

Annual Report 2017

Inclusion Europe Respect, solidarity and inclusion for persons with intellectual disabilities and their families



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Maureen Piggot talks about her time as a president



My name is Maureen Piggot.

I am the president of Inclusion Europe.

I worked at Inclusion Europe for ten years.

We fought for many important things, for example:



- the right of everyone to have legal capacity.
- the right to inclusive education.
- the right of everyone to live independently.

Many **self-advocates** are now speaking up all over Europe.

The European Platform of Self-Advocates

did a lot to make this happen.

They helped our members to make sure

that **self-advocates** have a say

in their organisations.

They helped setting up self-advocacy groups in many countries.

It is great that so many self-advocates are speaking up now!



> Find explanations of the words marked in **bold** at the end of the report (pages 40-48)





I am a bit sad because I will soon retire as a president.

Jyrki Pinomaa will be the new president.

I think he will do a great job!

I want to thank you all for teaching me so many things when I was the president.



In 2018, we are celebrating
the 30th anniversary of Inclusion Europe.
I think we are well prepared for the next 30 years!

"Our messages are picked up, our inclusive practices adopted, our advocates heard"

Dear friends.

In June, at our Annual General Meeting in Birmingham, I pass 'the baton' of the presidency to Jyrki Pinomaa. I do it with a little sadness but with complete confidence that Inclusion Europe will surge forward under Jyrki's experienced and enthusiastic leadership.

It has been a privilege to have served Inclusion Europe for a whole decade. My terms as vice-president and then president have coincided with the first ten years of the UN Convention on the Rights of Persons with Disabilities. In 2018, at Inclusion International's World Congress, we will celebrate Inclusion Europe's 30th anniversary, inviting the world to join us.

In these years we have seen how we can use the framework of the Convention to move forward together and to influence how the rights laid down in this important document are interpreted and implemented.

The most striking example is Article 12 on legal capacity. Because we had had the debates within our membership, and continued to inform ourselves and develop our thinking, we were able to hold a strong position: denying anyone their right to a legal identity and to make decisions about their own life – with support when needed – is unacceptable.

In 2016, we again showed the value of our network and the importance of having a clear view of where we want to go. Working together at international, European and national level we were able to get others to go there with us. That led to a General Comment on education that affirmed that full inclusion is the only way to ensure all children get prepared for life as equal members of their communities.

In 2017 we repeated this success as we challenged the view that institutional care was ok. We helped to reinforce the key role families play in preparing their children for successful independent living as envisaged in Article 19.

The other critical change I witnessed during my time at Inclusion Europe has been the growing presence and voice of people with intellectual disability in



Maureen Piggot President

the places where decisions are made. The experienced and committed steering group of the European Platform of Self-Advocates (EPSA) has encouraged our member organisations to develop self-advocacy within or parallel to their existing structures. The turnout at the European Disability Parliament in December showed that powerfully in the strength of Inclusion Europe's delegation but also in the numbers of people with intellectual disability included in the delegations of national disability councils.

Our messages are picked up, our inclusive practices adopted, our advocates heard.

At our Directors' Meeting in Madrid recently, we recognised that we are in the business of transforming society. To do that we must continue to transform ourselves and our organisations to 'be the change.' Open minds, welcoming hearts, learning from each other and demonstrating how everyone benefits when we are inclusive will make the world a better place for all.

Getting to know and working with the extraordinarily committed, inspirational, generous and thoughtful people who make up our network has been a pleasure. I thank you for all I have learned and the many happy memories.

With a new energetic leadership willing to think and act boldly, a clear strategy and the continuing support of its members and friends, Inclusion Europe is ready for the next 30 years.

I look forward to that inclusive future,

Maureen Piggot President

Mourea Paged

Senada Halilčević: "Things that were important in 2017"





My name is Senada Halilčević.

I am the vice-president of Inclusion Europe.

I am also the **chair** of EPSA, the **European Platform of Self-Advocates**.

I want to tell you about things that were important to me that happened in 2017.

Europe in Action conference



I went to many events of Inclusion Europe in 2017.

For example, I went to the conference Europe in Action.

The conference was held in Prague.



At the conference self-advocates talked about an important topic: Love, life and friendship.

The conference was well organised and accessible.

I was surprised by what some parents said: They said that they have never talked about love and relationships with their children because they think it is not for them.

> Find explanations of the words marked in **bold** at the end of the report (pages 40-48)

I do not agree.

I think that everybody should hear about love and relationships!

EPSA meeting

EPSA also held its annual meeting in Prague.

We accepted a new member from Austria.

We also received one membership request from Serbia.

This means that EPSA is getting stronger.

I am glad about that!

EPSA and Inclusion Europe



I am also happy that Inclusion Europe worked on new rules for EPSA.

These rules are easier to understand and we can work with them better.

This way Inclusion Europe made the voices of persons with **intellectual disabilities** stronger.

