

Peer support survey

Summary of the findings and
recommendations

European Network on Independent Living
December 2016



About the European Network on Independent Living

The European Network on Independent Living (ENIL) is a Europe-wide network of disabled people, with members throughout Europe. ENIL is a forum for all disabled people, Independent Living organisations and their non-disabled allies on the issues of Independent Living. ENIL represents the disability movement for human rights and social inclusion based on solidarity, peer support, deinstitutionalisation, democracy, self-representation, cross disability and self-determination.

Acknowledgments

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1. Introduction

The European Network on Independent Living (ENIL) advocates for better access to peer support for disabled people, as essential to the implementation of the right to independent living. Since its establishment in 1989, ENIL has been highlighting the importance of peer support for the self-determination of disabled people.

Any organization, governmental or non-governmental including organizations for disabled persons, individuals and professionals who use the term 'Independent Living' in their work have to comply with the following principles:

a) to use peer support as the foremost educational tool for sharing information, experiences and insights in order to make people with disabilities conscious of the audio, visual and cultural, psychological, social, economic and political oppression and discrimination that they are exposed to,

b) to make persons with disabilities aware of their possibilities to reach full equality and participation,

c) to empower persons with disabilities by assisting them to acquire the skills to manage their social and physical environment with the goal of full equality and participation in their families and society.¹

ENIL is concerned that, although most European countries have ratified the UN Convention on the Rights of Persons with Disabilities (CRPD), they still fail to ensure adequate access to peer support. Information about where and how peer support is provided, and how it is funded, is also lacking. ENIL had therefore decided to carry out a survey, in order to obtain a better picture of the provision of peer support to disabled people in the European Union (EU) and the Council of Europe area. The survey questions can be found in Annex 1.

This survey was just one of ENIL's activities aimed at promoting peer support at the European level. Another activity was the peer support training organized by ENIL and CIL Sofia, which took place in Sofia in September 2016. After this event, the Peer Support Training Manual, produced in 2014, was updated and can be found at this link.

2. Definition of peer support

According to ENIL, 'peer support' refers to people with a common experience supporting each other on an equal basis. This involves the provision of information and practical, emotional, social or physical support through listening, education, mentoring, mediation, (self-)advocacy, and other. Peer support can be provided one-to-one or in groups and can take place in different settings (for example, people's own home, peer-run organisations, such as Centres for Independent Living or self-advocacy groups, schools, work places, and social or health services), as well as by

¹ For more information, please see: <http://www.independentliving.org/docs2/enildocs.html>

phone or online (e.g. social media, websites, forums, email, etc.). It can be paid or unpaid and can be provided by people with or without training.

Peer support is central to the philosophy and practice of Independent Living and to the effective implementation of Article 19 of the CRPD – Living Independently and Being Included in the Community (Box 1). It is one of the pillars of Independent Living and a tool for empowerment of disabled people. Peer support is also key to implementing deinstitutionalisation, if the process is to result in the full inclusion and participation of disabled people in society, as required by Article 19².

BOX 1: Article 19 – Living independently and being included in the community

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

(b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

(c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

3. Objectives of the survey

ENIL aimed to achieve the following by disseminating the survey:

- To obtain general information about disabled people's access to peer support in Europe, and ways in which peer support is provided;

² For more information, please see, for example: Jaillet, C (2009) *From institutions to Independent Living: the need of peer-support and education programs*, at <http://www.independentliving.org/docs7/JAILLET-C-2009-From-institutions-to-independent-living-peer-support-and-education.html>; R. Barbuto, M. Biggeri, G. Griffo, *Life project, peer counseling and self-help groups as tools to expand capabilities, agency and human rights*, pp. 192-205 in Alter, Vol. 5, Issue 3, (July – September 2011), Paris, at <http://www.sciencedirect.com/science/article/pii/S1875067211000575>; Barguto, R., Ferrarese VI, Griffo G., Napoletano E., Spinuso G. *Peer Counselling. From victims of history to protagonists of the life*. Lamezia Terme (CZ), Comunita Edizioni, 2006; and World Health Organisation (2014) *Innovation in deinstitutionalization: a WHO expert survey*, at http://www.lisboninstitutegmh.org/assets/docs/publications/9789241506816_eng.pdf.

