

Number 2 / 2020

# Europe for us

Impact of the Coronavirus on the lives of people with intellectual disabilities and their families





Find explanations for words in **bold** at the end of Europe For Us on pages 29 to 38.

"Europe for us" is available in:



- French
- German
- Hungarian
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- Spanish

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# Introduction



The main topic of this issue of Europe for Us is news and impact of the Coronavirus on the lives of people with intellectual disabilities and their families.

In this issue of Europe for Us, we also share guidelines on how to protect people with disabilities in the Coronavirus emergency, and we talk about the self-advocacy activities during the Coronavirus emergency.

#### We hope you like this issue of Europe for Us!

# Protect people with disabilities in the Coronavirus emergency

### Inform clearly

Inform clearly about what people should do to protect themselves and others. Deliver the information to people with **intellectual disabilities** and their families.



Easy to understand information is important. Especially when there are many news and information.



Tell people clearly what they need to do to protect themselves and others. Provide a phone number and email address where people can get more information.

Here are:



- Examples of <u>easy-to-read</u> about the Coronavirus
- More information on <u>easy-to-read is and how to produce it</u>.

Easy to understand is not only about written text. Video can also be produced in that way. We have <u>examples</u>.

### **Deliver the information**



<u>Reach out</u> to organisations of people with intellectual disabilities and ask them for help to get the information out.



We can also help spread the message:

- comms@inclusion-europe.org
- <u>Facebook</u>
- <u>Twitter</u>
- <u>LinkedIn</u>

Ensure the accessibility of apps, websites and phone-lines by providing support during the emergency.

### Help to deal with the emergency

Help to deal with the emergency, limited services and crisis plans.

Help to overcome social distancing measures.

Provide protective equipment to people with disabilities and to those who <u>support them</u>: Does your distribution reach families of children and adults with disabilities?



Many day-care centres are closed. This means families taking over and being exposed to many risks: loss of income, high levels of stress. Look for ways to support them.

Apply emergency social security measures to families caring for people with disabilities, including adults. Support people with disabilities and families in crisis planning and arrangements.

If you take part in voluntary activities such as grocery shopping for others, please consider people with disabilities and their families.

Learn from countries and organisations are <u>doing for people with disabilities</u>.

It's one thing juggling work, home-schooling and isolation for you or me. It's something else for parents who care for children with severe disabilities.

When it comes to education, the priority seems to be on the administration of exams, and we are yet to hear about schools for children with disabilities during this crisis.



Even if things go back to normal, it still means people with disabilities being segregated from their communities and from schools. Families will still have to provide most care and support, and to fight for progress and recognition.

We have seen the impact of the 2009 financial crisis: closed services, disability and social benefits lowered, unemployment and the toll on peoples' well being and lives.



Inclusion Europe invites the governments and The **European Union** to ensure financial support first for people with disabilities and their families.



# Reflection on the Coronavirus emergency



Inclusion Europe's director Milan Šveřepa wrote a reflection about the Coronavirus emergency. This is a summary of what Milan wrote:

Coronavirus changed many things.



But it highlights the ongoing segregation and for many people with intellectual disabilities the situation is even more challenging. Especially for those who live **segregated** in **institutions** and their families.



Large groups of people including staff are being completely left alone and locked-down in institutions for weeks, months even.

It's one thing juggling work, home-schooling and isolation for you or me.

It's something else for parents who care for children with severe disabilities.

When it comes to education, the priority seems to be on the administration of exams, and we are yet to hear about schools for children with disabilities during this crisis. Even if things go back to normal, it still means people with disabilities being segregated from their communities and from schools.



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Inclusion Europe invites the **governments** and the **European Union** to ensure financial support first for people with disabilities and their families.



## Helena Dalli's speech on the impact of COVID-19 on people with disabilities



Helena Dalli gave a speech on the impact of COVID-19 on people with disabilities. Helena Dalli is the **European Commissioner** for Equality.

Helena Dalli gave the speech to the Disability Intergroup in the **European Parliament**.

Helena Dalli said that people with disabilities and old people who live in **institutions** are having hard time because of COVID-19.

Dalli said that the **European Union** and countries in Europe need to respect the rights protected by the **United Nations Convention on the Rights of Persons with Disabilities**.

The safety and well beings of all the citizens is the most important thing for the **European Commission**.

The European Commission has already put in place many different solutions in the domain of health to help citizens and **Member States** during COVID-19.



The European Commission created guidance on how to use European materials to get financial support.

The European Commission is facilitating the possibility to get protective equipment in the European Union.

The European Commission created the "Solidarity for Health Initiative". This plan helps the healthcare systems of the Member States.



The European Commission made it easier to use the European Union funds during this crisis.

Helena Dalli talked about some aspects of the Covid-19 crisis:

• Confinement measures are very difficult for persons with disabilities and their families.



- Online schooling is difficult or not **accessible** for all children and students.
- Parents have to take care of their children because there is no support.