Inclusion Europe also made a new strategy.

In the next 5 years Inclusion Europe will fight for the right of persons with **intellectual disabilities** to:



- live independently and be included in the community
- make decisions about their lives and
- have jobs that pay enough money

I think this is good because these things are important for people with intellectual disabilities.

And we need the right support to make these things happen.

The 4th European Disability Parliament

There was a big event in Brussels where many **self-advocates** participated.

It was called the 4th European Disability Parliament.



Many people with disabilities from all over Europe came to talk about their rights and needs.

My colleague and self-advocate Harry Roche from the United Kingdom spoke at the event.

He did a very good speech.

He said that that people with intellectual disabilities should participate in politics.



They should have the right to vote and the right to be **elected** in their countries.

Harry was interrupted before he had the time to finish his speech.



This made me very angry because some politicians and experts talked longer than they were allowed.

This must not happen again.

We all have equal rights.

But the participants at the event agreed with Harry's speech and I think this is a good sign!

I am looking forward to the work we will do with EPSA in the next years.

I am sure it will be exciting for everyone!

Warm regards,

HALILGEVIC

Senada Halilčević

What Inclusion Europe did in 2017



Inclusion Europe did a lot in 2017.



We wrote to the **UN CRPD Committee** about a **General Comment** they were preparing.

The General Comment deals with the right to live independently.

The UN CRPD Committee listened to us!

We are happy about that.

You can read more about it on page 31.

We also met many **Members of the European Parliament (MEPs)**.

We talked to them about different things.

Also about **guardianship**.

Some MEPs want to talk about this topic with all the other MEPs when the European Parliament meets.

We hope that they will be able to do that.

It is important that everyone in the **European Parliament** knows about topics like guardianship.

Because only then things can change.

> Find explanations of the words marked in **bold** at the end of the report (pages 40-48)

The European Disability Parliament happened in December 2017.

There were two great things:

Many people with **intellectual disabilities** participated.



Harry Roche spoke at the European Disability Parliament. Harry Roche is a board member of **Inclusion Europe.**

You can learn more about this on page 29.

We organised the Europe in Action conference and a leadership training for **self-advocates** and family members.

You can read about the Europe in Action conference on page 20.

You can read about the leadership training on page 25.



We also organised the Hear our Voices conference.

It was a great success.

You can read about the conference on page 23. We worked on many different projects together with our members. For example, on making things **accessible**.

We also worked hard on making your voices heard.



For example, on **social media** and our website.

You can read about what we did on page 33.

2017 was a great year and we are looking forward to 2018.

Influencing, collaborating, developing: what happened in 2017

A year in the life of Inclusion Europe means influencing key policies, collaborating with members and partners on a range of projects and events, as well as developing tools for inclusion.

2017 again demonstrated the value of European collaboration for people with intellectual disabilities and their families. You can read all about the main interventions and developments in dedicated articles in this Annual report.

What are the main things that happened?

Influencing

Together, we saw an intervention on the proposed CRPD Committee General Comment succeed and provide much better reflection of the views of people with intellectual disabilities and their family members.

We also met with several Members of the European Parliament (MEPs), providing them with information on matters such as legal capacity or violence against women with intellectual disabilities, and giving them a chance to get to know self-advocates who could tell them about their personal experiences. These meetings resulted in a closer collaboration with MEPs and in 50 of them drafting and tabling an intervention to discuss guardianship. If successful, this would be a historic first for such an issue to be discussed by the European Parliament.

In a truly historic moment for people with intellectual disabilities in Europe, there was a strong, visible and vocal presence of self-advocates at the European Disability Parliament in December. Out of 800 participants, some 200 were people with intellectual disabilities. Inclusion Europe's delegation was among the largest ones, and our board member Harry Roche (member of the EPSA Steering Group) provided the first expert speech of the day – talking about the right to vote. Another five people with intellectual disabilities spoke on that day.

Collaborating

Together, we created many successful events, meetings

and projects which support the exchange of ideas, and helped establish relationships and partnerships.

The Europe in Action conference (which in 2017 took place in Prague) did what it has been doing since 2001: it brought together close to 200 people from our movement and provided them with an opportunity to discuss an important subject and get to know each other. Having a national member – Inclusion Czech Republic in this case – hosting the conference is essential to the success of such an event.

The Hear our Voices self-advocacy conference in Brussels saw self-advocates focus on topics such as independent living, inclusive organisations or the right kind of support for them.

We also continued to work on projects on topics such as inclusive education, accessibility and violence against women, to name but a few examples. These projects provide us with an opportunity to develop detailed policies and tools for specific issues, and to reaffirm or establish our close relationships with members and partners such as universities.

Developing

Together, we were improving the way Inclusion Europe works and setting foundations for the years to come. A big step forward to achieve this was the writing of our new strategy (you can read more on page 16).

