



Europe for us

**Guide for
self-advocates and journalists in
disability rights advocacy**



Find explanations for words in **bold** at the end of Europe for us on pages 36 to 44.

Europe for us is available in:

- English
- French
- German
- Hungarian
- Italian
- Dutch
- Romanian
- Spanish
- Ukrainian

Go to www.inclusion-europe.eu/europe-for-us to find the other language versions.

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Editor's note

Soufiane El Amrani

How self-advocacy helps people with intellectual disabilities





All people with intellectual disabilities
have the right to become self-advocates.

We as people with intellectual disabilities
have the right to have our voice heard and listened to.



We have rights just like everyone else.



We as people with intellectual disabilities
have the right to have our own self-advocacy group.

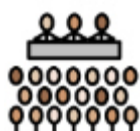
I think it would be great if there
were more people with intellectual disabilities
who have the right to start their own self-advocacy.



If people with intellectual disabilities
have their own self-advocacy,
they can talk with the other members
of their group about things that are important for them.



There is already a group of self-advocates
called the European Platform of Self-Advocates
who are part of Inclusion Europe.



The European Platform of Self-Advocates
organise conference every 2 years.

The European Platform of Self-Advocates
is made up of people with intellectual disabilities.



The conference is totally run by
people with intellectual disabilities
from many different countries.



It is super important that people
with intellectual disabilities have
their voice heard, and they have
the right to start their own
self-advocacy group.

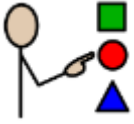
What is self-advocacy?



Self-advocacy is about independent groups of people with all types of disabilities working together for justice.



We help each other take charge
of our lives and fight discrimination.



It teaches us how to make
decisions and choices
that affect our lives.



We can be more independent.



It teaches us about our rights,
but along with learning about our rights,
we learn what we have to do.



The way we learn about advocating
is by helping each other
gain confidence to
speak out for what we believe in.



Self-advocacy is:

- Saying what you want and need.
- Saying what affects you so
that things get better for you.
- Learning how to speak up for yourself
so you are heard, and things can change.

- Understanding your rights within the law.
- Standing up for your human rights.
- Speaking up about important things.

What is advocacy about?



Self-advocacy means speaking up for yourself.



Advocacy means speaking up for someone else.

Why is advocacy important?



It can be hard for people with disabilities to have a say about things that are important.



Being part of an advocacy group can make it easier and give you support to:

- Speak up for yourself.
- Say what you want.

A good self-advocacy group:



- Uses information all members can understand.
- Agrees and makes a work plan.
- Works as a team.



- Respects and treats everyone equally.
- Agrees on good rules for members and support staff.



- Works with other groups and services that will make them more powerful.
- Meets people and stays in touch with them.



- Gets funding and resources, like computers, internet and good support.



- Finds out who makes the decisions about the things that are important to you.
- Makes an action plan that everyone agrees to.

Setting up an advocacy group

Successful groups try to have three goals or reasons for coming together.

Each of these goals or reasons helps to keep members in the group.



- **Goal 1:**

- Be part of the community.**

- What can you do in your self-advocacy group to bring people together?



- **Goal 2:**

- Learn new things.**

- What do you want to learn as a member of your self-advocacy group?

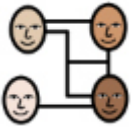


- **Goal 3:**

- Advocate for disability rights.**

- What do you want to work on together as a self-advocacy group?

Self-advocacy at Inclusion Europe



Here is a [link](#) to the members of Inclusion Europe, each member offers lots of opportunities for self-advocacy.



Here is a [link](#) to the guide on how to become a self-advocate.



And if you click on this [link](#) you will find out about Inclusion Europe.

Importance of self-advocacy for people with intellectual disabilities



Elisabeta Moldovan

Self-advocate from Romania



I became a self-advocate because I wanted to know my rights as a person with disabilities.

**In the institutions I lived in,
I experienced a lot of abuse.**

**I wanted to change this situation
for others.**

**As a self-advocate,
I also wanted to develop myself as a person.**





László Bercse

Vice-President of Inclusion Europe



Independence is crucial.

We can only thrive if people around us provide support, but also give us the chance to decide independently.

