

Peer Support for Independent Living A Training Manual

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Introduction

The European Network on Independent Living (ENIL) and Centre for Independent Living Sofia (CIL Sofia) held a 1-day training event on Peer Support as part of the project 'Proud, Strong and Visible – Promoting Choice, Control and Participation of Disabled People in Europe'. The project's main goal is to facilitate the implementation of Article 19 (Living independently and being included in the community) of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the Member States and the European Union. Since Peer Support is one of the pillars of the independent living philosophy and a tool for achieving the core objectives of the Independent Living movement, it was decided that a training event would be beneficial. Therefore, CIL Sofia members with experience in the field took the responsibility to organise such an event targeted at independent living activists willing to provide peer support by themselves and/or to spread their experiential knowledge in order for such a service to be provided by centres for independent living or other organisations of and for disabled people.

The training brought together 11 participants from Bulgaria and Macedonia, their personal assistants, 1 trainer and 1 facilitator. The training took place in the capital of Bulgaria – Sofia, in CIL Sofia's office – a place where numerous initiatives promoting the independent living philosophy have been held in the last 20 years.

Context of the Training Manual

This training manual brings together materials developed for the Peer Support Training held on 21st June 2014 in Sofia, Bulgaria. These can be used by other Disabled Persons' Organisations at the local, national or European level, when organising similar events on Peer Support and Independent Living. Materials in this publication should be adapted based on the objective of the training event, its length and the target audience (also taking into consideration different access requirements).

This training manual comprises of two sections: **Part A** outlines the theory behind Independent Living and Peer Support. Section one describes the term 'Independent Living' and how the right to Independent Living is recognised in the UN Convention on the Rights of Persons with Disabilities. It also explains the objectives, principles and origin of the Independent Living Movement along with the establishment of the European Network on Independent Living. Section two illustrates what Peer Support is and what role it can play in Deinstitutionalisation, along with its benefits, functions and necessary ingredients. This section also describes a case study of Peer Support and includes two personal accounts of Peer Support.

Part B, on the other hand, highlights the session outlines, practical training and personal reflections from the actual Peer Support Training event held on 21st June 2014 in Sofia, Bulgaria.

PART A: Background information



Section 1: Independent Living

What is Independent Living?

The European Network on Independent Living defines independent living as ‘the daily demonstration of human rights-based disability policies. Independent Living is possible through the combination of various environmental and individual factors that allow disabled people to have control over their own lives. This includes the opportunity to make choices and decisions regarding where to live, with whom to live and how to live. Services must be accessible to all and provided on the basis of equal opportunity, allowing disabled people flexibility in their daily life. Independent Living requires that the built environment and transport are accessible, that there is availability of technical aids, access to personal assistance and/or community-based services. Independent Living is for all disabled persons, regardless of the level of their support needs’. The key principles of Independent Living are: choice, control, freedom, equality.

“Living independently” does not mean that disabled people have to be independent in the sense of living a highly individualised and self-sufficient life, at a distance from other people. It is, rather, based on a social model of disability, which recognises that people are not limited in their choices because of any inherent feature or condition of the person themselves, but by the social and physical environment in which they live. In enabling environments, things are not done *to* a person, but rather disabled people are supported, just like anyone else, to make independent and autonomous, and when needed, supported decisions.

The Academic Network of European Disability Experts (ANED) (2010, p.8) explains that ‘Independent living has a number of different dimensions, in terms of both its *goals* and the *means* to be used to achieve these goals. Overall, the *goal* of independent living for disabled people is that they should have choice and control over the decisions, equipment and assistance that they need to go about their daily lives, so that they can participate in society on the same basis as other people. This ultimately involves access not only to personal support services but also to wider services like appropriate housing, transport, education, employment and training.’

Independent Living as a Right: Article 19 of UN CRPD

Article 19 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) explicitly recognises independent living as a human right. Article 19 is entitled ‘*living independently and being included in the community*’ and it explains that all disabled people should be able to decide where and how they live in their local communities, just like everybody else. Importantly, it imposes obligations on States. It requires that disabled people be provided with the support that they may need to participate in every-day life, such as going to work, going to school and taking part in community activities. This entitles disabled people access to a range of personal support services, such as personal assistance, and also equal access to wider services such as appropriate housing, transport, education, employment and training, on an equal basis with other citizens. Therefore, this demands not only the removal of the

barriers to inclusion, such as discriminatory practices, but also the development of creative, personalised support services which cater for personal circumstances. Ultimately, it means that disabled people are to be treated as equal, participating citizens capable of directing their own lives and not as objects of care to be 'managed' (the social model of disability). Article 19 does not differentiate between people with different impairments and applies equally to all disabled people. This means that everyone should have the right to live independently, regardless of the "severity" of their impairment, their age, gender, ethnicity, material status or any other characteristic.

