# **TOPSIDE+**

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



## Peer support for making decisions

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







Lebenshilfe





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#### Contents

Executive Summary	
1.	Introduction
2.	The concept of Peer Support
2.1.	Peer Support and supported decision-making: Definitions5
2.2.	The legal basis in the CRPD and General Comment No 16
2.3.	A consideration of the possibilities and limitations of Peer Support7
2.4.	Peer Support in interaction with other forms of support in decision-making
3.	Peer Support in practice
3.1.	TOPSIDE: Training opportunities for Peer Supporters10
3.2.	Implementing Peer Support at local level12
3.3.	Self-advocacy and Peer Support12
3.4.	Peer Support in social services
3.5.	The necessary legal framework for Peer Support13
4.	Recommendations
4.1.	Recommendations for promoting Peer Support at national level
4.2.	Recommendations for support by the European institutions

#### **Executive Summary**

The UN Convention on the Rights of People with Disabilities stipulates in Article 12 the right to full legal capacity and the right to receive support to realise this capacity. The General Comment No. 1 sustains the right of support for decision-making and mentions Peer Support as one possible form to provide this necessary support. However, the CRPD Committee *"notes with deep concern that across the European Union, the full legal capacity of a large number of persons with disabilities is restricted"*.

Peer support occurs when people provide knowledge, experience, emotional, social or practical help to each other. The supporter is a "peer" who has similar life experiences and thus the support relationship is one of equality. People with similar life experiences may exchange practical advice and suggestions for strategies that professionals may not offer or even know about and can consequently offer more authentic empathy and support.

TOPSIDE+ supports the implementation process of the Convention and is the only fully developed and internationally recognised methodology to train Peer Supporters for people with intellectual disabilities. It was developed based on an inventory of the necessary skills by partners in the Czech Republic, Finland, France, Germany, Lithuania, the Netherlands, Portugal, Romania, Scotland, and Spain. It comprises important resources which are all published at <u>www.peer-support.eu</u>:

- The <u>TOPSIDE Methodological Guidelines for Trainers</u>, which guide trainers through the process of planning and preparing the training programme.
- The <u>TOPSIDE Curriculum in Easy-to-Read Language</u> supports trainers with intellectual disabilities to prepare and run the TOPSIDE training.
- The <u>TOPSIDE Curriculum</u>, which is composed of a database of exercises with easy-to-read summaries to train people with intellectual disabilities to become peer supporters.
- The <u>TOPSIDE Guidelines for Mentors</u>, which should advise and direct the activities of the mentors to peer supporters, once they have gone through the training programme.

For people with intellectual disabilities, peer support was a concept that broke up with the current support arrangements, where support comes exclusively from people without a disability and where own life experiences are not a valued resource. For many of them it was a new and empowering experience that their experiences are valued and that they were able to support other people.

These recommendations provide national and European policy-makers with guidelines on how to implement Peer Support. TOPSIDE+ has developed these in close cooperation with stakeholders and policy-makers at national and European levels. The most important recommendations are:

- Governments must fully implement Article 12 of the UN Convention on the Rights of People with Disabilities and abolish regulations that include substitute decision-making.
- Governments must also provide access by persons with disabilities to the support they may require in exercising their legal capacity. This entails the development and support for a variety of measures to support decision-making, among them peer support.
- Governments and the European Union should support awareness-raising about legal capacity and support for decision-making in accessible formats and develop (financial) incentives for organisations and service providers to establish peer support in decision-making.
- The EU should support model projects that are scientifically supervised, testing new schemes for supported decision-making that are not based on a mandate for legal representation.
- The EU should support the development of quality standards for supported decision-making mechanisms and involve people with intellectual disabilities themselves the evaluation.
- The European Union should ensure that all its citizens can benefit from European legislation and insist that Member States no longer ban access to European citizen's rights through outdated legal capacity legislation.
- Governments and the European Union should promote inclusion and empowerment of people with intellectual disabilities, including peer-support and the self-advocacy movement.