- Measures should be taken to stop discrimination against people with disabilities.
- Remote education must be accessible.

- Information about Covid-19 also needs to be accessible.
- People with disabilities who are living in the community must not be institutionalised because of the Covid-19 crisis.



• People with disabilities in institutions are being isolated.

Helena Dalli said no-one should be left behind, without support or essential services.

## Briefing: impact of the Coronavirus shutdown of schools



**Inclusion Europe** is publishing a briefing on the lack of education for children with **intellectual disabilities** in the Coronavirus emergency.



Coronavirus changes many things. But it highlights the ongoing **segregation** and **discrimination** of people with intellectual disabilities.

In the Coronavirus emergency, schools are closed.



The shutdown of schools is a major problem for students with intellectual disabilities, their families and their teachers.

Most students with intellectual disabilities are not able to continue their learning during the Coronavirus lockdown.

Schools and **governments** must ensure that discrimination and exclusion of students with intellectual disabilities do not become normal.



Schools and governments need to ensure that students with intellectual disabilities are not disadvantaged from other students.

This briefing reminds governments to provide education to students with disabilities during the Coronavirus emergency.

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Here is what the brief contains:

- Situation analysis that show how students with intellectual disabilities are being further excluded from education by the Coronavirus measures.
- Potential solutions and suggestions that could improve the lives of students with intellectual disabilities and their families.
- Issues and error to watch out for and mistakes to avoid when schools start again.
- Resources on **inclusive education** in times of Coronavirus.



 A survey for completion by parents, teachers and children with intellectual disabilities.

## Petition to defend the rights of people with intellectual disabilities in times of COVID-19 emergency



**Inclusion Europe** submitted a petition to protect the rights of people with **intellectual disabilities** and their families during and after the Coronavirus emergency.

The Coronavirus emergency puts the rights of people with disabilities at risk.



Several national laws and practices did not respect European legislation and the **UN CRPD**.

Some rules denied people with disabilities healthcare.

People with intellectual disabilities could no longer access the support and care they need.



Most of children with intellectual disabilities are not able to continue their learning because schools cannot communicate with them.

Families are left on their own.



People in care homes or **institutions** were being locked down.

They could not see their families and friends.

A lot of people with disabilities have been infected and died from the virus in institutions.

The petition calls for:

- Post-Corona financial measures that reach out to people with intellectual disabilities.
- Post-Corona health measures that protect people with intellectual disabilities.

On 19 May 2020,

the Committee on Petitions of the **European Parliament** heard the petition.

The Committee on Petitions is a group of people.

This group of people examines petitions submitted by citizens of the **European Union**.



The petition was well received by all **MEP**s.

7 out of 8 MEPs declared their support to keep the petition open.



Ádám Kósa is a MEP.

He agrees with the petition.

He said that:

"it is important that people with intellectual disabilities are treated with respect".



Monica Semedo is also a MEP.

She said that:

"safety and access to healthcare should be guaranteed to everyone".

# Self-advocacy activities during the Coronavirus emergency

On Friday 22 May 2020, Inclusion Europe held an online meeting about self-advocacy activities during the Coronavirus emergency.



László Bercse was one of the speakers.

He is **Chair** of the **European Platform of Self-Advocates** and Vice-President of Inclusion Europe. Here is his statement. (here is a summary of what he said)

## How are self-advocacy and self-advocate organisations advocating in these times?

The COVID-19 changed the way we work and live.

We had to adapt ourselves to this new reality. Most of our organisations and support networks are closed and not available as before.

Our families are also dealing with changes in the way they live.

In some cases, we are now all staying together 24 hours. This can be stressful for us and for our families.



Some of us are "locked down" inside the institutions or living facilities, without any visits. This is tough for us and for our families.

We are not able to see our friends or family. We cannot go to work as usual.

Attending online meetings can be a challenge if our supporters are not with us. This is especially true for European network, because of the translations.



We are struggling with getting the care and support that we used to have and need.

### How did we respond to this?

The most important thing for us is to be connected. We need to feel that we are not alone.

In some cases, our organisations were able to distribute smartphones.

So, we can attend the online meetings and chat with our friends, family, and supporters.



We are organizing online meetings or chats. This is helping us to deal with our feelings of anxiety and fear. Some of us are also doing online teaching for self-advocates.

But for some of us it's more difficult to get this type of support. We may not know how to do it or we may not have computers, mobile phones or internet access.



This is creating differences among us.

#### What are the main problems we see?

Self-advocates and their organisations may have big problems in connecting with each other. It's important to be able to share our experiences and how are we dealing with the situation.



We see big problems on the way persons with intellectual disabilities are accessing education now. Distance learning and online classes are not accessible to all of us. We do not see any measures in place to make sure we are not left behind.

We are worried about the effect of the COVID-19 on employment of persons with intellectual disabilities. We know that we are the first ones to be pushed outside the labor market when a financial and social crisis happens.



Violence against women and girls with disabilities and the disrespect for their rights is also worrying us.