Article 19 - Living independently and being included in the community

States Parties to the present 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.

The Independent Living Movement

The main objective of the Independent Living Movement is to change the status of disabled people - from patients and objects of care and charity to equal citizens and rights holders. Independent Living focuses on empowerment and demands the same degree of self-determination, freedom of choice and control over everyday life for disabled people, as expected by any other citizen.

Any organization, governmental or non-governmental including organisations for disabled persons, individuals and professionals, which uses the term 'Independent Living' in their work, should comply with the following principles:

1. Solidarity

- To work actively for the development of **full equality and participation** for disabled persons regardless of type or extent of their impairment, sex, age, residence, ethnic origin, sexuality or religion.

- To work so that disabled people can have the **resources** to live independently.
- To recognise **Independent Living as a basic human right**.
- To share or exchange information, advice, support and training for persons with disabilities in appropriate form, e.g. tape, braille, large print, easy read, free of charge, or, where there is a charge, to ensure that disabled people have the resources to pay for these services.
- To cooperate with and support other organisations who belong to the international Independent Living network or who support the goals of the Independent Living movement.

2. Peer support

- To use peer support as the foremost **educational tool** for sharing information, experiences and insights, in order to make disabled people conscious of the audio, visual and cultural, psychological, social, economic and political oppression and discrimination that they are exposed to.
- To make disabled persons **aware of their right** to be fully included and participate in the society.
- To **empower** disabled persons 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.

3. Deinstitutionalisation

- To **oppose all types of institutions**, stationary or mobile, especially designed for disabled persons. An institution is any public or private establishment, organization or service which creates special segregated solutions for disabled people in education, work, housing, transportation, personal assistance and all other areas of life, which by its nature limits disabled persons' possibilities to make their own decisions about their lives or reduces their opportunities to participate in society on equal terms. In particular, establishments, organizations or services may not use the term 'Independent Living', if they promote or accept personal assistance services that require the user to live in special dwelling units or which deny or reduce the individual user's right to full choice and control over his or her life by forcing the user to live by the routine of others.

4. Democracy and self-determination

Organizations may use the term 'Independent Living' to describe themselves only if all the following conditions are satisfied:

- If they are membership organisations based on democratic principles such as one person - one vote, and
- If full membership with voting rights is reserved for disabled persons only, and
- If the organisation as a practice **favours disabled persons for positions** within the organisation for both paid staff and volunteers, including the head of staff, and
- If the organisation as a rule is represented in negotiations, meetings and the media by disabled persons.

Origins of the Independent Living Movement

The Independent Living movement was active in the United States of America from the 1960s and 1970s and the first well-known Centre for Independent Living (CIL) was established at the California University in Berkeley in 1972 by Ed Roberts, who is often credited as the 'Father of Independent Living'. The history of the Independent Living movement in the U.S. is closely tied to the civil rights movement of the 1950s and 1960s among African Americans. The idea of the Independent Living movement began to spread to Europe in the late 1970's. One of the pioneers of the movement in Europe was Adolf Ratzka. At the age of 22, he won a scholarship to study in California. There, he experienced personal assistance and other accessible facilities. In 1973, he moved to Sweden, where he found that attitudes towards disabled people were much different. In 1984, he founded STIL – the Stockholm Cooperative for Independent Living. The idea was to reverse the situation of disabled people, where they are perceived as service users, not patients or objects of care. In the UK, the Independent Living movement began in the early 1980's by disabled people, such as John Evans, who wanted to move out of institutions and into the community, with the most notable of these being the group known as 'Project 81'. Similar self-advocacy movements emerged around this time in Finland, Zimbabwe, Switzerland, Japan and Canada.

