <u>UN CRPD</u>.

In 2018, we began providing papers for our board meetings in easy-to-read, as well as improving the meeting structure to make them easier to follow.

#### Working with our members

Throughout the year, we had the opportunity to work with our members, and facilitate exchange between them:

Our annual roundtable on the UN CRPD implementation took place during the World Congress, with more than 100 participants and 12 speakers from 5 continents contributing.



At our study visit to Austria members could find out more about the country's recent reform of the law on legal capacity and learn about each other's initiatives in this area.

For the first time, we organised focus meetings for members on subjects such as accessibility and easyto-read; access to health care and the inclusion of people with complex support needs.

We contributed to numerous members' conferences on easy-to-read, accessibility, deinstitutionalisation etc. in for example Belarus, Czechia, France, Germany, Italy, Luxembourg, Portugal and Spain.

Four new members joined us last year, which had our membership grow to 74 organisations in 39 countries. Of course, we hope to see these numbers further increasing!

#### **Promoting progress**

In 2018, often in collaboration with other organisations, we wrote several reports and papers putting pressure on governments and institutions on crucial issues such as

- the inclusion of pupils with complex support needs (find out more)
- safeguards in measures relating to the exercise of legal capacity
- the optional protocol to the Council of Europe's Oviedo convention which, if adopted, would result in legitimising forced treatment and segregation of people with intellectual disabilities
- the proposed EU budget, to ensure funding continues to promote inclusion
- ending segregation of people with intellectual disabilities in institutions

We also promoted progress by advocating for the adoption of both the EU Accessibility Act and the Work-Life Balance Directive.

We thank everyone who supported our fight for the rights of people with intellectual disabilities and their families in 2018 – let's keep it up!

# Timeline 2018

#### January

"Discrimination is often underreported": Inclusion Europe sends a contribution on UN CRPD article 5 to the CRPD committee

#### April

EPSA members meet in Peniche, Portugal, to learn about violence against women with intellectual disabilities and to prepare for the Global Self-advocacy summit and other events

#### June

We celebrate the successful participation in Inclusion International's World Congress, including our anniversary event which gave members the opportunity to present their work



#### February

Inclusion Europe writes an analysis of the EU Council conclusions on Independent living: "Residential institutions can never be the 'preferred option' for anyone"

#### May

Inclusion Europe and the European Disability Forum lodge a collective complaint against France for breaching the rights of people with disabilities protected by the European Social Charter

#### July

Inclusion Europe and ENIL publish a <u>factsheet on</u> <u>independent</u> <u>living</u>

#### August

Self-advocates voice their opinions during the UN CRPD Committee hearing in Geneva

#### October

At the leadership training, self-advocates and family members meet to talk about voting rights and voting accessibility, as well as Inclusion Europe's election manifesto. They meet with policymakers and party representatives

#### December

Inclusion Europe publishes an infographic on "<u>How</u> to be empowered"

# and party representatives

#### September

Together with other organisations Inclusion Europe advocates for amendments to the proposed EU budget regulation to ensure funding for inclusion

#### November

The board approves <u>Inclusion</u> <u>Europe's manifesto</u> for the European elections 2019. The "Life after violence" report is launched at an event at the European Parliament

# Inclusion Europe has turned 30 years old!





In 2018, we celebrated our 30th birthday.

Our topic for the year was "Empowerment".

We did many things for our birthday.



For example, we interviewed many Inclusion Heroes who are fighting for inclusion.

Read the interviews

We also did two videos on how to participate in **politics** and on how we support **self-advocates**.

Watch the videos

We also explained how to get empowered with a text and some drawings.

Read it here

> Find explanations of the words marked in **bold** at the end of the report (pages 43-55)

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We did two special issues of the "Europe for Us" newsletter. One on our birthday and one on empowerment.

Read the newsletters

We also looked at the good things that have happened in the last 30 years.

For example, the first European meeting of self-advocates was held in 1997.



The **easy-to-read** logo was created in 2002.

The easy-to-read newsletter "Europe for Us" started in 2007.

It was great celebrating our birthday in 2018!