In 2017, we also dedicated a lot of attention to improving how we interact and communicate with our members and other partners. We are happy to see a growth in people who engage with us on social media and subscribers to our newsletters (see also page 34). And we are always listening to feedback and reactions to what we do! Keep them coming.

2017 has been a year where we helped advance inclusion in Europe in many different ways. We are looking forward to what 2018 will bring!

What we want to do in the next years



In 2017, we asked our members about what they think of our work.



Then we did a new strategy for **Inclusion Europe** for the next 5 years.

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

You can read our strategy online.

> Find explanations of the words marked in **bold** at the end of the report (pages 40-48)

Working towards inclusion: our new strategy

Taking into account feedback from our members provided in previous evaluations, in 2017 Inclusion Europe prepared a new strategy. Following consultations with our members and with EPSA, the 2018-2022 strategy was approved by the General Assembly in Prague:

What we stand for

Respect, solidarity and inclusion for people with intellectual disabilities and their families.

The world we want to see

- * People with intellectual disabilities enjoying the same rights as everyone else, everywhere, all the time.
 - * We fight for self-determination: For supported decision-making instead of guardianship; For giving people affected by quardianship laws their legal capacity back.
 - * We demand that people with intellectual disabilities can exercise their right to vote and stand for election.
 - * We fight for the right to live in the community. This means ending all forms of segregation, such as in education, at the workplace or in residential care institutions.
- * Family members of people with intellectual disabilities being just that family members.
 - * We advocate for support in the community for people with intellectual disabilities.
 - * We demand that the role of family members should be recognised and their needs met.
 - * We support family members to be active in the inclusion movement.
- People in the society engaging with and relating to people with intellectual disabilities.
 - * We support people with intellectual disabilities in expressing their views and telling their stories.
 - * We highlight inclusive behaviour.
 - * We develop and promote easy-to-read and other accessibility measures.

How we do things

- * We provide a platform for people with intellectual disabilities and family members to express their views and participate in decisions in Europe.
- * We contribute to the self-advocacy movement and help it grow.
- * We include people with intellectual disabilities in our work.
- * We influence organisations to become more inclusive.
- * We develop policies and tools to make inclusion become a reality.
- * We continue to develop easy-to-read and accessibility.
- * We raise awareness and fight prejudices and discrimination.
- * We enlarge and develop the inclusion movement in Europe.
- * We pay specific attention to children with intellectual disabilities, to women with intellectual disabilities and to people with complex support needs in all the work we do.

Based upon this new strategy, we prepared a framework plan of specific activities. This plan was essential in securing our core funding from the European Union for the years 2018-2021. It is focused on key issues that are important to us, and, in working on them, foresees many possibilities to engage with our members.

The "5 Es" representing our fight for respect, solidarity and inclusion will become key topics for the years to come:

	Empower	2018
	Elect	2019
	Educate	2020
*	Employ	2021
ite	End segregation	2022

Sustained focus to the year's "E" will be provided following a recurring pattern:

- * Organizing a fact-finding mission
- * Analysing the situation
- * Putting together task forces focussing on the different topics
- * Drawing up a policy brief
- * Launching a year-long campaign (including a video, infographics etc.)
- * Coordinating different events, for example: European Parliament launch event, Europe in Action conference etc.
- * Releasing an impact paper to summarise the link between the issue and the right to make decisions

We are confident that the new strategy and framework plan will help us in working towards inclusion during the next 5 years.

Timeline 2017

March

Inclusion Europe participates at a demonstration for an Accessibility Act that makes a difference

January

Self-advocates at EPSA establish their priorities for the next three years:

- * Supported decision-making / ending guardianship
- * Independent living and deinstitutionalisation
- * Inclusive education, training and development





The new strategy is approved by members



February

The "Able to Include" project finishes with an event in Brussels



May/June

More than 200 participants exchange ideas and experiences about "Love, life and friendship" at Europe in Action in Prague



July

Three submissions on articles 5 and 19 are presented to the UN CRPD Committee by Inclusion Europe

October

European Expert Group on the Transition from Institutional to Community-based Care (EEG) publishes recommendations on how to use the Social Pillar to move people out of institutions

XXXX

December

- * Self-advocates make their voices heard "Strong, loud and clear" at Hear our Voices in Brussels
- Harry Roche speaks at the European Disability Parliament which features a record number of selfadvocates



August

Inclusion Europe celebrates in Geneva the adoption of article 19 of the UN CRPD that strengthens the right to live independently. Meeting with Robert Martin, the first person with an intellectual disability to sit on a UN committee





September

- * Self-advocates and family members learn about violence against women at the leadership training and meet 9 MEPs.
- * Inclusion Europe gathers signatures for a strong Accessibility Act



November

Participants at a meeting organised by Inclusion Europe discuss how to support people with complex support needs to live in the community

Europe in Action 2017 – a big success





The Europe in Action conference in 2017 took place in Czechia.

It took place in June.