Initially, the Independent Living movement was primarily focused on the critical analysis of the over-medicalisation and professionalisation of the rehabilitation system. It has since developed into a thriving grassroots movement with disabled people themselves running and controlling CILs and developing expertise around independent living issues by using approaches such as peer support and advocacy. Although the Independent Living movement has spread to many countries, personal assistance is still not widely available and large numbers of disabled people are still segregated in institutions.

The European Network on Independent Living

The European Network on Independent Living (ENIL) was established in 1989 when over eighty disabled persons and supporters from the Independent Living movement gathered in Strasbourg, France for a conference on personal assistance. There, they agreed on the need for a Europe-wide forum for disabled people to foster and develop the independent living ideas across Europe. ENIL has since become a strong, grassroots NGO that advocates and lobbies for independent living values and principles by targeting European, national and local administrations, politicians, media and the general society. ENIL's mission is to:

- Promote the Independent Living philosophy among disabled people, general public, national policy makers, government administrations, as well as among regional bodies such as the European Union, the Council of Europe and the Organisation for Security and Co-operation in Europe (OSCE);

- Develop the concept, principles and definition of Independent Living. Promote the development of Centres of Independent Living throughout Europe and enhance solidarity and networking among them;
- Carry out training and awareness raising activities at the European level;
- Represent Independent Living Organizations and the Independent Living movement at the European level and in different European bodies and organizations (the European Disability Forum, the EU Fundamental Rights Agency's Fundamental Rights Platform, the Council of Europe Conference of INGOs etc.);
- Combat social exclusion and discrimination through policies which promote Independent Living of disabled people. Make the Independent Living framework instrumental to ending discrimination against disabled people in Europe;
- Embrace the social model of disability in acquiring independence and self-determination by overcoming the barriers of the medical and attitudinal models.

Section 2: Peer support

What is Peer Support?

Peer support is the term used to describe the help and support that people with lived experience are able to give to another individual similarly situated; for example, it can refer to support provided by somebody who has lived in an institution to other people living in institutions. This support may be social, emotional or practical (or all of these).

In mental health, peer support is described as 'a system of giving and receiving help founded on key principles of respect, shared responsibility and mutual agreement of what is helpful. Peer support is not based on psychiatric models and diagnostic criteria' (Mead et al, 2001, p.135).

Peer support has and continues to be fundamental to the philosophy and practice of independent living organisations in the empowerment of disabled people because it facilitates a grass-roots process. The development of peer support and peer advocacy began in the mental health field in the U.S., New Zealand and Australia, when people began to move from institutional to community-based services. The Independent Living Movement and disabled people's organisations continue to view **peer support as an essential element in the bridging between dependency and independent living** and understand that **disabled people are experts in recognising the barriers they face and the means in which those barriers can be tackled.**

What Role can Peer Support Play in Deinstitutionalisation?

Only through sharing personal experience and social networks is it possible for an individual who has been living in an institution, sometimes for years, to make the necessary steps towards life guided by his/her own choice and control. No expert authority can provide that needed support in terms of advice and discussion about possible mistakes and achieved successes, and sharing of personal social contacts. Someone who has gone through the same difficulties and adversities can provide not only valuable and practical support, but also support which is trustworthy in the eyes of the recipient. For these reasons peer support can play a vital role in deinstitutionalisation processes, especially when disabled people are initially transitioning from the institution to housing options in the community. It is important to see **peer support/social networking as part of an independent living package that disabled people can receive in their respective countries to support them in making choices in their community.**

Peer support is a strengths-based approach to supporting independent living which focuses on what the individual can do and their personal strengths. It is the foremost educational tool for sharing information, experiences and insights, in order to make persons with disabilities aware of their possibilities to reach full equality and participation. Peer support empowers 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.

What are the Benefits of Peer Support?

- Peer Support offers a valuable exchange of experiences as peer supporters have a better understanding of the situation experienced by the person seeking advice. Fears and insecurities are better understood and mutual trust can be more easily established between the person seeking advice and the peer supporter. In this way, peer support offers unique perspectives.
- Peer supporters can provide the assistance required for people with disabilities to really be in control and direct their own support.
- Peer supporters often have an intimate knowledge of community resources and what works best. Peer supporters can offer guidance through what can appear a maze of services.
- Peer support often involves awareness raising about injustice and discrimination.
- Because of their experiences, peer supporters are more credible role models for others similarly situated.
- Peer support is a way of validating people's differences and challenging mainstream approaches.