#### 1. Introduction

Many adults with intellectual disabilities in Europe cannot participate as active citizens in their societies, because of the many barriers they are facing, starting with restrictions to their legal capacity, or limited education opportunities.

Since most people with intellectual disabilities have only limited access to formal or informal adult education and training, one of the main challenges lies in providing them with the appropriate training needed to take their own decisions, to take control over their lives and to perform their role as active citizens. Recognising this need, the first TOPSIDE project in 2011-2013 set out to develop a new component in informal adult education for this group of citizens: peer support and peer training, i.e. to develop the capacity of adults with intellectual disabilities to provide support and training to their peers. That project was supported by the EU Life Long Learning Programme.

On the basis of an inventory of the necessary skills, the project partners developed and tested a training curriculum for adult peer supporters and trainers. The TOPSIDE Curriculum was complemented by Methodological Guidelines for adult education trainers. To test, improve and validate these deliverables, adult education courses for future Peer Supporters and Trainers were organized in the Czech Republic, Finland, the Netherlands, Romania, Scotland, and Spain. A European version of the Deliverables was also created for the transfer to other EU countries.

The TOPSIDE partners got recognition of the project and its work by the leading organisations of and for people with intellectual disabilities in Europe. They presented them at local, national and European level to promote the qualification as Peer Supporter and Trainer as new educational and eventually even employment opportunity for the target group. The Peer Supporters indeed used their skills in different settings: in self-advocacy organisations, in counselling services, or in organisations of guardians/supporters.

Ultimately, this project contributed to reinforcing the capacity of people with intellectual disabilities to live and work as active citizens in society.

However, the project partners also realised one shortcoming: people with intellectual disabilities themselves were involved only as trainees and not as equal trainers. Thus a continuation of the project was sought with co-financing of the Erasmus+ programme of the European Union under the title "TOPSIDE+: Training Opportunities for Peer Supporters with Intellectual Disabilities in Europe – New Horizons". Running from 2014 to 2016, TOPSIDE+ had three main objectives:

- 1. To extend the TOPSIDE training to four new countries: Germany, France, Lithuania and Portugal.
- 2. To make the curriculum accessible to persons with intellectual disabilities so that they can work as trainers in cooperation with the non-disabled trainers.
- 3. To develop Policy Recommendations at national and European level as a basis for further dissemination and use of this innovative concept.

All of these objectives were reached and its results have been published at <u>www.peer-support.eu</u>. The present Policy Recommendations have been launched at the European Parliament and have found much support.

Inclusion Europe and all TOPSIDE partners are fully committed to continue with this innovative concept in their efforts to achieve more independence and inclusion of citizens with intellectual disabilities.

#### 2. The concept of Peer Support

Since Peer Support in decision-making for people with intellectual disabilities is a rather new concept and approach, this chapter will look at some basic aspects, such as a definition as well as the legal and political basis for it and the limitations and interactions of the concept with other forms of support.

#### 2.1. Peer Support and supported decision-making: Definitions

**Peer support** is a concept that is known in many domains, such as (mental) health, schools, education, disability, etc. It occurs when people provide knowledge, experience, emotional, social or practical help to each other. The supporter is a "peer" who has similar life experiences and thus the support relationship is one of equality. People with similar life experiences may exchange practical advice and suggestions for strategies that professionals may not offer or even know about.

Peer support is also used when members of self-help organizations and others meet, in person or online, as equals to give each other support on a reciprocal basis. The worldwide Inclusion movement<sup>1</sup> is founded on this concept, originating from family members of persons with intellectual disabilities organising themselves to provide mutual support.

It is a consequence of the developments of concepts such as self-advocacy, empowerment, inclusion and independent living that peer support now is also explored for support relationships between people with intellectual disabilities themselves. It is clear that people who have similar experiences of living with an intellectual disability can better relate and can consequently offer more authentic empathy and support.