The conference was about love, life and friendship for people with **intellectual disabilities**.

We talked about different things.

- We talked about how friends can help you to get out of an institution and live independently.
- We also talked about how important it is to have legal capacity.
 For example, if you want to marry someone.
- We also talked about how families can help people with intellectual disabilities to find friends and relationships.

Participants really liked the Europe in Action conference.

> Find explanations of the words marked in **bold** at the end of the report (pages 40-48)

"Love and friendship are the most intense things in life"

Europe in Action 2017 gathers participants from all over Europe in Prague



More than 200 participants and over 50 speakers, and 3 days of workshops, presentations and intensive discussions: This was the outcome of Inclusion Europe's "Europe in Action" conference, which took place in Prague from 1-3 June 2017.

The topic was dear to the hearts of those who came: "Love, life and friendship" – and how we can make sure that people with intellectual disabilities can experience these things just like everyone else.

Apart from self-advocates, speakers also included representatives from the European Commission, Inclusion Europe, co-organiser Inclusion Czech Republic as well as family members, professionals and politicians.

"If it wasn't for my friends, I would be back in a residential institution by now!"

Deinstitutionalisation is a crucial step for an active social life. This fact was illustrated by speaker Juultje Holla, who helps people with intellectual disabilities who have left institutions to find friends and build up a social life. She took the example of her former client Jack: "In the institution, he only had a limited choice of leisure activities. Once

he was out, he could find out what he was really interested in – and develop relationships while pursuing his hobbies."

These relationships in turn are vital to stay out of institutions, as self-advocate and former Inclusion Europe board member Elisabeta Moldovan stressed: She said that "if it wasn't for my friends, I would be back in a residential institution by now!"

Another critical point was made by Inclusion Europe's vice-president and EPSA chair Senada Halilčević – she related a story that underlines



how the denial of legal capacity can lead to absurd situations: In Croatia, a judge had been confronted with the "task" to decide if a couple with intellectual disabilities had the "capacity to get married". He chose to ask them a question that no one can give a definitive answer to: "What is love?"

New "bridges and friendships"

Other speakers brought the family perspective into the discussion: Iva Šiková, for example, spoke about her daughter Zuzka, who has high support needs, and how she helps her find friends, while balancing her own social life with her job and working on the family farm.

The conference was also a safe space to discuss the worries parents and other family members might have, as well as difficult issues like neglect or abuse.

"Love and friendship are the most intense things in life." – This is what Inclusion Europe's President Maureen Piggot underlined – and therefore, they should be accessible to everyone.

Senada Halilčević, on the other hand, pointed out how the conference itself could be an opportunity to build "bridges and friendships". She proved to be right, because the conference certainly did result in new friendships and bridges between the participants from all over Europe.

Participants agreed that the topic was of utmost importance, and that a lot needs still to be done both on the legal side and in society so people with intellectual disabilities can have equal rights to find and maintain friendships and love relationships.



Hear our Voices!





Hear our Voices is a conference for **self-advocates**.

In 2017, it happened in Brussels in Belgium.

It happened in December.

There were more than 70 self-advocates and their supporters at the conference.

They had come from nearly 20 countries.

During the conference self-advocates said some important things.



One thing was that we need to fight to make sure everyone has the same rights everywhere.

Another thing was that politicians should live the lives of people with **intellectual disabilities** for a day to see what it is like.

Also that people with intellectual disabilities do not need help, they need support.



> Find explanations of the words marked in **bold** at the end of the report (pages 40-48)

"We need to fight for the same rights everywhere!"

Self-advocates meet in Brussels



"We don't need help, we need support!" – this was one of the conclusions made at Inclusion Europe's "Hear our Voices" conference, which took place in Brussels from 5-7 December 2017.

More than 70 self-advocates and their supporters from nearly 20 countries came to the event to discuss topics such as being a board member in an organisation, being included in the community, setting up a self-advocacy group or the right to vote.

All workshops were led by self-advocates, namely Elisabeta Moldovan from Ceva de Spus (Romania), László Bercse from ÉFOÉSZ (Hungary), Andreas Zehetner from Lebenshilfe (Austria), Senada Halilčević – Inclusion Europe's vice-president – from ASA (Croatia), and board member Harry Roche from Mencap (United Kingdom).

Attending the 4th European Disability Parliament

Hear our Voices participants also got the opportunity to attend the 4th European Disability Parliament: Self-advocates were impressed with the high-level event, which saw a record number of persons with intellectual disabilities participate (see also page 30).

At the end of the conference, self-advocate Sarah Pickard from Inclusion International led the discussion on the demands of self-advocates and on how to move forward.

"In some countries, people with intellectual disabilities can vote and in others, they can't. We need to fight for the same rights everywhere!" was one of the participants' messages. Another demand was that "politicians should live our lives for one day so they can better understand how it is", followed by the statement mentioned earlier: "We don't need help, we need support!"