# Celebrating inclusion





#### 30 years!

This doesn't only mean being grown-up, it means having both feet firmly on the ground, with achievements to look back to. In 2018, we celebrated our anniversary all year round, with the theme "Empowerment": We organised a big party at the Inclusion International World Congress in Birmingham (see page 24-25), and published a range of communication material on the topic:

- Our "<u>Inclusion Heroes</u>" series featured people who brought the Inclusion movement forward in Europe – amongst them many selfadvocates
- <u>Two videos</u> explained how to participate in politics (available in English and French) and how Inclusion Europe supports self-advocacy
- An infographic was developed on how to get empowered
- Our easy-to-read newsletter "Europe for Us" ran two special issues on the anniversary and on empowerment

Read everything about our anniversary



In 2018, we also took the time to take a step back and look at the past:

# **Our highlights of** the last 30 years

#### 1988

Inclusion Europe is set up under the name ILSMH-EA, which is the acronym for "International League of Societies for the Mentally Handicapped – European Association". Tom Mutters becomes its president.





Then ...

#### 1991

Inclusion Europe adopts recom- Iain McMurray from Scotland is mendations for community-based elected as the new president. housing, committing all its members to work towards community-based living.

#### 1992

#### 1995

John O'Gorman from Ireland becomes president.



#### 1997

The first European Meeting of Self-Advocates is held in Durdent Court, UK.

#### 1998

Thérèse Kempeneers-Foulon from Belgium becomes president.

#### 2000

ILSMH-EA changes its name to Inclusion Europe.

The European Platform of Self-Advocates (EPSA) is created as part of Inclusion Europe's drive to be an inclusive organisation.

Gianina Gendelon is the first self-advocate ever to address the European Parliament in Strasbourg.

The newsletter "Include" is established.



Inclusion Europe

#### 2001

Françoise Jan from France is elected as the new president. Ulla Topi from Finland becomes EPSA chairperson.

Inclusion Europe publishes materials for making meetings and conferences accessible.

#### 2002

Following the publication of the first ever Easy-toread guidelines in 1998, Inclusion Europe creates the Easy-to-read Logo to make accessible materials easily recognisable for self-advocates.



# H

#### 2004

Foundation of the European Coalition for Community Living

#### 2006

Ingrid Körner from Germany replaces Françoise Jan as president. Andrew Doyle from Scotland becomes the new EPSA chairperson.

The UN General Assembly adopts the Convention on the Rights of Persons with Disabilities and its Optional Protocol. The Convention has a strong commitment to inclusive education and universal recognition of legal capacity as advocated for by Inclusion International and Inclusion Europe.

#### **2012** Senada Halilčević becomes EPSA chairperson.



#### 2014

Inclusion Europe campaigns to raise awareness of the fact that more than five million Europeans with intellectual disabilities are at risk of not being able to vote or stand for election in the European elections.

Inclusion Europe launches the Choices platform (www.right-to-decide.eu).

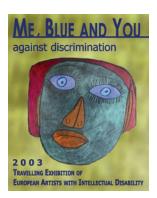
#### 2014 / 2015

Inclusion Europe receives the "Zero Project" awards for "promoting Europe-wide quality standards for accessible information for persons with intellectual disabilities" and for its guidelines for accessible elections.



#### 2003

Inclusion Europe's art exhibition "Me, Blue and You ... against discrimination" advocates for non-discrimination of people with disabilities and for building an inclusive Europe. The exhibition is on display in Greece, Slovenia, Germany, Sweden, Estonia, Finland, England, Scotland, France, Portugal, Spain, Belgium, the Netherlands and Ireland. It is shown in very prominent places, such as the Louvre in Paris, the Foreign Ministry in Germany and the national Parliament in Slovenia.



In the same year, the first conference organised by the European Platform of Self-Advocates is held, called "Empowerment. Together against Discrimination!". It is later to become "Hear our Voices".

#### 2007

EPSA starts its easy-to-read newsletter called "Europe for Us".

The International Conference on Deinstitutionalisation and Community living takes place in Prague, Czechia.

#### 2010

Ivo Vykydal from Czechia becomes the new president.

Inclusion Europe develops an easy-to-read version of the new European Union Disability Strategy 2010-2020, a key document for the European Union's work in the field of disability.

