

TOPSIDE+

Training Opportunities for Peer Supporters
with Intellectual Disabilities in Europe: New horizons



Peer support for making decisions

A new way to help people to take their own decisions



www.peer-support.eu

This is an easy-to-read version of the paper

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Possibilities and Recommendations for the implementation of a
new concept to support legal capacity for all citizens”

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1. Introduction

Being included means to be part of something.
When we talk about inclusion,
we are talking about taking part in society:
Being able to go to school, to be employed,
to have a training,
and political participation like everybody else.
An inclusive society is one that gives the same opportunities
to all citizens.

For a long time people with disabilities were excluded from society.
This happens even today.
They did not have the opportunity to take part and to contribute.

The TOPSIDE project is build up in a way
that all participants are included.
They feel valued.
They are able to participate and share their own life experiences.

TOPSIDE is about Peer Support.
Peer support happens when people help each other.
The supporter is a “peer” who has similar life experiences.
The support happens from equal to equal.

TOPSIDE trains Peer Supporters for people with intellectual disabilities.
It was developed in Catalonia, the Czech Republic, Finland,
France, Germany, Lithuania, the Netherlands, Portugal,
Romania, Scotland and Spain.

Its results can be found at www.peer-support.eu:

- The [TOPSIDE Guidelines for Trainers](#),
help trainers to plan and prepare the training.
- The [TOPSIDE Curriculum in Easy-to-Read Language](#)
supports trainers with intellectual disabilities
to prepare and run the TOPSIDE training.

- The TOPSIDE Curriculum, which is a list of exercises to train people with intellectual disabilities to become peer supporters.
- The TOPSIDE Guidelines for Mentors, which advise and direct the mentors of peer supporters.

For people with intellectual disabilities, peer support is a new form of support. So far, support came mainly from people without a disability. With peer support, support comes also from people with a disability. Their own life experiences are valued. For many, this is a new and empowering experience.

The Policy Recommendations of our project have been launched at the European Parliament and were much supported.

Inclusion Europe and all TOPSIDE partners will continue with this work. We want to achieve more independence and more inclusion of citizens with intellectual disabilities.

2. What is Peer Support?

The word “**peer**” is not used very often. In our project it means a person who has some of the same life experiences as you. Peers often understand you better because they share the same experiences. They often understand better how you feel. You may feel more comfortable to talk with them than with other people.

A peer can become someone you trust. But they are not always close friends.

In our project, we use “peers” mainly for other people with intellectual or learning disabilities. But peers can also share other experiences with you, for example work at the same place or go to the same school.

“Peer support” is about getting support from people you can trust, getting support from people you can understand. It is about support from people who share common experiences with you. Peer support is about being included in your community. It is about getting support from people like you.

Peer support is all about people helping each other. Many groups or organisations are built on this principle. People help themselves if they are not happy with other help they get.

This can happen in many different areas:

- Pregnant women and mothers with small babies may meet to share experiences.
- People who have the same form of illness may come together to talk to each other.

This kind of support helps people to be stronger and to feel better. But it does not replace other forms of support. You need to make sure that you still get support and contacts with other people than your peers.

Everybody can be a Peer Supporter.

But to give the support in the best way, people need some training. Below, we explain how TOPSIDE is providing this training.

3. What is Supported Decision-Making?

All people can make their own choices.

This means that you can decide what you want.

You can decide for example about where to live.

You can also decide about what you want to eat for dinner.

There are easy and difficult decisions to make.

- It may be easy to decide what you want to eat.
- It may be more difficult to decide what kind of trousers to buy.
- It may be even more difficult to decide where you want to live.
- Most difficult decisions are often about health, for example if you agree to have a surgery or not.

We need to make decisions every day.

You do not always make a good decision.

People sometimes make bad decisions.

Bad decisions are something that you regret.

Up to now, many people with intellectual disabilities are not allowed to take all decisions by themselves.

Many times they have a guardian who takes important decisions for them.

But there is a new law that says that all people should take decisions by themselves.

It also says that they have the right to get support to make difficult decisions.

You can ask for other people's opinion when making your decisions.

For easy decisions, these can be friends or family members.