The conclusion that Sara Pickard drew was widely welcomed by the participants: "We must make sure that our voices are being heard stronger, louder and clearer!"



Leadership training

Inclusion Europe held a leadership training for **self-advocates** and family members.

It was held in September.

It took place in Brussels in Belgium.

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

Participants came from different places all over Europe.



The topic of the training was how to help stop violence against women with **intellectual disabilities**.

We heard about a project called "Life after violence".



The project is about how women with intellectual disabilities deal with violence they experienced in **institutions**.

Participants also met **Members of the European Parliament** (MEPs).

They told the MEPs about their experiences with violence.

Participants liked the training a lot.

One participant said:

"I felt that my opinion was important."

> Find explanations of the words marked in **bold** at the end of the report (pages 40-48)

"I felt that my opinion matters"

Leadership training deals with topic of violence against women with intellectual disabilities

"This experience has been so important to me. I felt that my opinion matters, that people are interested in what I have to say."

Sara Pickard from Inclusion International expressed the feeling of many participants at the end of Inclusion Europe's leadership training, which took place from 26 to 28 September in Brussels.

Around 25 self-advocates and family members had come to the training, which focused on the issue of violence against women with intellectual disabilities and the question how to better advocate for effective solutions.

The training consisted of two intensive preparatory days and, as a highlight, meetings with nine Members of the European Parliament (MEPs).





"It was great to meet other self-advocates. We are not that different" "It was really cool to be at the European Parliament and talk with MEPs"

"Members of the European Parliament are just people like everybody else"

During the preparatory days, researcher Juultje Holla introduced Inclusion Europe's project "Life after violence", which examines how women who have experienced violence in institutions deal with it after leaving those institutions.

Juultje Holla uses hand-drawn images to facilitate the communication with the women she talks with, and she shared them with the participants of the leadership training.

Self-advocates and family members also learned "How to talk with MEPs" and "How to prepare information for them", but also "How the MEPs work and how they can help" and "How to make sure to deliver your message well."

Training participants were thus well-prepared when they set out to get to know MEPs from different parties, all of whom had shown an interest in the topic.

The impact they made was also shown through the reactions of MEPs – ranging from "deeply moving testimonies" to "the best moment of my day" to the affirmation that "women with disabilities must have the same human rights and fundamental freedoms as all women".

Self-advocates and family members received invitations to a multitude of events on violence against women and the rights of people with disabilities, alongside the encouragement to keep up their determination and good work.

As mentioned before, the experience made a big impression on self-advocates and family members. "We learned a lot, we could tell our stories and we were listened to", was the unanimous feedback. And, above all, "MEPs are just people like everybody else. You can talk to them and as our representatives, they need to lend us an ear."

"I did not know that other women also have had the same experiences as I did"

"I have learned a lot about the Istanbul convention"

"Super!
I have
learned
so many
things!"

"Some MEPs do not know a lot about women with disabilities. We can tell them about this issue"





Harry Roche speaks at European Disability Parliament



Harry Roche spoke at the 4th **European Disability Parliament**.

Harry Roche is a board member of **Inclusion Europe**.

The European Disability Parliament was in December.

At the Parliament there were 800 people.

There were 200 people with intellectual disabilities there.

This is a record number.



Harry spoke about voting rights for people with intellectual disabilities.

Harry said that when people with intellectual disabilities are not allowed to vote, this is **discrimination**.

Harry explained that the **European Union** can do lots of things to help stop this discrimination.

At the end of his speech Harry talked about some good examples of people with intellectual disabilities who participate in politics.

> Find explanations of the words marked in **bold** at the end of the report (pages 40-48)

What if all people had to do a test to vote?

European Disability Parliament: Harry Roche speaks about legal capacity

Around 800 delegates including several high-profile EU leaders and the record number of 200 persons with intellectual disabilities: This was the audience our board member Harry Roche addressed at the 4th European Disability Parliament on 6 December 2017. He spoke about a topic he has been passionately campaigning for – voting rights.

"Imagine everyone would need to take a test to see if they are 'fit to vote'. How many people would pass that test?", Harry Roche started off his speech, alluding to the case of a Spanish woman with intellectual disabilities who had been denied the right to vote.

Even though the Spanish law will be changed following pressure from the disability movement, "in 10 countries

H. ROCHE

of the EU laws on legal capacity still deny people with intellectual disability the vote" – and this is just one type of blatant discrimination people with intellectual disabilities face in Europe.

"The United Nations have expressed deep concern that persons with disabilities cannot exercise their right to vote", Harry Roche reminded the audience, and he listed several forms of this ongoing discrimination: for example laws on guardianship and the lack of easy-to-read information. Harry Roche also mentioned a number of things the European Union can do to address these issues. This includes

- * setting standards for EU elections
- developing and sharing expertise in reform of capacity laws
- * collecting information on participation of people with disabilities in elections

At the end of his speech, Harry Roche presented positive examples of political participation such as Sara Pickard, a woman from the United Kingdom who has Down Syndrome and is an active leader both in her community and on the international level, and Ángela Covadonga Bachiller, Spain's first city councillor with Down Syndrome. He concluded: "I am confident that this event means the European Parliament takes these issues seriously and will make sure people with intellectual disabilities can fully exercise their rights."