#### 2011

Maureen Piggot from the UK becomes Inclusion Europe's new president.

The Topside Project on developing peer support and training is launched. In the context of the project, a curriculum for teaching peer supporters and trainers is published.



#### 2015

"Europe in Action" conference in Rome on "Families and Self-Advocacy"

#### 2017

Board member Harry Roche speaks at the European Parliament for Persons with Disabilities, attended by 200 persons with intellectual disabilities.



**2018** Jyrki Pinomaa becomes Inclusion Europe's new president.



# **save the date Hear our voices!** 18-20 September Graz, Austria



EPSA organises a bi-annual conference for self-advocates called "Hear our Voices".

At this conference, people with an intellectual disability come together to talk about and share ideas and experiences about intellectual disability.

In 2019, Hear our voices will take place from 18-20 September in Graz, Austria.

Please put this date in your calender.

# We took part in the World Congress 2018





The **World Congress** of **Inclusion International** took place from 30 May to 1 June 2018.

It happened in Birmingham, in the United Kingdom.

The topic was "Learn, Inspire, Lead".

**Inclusion Europe** was a partner in the event.

Around 1,000 people came to the World Congress.

500 of them have an **intellectual disability**.



Inclusion Europe also had its 30th birthday party!

Our members from 30 countries shared their national foods and showed how they work for inclusion.

The **European Platform of Self-Advocates** met at the World Congress.

They talked about their activities in 2017.

Read more about that on page 7.

# Inclusion Europe at the World Congress

Anniversary celebration and several sessions organised with up to 1000 participants from all over the world

> A glittering anniversary celebration, insightful sessions and, as a result, extremely satisfied attendees: We were very happy about our participation at the World Congress of Inclusion International!



The congress, which took place from 30 May to 1 June, gathered up to 1000 people with an intellectual disability, their family members and professionals from 71 countries in Birmingham (United Kingdom).

The event which went under the slogan "Learn, Inspire, Lead" saw a full programme with workshops empowering people to campaign and share personal stories, completed by debates and talks by highprofile speakers. 500 self-advocates from all over the world took part in the "Global Self-Advocacy Summit".



One main result of the World Congress: The demands of people with intellectual disabilities and their families are very similar all over the world, namely

- being part of the community
- being valued equally, including the right to take one's own decisions and the right to vote
- having real jobs with fair pay
- getting an inclusive education
- · closing institutions and ending segregation

At the World Congress, participants had the opportunity to exchange good practices in the fight for these demands, and they were given a boost of motivation to continue their work in their home countries.





Inclusion Europe organised several sessions at the World Congress, and we also celebrated our 30th anniversary at the event with the fair "Flavours of European Inclusion". The fair was a big success, with many of our members contributing: At 30 stalls they presented their inclusion practices and achievements – and shared their national traditions and typical food of their home country with visitors! Visitors at the fair were invited to express their wishes for the next 30 years of the Inclusion movement. Some of them were picked and read out loud at the end of the event, including:

setting up a global fund to support self-advocatesmore people with a disability in government

The European Platform of Self-Advocates (EPSA) also met at the World Congress. At the General Meeting, the steering group presented the 2017 activity report. Afterwards, participants joined different workshops led by self-advocates on topics such as employment, inclusive education or sex and relationships.

Thank you to all the participants who joined us at the World Congress!

# Inclusion Europe has a new president



Jyrki Pinomaa is Inclusion Europe's new president.

He has replaced Maureen Piggot.

Jyrki is from Finland.

He has been working for many years for the rights of people with **intellectual disabilities**.

Jyrki has four children with his wife Marianne.



Two of their children have intellectual disabilities: Markus, who is 31, and Robin, who is 27.

Jyrki wants to make sure that Inclusion Europe works well together with other organisations.



He also wants to get the members of Inclusion Europe to use the **UN CRPD**.



There were a few more changes in the board of Inclusion Europe.

Hannes Traxler is no longer in charge of the money at Inclusion Europe.

Gerhard Kowalski is now in charge of this.

Theresa Shearer from Scotland and Dana Migaliova from Lithuania were **elected** to the board of Inclusion Europe.