You get support from someone you trust.

For more difficult decisions you may need support from a specialist.

For example from a medical doctor or a finance manager.

Most important is that you decide yourself whom to ask for help.

But you always decide at the end how you think is best.

You should always have a lot of information about the subject.

You can remember and use this information when you make your decision.

It is easier to make a decision if you have information about the topic.

4. From rights to reality

Most people with intellectual disabilities find all this quite confusing.

During their lives they never were allowed to take own decisions. There were always family members, staff or guardians who took the decisions for them.

This was confirmed by an Expert Committee:

*We are very concerned
that all over the European Union
many people with disabilities
do not have the right to take their own decisions.*

To change this, people have to change the way they see people with intellectual disabilities:

- People with intellectual disabilities should be brave enough to take their own decisions.
- Family members and staff should let people take their own decisions.
- The governments should provide the support for making decisions.

One possibility to give this support is peer-support.

To give the support in the best way, people need some training. TOPSIDE is providing this training.

5. How TOPSIDE works

TOPSIDE helps people with intellectual disabilities to become good peer supporters.

We have asked ourselves first, what skills people with disabilities need to become good supporters. We came up with the following long list of skills:

1. Peer to Peer Skills:

these are the skills that people need to work well with each other.

- Communication
- Confidentiality
- Understanding our roles in society
- Finding out about another person's situation
- Find out about support needs
- How to give meaning to life stories
- Looking at stories in a positive way
- Public and private information
- Understanding my role as peer supporter

2. Inclusive Skills

these are the skills to promote inclusion in society

- Understanding the importance of informed decisions
- Knowing my rights and duties
- Know about tools that help people to plan their future
- Understand and accept that people are different
- Understanding inclusion in different life situations
- Understanding people learn differently
- Understanding socially valid roles
- Understanding that each person learn at their own rhythm
- Understanding that some people may have more power than others
- Understanding the importance of taking part

3. Practical Skills

these are about being able

to use real life examples to support others.

- Asking for help when making decisions
- Recognise good and bad decisions
- How to get help
- How to use support
- Learning from decisions
- The power to choose and to make decisions
- Understanding different kinds of support

We then developed exercises to train people in all these skills.
The exercises are all at
Through these exercises
many people with intellectual disabilities in Europe
became good peer supporters.
They are now helping other people to take their own decisions.

We also looked at the role of the trainers who run these exercises.
We found that the training can best be done by a team of 2 trainers:

- 1 trainer who has the experience of living with an intellectual disability.
- 1 trainer who does not have an intellectual disability.

For both trainers we have written some guidelines that help them to do their training.

After the training, the peer supporter

- can show others how to get the right support.
- can support people how they can enjoy a better quality of life.
- can help others become more socially included.
- can open other peoples' eyes to what is possible
- can help to create new opportunities in the life of their peers.

The peer supporter also:

- offers experiences, and does not propose solutions;
- is independent from organisations providing services;
- is not replacing social workers;
- raises awareness about the rights a supported person has;
- contributes to society and the community, as a friend, a volunteer or as a worker;
- respects the person and his/her environment;
- has an open attitude and is not judging anyone;
- respects decisions others' make;
- acts as a „guest“ in the life of another person;
- is trustworthy and able to respect confidentiality and privacy.

6. Our experiences with TOPSIDE

We have learned a lot of important things in the TOPSIDE project. Here, we want to look at different results.

Positive Developments

In our project, many people with intellectual disabilities learned how to support others. Many people also learned how to take better decisions for themselves. They got stronger and also became better self-advocates. Self-advocacy is the movement of people with intellectual disabilities who speak for themselves. There are many links between peer support and self-advocacy. Both make people stronger and work for inclusion. They want that people with intellectual disabilities participate in all decisions that concern their lives. You can find out more about self-advocacy at www.self-advocacy.eu

What peer support cannot do

Peer support is not a solution for everything. People with intellectual disabilities will need also other forms of support to take decisions.

There may also be people who have very serious health problems. This is something a peer-supporter cannot solve. But they can make sure that the person gets the necessary help, for example by a medical doctor.

We also found that some support may be emotionally very different for a peer supporter. For example, if it reminds them too much about a situation of their own.