The event at the European Parliament saw a number of self-advocates taking the floor, including Oswald Föllerer from our member Selbstvertretungszentrum Wien (Austria) and Victorio Latasa from our member Plena Inclusión (Spain).

All Hear our Voices participants (see page 24) attended the European Disability Parliament.



The right to live how you want to live

Everyone has the right to live how they want to live.

Also people with intellectual disabilities.

This is called the right to live independently.



The United Nations made a text called the UN CRPD.

Part of the text talks about the right to live independently.

A **General Comment** was written to help explain what this right means for people with disabilities.

Inclusion Europe told the United Nations about what we think should be written in the General Comment.

And we are glad that they listened to us!

For example, the United Nations now say that **institutions** are not okay and people should not live in them.

They should live in the community instead.

We think that the General Comment shows that our work is important.

> Find explanations of the words marked in **bold** at the end of the report (pages 40-48)

The General Comment on article 19 of the UN CRPD: a big step forward towards independent living

Rights of persons with disabilities strengthened thanks to submissions by Inclusion Europe, Inclusion International and other organisations

Independent living is a right for everyone, including persons with intellectual disabilities, and the inclusion movement has fought hard for this right since its very beginnings. The General Comment on article 19 ("Living independently and being included in the community") of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) further defines what the article means. This is important when it comes to the concrete demands that people can make when referring to article 19. Inclusion Europe alongside Inclusion International and other organisations provided the Committee with submissions expressing our view on the General Comment - and we were glad when they paid off!



The final text of the General Comment, published in August 2017, strengthens the right to live independently and has taken up the main demands of civil society actors such as Inclusion Europe.

For example,

- * Institutions are no longer presented as a viable alternative to community-based care (the paragraph on this issue was completely removed)
- * A focus is put on the fact that also people with complex support needs have the right to live outside institutions
- * Supported decision making is recommended as an alternative to guardianship laws
- * States are called upon to give specific support for independent living to women, as they are often "more excluded and isolated"
- * The General Comment states that children have the right to grow up in their families

Inclusion Europe is very pleased about the final General Comment on article 19, which shows how important the work of civil society organisations is.



How we make your voices heard

At **Inclusion Europe**, we want to make everyone know about the work we do.

We also want to make everyone know about the things that are important to people with **intellectual disabilities** and their families.

So we want to make your voices heard!

We do this in many ways and we were very successful in 2017!

For example, we did a new design for our newsletters.

This includes our **easy-to-read** newsletter "Europe for Us"



The newsletter is published in English, French, German, Spanish, Hungarian and Romanian.

You can sign up here.

We also did a dictionary in easy-to-read.

We are always adding new words to the dictionary.

> Find explanations of the words marked in **bold** at the end of the report (pages 40-48)



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

You can like us on Facebook and follow us on Twitter.

We also did many <u>interviews</u> with self-advocates and family members.

We also did many interviews with **self-advocates** and family members.

We will add more interviews in 2018.

In 2018, we will celebrate our 30th anniversary.

Please search for #30yearsofInclusion on <u>Facebook</u> and <u>Twitter</u> to find out what we're up to!

Reaching more people through different channels

Inclusion Europe has been enhancing its communication activities throughout 2017.

We did a complete redesign of many of our publications, namely

- * the easy-to-read newsletter "<u>Europe for Us</u>" published in English, French, German, Spanish, Hungarian and Romanian (sign up <u>here</u>)
- * the general newsletter "Include" (sign up <u>here</u>)

In addition to launching a member's newsletter, we streamlined all our communication within one website: www.inclusion-europe.eu. We also started putting together a dictionary in easy-to-read, and are constantly adding terms to this dictionary.

Our social media efforts paid off with a followership of 7000 people on both <u>Facebook</u> and <u>Twitter</u>, which represents an increase from last year of 11% and 21%, respectively.

It is important for us to amplify the voices of self-advocates and family members from all over Europe. We therefore published a number of their <u>testimonies</u> on our website, and will continue doing so in 2018 within the context of our 30th anniversary.

Make sure to check #30yearsofInclusion on <u>Facebook</u> and <u>Twitter</u> to find out what we're up to!

We enjoy making your voices heard in 2018!



The Able to Include project

Many people use **social media** to do things online.

For example, they write a short note to a friend.

Or they share a picture.



It can be difficult for people with **intellectual disabilities** to use social media.

Social media is often not easy-to-use.

Inclusion Europe wants to change that.

Inclusion Europe took part in a project called Able to Include.