People have now less access to complaints mechanisms and are less visible. This may cause more violence

inside the homes and the institutions.

#### What do we want?

We want to be included in the discussions about the way the services will be provided in the future. Nothing will be done in the same way. We need to make sure that our rights are respected and that we are not left behind.



#### Self-advocates have a voice. We want to be heard.

### Letter from our president: 13 weeks of heart-breaking separation



Jyrki Pinomaa is the President of **Inclusion Europe**. He is from Finland. He wrote a letter about his experience in Finland in times of COVID-19 emergency.

This is a summary of what Jyrki wrote:

During Coronavirus emergency, I could not see my sons who have an **intellectual disability** for several weeks.

Their names are Markus and Robin.

I saw Markus and Robin for the last time when they came at home for their regular one-night visit.

It was in March.



After their visit my wife and I went on holiday to Spain. But a few days later, Coronavirus emergency was declared in Europe.

The news in Finland were saying that supermarkets were running of things for people to buy in supermarkets.



Finish **government** called for all travelers abroad to stay two weeks at home after returning to Finland.

When my wife and I got back to Finland, We had to stay two weeks at home without seeing our children.

# The pause stretched to thirteen weeks

On March 18<sup>th</sup>,

the care home for the two boys said that They were no visit allowed for the time being.



I couldn't visit my sons. My sons couldn't come home.

To keep contact with my sons, I bought an iPad.

We had video calls together. My sons said that they wanted to go home. The situation was complicated for all the residents and their families.

In mid-May I asked with other families to the service provider to stop prohibit home visits.



The service provider accepted our request. Home visits are not forbidden anymore.

After 13 weeks of separation, I can finally be reunited with my sons.

## General assembly 29 June 2020

Under exceptional circumstances, the General Assembly of **Inclusion Europe** took place online on the 29th of June 2020.

At the online meeting, we launched Inclusion Europe's Annual report 2019. The report covers our activity and projects of 2019.

We also presented the financial report 2019. And we adopted the budget for the next year.



The **European Platform of Self-Advocates** presented Ana Martínez from Spain as the new member of its Board of Directors. Ana has spent years at GADIR defending the rights of people with intellectual disabilities.

We welcomed 2 new members to our network:

- All Ukrainian NGO Coalition of persons with intellectual disability
- Learning Disability England

4 members left the Board:

- José Smits,
- Harry Roche,
- Maria Antonia Fortuño Cebamanos,
- Denise Roza

Thank you for their great work!

We elected 3 new members of the Board of 2020:

Anastasiya Zhyrmont



Jeanne Nicklas-Faust



Maria Cristina Schiratti

Welcome to Anastasiya, Jeanne, and Maria Cristina!



We decided on the dates of the next Europe in Action conference.

It will take place from 9 – 11 June 2021 in Tampere, in Finland.



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## **Explanations**



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



### **Commissioner at the European Commission**

A Commissioner is a person who is responsible for a field of work at the European Commission and manages a lot of people.



### Discrimination

Discrimination means that you are treated worse than others 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, an explanation is provided.

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

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

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



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

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



Educate

Educate means to teach.

It means to make sure people have access to training so they can learn new skills.





The European Platform of Self-Advocates is made up of organisations of self-advocates from different countries in Europe.

We call it EPSA for short.

It is a part of **Inclusion Europe**.



**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.



### **European Parliament**

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

The Members of the European Parliament (in short, MEPs) make these decisions and speak for 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 Union**

The European Union (in short, EU) is a group of 28 countries. We call these countries "member states".

They have joined together to be stronger politically and economically.

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

The EU also makes laws that are important for people with disabilities.

For example, the **Accessibility Act**.

It also made a law that gives people with disabilities more rights when they are traveling.

The EU also gives money to its member states.

Some of this money is used for people with disabilities.



### Government

A government is a group of people that make decisions on how to run a country.

For example,

- about where the money is spent,
- about public transport,
- about schools,
- about hospitals.

Every few years there are **elections** to vote for a new government.



### 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.



### **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 the laws in Europe.

We started in 1988.

We have 75 members in 39 European countries.

We are based in Brussels in Belgium.



### Inclusive education, training or employment

Inclusive education, training or employment means that people with intellectual disabilities can learn and work together with other people without disabilities.



### 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.

People who live in institutions have to follow the rules of the institution and cannot decide for themselves.

### Intellectual disability

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

This makes some parts of life harder.



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

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.

Some people say learning disabilities instead of intellectual disabilities.





The members of the **European Parliament** are the **politicians** who sit in the European Parliament.

We call them MEPs for short.





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

These people are called self-advocates.



### Segregation

Segregation is when someone is set apart from

others for an unfair reason. For example, because of their disability.





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.





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

You can vote in different areas.

For example:

- in your town or city when you elect a new mayor
- in your country when you elect a new president
- or at the European elections, when you choose the new Members of the European Parliament (MEPs).



Ambitions. Rights. Belonging.

# Contact us and share your self-advocacy stories!



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