We also agreed that Mateja de Reya from Slovenia will stay on our board.

## Inclusion Europe's new president takes over



New board members and treasurer elected

At the General Assembly in Birmingham, Jyrki Pinomaa from Finland took over the presidency from Maureen Piggot following a two-year transition period.

Jyrki Pinomaa has decades of experience in advocating for the rights of people with intellectual disabilities and their families: Until May 2018 he served as managing director of the Aspa Foundation, a service provider founded by the



main Finnish disabled people organisations, which provides inclusive housing and person-centred services for thousands of persons with disabilities in Finland.

Since 2010 Jyrki has been the president of Inclusion Finland KVTL, one of Inclusion Europe's member organisations, and has thus had a central and visible role in putting the rights of persons with intellectual disabilities onto the agenda of politicians and the general public in his home country.

Jyrki and his wife Marianne have four children, of which two have intellectual disabilities.

During his presidency, Jyrki Pinomaa wants to pay particular attention to maintaining Inclusion Europe's position as a well-known and trustworthy organisation both among its members and European institutions. He also wants to encourage all members to use the UNCRPD as the sharpest tool on our common journey towards a fully inclusive Europe.

Jyrki Pinomaa's presidency will last for four years.

Other changes to the composition of the board were:

- Hannes Traxler retired as a long-standing treasurer and board member – Gerhard Kowalski is his successor as treasurer.
- Theresa Shearer from Scotland and Dana Migaliova from Lithuania got elected to the board. (For Dana it is a return to the board, as she was a member some years ago.)

In addition, Mateja de Reya from Slovenia was confirmed as board member for a second term. Thank you to Hannes Traxler for his committed work for the organisation and welcome to the new and re-elected board members!

# Leadership training



Like every year, **Inclusion Europe** held a leadership training for **self-advocates** and family members.

Many self-advocates and family members came to the training.

They came from different places all over Europe.



The topic of the training was the right to **vote**.



We chose this topic because of the **elections** to the **European Parliament**.

The elections are in 2019.

In many European countries, people under **guardianship** do not have the right to vote.

This must change.

Participants met with **politicians** and with people who work at the **European Union**.

They told them that voting must be **accessible** to people with **intellectual disabilities**.

Many countries have given the right to vote to people under guardianship.

For example, Spain and France.

# Make the right to vote a reality for people with intellectual disabilities!

#### Leadership training deals with voting rights and voting accessibility ahead of the European elections

"A fellow self-advocate once told me: 'I don't feel equal to the others because I'm not allowed to vote!" Inclusion Europe's board member László Bercse got to the heart of the topic when speaking at the 2018 leadership training, dedicated to elections and the right to vote: Voting is a fundamental right, it is one of the most important ways of making one's voice count. Withdrawing this right from someone means not recognizing them as equal citizens.

Nearly 30 self-advocates, family members, supporters and professionals from 10 European countries attended the leadership training to prepare for the European elections and meet with representatives from the European institutions and political groups to share their views.

#### Accessibility of voting procedures: a challenge

During the 3-day training, participants had the opportunity to compare the situation in their home countries. In many European countries, people under guardianship do not have the right to vote. But even in countries where the vote has been opened up, accessibility of voting remains a challenge: Issues raised included the lack of easy-to-read information on voting procedures, candidates and party programmes. The absence of support staff on the day of the election was also mentioned.

Addressing these shortcomings is one of the demands of Inclusion Europe's election manifesto, which selfadvocates and family members analysed during the training. They also talked about topics such as "How can the European Parliament candidates include and involve us in their campaigns?" or "What can politicians do for people with intellectual disabilities in the European Parliament?". Participants learned about the functioning of the European Parliament, its political groups and committees. They could directly apply their knowledge and deliver their messages and demands when meeting representatives of the European institutions and political groups on the last day of the training.