The project wanted to make it easier for people with intellectual disabilities to use social media.



The project created many tools that people with intellectual disabilities can use.

People with intellectual disabilities helped create these tools.

Many of them liked the tools.

You can find out more about the project on the <u>Able to Include website</u>.

> Find explanations of the words marked in **bold** at the end of the report (pages 40-48)

Making digital inclusion possible

Able to Include project launched several applications to help people with intellectual disabilities use social media

Writing a short note to a friend, sharing pictures, reading updates ... most of everyday communication nowadays happens through social media and messaging services. Using these tools is not always easy for people with intellectual disabilities. "Making digital inclusion possible" therefore was the goal of the <u>Able to Include project</u>, which Inclusion Europe participated in.

The project, which ended in March 2017, produced a number of outputs, namely:

- * a text-to-pictogram translator
- * a text simplifier
- * a text-to-speech programme
- * a social network app
- * a messaging app
- * an easy-to-use e-mail web client
- * an accessibility layer which is open-source and can be used by developers everywhere

All the tools developed aim to support people with intellectual disabilities in using social media and messaging services independently, to give them more confidence and make them less dependent on a support person.

People with intellectual disabilities were also involved in the development phase, and the feedback they gave shows that digital inclusion is indeed possible: One client of the Spanish project partner Prodis, for example, now writes e-mails every day thanks to the easy-to-use



e-mail client. The messaging app, on the other hand, enabled a client of the Belgian non-profit De Schakel to easily set up meetings with his friends, tell his family that he is at work – and to message his mother to let her know that his favourite football club had won 3-1!

As our information society becomes more and more digitalised, we should make sure to not leave people with intellectual disabilities behind. Able to Include is a good example of how to approach this challenge.





2017 in numbers



7000

Twitter followers (21% increase from last year)



7000

Facebook friends
(11% increase from last year)



93
articles published



events organised with more than

300 participants



3 projects with

15 other project partners



~ € 11400

project revenue generated for members that worked with us on projects

Our income and expenses in 2017



Inclusion Europe managed its money well in 2017.

We received money from our members and the **European Union**.

We also received money from projects.

We spent money to keep Inclusion Europe running.

For example for the staff at Inclusion Europe.

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

She said that everything was in order.

> Find explanations of the words marked in **bold** at the end of the report (pages 40-48)

Inclusion Europe's finances in 2017

In 2017 the financial result of Inclusion Europe was negative with a small operating loss of EUR 6.113,54, mainly caused by necessary write-offs due to unpaid membership fees. Possibly as a result of the effects of economic constraints a few members suffer financial difficulties.

On the other hand, despite many challenges our members are facing, we could rely on the constant payments of the majority of them. This provides a great deal of financial security to the association.

The second major pillar of income once again was the European Union running cost grant, representing almost 40% of income.

In 2017 also the co-financing of several projects, such as "Life after violence" and "Inclusive Campus Life", had

a strong impact on Inclusion Europe's overall financial stability.

I therefore want to express my appreciation to our members, the European Union and the Open Society Foundations for their trust in our efforts and their support.

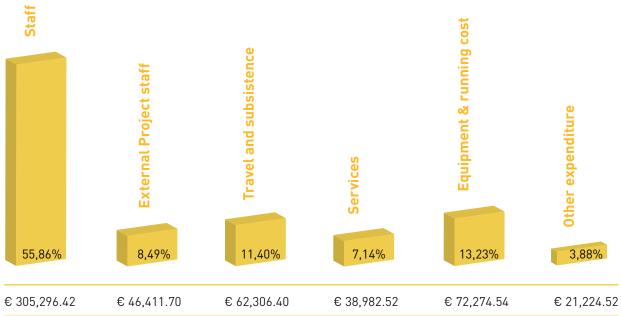
We carefully monitor all of Inclusion Europe's expenses. For the most part, our spending goes towards our staff, travel and the office.

The annual audit was conducted in accordance with the required standards and terms of reference by examining the financial statements, with a balance sheet of EUR 271.147. The auditor confirmed that the financial statements are presenting correctly Inclusion Europe's net worth and the association's financial position.

Financial report 2017 - resume



Expenditure



Total expenditure

€ 546,496.10

Easy-to-read dictionary



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

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.

Chair

The person in charge of a meeting or of an organisation.

Discrimination



Discrimination means that you are treated unfairly or that you do not get the chances you deserve.

It is discrimination when it happens because of your disability.

It can also happen to other people.

For example people who have a different skin colour. Or older people.

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

European Disability Parliament



The European Disability Parliament is a meeting of people with disabilities who live in Europe.

It takes place in Brussels in Belgium.

It has taken place 4 times so far.

Last time it happened in 2017.

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.

General Comment

A General Comment is when an organisation like the **United Nations** explains the different words and ideas that they use.

Guardianship

Guardianship allows some people to make life choices for others.

The person who makes choices for you is your quardian.

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.