Peer support is frequent, ongoing, accessible and flexible. Peer support can take many forms – phone calls, text messaging, group meetings, home visits, going for walks together, and even shopping. It complements and enhances other support services by creating the emotional, social and practical dimensions of support that other services may be lacking. Through empathetic listening and encouragement, peer supporters can motivate and encourage individuals to take decisions and empower them to lead a more self-determined life.

For people with intellectual disabilities, peer support proved to be a new concept that was at the beginning difficult to understand. This is the legacy of current support arrangements, where support comes exclusively from people without an intellectual disability and where own life experiences are not a valued resource at all. For many people with intellectual disabilities it was a new and very empowering experience that their lives are valued and that they were able to support other people.

The TOPSIDE+ project developed the following definitions of Peer and Peer Support in easy to understand language:

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 often 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.

<sup>&</sup>lt;sup>1</sup> <u>www.inclusion-europe.org</u> and <u>www.inclusion-international.org</u>

"Peer support" is about getting support from people you can trust, getting support from people you can understand.
It is about support from people with intellectual disabilities 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.
Everybody can be a Peer Supporter.
But to give the support in the best way, people need some training.

**Supported decision-making** is an alternative to the established form of substituted decision-making which is still very much a reality for most persons with intellectual disabilities. Under substituted decision-making, guardians, family members or caregivers make decisions on behalf of the person with intellectual disability. Supported decision-making allows an individual with a disability to make his or her own choices about his or her own life. It promotes self-determination, control and autonomy and fosters independence.

In this debate and process, it is important to recognise that everybody seeks and receives support in making decisions. Depending on the issue, we reach out to families or friends, colleagues or classmates, specialists or people with similar experiences before we decide to go on a date, buy a car, change jobs, renew a lease, sign up for a yoga class or undergo surgery. We confer and consult with others, and then we decide on our own.

People with intellectual disabilities can make their decisions exactly in the same way. As all others, they may need advice and support in making decisions about living arrangements, health care, lifestyles and financial matters, but they don't need someone to make those decisions for them.

However, what they might need is a trusted network of supporters to field their questions and review their options so they too can confer and consult, and then reach their own decisions. Supporters can be family members, co-workers, peers, or friends. It is critically important that the individual selects supporters who know and respect his or her will and preferences, and will honour the choices and decisions the individual makes.

It is the legal responsibility of the States in which they are living to ensure that also people with intellectual disabilities have the access, support and possibilities to develop the natural support relationships that all other citizens have as well.

It is a challenge for each individual citizen with intellectual disability to understand and realise after many years of substitute decision-making that they are able and allowed to take their own decisions in life.

#### 2.2. The legal basis in the CRPD and General Comment No 1

Supported decision-making is a cornerstone of the United Nations Convention on the Rights of People with Disabilities (CRPD) in Article 12: Equal recognition before the law:

- 1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
- 2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
- 3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

With this recognition in international law, it is clear that substitute decision-making and guardianship are no longer acceptable. It is now a challenge for all States to comply with Article 12.3 to provide the necessary support for making decisions.

In its General Comment no.1, the CRPD Committee clearly stipulates: "Article 12, paragraph 3, recognizes that States parties have an obligation to provide persons with disabilities with access to support in the exercise of their legal capacity. States parties must refrain from denying persons with disabilities their legal capacity and must, rather, provide persons with disabilities access to the support necessary to enable them to make decisions that have legal effect."

They also clarify that support in the exercise of legal capacity must respect the rights, will and preferences of persons with disabilities. The Convention, however, does not define how the support in making decisions should be realised. This means that the support arrangements can take many forms, both formal and informal. The General Comment lists some of these forms, among them also Peer Support. It is very clear in highlighting that *"the type and intensity of support to be provided will vary significantly from one person to another owing to the diversity of persons with disabilities"*.

In its regular reviews of the implementation on the UNCRPD, the Committee always pays specific attention to the implementation of the right to supported decision-making. Unfortunately, an analysis of the available documentation shows that the answers of the States and also in the Alternative Reports are rather weak, indicating that Member States and Civil Society do not have many solutions in this area. They also show that the European Union does not have strong competencies in this area.