- People are more likely to be honest and open up to a peer.
- It provides great flexibility in the type and variety of support provided.
- Peer support has proven to be an essential element in giving people opportunities to control their own lives and, where such support does not exist, this has had a negative impact on the implementation of self-directed support.
- Peer support is often pragmatic and tailored to an individual's own circumstances.

What are the Different Types of Peer Support?

Broadly, there are three models of peer support:

1. **Informal and ad-hoc support among peers** is where support is offered and reciprocated to similarly situated individuals without being formally organised (such as an individual who reaches out and supports a new colleague in work without being directed to do so).
2. **Organised but unpaid peer support** is generally undertaken by volunteers who take on roles such as 'mentors' or 'peer buddies'. This is commonly offered by disability organisations because they often do not receive adequate funding by local governments to carry out their work and so must rely on volunteers for vital services. Most disability organisations employ a person as a volunteer co-ordinator to organise and manage this type of support.
3. **Paid peer support** is where disabled participants are generally part of a team contracted to provide services to users of disabled people's organisations, such as Centres of Independent Living.

What are the Functions of Peer Support?

Some functions of peer support include:

- **Informing and connecting** – supporting people by providing good information about local resources and entitlements, researching new possibilities, offering advice around self-directed support and assisting people make helpful connections. It may be social, emotional or practical support (or all of these).
- **Guidance and planning** – supporting people to think through their needs and desired outcomes and helping people to develop their support plans.

- **Negotiating and advocating** – supporting people to negotiate contracts and agreements with others and to advocate for their own needs when necessary. Offering solutions to barriers.
- **Organising and setting up** – supporting people organise their support systems, recruiting supporters and agreeing guidelines.
- **Managing and improving** – supporting people manage their funding, their supports and using expert advice to make improvements.
- **Reflecting and developing** – supporting people to review their needs and their support arrangements and to initiate changes when necessary.

What are the Necessary Ingredients of Peer Support?

- Maintaining its non-professional vantage point is crucial in helping people rebuild their sense of community when they've had a negative experience and feel cut off from their family and friends.
- It is important that those involved in providing peer support understand their role and are careful not to overstep the boundaries from offering support to being an instructor or creating a relationship of dependency.
- Peer support is about people with a particular experience or background advising and supporting others in a similar situation. While this support often happens in informal ways, there is also clear evidence of the value of a more formal delivery of peer support as a service, whether this is provided by volunteers or paid workers.
- The boundaries of peer support need to be clear. There is a difference between providing information and advice, and providing peer to peer support. It is also necessary to distinguish between peer support and counselling, and peer support and independent advocacy. There can be a fine line between peer support and befriending. Both peer support and befriending aim to build supportive relationships over time and both include social elements within them. The main difference between the two is the emphasis placed on goals. Peer support focuses more on goal setting within a time-limited process whereas befriending tends to develop more informal, supportive relationships, often over a longer period of time.
- It is important for the people involved to understand that whilst two people might share much in common, they will not necessarily take the same view about everything. A peer supporter should not impose their views on the person to whom they are providing support.

- A defining feature of peer support is that it refers to relationships and interactions between people who are peers. The focus should not simply be on 'activities', because the nature of the relationship is crucial in really understanding peer support and its potential. However, limits do need to be set within those peer relationships.
- Peer support is mutually offered and reciprocal, allowing peers to benefit from the support whether they are giving or receiving it and for mutual responsibility to be promoted.

ENIL and Peer Support

Promoting the role of peer support in the transition from institutional care to community living has been an important part of ENIL's work for a number of years. In partnership with CIL Sofia, ENIL launched a project to support young disabled people living in institutions in Bulgaria. This project aimed for Peer Support to be the bridging element between dependency and independent living. Only through sharing of personal experiences and social networks is it possible for someone who has been living in an institution for years to make the necessary steps towards life guided by his/her own choices. No expert authority can provide that needed support in terms of advice, discussion about various opportunities, but also risks, and sharing of personal social contacts. Someone who has gone through the same difficulties and adversities can provide not only valuable and practical support, but also support which is trustworthy in the eyes of the recipient. It is important to view peer support/social networking as part of an independent living package that disabled people may receive in their countries to live a life they choose. That is why, in cooperation with ENIL, CIL Sofia has been working with young disabled people from three small group homes in Bulgaria, providing the peer support they need in order to live independently.