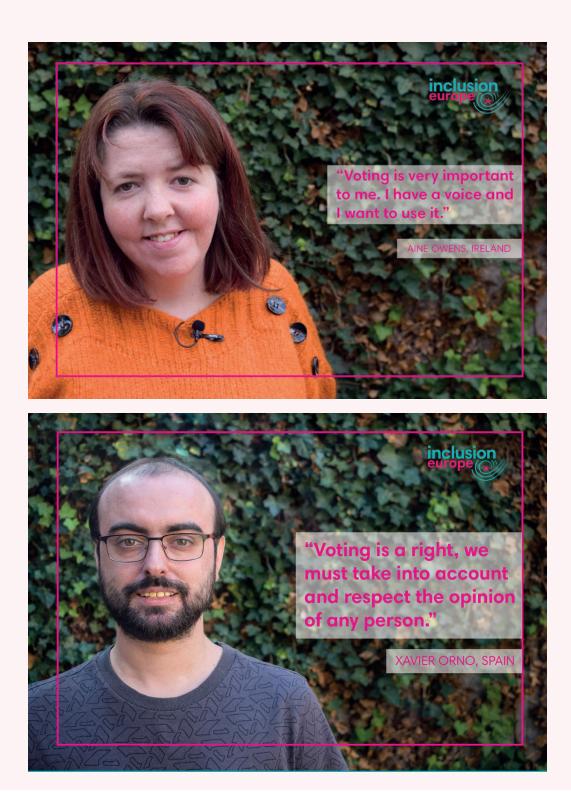
Self-advocates and family members made it clear to them how important it is that adaptations are made so people with intellectual disabilities can enjoy their civil rights and go vote.

They went back home even more determined than before to make the right to vote and actual access to voting a reality for people with intellectual disabilities in their home countries.

Several encouraging developments regarding the right to vote took place in 2018 in different European countries:

- 100.000 people under guardianship in Spain received the right to vote thanks to a campaign by our member Plena Inclusión and other organisations.
- In France, President Emmanuel Macron committed to scrapping a law that made voting rights for 360.000 people under guardianship subject to approval by a judge.
- In Denmark, the government announced to change a law that excluded people under a specific type of guardianship from the right to vote following advocacy work by our member LEV and others.





# What we did in communications in 2018

At Inclusion Europe, we want to tell everyone about the things that are important to people with **intellectual disabilities** and their families.



We write articles about these things, we publish videos and we post on **social media**.

This is called communications.

In 2018, we did many things to make our communications better.



For example:

- We did a new logo.
- We also did a new website.

Have a look at the website

• We also chose new words to describe what we do.

The new words are "Ambitions. Choices. Belonging.".



We also explained more words in **easy-to-read**.

Look up the words

We got new followers on Facebook and Twitter, and we are happy about that.

Like our Facebook page

Follow us on Twitter



We also did many interviews with people who we called "Inclusion Heroes".

hero

These are people who help bring inclusion forward.
 For example, self-advocates.

Read the interviews

# New logo, new visual identity, new website

A complete rebranding of our organisation took place in 2018:

- We introduced our new logo, which draws on the traditions of the movement and the previous version of the logo.
- Based upon the logo, a visual identity was developed and applied to all communication channels.
- Our website <u>www.inclusion-europe.eu</u> was redesigned, presenting an overview of all our news, activities and campaigns as well as access to the library of Inclusion Europe documents.
- We adopted a new slogan for Inclusion Europe -"Ambitions. Rights. Belonging.". The slogan aims to represent the strengths of the movement of people with intellectual disabilities and their families. Our values "Respect", "Solidarity" and "Inclusion" remain unchanged.



As for our publications:

• The design for the easy-to-read newsletter "Europe for Us" was adapted to the new visual identity. The newsletter is currently being published in English, French, German, Hungarian, Italian, Romanian and Spanish.

inclusion

• The general newsletter "Include" also underwent changes in response to our new visual identity (sign up for our newsletters).

We extended our dictionary in easy-to-read, which is now available in <u>English</u>, <u>French</u>, <u>German</u> and, with fewer words, <u>Spanish</u>.

Our social media efforts were rewarded with 8,000 followers both on <u>Facebook</u> and <u>Twitter</u>. This is a 14% increase from last year.

The "Inclusion Heroes" series, launched in the context of our anniversary (see pages 18-21), was an exceptional success, with interviews with self-advocates, family members, employers and others showing how far the inclusion movement has come in the last 30 years (read more).

Thank you to our members for providing us with their input for our communications, and to everyone who helps us spreading the word about inclusion!