In the Concluding Observations of the review of the European Union, "the Committee notes with deep concern that across the European Union, the full legal capacity of a large number of persons with disabilities is restricted. The Committee also recommends that the European Union step up efforts to foster research, data collection and exchange of good practices on supported decision-making, in consultation with representative organizations of persons with disabilities."

From the Concluding Observations of a number of States Parties, the following useful ideas can be deducted:

- There is a need for model projects that are scientifically supervised, with the aim of testing new schemes for supported decision-making that are not based on a mandate for legal representation.
- Support for decision-making must be established in the law as a separate entitlement
- Develop professional quality standards for supported decision-making mechanisms.
- An adult person can sign a written agreement with another adult he/she trusts for assistance in making decisions in certain fields of life.
- Types of support in decision-making could be defined.

#### 2.3. A consideration of the possibilities and limitations of Peer Support

The TOPSIDE+ project has demonstrated the many benefits of Peer Support for people with intellectual disabilities. However, there may be also a number of limitations to using this approach that should be considered.

Peer support cannot replace other support systems. It is not suitable for every individual: for example, persons at risk of suicide are likely to require more treatment focused and professional help, while catering to their needs would exceed the abilities and responsibility of a peer supporter. Peer support can provide social support, but it is not suitable for treating existing mental health problems.

Peer supporters with intellectual disabilities may find themselves in situations where the supported person presents a challenge that may be beyond the supporters' capacity to cope with. An important part of the TOPSIDE training is where to find help in these cases. Peer support in intellectual disability will require regular assistance and mentoring, sometimes even the presence of a mentor or tutor where the peer supporters can find help themselves in case of need.

A challenge may be also a clear understanding of the roles, boundaries and responsibilities in the peer support relationship. The process of negotiating personal and professional boundaries is challenging for people with intellectual disabilities who never had to define and develop their professional conduct before.

Peer support will also never be anonymous. While the TOPSIDE training places a lot of emphasis on the issue of confidentiality, the basic concepts of peer and equality rule out real anonymity which may be available in online support.

Finally, there is the danger that peer support is envisaged to be a cheap solution for support in decision-making. Peer support should always be seen as only one possibility in the support options available and programs still require a high level of investment in personnel, planning, finance, research and time.

#### 2.4. Peer Support in interaction with other forms of support in decision-making

The experiences from the implementation of the TOPSIDE project have shown that peer support for people with intellectual disability is an effective and empowering way to provide the necessary support. However, it should never be understood as being the one and only solution for the support needs of this group of citizens.

It is absolutely necessary to develop, create and maintain a number of different flexible options that can be used in different situations. The following list gives a non-exhausting overview, ordered by the support categories mentioned by the CRPD Committee:

Universal design and accessibility

- Accessibility concept for people with intellectual disabilities
- Providing understandable information
  - European Easy-to-Read Guidelines

Empowerment through formal and informal education and training

- Inclusive education
- Adult education
- Empowerment in public and political participation

Assistance in communication

• Development and recognition of diverse and unconventional methods of communication

Informal support arrangements

- Peer support
  - TOPSIDE training of peer supporters
- Self-advocacy support
  - Self-advocacy training
- Support by neighbours, friends and family
- One or more trusted support persons
  - Circle of friends
  - Strengthening the family

Formal support arrangements

- Professional support by mainstream experts (lawyers, notaries, physicians, bank staff, etc.)
  - Awareness raising and training

- Paid support, social workers, etc.
  - Transforming guardianship, legal reforms
  - Capacity building
  - Person Centred Planning
- One or more trusted support persons
  - Legal reforms, recognition, liability
  - Volunteers, capacity building
- Advocacy
  - Support for Civil Society

There are some basic criteria for all support possibilities in the area of decision-making. While the type and intensity of support desired will vary significantly between individuals, it is the state's responsibility to ensure that supported decision-making is available to all. An individual's mode of communication must not be a barrier and it must ensure access for people who are isolated. Any support must respect the rights, will and preferences of the supported person and should never amount to substitute decision-making. The individual autonomy and capacity of persons to make decisions must be respected and it must not limit any other fundamental right. It is essential for the accessibility of support that there are only nominal or no cost to persons with intellectual disabilities.