Case Study of Peer Support: CIL Sofia

Supporting disabled people in institutions to transition to Independent Living arrangements in the community – regardless of their impairment or the size of the institution – is one of the major goals of CIL Sofia. This important work takes place in close cooperation with ENIL as part of promoting the right to independent living.

It all started when a member of CIL Sofia was contacted by a resident of a small group home. This encouraged the team to start providing peer support as part of its work on deinstitutionalization. A project for peer support of young disabled people living in institutions was developed and its implementation started in 2012, with two group homes. In 2013, one more group of young disabled people placed in a small group home joined the network.

The main goal of this project was to set the stage for transition from institutional care to social housing and community living for people with disabilities who spent years in institutional care, regardless of their impairment and level of support needs – as prescribed by the CRPD. CIL Sofia's aim was that disabled people should be supported to move from institutional care (which, in this case, includes small group homes) to Independent Living arrangements. In order for this to become a reality, CIL Sofia selected a group of Independent Living activists to help the institutions' residents to cope with the process of deinstitutionalisation through transfer of skills and individual support. Among the objectives of this work is to empower the young disabled adults who are willing to take the journey to Independent Living through coaching and peer support; enabling them to get access to resources they need to live in the community; mobilizing support for regular social housing and supported living in the community with personal assistance and peer support.

The institutions in all three locations (Stara Zagora, Lukovit and Dalbok Dol) are now regularly visited by Independent Living activists (CIL Sofia members) and a particular peer support agenda is followed. Of course, this agenda and all planned activities are designed according to the specific needs of the young people being supported. A great amount of individualised work is involved in this project. It laid the foundations for the next steps in the peer support scheme – the creation of individual work plans. Each participant prepared this plan with the help of their peer supporters, and engaged with its implementation. *(More information about the work involved can be found in the personal accounts below.)*

In their work as peer supporters, CIL Sofia members try to provide the young people with role models of disabled people who are living an independent life, and have achieved something in their professional and/or personal life. One such person is Mirko Tomassoni – ex-captain regent (equivalent to 'president') of San Marino. He came to Sofia for a study visit in September 2013 and dedicated a part of his time to the young disabled people in one of the small group homes in Bulgaria. His study visit contributed to the training process immensely. He met the residents of the social home in Dalbok Dol and shared his valuable experience from San Marino. It was an open, sincere meeting between a man who has reached the highest level of the political hierarchy in his country and young people who were so far denied any opportunity to become active citizens. The difference was dramatic, but interestingly, there was no gap in the communication – the young people were asking

their questions with unhidden curiosity, and Mr. Tomassoni was more than willing to reply to everything. Afterwards, he shared his impressions from the visit in the small group home with the Head of the Commission of Labour and Social Affairs of Bulgaria. This was also helpful for the ongoing work of CIL Sofia in the area of deinstitutionalization.

Experience of Being a Peer Supporter: Maria

The day of 21st December 2012 is when I first had the chance to meet the young residents of the small group home in Lukovit. This was a meeting which changed me personally, and I hope them too. The first moment I saw them I felt an inner contradiction about what kind of people they are – there was fear in them which I felt. And why not – this was the second time in their lives they were leaving the social institution and coming to Sofia to meet somebody they don't know. There is one more thing I felt in them – they were feeling proud. A strong word, I know, but it describes them best – they were proud to go out of the home without the staff members supervising them. This was a small but a very important step for them. During the next two years, many such small but at the same time big steps were about to come.

I found common language with them immediately – probably because we are mostly of the same age. The first thing I noticed in the communication from the first hours was that they were treating me with great respect – as towards an authority figure. Despite being young adults, they were behaving like children – kind of shocking to me. They were looking at me like a person they can rely on, they can ask for advice and even protection. I thought that this was understandable since they were coming from a world where their concepts for things like relationships were distorted. They were perplexed by the way I was behaving towards them – I was treating them as an equal. We were talking about different topics, we were sharing themes from our everyday lives, sharing our personal experience with each other. And now after about two years I hope they see a friend in my face, not only an authority figure.