# The project "Life after Violence"



Many women with **intellectual disabilities** are **abused**.



Many of these women are abused when they live in **institutions**.

**Inclusion Europe** did a project called "Life after Violence".

For this project, we talked to 10 women who were abused.

The 10 women have moved out of the institution.

They told us about their experiences.

They told us how they feel now.

We did this project between 2016 and 2018.

We did the project in the Netherlands.



We are now also asking women in other European countries about their experiences.

> Find explanations of the words marked in **bold** at the end of the report (pages 43-55)

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# "My biggest fear is that I will be put back in an institution"

*Life after Violence project shows how women with intellectual disabilities cope with violence they experienced in institutions* 



Silence, stigma, not being believed: This is what makes it so difficult to talk about violence against women. For women with intellectual disabilities, these barriers are even higher – especially if they are living in institutions, segregated from the rest of society, with no one who would listen.

The "Life after violence" report, a result of our project with the same name, breaks down these barriers: Women with intellectual disabilities who have lived many years in institutions recount their experience and how it influenced their lives.

One of its key findings: A big part of the violence women suffer from in institutions is structural and remains unseen. As self-advocate Mirjam Braspenning, who helped conduct the research, says: "Getting medicine against your wishes, not being allowed to speak up, not being allowed to make your own decisions: All of this is violence. And it adds up."

As opposed to physical violence, there is no help available, so people adapt in their own ways. According to self-advocate Dounia Bouchikhi:

"People avoid certain situations. They avoid new painful experiences. And they communicate in their own way. One person might get angry, someone else might sleep all day through. But in fact, they are telling you that something is bothering them: We need to listen and try to understand."

Even women who have moved out of an institution cannot easily forget their negative experiences. For Mirjam Braspenning, "my biggest fear is that I will be put back into an institution. If I feel good about something I also fear that this good feeling will be taken away from me."

The report, which was published at an event in the European Parliament in November 2018, also provides a number of recommendations starting with inclusive education from early age and most importantly putting an end to the institutionalisation and segregation of women with intellectual disabilities. Given that living in institutions is still a reality for hundreds of thousands of people with intellectual disabilities, these should have proactive strategies to combat all types of violence and undergo external evaluations by people with intellectual disabilities themselves.

The "Life after violence" project has been extended to include countries such as Romania, Croatia and Lithuania.

Read more about the project







# **Our strategy**



A strategy is a text where you write about what you want to do and how you want to do it.

2018 was the first year of our new strategy.



We talked a lot about empowerment.

You are empowered if you speak up for yourself and make your own decisions.

We will have other topics in the next years:

2019: Elect – on the elections to the European Parliament
2020: Educate – on inclusive education
2021: Employ – on good jobs for everyone
2022: End segregation – on moving people out of institutions

> Find explanations of the words marked in **bold** at the end of the report (pages 43-55)

# The "5 Es" – our strategy

2018 was the first year of implementation of our five-year strategy. "Empower", the topic of the year, celebrated the achievements of the Inclusion movement, and showed ways in which people with intellectual disabilities and their families can become active and make their voices heard (see page 18).



These will be the themes of the following years:

A	Elect	2019
	Educate	2020
*	Employ	2021
ЙХ.	<b>End segregation</b>	2022

2018

# Our income and expenses in 2018





Inclusion Europe managed its money well in 2018.

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

We also received money from projects.

We spent money for different things.

For example, for the staff at Inclusion Europe.

Or for our new website.

A professional came to check how Inclusion Europe manages its money.

She said that everything was fine.

> Find explanations of the words marked in **bold** at the end of the report (pages 43-55)

# Inclusion Europe's finances in 2018



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 EUR 562,707.82. The auditor confirmed that the financial statements are presenting correctly Inclusion Europe's net worth and the association's financial position. All expenses are monitored very carefully to avoid unnecessary and undue costs.

The 2018 financial result of Inclusion Europe was a small operating loss of EUR 9.986,46. This was caused by some unforeseen costs. These include costs responding to various needs and opportunities such as CRPD hearings and meetings with partners in Europe. There were also unbudgeted costs connected to the necessary improvement of IT services and the development of the new website.