- To map the differences between countries, and to identify the main gaps in the provision of peer support;
- Based on the information provided, to identify actions that should be taken to improve the provision of peer support in Europe;
- To feed into the training on peer support, organised in September 2016;
- To raise awareness among our members, other disabled people's organisations, service providers and the European Commission about the importance of peer support;
- To be able to better plan future work on peer support, based on what is most lacking and what can be achieved at the EU level.

4. Geographical coverage

Twenty six respondents completed the survey, from the following countries: Albania, Armenia, Belgium, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Estonia, Finland, France, Greece, Hungary, Iceland, Italy, Latvia, Lithuania, Moldova, Montenegro, Romania, San Marino, Serbia, Slovenia, Spain, Sweden and the UK. For the UK and Italy, two surveys were completed: for Scotland and Wales in the UK, and for the regions of Latium and Umbria in Italy. Our Greek member did not complete the survey, noting that the concept of peer support is unknown in the country, and there is no peer support provided either by the state or non-governmental organisations.

5. Limitations

Although the survey was sent to people who actively work in the area of Independent Living, disability and human rights, there may be inaccuracies in the information provided. There is no official data available on the provision of peer support in the EU or the Council of Europe area, therefore it was not possible to verify whether the information obtained is correct. In addition, some of the respondents have not provided a full picture of the situation in their respective country, making it difficult to set out in more detail to what extent peer support is available and how it is provided.

6. Summary of the findings

a) Types of peer support available

In a number of countries, including Cyprus, Greece, Montenegro and San Marino, there are no peer support services available to disabled people.

Where peer support is available, it is provided both one-to-one and in groups. The most common types of peer support are self-advocacy groups (16 countries) and individual counselling services (14 countries). Job coaching is the third most popular type of peer support (12 countries). In Belgium, France, Hungary, Iceland and Italy, more than one type of peer support is available.

There are certain differences between different regions within a country or between municipalities, in how peer support is provided: whether it is formal or informal, the types of peer support available, how it is funded and who provides it. The respondent from Italy noted the difficulty in collecting data about the peer support provided when there is no separate budget line for peer support:

“Everything depends on the regions and there is no funding allocated specifically for peer support. There can be cases in which some associations get general funding and then, among other things, provide peer support. But you cannot know, because the funding is general and then each association allocates it to different activities.”

b) Providers of peer support

Peer support is provided by a wide range of providers (Box 2).

A total of 18 countries reported that peer support is provided by non-governmental organisations (NGOs), disabled people’s organisations (DPOs) or Centres for Independent Living (CILs). It should be noted, however, that not every country has a CIL, or there can be only one CIL in the country; for example, in Bulgaria, CIL Sofia is the sole existing Independent Living organisation. In 5 countries, peer support is provided by self-advocacy groups³: Albania, Belgium, France, Hungary and Scotland. In 6 countries, peer support is provided through service providers, both public and private. For example, in France, private companies provide job coaching, as is the case in Serbia. It was again highlighted that the type of support and the way peer support is provided depend on the region/municipality where the disabled person lives.

BOX 2: Providers of peer support

Country	DPO/NGO/CIL	Self-advocacy groups	Service provider	Rehab centre	Housing services
Albania	x	x			
Armenia	x				
Belgium	x	x	X		
Bosnia & Herzegovina	x			x	
Bulgaria	x	N/A	N/A	N/A	N/A
Cyprus ⁴					
Croatia	x				
Estonia					
Finland					x
France		x	x (job		

³ This term refers to all types of self-advocacy groups, regardless of the type of impairment.

⁴ The respondent from Cyprus indicated peer support was provided by paid staff, but did not state where they were based.

			coaching)		
Greece	N/A	N/A	N/A	N/A	N/A
Hungary	x	x			x
Iceland	x				
Italy (Latium)	x				
Italy (Umbria)	x		x		
Latvia			x		
Lithuania	x				
Moldova	x				
Montenegro	N/A	N/A	N/A	N/A	N/A
Romania	x				
San Marino	N/A	N/A	N/A	N/A	N/A
Serbia	x				
Slovenia	x				
Spain	x		x		
Sweden	x		x		
UK (Scotland)	x	x			
UK (Wales)					
Total:	18	5	6	1	2

c) Funding

By the state/region/municipality or other official authority

In most countries (17 in total), there is no state, regional or local funding for peer support. These include: Albania, Armenia, Belgium, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Hungary, Iceland, Italy (Latium), Lithuania, Montenegro, Romania, Serbia, Slovenia, Spain and Wales.