With two or three girls I have been having everyday conversations on different topics – from what we've cooked that day to sharing how they cope with the other young people in the home and finally – to sharing some dramatic experiences from their childhood spent in different institutions. It was very difficult to gain their trust. From the beginning, we set some rules of communication (including certain boundaries for both sides), we proceeded gradually with many conversations and in this way a mutual trust relationship was established. They were used to rely solely on themselves and at the most – on other people from the home. They didn't have anyone in their lives to listen and try to understand them.

With the trust built between us came the moment when they actively looked for us, not just the other way around. As an example, one of the girls from Lukovit – Petya - asked me to accompany her in Spain for 5 days. This was the first time she was leaving the country, and the first time she was without any of the institution's staff. Of course, she was anxious before the trip and constantly seeking my help and advice – about what to bring with her, how to behave, etc. My colleagues and I supported her in every way we could and eventually Petya overcame her fear and enjoyed the whole travel experience a lot.

One of the topics we discuss often with the young residents of the small group home in Lukovit is what they will do next in their lives – whether/how/when they will study and work. Prior to our peer support programme, they hadn't really considered this. I have shared with them my personal experience of moving out of my hometown and coming to the capital to study at the university and live alone, which involved taking some responsibility for my own life. This is probably something that the young people we support lack most – they have never been responsible for anything in their lives. Neither for anything big and important, nor for small, everyday, mundane things. So learning to take responsibility is among the greatest challenges for us as peer supporters and, in my opinion – I think our work was quite successful in this respect.

The change was definitely two-way – first and foremost for them, but for me as well. I learned to appreciate what I had taken for granted before. But above all – I learned never to give up (something which I tell them all the time).

I would say that the peer support my colleagues and I give to the young people from Lukovit is essential for their development as persons who are coming closer to the moment when they will be ready to leave the group home and start living independently and become active members of the society. Of course, there is still a lot of work ahead – on their self-confidence and decision making skills, but like I said above – they also learn to never give up.

Experience of Being a Peer Supporter: Nina

My first meeting with the young people from the small group home in Lukovit was at the end of August 2012 at the Sofia Zoo. That day, I thought of them as strange – they were timid, shy, indecisive and at the same time quite tense boys and girls. I was not able to determine their age, but from the conversations we had (which was going far from smoothly) I understood they are students in the higher classes of high school, despite being above 18. I was surprised to notice their behaviour – typical of teenagers aged 14 to 15 years. Most of them were dressed in clothes with cartoon characters – Mickey Mouse, Mini Mouse and some fairy tale princesses. There were three staff members from the group home who were constantly keeping an eye on them, but not only for their behavior; it was evident that they were very controlling. This was not good – the young people seemed very afraid of them and were very careful all the time, like 'walking on thin ice'. At that time, it was very difficult for me to see the group as young adults. To me, they were children and I was justifying my attitude towards them with the fact that my son and daughter were their age. Today I can't imagine calling any of them a 'kid' – for these two years they changed a lot – grew up, became more mature, some of them graduated from high school.

In fact, during these two years I was mainly working with Petya Garova, also known as Thumbelina (her nickname in the group home). I've also been a peer supporter to one more boy and a girl from the group home in Lukovit. In addition, I've had occasional conversations with the other residents, but I wouldn't call these systematic peer support.

I can't say it all happened smoothly with Petya, nor quickly. Petya was very suspicious and timid, she didn't allow people to come close to her emotionally. I say 'emotionally', because she doesn't have any physical private area at all. In the group home, nobody has his/her own

space. They know each other so well (all their life stories, what they like to eat, to wear) because they are together all the time, but they keep their emotions to themselves. I share all this because it was what I was thinking when I considered whether to take the huge responsibility to become a peer supporter. I took the commitment knowing that I will be doing something which could change somebody's life and it is up to me whether this change would be positive or negative. I decided to be a peer supporter of the girl who seemed most close to me from first moment – Petya.