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 71 members in 38 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.

Independent living

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

They also can:

- Live in the community.
- 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 "segregated".

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

Member of the European Parliament (MEP)

See European Parliament



Self-advocacy

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

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.

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.

Our team



Maureen PiggotPresident
United Kingdom

The Board

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



Gerhard KowalskiVice-President
France



Senada Halilčević Vice-President Croatia



José Smits Secretary-General Netherlands



Hannes Traxler Treasurer Austria



László BercseHungary



Maria Antonia Fortuño Cebamanos Spain



Helene Holand Norway



Thomas Jansson (coopted)
Sweden



Jyrki PinomaaFinland



Mateja de Reya Slovenia



Roche
United Kingdom

Harry



Denise Roza Russia

The Secretariat

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Soufiane El Amrani, Easy-to-read Editor
Jacqueline Pareys, Office Assistant
Daniel Scheiff, Volunteer
Harriet Brooker, Communications Trainee
Aisling Galvin, Policy Trainee

Our members

Inclusion Europe has 71 member organisations in 38 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 71 members in 38 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

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 Island

Javni www.javni.fo

Finland

Kehitysvammaisten Tukiliitto r.y. www.tukiliitto.fi

FDUV www.fduv.fi

Steg för Steg www.stegforsteg.fi

France

UNAPEI www.unapei.org

Nous Aussi www.nousaussi.org

Les Papillons Blancs de Dunkerque www.papillonsblancsdunkerque.fr

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 Orszagos Érdekvedelmi Szvotsege www.efoesz.hu

ÉFOÉSZ Self-Advocacy Group www.efoesz.hu

Iceland

Landssamtökin Þroskahjálp 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

Lithuania

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

Luxemburg

APEMH www.apemh.lu Ligue HMC www.ligue-hmc.lu

Former Yugoslav Republic of 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

Malta

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

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

Netherlands

Inclusie Nederland www.inclusie.nl

Vereniging LFB www.lfb.nu

leder(in)
www.iederin.nl

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

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

APPS – Federacio Catalana Pro Persones amb discapacitat intellectual www.dincat.cat

SOM fundació www.somfundacio.org

Sweden

FUB www.fub.se

Rikssektionen Klippan www.klippan.fub.se

Switzerland

INSIEME www.insieme.ch

United Kingdom

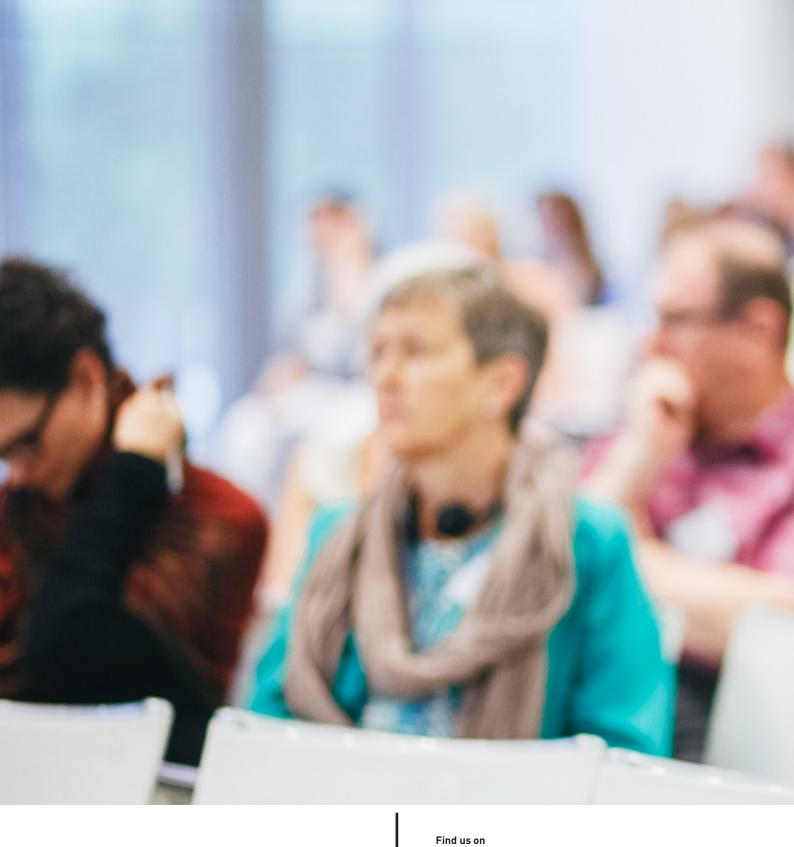
MENCAP www.mencap.org.uk

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 Euroasia www.specialolympics.eu



INCLUSION EUROPE

The European Association of Societies of Persons with Intellectual Disabilities and their Families

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facebook.com/inclusioneurope twitter.com/inclusioneurope

youtube.com/inclusioneurope

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www.inclusion-europe.eu