In Estonia, the state is funding peer counselling as a rehabilitation service or as a measure to get disabled people into the labour market. The state budget and the European Social Fund (ESF) jointly fund the service. There are no legal restrictions on the type of body which can provide social rehabilitation services or peer support as a labour market inclusion method.

In Finland, peer support has been available for 10 years, with the funding considered as sufficient for the needs of disabled people. In Latvia, the service has also been available for 10 years. However, the limited funding does not cover all who need this kind of support. France reports that only “*the funding of the peer support group for*

people with psychosis (GEM) comes from the State". In Moldova, a small amount of funding is provided by the local community centres.

In Scotland, funding for peer support services comes partly from the Scottish Government and partly from the local authorities. Some funding is also raised by charitable donations or grants from charitable trusts. The level of support varies across local authorities and, therefore, the level of service and availability of peer support also varies.

In Serbia, peer counselling is a compulsory element of personal assistance services. However, this service receives limited funding or none at all, leading to the provision of peer support by non-governmental organisations on a voluntary basis.

Other funding

Asked whether peer support is provided through other funding, such as projects, donations, lottery, etc., 20 respondents reported that organisations apply for funding through projects. Only Belgium, France and Montenegro answered with a 'no'. Peer support was reported as being provided on a voluntary basis in Bulgaria, Belgium, Iceland and Romania.

d) Legislation and policy covering peer support

ENIL's survey showed that 7 out of 16 countries have legislation or policy on peer support in place at the national level. These include: Albania, Estonia, France, Latvia, Scotland, Serbia and Sweden. In Albania and Serbia, peer support is not explicitly mentioned in the legislation, but the law offers the possibility to organise and license a service that responds to users' needs.

Sixteen countries have no policy on peer support. These are: Armenia, Belgium, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Hungary, Iceland, Italy (Latium), Lithuania, Moldova, Montenegro, Romania, Slovenia, Spain, Wales.

e) Understanding the importance of peer support

The survey aimed to assess the degree to which key stakeholders – disabled people, local authorities and service providers – understand the importance of peer support for Independent Living. The level of understanding was assessed on a scale from 0 to 10, where 0 means 'do not understand at all' and 10 means 'fully understand'. The results show that disabled people and their organisations are considered to be those most aware of the importance of peer support, with an average score of 6,2. Authorities scored low, with an average estimate of 2,7 out of 10. Service providers were rated slightly better, with 4,2 out of 10.

7. Conclusions

Results of the ENIL survey indicate that the concept of 'peer support' is still not well known in many European countries, and that peer support lacks state funding. ENIL

finds this problematic, as peer support is central to the effective implementation of Article 19 of the CRPD and the closure of institutions. There is, therefore, a need to advocate for the provision of peer support services at all levels in society, as everyone, regardless of where they live, should have access to this important tool for empowerment. It is discriminatory if individuals in the same country cannot access the same service.

Considering that funding from the state, regional or local authorities is either lacking or is too scarce, DPOs are forced to look for project funding. Although project funding enables them to provide peer support, it is usually short term, which severely limits the availability of the service. As a result, many DPO members become peer supporters on a voluntary basis – they provide peer support in their free time and without being paid, which is unsustainable. There is, therefore, a need to raise awareness about the crucial importance of peer support for independent living of disabled people.

The survey shows that disabled people themselves and their organisations lack understanding about the importance of peer support. Possible reasons for this, as suggested by those who completed the survey, are: mentality, the prevailing medical model of disability and the lack of awareness raising about the concept of peer support, which is still unknown in many European countries. This points to the need for awareness raising and empowerment of disabled people themselves.