In relation to any third parties, such as banks or other businesses, it is important for some forms of support that the supporter is in some form legally recognised and that there is a mechanism for third parties to verify the identity of a support person. Supervision and mechanisms to challenge a provided form of support need to be developed as well.

#### 3. Peer Support in practice

In this part of our recommendations we want to share more details about the experiences with peer support and peer supporters in the past years.

All participating people with intellectual disabilities and professionals found the work personally enriching and there are many examples and stories of significant personal developments of the participating peer supporters. Some testimonies and stories have been published on the site <u>www.peer-support.eu</u>.

It has been discussed above that peer supporters need some training before they can fulfil their role. The core of TOPSIDE is about providing this training. In order to facilitate its implementation, the project has developed a number of resources that aim to help organising and running the training. A specific aspect is the TOPSIDE+ Easy-to-Read curriculum that allows trainers with intellectual disabilities to provide this training.

- The <u>TOPSIDE Methodological Guidelines for Trainers</u>, which guide trainers through the process of planning and preparing the training programme.
- The <u>TOPSIDE Curriculum in Easy-to-Read Language</u> supports trainers with intellectual disabilities to prepare and run the TOPSIDE training.
- The <u>TOPSIDE Curriculum</u>, which is composed of a database of exercises with easy-to-read summaries to train people with intellectual disabilities to become peer supporters.
- The <u>TOPSIDE Material for Peers</u>, which contains examples of portfolios and materials peers will keep to record and display their competences and to remind them what they have learned.
- The <u>TOPSIDE Guidelines for Mentors</u>, which should advise and direct the activities of the mentors to peer supporters, once those peer supporters have gone through the training programme.

These documents are available at <u>www.peer-support.eu</u>.

#### **3.1. TOPSIDE: Training opportunities for Peer Supporters**

The peer supporter is a lever for change for others with intellectual disabilities. A peer supporter relates experiences from his/her own life and from others to support peers to achieve their goals. People's goals will be about the life they want, about a real quality of life. For many people this means having a good life as part of the community, being as independent as possible, taking decisions and having choices, being valued for who they are and having a valued role in society.

Preferably, peer supporters are people with intellectual disabilities who have experiences of inclusion. Maybe they have a paid job, their own home in the community, or simply personal life situations, experiences and attitudes which can serve as a good example to others and allow then to benefit from this peer support.

#### Peer supporter

The peer supporter:

- can show others how to get the right support in inclusive settings.
- can support someone to see how they can enjoy a good or better quality of life.
- can help others become more socially included.
- can support people who do not see these possibilities for themselves.
- can open other peoples' eyes to what is possible and can help to create new opportunities in the life of their peers.
- can have different roles in the life of the supported person.

The peer supporter also:

- offers experiences, 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.

#### Peer support setting

Peer support can be provided in a range of ways:

- Formal or informal
- One-to-one or in a group
- By volunteers or by paid staff
- Peer-led or facilitated by others
- In person, on the phone or via the internet
- Through workshops or social activities
- Once in a while or on-going

#### Peer support training programme

We have developed a training programme in which everyone can participate. It is flexible for trainers and adaptable for any participants. It is based on ideas from the Index for Inclusion<sup>2</sup>. This index describes how to make learning accessible to everyone. The main idea is that **it is easier to learn from real life situations.** 

2 Index for Inclusion, Tony Booth and Mel Ainscow, CSIE Ld, Bristol, Revised edition, 2002 ISBN: 1 872001 1 81

#### Peer support attitudes

The TOPSIDE project developed a list of skills that a peer supporter should have or develop to be able to provide effective support (see below). When doing the training people should become aware of the following attitudes to other people:

- Respect for the person and his/her environment is important
- Open, not judging anyone
- Respect decisions others' make, not manipulating their decision-making.
- Equal relation: not "showing off" or imposing their views or attitudes on their peer.
- Acting as a "guest" in the life of another person
- Ability to relate different experiences of their own to the person and their situation.
- Trustworthy ( able to respect confidentiality and privacy)
- Having an inclusive attitude

#### Peer supporter skills

The TOPSIDE training is a skill-oriented curriculum. It helps trainees to learn how to support their peers. The skills can be taught using a variety of topics. Repetition is also good to remember skills learnt. Skills should be tied to peer support situations. That way people will understand why the skill is important and what they can use it for as a peer supporters.

The skills we identified during development can be divided in three categories:

**1. Peer to Peer Skills**: these are about communication, reaction and empathy in a face to face or group exchange.

- Communication
- Confidentiality
- Development of roles in society
- Finding out about another person's situation (fear, help, need)
- Find out about support needs
- Giving 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 about inclusion, person centred thinking, valued social roles, and about the importance being a citizen in your community

- Importance of informed decisions
- Knowing my rights and duties
- 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 has 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 relating experiences from different areas of their and others life to the inclusion agenda. It's about being able to use real life examples to support others.

- Asking for help when making decisions
- 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

#### **3.2.** Implementing Peer Support at local level

The implementation of the TOPSIDE training at local level during the project has pointed at a number of issues which facilitate or hinder successful peer support. The most important initial issue was always to achieve the understanding of professionals, family members and people with intellectual disabilities about what peer support is all about. This is an outcome of the very deeply rooted role distribution where professionals and family members are always the "supporters" and the persons with disabilities are always the ones receiving help.

It is very important to discuss and question this role perspective with professionals and family members at local level. They should understand and accept that the fact of **living with an intellectual disability brings about experiences and expertise that other people cannot have.** Valuing and building on this special knowledge changes the perspective on people with intellectual disabilities and opens new roles and opportunities for them. Staff members of partner organisations who were not directly involved in the TOPSIDE project expressed in all participating countries the benefits of such a change of perspectives.

For people living with an intellectual disability, the role change may be even more radical and different. For all of their previous lives they were in the role of recipients of help and support and their life experiences were hardly valued. To experience now that they themselves can support others is often a completely new and very empowering perspective. The same applies also to the supported person: having before always turned to non-disabled people for advice and support, they now benefit from advice of their peers, allowing them to experience a new role model.

The TOPSIDE curriculum includes the necessary steps to train people with intellectual disabilities to become peer supporters. However, it is clear that after the initial training further support for the trained peer supporters will be necessary:

- 1. Re-training may be necessary to retain the learned skills and to refresh and update the skills learned.
- 2. A person in the role of a "mentor" is necessary for a long-time period in order to provide support in difficult situations.

#### **3.3.** Self-advocacy and Peer Support

Self-advocacy is the growing movement of people with intellectual disabilities who speak for themselves. As such it is obvious that there are many links between these two concepts of peer support and self-advocacy. Both are built on the paradigm of empowerment and inclusion and encourage people with intellectual disabilities to participate in all decisions that concern their lives.

Most self-advocacy groups and organisations employ supporters without a disability. The TOPSIDE peer support training is able to add a new perspective to the work of these groups and what they can offer to their members. If qualified peer support became part of the work of these groups, members would certainly benefit from more and more adequate support in making everyday decisions.

Lear more about self-advocacy at <u>www.self-advocacy.eu</u>.

#### 3.4. Peer Support in social services

Peer support can also be a tool to enhance client satisfaction and support in social services. Encouraging and training some clients to become good peer supporters can ensure that client's needs or wishes are easier and better communicated to the professional staff. The advantage is also that professional back-up in case of difficult situations is always available. However, the service provider has to be clear about the roles and responsibilities of the different actors and should ensure the independence of the peer support from any provider interests.