We need good support.

From organisations, families and other self-advocates.

**We need to learn a lot,
and we need to work hard for ourselves.**

We need to make our voices heard.





Vjatseslav Zagorski

EVPIT board member



**Our lives must be up to us,
we need to make decisions for ourselves.**

**Everyone has the right to make
decisions for themselves.**

We need other people to trust us.

**We must have a chance to need for help
if necessary and receive support.**

**We must learn, make mistakes,
and be responsible for our decisions.**

We need to be listened to.





Paul Alford

Self-advocate from Ireland



What we need in Ireland is for the government and the media to listen to people with disability.

I had to fight all my life and it was a hard life.

I never lived my life with my family.

I wish for others to do the same things that I have done.

Live a life of your own, live your life independently, do those courses, get more experience, get a job, and get proper money.

There is nothing about us without us.

Our voices, our choices.

We need to be listened to and taken on board.



Self-advocacy at Inclusion Ireland



Inclusion Ireland is a member of Inclusion Europe.



Inclusion Ireland works for full inclusion of people with intellectual disabilities by supporting people to have their voices heard and advocating for rights under the United Nations Convention (UNCRC).



Inclusion Ireland made a working group of people with an intellectual disability who were interested in advocating for themselves.

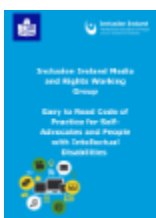


This working group went through media training on how they can communicate their experiences in the media and advocate for themselves.



The working group made the Code of Practice for Journalists.

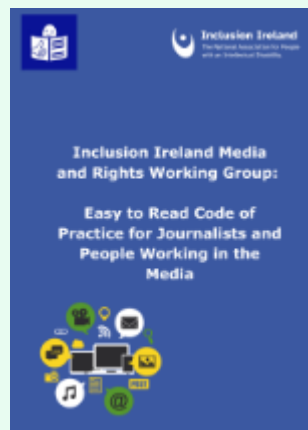
The guide helps journalists who are interviewing people with intellectual disabilities.



The working group made the Code of Practice for Self-Advocates.

The guide is for people with intellectual disabilities to support them when journalists are interviewing them.

You can access the original files here:



Code of practice for self-advocates being interviewed

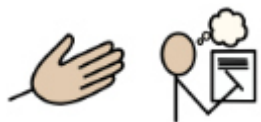


Getting into the media is important because:

- It helps people with intellectual disabilities get their voices heard
- It helps people hear about people with intellectual disabilities and their stories
- It helps to change how people behave



This code of practice is for self-advocates and people with intellectual disabilities to use when they are going to be interviewed.



This will help you know what to expect and how to prepare for an interview.

General tips for becoming a spokesperson



Remember that you are good enough.

Our voices are important, and we should be heard.
We can help to raise awareness ourselves instead of waiting for someone else to do it for us.



Try to get out into your local community and get to know more people.



It is important to have family, friends, or people you know in your community who can get behind you and support your message.



If you have a message you want to spread, there are different ways to be heard.



You could go to advocacy meetings and events, publish a book or article, or post about it on social media.



Not everyone can speak up for themselves so we need to speak up for everyone in our community. Nobody is left behind.



Always believe in yourself and be confident. Nobody can tell you what you can and cannot do.



Telling human stories can be powerful. This means talking about your own life experience.



We need to tell positive stories that show how we can make our own decisions.

Preparing for an interview



An interview could:

- be over the phone
- be face-to-face
- be in a studio



When you are contacted by a journalist, here are some useful questions you might ask:

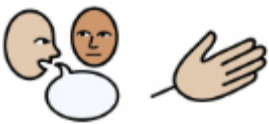
1. Who is calling
2. Where they are calling from
3. What they want to talk about and why they are calling you
4. Whether the interview is live or pre-recorded
5. Whether it is in a studio or elsewhere
6. Who will do the interview

7. Is anyone being interviewed with you
8. What is accessibility like at the venue for interview

If a journalist contacts you to do an interview, you do not have to do it right then.



Ask for their contact details and say you'll get back to them.



If you will need any kind of support during the interview, make sure to let the journalists know.