TOPSIDE trains peer supporters about how to find help in these cases.

Peer supporters need someone who they can turn to if they encounter problems.

We have called this person a “Mentor” and we have written guidelines also for this person.

Finally, there is also the danger that peer support is seen as a cheap solution for support in decision-making. Peer support is always only one of the possibilities of support. It needs still much money to pay for support people, planning and research.

What organisational support does peer support need

We have made the experience that it is very important to get the understanding of professionals, family members and people with intellectual disabilities about what peer support is all about.

Professionals and family members were always the “supporters” The persons with disabilities were always the ones receiving help. It is very difficult to change that kind of thinking.

Professionals and family members should understand one important thing:

**Living with an intellectual disability
brings experiences and expertise
that other people cannot have.**

This experience we should value and build on.

TOPSIDE helps people to do just that.

It trains people with intellectual disabilities to become peer supporters.

But we need support from the organisations as well:

1. Peer supporters need regular trainings to refresh and update the skills learned.

2. A person in the role of a “mentor” is necessary to provide support in difficult situations.

What other support should be available

Peer support will never be the one and only solution for the support needs of people with intellectual disabilities. It is necessary to develop, create and maintain different support possibilities for different situations.

Some of them are:

- Make sure that everything is accessible for everybody.
- Provide understandable information in easy-to-read language.
- Better education
- Support in communication
- Self-advocacy support
- Support by neighbours, friends and family
- One or more trusted support persons
- Support by mainstream experts like lawyers, notaries, physicians, or bank staff
- Capacity building
- Person Centred Planning

The governments must make sure that supported decision-making is available to all. Any support must respect the rights, will and preferences of the supported person.

There should be little or no costs for this support

7. What should be done now?

To develop more peer-support needs still a lot of work.

This can be done at two levels:

1. In the counties where the people live.
2. At the European Union which can give advice and guidelines.

7.1. What should be done at national level?

TOPSIDE peer support has been done in 11 countries or languages:

- Catalonia
- Czech Republic
- Finland
- France
- Germany
- Lithuania
- the Netherlands
- Portugal
- Romania
- Scotland
- Spain

People can go there and see how it works.

We ask the national governments to do the following:

- Governments must stop laws and regulations that allow guardians to make decisions for other people.
- Governments must also provide persons with disabilities with the support they may need to take their own decisions. This support may be different for different people. It can include peer-support and other types of support. Governments should work out several possibilities to support people in making decisions.
- Governments should inform all people about the fact that everyone has the right to take their own decisions. They should do that in easy-to-understand language and other accessible formats. This should include information about the possibilities of peer-support.
- Governments should find out how peer supporters could be recognised. They could for example be personal assistants or social mediators.

- Governments should do a law that gives people the right to support when making decisions. They should make sure that peer-support is included in all plans for a system of supported decision-making.
- Governments should support organisations and service providers to set up peer support in decision-making.
- Governments should make sure that decision-making of people with intellectual disabilities is taught already at school.
- Governments should involve people with intellectual disabilities when they make laws for people with intellectual disabilities. .
- Governments should support inclusion and empowerment of people with intellectual disabilities, including peer-support and the self-advocacy movement.

7.2. What the European Union should do

The review of the rights of people with disabilities in the European Union came to very clear results:

We are very concerned that all over the European Union many people with disabilities do not have the right to take their own decisions.

We recommend that the European Union should do more to find the best ways to support decision-making. This should be done together with organizations of persons with disabilities.

We ask the European Union to do the following:

- The European Union should pay for the testing of new models to support decision-making. These new models should not require that someone else decides for a person.

- The European Union should pay to inform everybody that all people in the European Union have the right to take their own decisions. They have also the right to receive support with that.
- The European Union should develop rules for the quality of support in making decisions. They should involve people with intellectual disabilities in checking if this quality is ok.
- The European Union should make sure that all its people can benefit from European laws. It should insist that national governments do not ban access to these European laws because people have no right to decide for themselves.
- The European Union should support inclusion and empowerment of people with intellectual disabilities, including peer-support and the self-advocacy movement.



Inclusion Europe



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