Some project income planned for 2018 will only be realized in 2019, which also impacted the result for the year.

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

- Membership fees: 25% of our income. This corresponds with the budget and shows that our members are aware of the necessity to support Inclusion Europe's activities through their regular contributions.
- Running costs grant from the European Union: This income represents almost 50% of our revenue.
- Project income: This item represents 25% of our revenue.

Inclusion Europe wishes to thank the European Union and the Open Society Foundations for their funding of our activities.

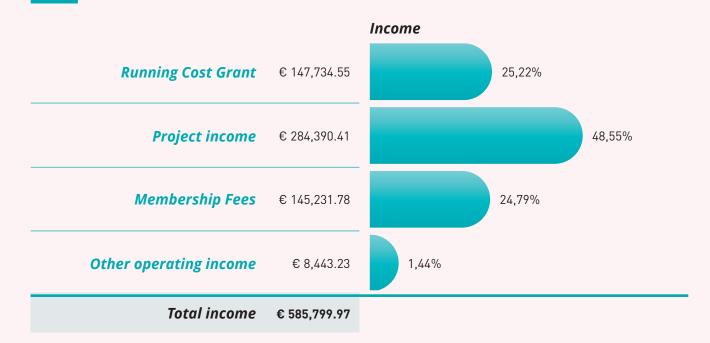
We also thank our members whose financial as well as policy contributions are a key element of our success.

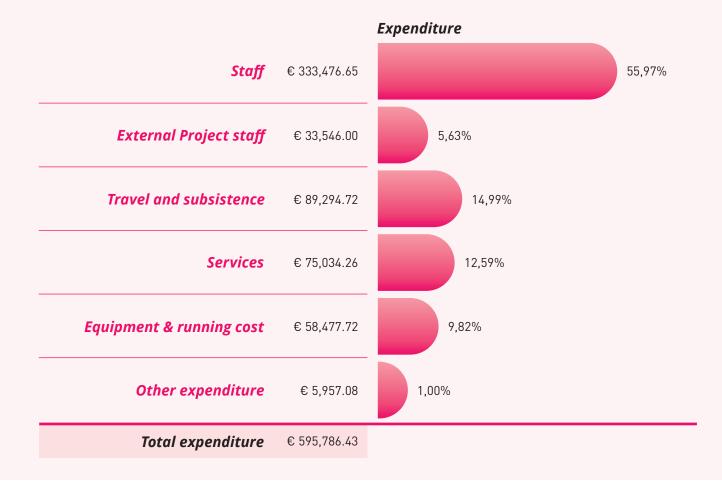
Gerhard Kowalski Treasurer

# Our projects in 2018

Name of the project	Source of funding	Role of Inclusion Europe
Life after violence	Open Society Foundations	Coordinator
ICLife (Inclusive Campus Life)	Erasmus+	Partner
Be.safe	Erasmus+	Partner
Implementation of the UN CRPD General Comment on Inclusive education	Open Society Foundations	Coordinator

# Financial report 2018 – resume





# 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



# **Council of the European Union**

The Council of the European Union is where the national ministers from the countries of the **European Union** meet.

They meet to adopt laws and talk about **politics** in the European Union.

The Council of the European Union is also called Council of Ministers.

## 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 if 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.

<u>Read</u> <u>about</u> <u>the</u> <u>European</u> <u>standards</u> <u>of</u> <u>easy-to-read</u> <u>information</u>



# **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.

Or in your country when you can elect a new president.

#### **EPSA**

See European Platform of Self-Advocates



# **European Commission**

The European Commission works with the **European Parliament**.

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 of the **European Union**.

# **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 elections happen every 5 years.



### **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 5 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 **politics** in Europe.

We started in 1988.

We have 74 members in 39 European countries.

We are based in Brussels in Belgium.



## **Inclusive education**

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



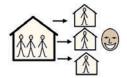
## **Inclusion International**

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 United Kingdom.



# **Independent living**

Independent living means that people with **intellectual disabilities** can choose with whom and where to live.

They also can:

- 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 job 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

# Member of the European Parliament (MEP)

See European Parliament

# OPEN SOCIETY 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 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**

# **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 who check how well countries respect the rights of persons with disabilities.