8. Recommendations

ENIL believes that all disabled people must have access to peer support, which facilitates and supports their right to live independently in the community. For this to happen, we urge the national, regional and local governments to take the following actions:

- Adopt legislation on peer support, which is compliant with the UN Convention on the Rights of Persons with Disabilities and reflects the philosophy of the Independent Living Movement;
- Ensure that peer support is supported at the national level, with the funding allocated to the individual, to ensure equal access throughout the country;
- Ensure that peer support services are in line with the social and the human rights model of disability, and not carried out using a medical approach;
- Improve data collection about the availability of peer support, to enable the development of adequate legislation and policy in this area.
- Support local CILs to improve their capacity for delivering and promoting peer support.
- Ensure deinstitutionalisation strategies or programmes include peer support services.

Annex 1: Questionnaire

I. General information

Country/region:	
Date:	
Contact person:	
Email address of the contact person:	

II. Information about peer support

1. What types of peer support exist in your country (<i>for example, individual counselling, job mentoring, self-advocacy groups, etc.</i>)?	
2. How is peer support provided (for example, by Centres for Independent Living, public or private service providers, etc.)?	
3. Is funding for peer support provided by the state/region/municipality or other official authority (<i>please specify the type of authority</i>)?	YES/NO <i>(If no, go to question 4)</i>
3.1. How long has such funding been available?	
3.2. Who can receive funding to provide peer support (e.g. non-governmental organisations, private companies)?	
3.3. In your opinion, is this funding adequate to the needs?	
4. Is peer support provided using other funding, such as projects, donations, lottery, etc. (<i>please give details</i>)?	
5. Is there legislation or policy covering peer support?	YES/NO <i>(If no, go to question 6)</i>

5.1. Please give the full name of the legislation/policy in English and in your language?	
5.2. When was it adopted?	
5.3. How is peer support defined in the legislation/policy?	
5.4. Does it say anything about funding for peer support?	
6. Do the main stakeholders understand the importance of peer support for the independent living of disabled people? <i>(Please, give your answers on a scale from 0 to 10, where 0 is 'do not understand at all' and 10 is 'fully understand')</i> ?	<p>Authorities</p> <p>0 – 1 – 2 – 3 – 4 – 5 – 6 – 7 – 8 – 9 – 10</p> <p>Disabled people and organisations of disabled people</p> <p>0 – 1 – 2 – 3 – 4 – 5 – 6 – 7 – 8 – 9 – 10</p> <p>Service providers</p> <p>0 – 1 – 2 – 3 – 4 – 5 – 6 – 7 – 8 – 9 – 10</p> <p>Comments:</p>
7. Other comments?	

Annex 2: List of respondents

Name	Organisation	Country
Anisa Proda		Albania
Suela Lala		Albania
Armen Alaverdyan	UNISON NGO	Armenia
Peter Lambreghts	Onafhankelijk Leven	Belgium
Sanja Jokic		Bosnia and Herzegovina
Tanja Mandić Djokić	Association Women with Disabilities "NIKA"	Bosnia and Herzegovina
Dilyana Deneva	Centre for Independent Living Sofia	Bulgaria
Janko Ehrlich-Zdvořák	Spinalne ozljede Zagreb	Croatia
Chrysis Michaelides		Cyprus
Mari Siilsalu	ENIL	Estonia
Maarit Aalto	Aspa	Finland
Eve Gardien		France
Kamil Goungor	i-living	Greece
Kata Kiss-Miklós & Eva Caesar	National Federation of Disabled Persons' Associations – MEOSZ	Hungary
Stefán Vilbergsson		Iceland
Marina Voudouri	ENIL, ENIL Italia	Italy (Latium)
Francesco Conti	ENIL Italia	Italy (Umbria)
Mārtiņš Karnītis		Latvia
Kristina Dūdonytė		Lithuania
Elena Ratoi	Mottivation	Moldova
Marijeta Mojašević		Montenegro
Iulia Danila	Fundatia Rafael Coldea	Romania
Raluca Oancea		
Mirko Tomassoni	Attiva Mente	San Marino
Bill Scott	Inclusion Scotland	Scotland
Milanka Lana Nikolić	Youth Initiative for Human Rights	Serbia
Milica Mima Ružičić-Novković	CIL Serbia	Serbia
Katrin Modic	YHD	Slovenia
Javier Arroyo Méndez	ASPAYM Madrid	Spain
Jamie Bolling	ENIL	Sweden
Joe Powell	All Wales People Frist	Wales

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