If you need support, you should get it. But it should be your decision and not forced on you.



Ask the journalist if you can meet them before the interview so you can get to know each other.



Ask the journalist if they can tell you what questions they will ask or what topics they will ask about before the interview. This will give you a chance to prepare.



Make sure to tell the journalist if you don't understand something.



You have the right to ask for easy-to-read and plain English. Or you can ask the journalist to talk you through it.



Think about your key messages you want to get across.

Try to pick 3 main points that you want to say in the interview.



You could ask someone like a friend or support worker to help you practice before the interview.

They could pretend to be the interviewer and ask you questions to prepare.



If you like,
you can ask for a quiet space to go to for a few minutes before the interview begins.



If you think a remote interview would be easier for you, you can ask to do the interview over the phone or on Zoom.



Remember that most people are nervous about doing interviews and being recorded. You could talk to someone you know about this to help calm your nerves.



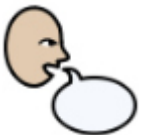
If you are going to be on camera, what you wear is important. Make sure you wear something appropriate and comfortable.

A lot of interviews happen every day and your interview might not happen if the journalist has to a different story. Don't be disappointed.

During the interview



Make sure to introduce yourself and tell a bit about yourself.



Remember not to speak too fast and take your time. You don't have to rush.



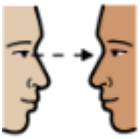
Remember to breathe. The key to being confident is being relaxed.



If you don't understand the question or don't hear what the journalist says, you can ask them to repeat the question.



Try to sit or stand up straight.
This will help you look more confident, and will make your voice sound better.



If the interview is in person, try to have eye-contact with the journalist when you are speaking.



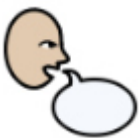
If the interview is on Zoom,
try to look at the person on the screen when you are speaking.



Listen carefully to what the journalist is saying before giving an answer.



Wait for the journalist to stop speaking before you start speaking.

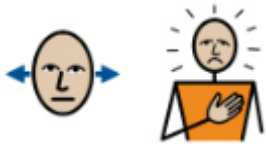


Remember that you can say whatever you want. Don't say what you think someone else wants to hear.

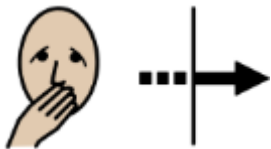


You can give your own opinion and say how you feel about something.

Try not to say the word 'sorry' during an interview.

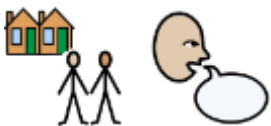


You don't have anything to apologise for.



If you make a mistake when speaking, that's okay. Try to move on and don't worry about it.

Remember that journalists are not out to catch you. They know you are not a politician or celebrity and are just giving your opinion.



When you are talking about rights, try to use examples about your life or someone you know with their permission.

Remember that it is okay to take a few seconds before you answer.

After the interview



Make sure to thank the journalist for their time and for the opportunity. Ask them when you will be able to see or hear the interview.



If you made a mistake during the interview, try not to think about it. As long as you got your key messages across then you did a great job.

Listen, watch, or read the interview after it comes out. That way you can see what you can improve on for the next one.

When the interview comes out, you can contact the journalist to tell them what you thought about it.



Be proud of yourself!

Code of practice for journalists and people working in the media

What language to use



Talk to the person about
what words or terms they like to use.
Use human language.

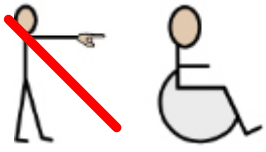
Some people might prefer the term disabled person.
Some people might prefer the term self-advocate.
Some people don't want to mention their disability at all.



Always use respectful language.
Never use outdated or upsetting language like:

- 'handicapped'
- 'retarded'
- 'mental disability'
- 'slow'
- 'stupid'
- 'invalid'
- 'suffers from ...'

Remember that a person's disability doesn't define them.



Some people don't like to be labelled by their disability.

Avoid highlighting an intellectual disability where possible.

For example, avoid 'Mary is from Dublin. Mary has an intellectual disability.'



You could describe the support Mary needs without highlighting the disability, like 'Mary is from Dublin, and has a support-person to support her in some activities.'