#### **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.

The law is called the work-life balance directive.

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

The law is good for family members of people with intellectual disabilities and parents with intellectual disabilities.

It helps them to have more time for their children and siblings.

# Our team



Jyrki Pinomaa President Finland



Senada Halilčević Vice-President Croatia



Gerhard Kowalski Vice-President France



José Smits Secretary-General Netherlands



The board

Maureen Piggot Past President United Kingdom



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

managing the affairs of Inclusion Europe.

László Bercse Hungary



Maria Antonia Fortuño Cebamanos Spain



Helene Holand



Dana Migaliova





Mateja de Reya Slovenia



Harry Roche United Kingdom



Denise Roza Russia





Shearer Scotland

#### **The Secretariat**

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**Contact Information:** Rue d'Arlon 55 1040 Brussels Belgium T. +3225022815 secretariat@inclusion-europe.org

#### Milan Šveřepa, Director

Angelika Hild, Communications and Engagement Officer Guillaume Jacquinot, Policy Officer Sandra Marques, Self-Advocacy Officer Nina Vertot, Finance Officer Justine Raymond, Junior Policy Officer Katherine Perry, EEG Coordinator Soufiane El Amrani, Easy-to-read Editor Jacqueline Pareys, Office Assistant Daniel Scheiff, Volunteer Federica Fantini, Communications Trainee Adrian Carroll, Policy Trainee





Inclusion Europe has 74 member organisations in 39 European countries, and the European Platform of Self-Advocates 18 members in 13 countries.

• Coloured countries mark countries with an Inclusion Europe member.

# Inclusion Europe has 74 members in 39 European countries.

#### 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

BelAPDIiMI 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

#### 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

#### **Czech Republic**

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

Sebeobhajci Praha

Rytmus www.rytmus.org

#### Denmark

Landesforeningen LEV www.lev.dk

#### Estonia

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

EVPIT Self-Advocacy Group

#### **Faroe Islands**

Javni <u>www.javni.fo</u>

#### Finland

Kehitysvammaisten Tukiliitto r.y. www.tukiliitto.fi

FDUV <u>www.fduv.fi</u>

Steg för Steg www.stegforsteg.fi

#### France

UNAPEI www.unapei.org

Nous Aussi

Les Papillons Blancs de Dunkerque <u>www.papillonsblancs-</u> <u>dunkerque.fr</u>

#### 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 <u>www.posgamea.gr</u>

**Hungary** ÉFOÉSZ – Értelmi Fogyatekosok Orszagos Érdekvedelmi Szvotsege www.efoesz.hu

ÉFOÉSZ Self-Advocacy Group www.efoesz.hu

**Iceland** Landssamtökin Þroskahjálp <u>www.throskahjalp.is</u>

**Ireland** Inclusion Ireland www.inclusionireland.ie **Israel** AKIM Israel <u>www.akim.org.il</u>

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

Luxemburg 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.inclusie.nl

Vereniging LFB <u>www.lfb.nu</u>

leder(in) <u>www.iederin.nl</u>

#### **North Macedonia**

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

Centre for Helping Persons with Mental Handicap (Poraka Negotino)

**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 <u>www.cevadespus.ro</u>

Pentru Voi <u>www.pentruvoi.ro</u>

Federatia Incluziune

#### Russia

Перспектива Perspektiva www.perspektiva-inva.ru

#### Scotland (UK) ENABLE SCOTLAND www.enable.org.uk

ENABLE ACE COMMITTEE <u>www.enable.org.uk</u>

#### Serbia

SAPI – Serbian Association for Promoting Inclusion

Serbian association for self-advocacy

#### Slovakia

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

#### Slovenia

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

Center for training, work and protection Dolfka Boštjančič, Draga

**Spain** Plena Inclusión www.plenainclusion.org

SOM fundació www.somfundacio.org

#### **Sweden** FUB

<u>www.fub.se</u>

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

Switzerland INSIEME www.insieme.ch

United Kingdom MENCAP www.mencap.org.uk

#### 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 Eurasia www.specialolympics.org



# **Inclusion Europe**

European movement of people with intellectual disabilities and their families

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