#### 3.5. The necessary legal framework for Peer Support

Peer support as such is not dependent on any legal framework and can be implemented in countries with different legislations and legal traditions. However, especially in countries where guardianship systems still persist, it is important to consider the legal limitations.

When a person is under full or partial guardianship it is essential to recognise and base the support on the recognition that the supported person cannot take decisions as they like. While states are on their way to abolish substitute decision-making according to the UN CRPD, this situation will be encountered quite often. This hampers the effectiveness of peer support, because the supported person and the peer supporter always have to take the guardian's opinions into account.

Another issue, depending again on the area of support, may be the legal liability for the advice and support given. It must be clear from the beginning between the supporter and the supported person that peer support has the status of advice of a friend or relative and that it is better to seek professional advice in complicated decisions. It is also important for organisations or providers who sustain peer support to ensure that the supporters are aware of this issue and are protected.

#### 4. Recommendations

#### 4.1. Recommendations for promoting Peer Support at national level

The situation of people with intellectual disabilities in the Member States of the European Union is very different. TOPSIDE peer support has been implemented so far in the following 10 countries: Czech Republic, Finland, France, Germany, Lithuania, the Netherlands, Portugal, Romania, Scotland and Spain. Thus working experiences with this type of support can be observed in quite a number of language areas. In order to promote and extend peer support, partners have the following recommendations to national governments in the European Union:

- Governments must fully implement Article 12 of the UN Convention on the Rights of People with Disabilities and abolish regulations that include substitute decision-making.
- Governments must also provide access by persons with disabilities to the support they may
  require in exercising their legal capacity. This entails the development and support for a
  variety of measures to support decision-making, among them peer support. It is absolutely
  necessary to develop, create and maintain a number of different flexible options that can be
  used in different situations.
- Governments should support awareness-raising about the issue of legal capacity and support for decision-making in accessible formats for people with intellectual disabilities. This should include awareness-raising for the possibilities of peer-support.
- Possibilities should be explored at national level on how peer supporters could be recognised as personal assistants or social mediators. A formal recognition of peer support or an accreditation of the TOPSIDE training may be possible in some countries.

- Ensure that peer support is included as one support measure in all plans to establish systems of supported decision-making in a country. Support for decision-making must be established in the law as a separate entitlement.
- Develop (financial) incentives for organisations and service providers to establish peer support in decision-making.
- Encourage independent decision-making of people with intellectual disabilities already at younger ages and at schools.
- Ensure that any legislation or policy that is relevant for people with intellectual disabilities is always designed in cooperation with people with intellectual disabilities.
- Governments should support all measures to promote inclusion and empowerment of people with intellectual disabilities, including peer-support and the self-advocacy movement.

#### 4.2. Recommendations for support by the European institutions

The Concluding Observations of the CRPD review of the European Union summarise our recommendations already quite clearly:

"The Committee notes with deep concern that across the European Union, the full legal capacity of a large number of persons with disabilities is restricted. The Committee also recommends that the European Union step up efforts to foster research, data collection and exchange of good practices on supported decision-making, in consultation with representative organizations of persons with disabilities."

From the experiences of the two successful TOPSIDE projects, the partners call upon the European Union to take the following actions:

- The EU should support new model projects that are scientifically supervised, with the aim of testing new schemes for supported decision-making that are not based on a mandate for legal representation.
- The European Union should support awareness-raising about the legal capacity of all its citizens and promote support for decision-making as a way to exercise this right.
- The EU should support the development of quality standards for supported decision-making mechanisms and involve people with intellectual disabilities themselves in evaluating this quality.
- The European Union should ensure that all its citizens can benefit from European legislation and insist that Member States no longer ban access to European citizen's rights through outdated legal capacity legislation.
- The European Union should support all measures to promote inclusion and empowerment of people with intellectual disabilities, including peer-support and the self-advocacy movement.





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