General guidelines for journalists



Don't judge people with intellectual disabilities. People should listen to our ideas and we should be asked on to big TV programmes.



When you are talking about intellectual disability, ask people with intellectual disabilities themselves to be part of interviews instead of supporters or family members.



When you are planning an interview or media event, the place where the event happens should always be fully accessible.



When you are reporting about intellectual disability you should include the voice of people with lived experience.

They are the real experts.

Preparing to interview a person with an intellectual disability



Don't assume you can think better than us or say things in a better way, we can speak and think for ourselves.



Find out more about where the person is coming from. Try to get to know the person to make them feel more comfortable.



Learn about different ways to communicate like:

- easy-to-read documents like this one
- technology like computers, phones, and tablets
- pictures and images

- sign language
- Braille
- communication boards
- any other communication support



Tell the person a bit about yourself so they feel more comfortable with you.



Ask the person for consent for everything like taking photos and videos.

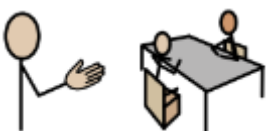
Agree with the person on the context and the way in which their images or quotes are going to be used.



Give people examples of the questions you're going to ask them before the interview so they can prepare.



This will give people more confidence in what they are saying.



Tell the person in advance they can have someone they are familiar with in the room when they are being interviewed if they want.

A friend or support person
might help them feel more comfortable.



It is important to tell the person in advance
where the place is and how to get there
so they can plan the journey.
Give them the details a week
or more before the interview.

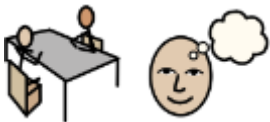


Make sure to ask the person if they need
any other support like having someone
there to guide them or transport.



Let the person tell you what support
they need or don't need.
Do not touch them without being asked to.

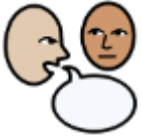
During the interview



Offer to shake hands when greeting your guest.
Be patient and calm.
Give people a chance to take their time
and think if they need to.
Journalists should know that
the person might be nervous.



Easy-to-read materials should always be available, and you should always speak in plain English. If someone is not answering the questions try and make the questions easier to understand.



When you are interviewing someone with an intellectual disability, speak slowly, clearly, make eye contact, and listen carefully to what they are saying.



Take time to understand each person's own experience with their disability. Everyone has a different experience. Do not describe your successful guest as a 'superhero' because it raises false expectations that all people with disabilities should 'achieve something'.

Give people the opportunity to speak. Don't talk over them or ask lots of questions at once. Ask them to repeat their answer if you do not understand.

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



Charter of Fundamental Rights

A paper that says what basic rights every person has.
For example, the right to freedom, the right to education.



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.



Community

People that belong to something.

For example, neighbourhood community.

People who live in the same neighbourhood.

Or religious community.

People who have the same religion.



Community-based services

Support given by people from the community.



Convention

An agreement between countries or

organisations which talks about many topics.



Deinstitutionalisation

Deinstitutionalisation is helping people
to move out of institutions.

It is when the people who lived in institutions get help
so they can live independently in the community.



Educate

Educate means to teach.

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



European Union

The European Union (in short, EU) is a group of 27 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.

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

The EU also gives money to its member states.

Some of this money is used for people with disabilities.



Fund

To give money to someone or to an organisation which helps people or organisations.



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 79 members in 39 European countries.
We are based in Brussels in Belgium.



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.



NGO **Non-governmental organisations**

Non-governmental organisations, or NGOs are
generally defined as nonprofit and independent of
governmental influence.



Online schooling

Online schooling is a way for students to attend
their classes using a computer or another device
to connect to the internet.

These classes happen with the help of online
applications for meetings or online classrooms.



Organisation

A group of people who work for the same thing.



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.

These people are called self-advocates.



Services

Support for people with disabilities.



Training

A class often given at work where people learn new things.



Ambitions. Rights. Belonging.

Contact us and share your self-advocacy stories!



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Sign up to get Europe for Us when it comes out:
[bit.ly/Inclusion Europe Newsletter](http://bit.ly/Inclusion_Europe_Newsletter)



Co-funded by
the European Union