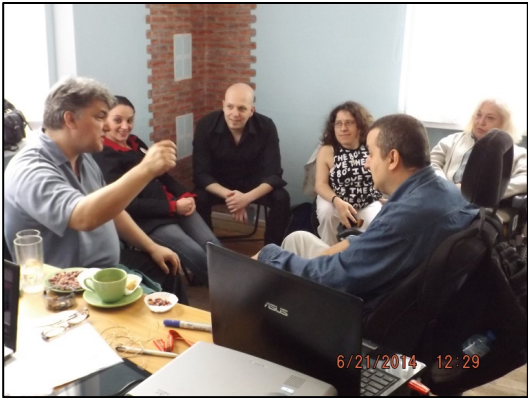
Petya is a small 25-year-old girl, about 1m20cm high and weighing not more than 25kg. Due to a decision by the group home staff she is using a huge and pretty uncomfortable wheelchair, which cannot be replaced by a more suitable one since the term defined by the state hasn't ended yet. Petya's eyes are her most impressive feature – big and brown, constantly touching the world around her with curiosity and not missing anything. She is noisy and clamorous, at times even intemperate – she can curse like the greatest cynic, but this behavior has saved her from the hell which she's gone through. Her life has passed in social institutions and social homes, her parents have abandoned her right after birth – they weren't able to care for a child with a serious impairment.

It wasn't easy to earn Petya's trust. Numerous times she's checked with my colleagues from CIL Sofia whether what I've told her is true or not. But the most significant moment is her trip to Spain with a group of CIL Sofia members and members of the Bulgarian Academy of Science – due to a mutual project. This trip was Petya's first chance to go out of the social institution, to escape her everyday surroundings, all alone, even to leave the country. Let alone flying with an aircraft... Completely understandable, she was terrified of all this. In my opinion, this trip turned out to be a turning point in Petya's life. To a great extent it changed her view of the world, made her dream, taught her that if you manage to overcome your fears, they cease to exist; it opened the door towards a world where disabled people are treated like normal human beings. Now she will surely be braver and far more confident if she has another chance to go abroad.

During my work as a peer supporter I frequently had to have long, motivating conversations about school, life, different everyday problems. I've given personal examples – regarding my adventures in building a house in the suburbs and on other topics as well. I've shared my life experience, accumulated during the long years I've been living as a disabled but independent person. I've given advice when needed, I've scolded her when she failed her school exams. I've helped her write poems. My last aim for the time being is to try to build enough boldness and faith in her in order to apply for university and believe that she is first and foremost a person – capable, smart, intelligent; and only after these – disabled.

Now after a bit more than two years of working as a peer supporter of Petya, I dare say that she is very different, far more mature and developed as a person. She has started accepting things in a slightly different way. Now she is brave enough to start thinking about living independently outside the institution, as long as the needed conditions for this are provided. All this has made me even more convinced that peer support is essential for these young people. Thanks to it they learn how to follow their own path, to build their future and live their lives independently and with dignity.

PART B: Peer Support Training Material



Peer Support Training - 21st June 2014/ Sofia, Bulgaria: Session Outlines

Session I

1. Title and duration	Official welcome and getting to know each other (1 hour)
2. Aims and objectives of the session	<ul style="list-style-type: none"> ➤ to be welcomed to Sofia, Bulgaria, and in particular to CIL Sofia office ➤ for the participants to familiarise themselves with the programme of the Peer Support Training ➤ to provide participants with an opportunity to get to know one another, to set the ground rules for the training and to ensure that participants are aware of each other’s access needs to help facilitate everybody’s inclusion throughout the day ➤ to get a sense of participants’ hopes and expectations from the training
3. methodology	<ul style="list-style-type: none"> ➤ verbal presentation ➤ game
4. Programme	<p>Welcome by the CIL Sofia president and the facilitator. Practical information about the meeting place is given, as well as need-to-know information about the building (where the accessible toilet is, how to use the electric ramp at the entrance, etc.)</p> <p>Introduction of the work of CIL Sofia and of the work of the participants from Macedonia (from DPO ‘Polio Plus’).</p> <p>The facilitator introduces the programme for the day by talking the group through the planned activities. All participants are given a printed agenda for the training.</p> <p>Discussing consent to take photos of the group.</p> <p>Previous experience of CIL Sofia in the field of deinstitutionalisation is discussed.</p> <p>Circle with names – each participant introduces him/herself with their name and where their name comes from/what it means</p>

Coffee break	30 min
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Session II

1. Title and duration	'What is independent living? Do we live independently?' (1h 45min)
2. Aims and objectives of the session	<ul style="list-style-type: none"> ➤ to discuss participants' understanding of the main concepts of the independent living philosophy ➤ to compare participants' understanding of these concepts and ENIL's key definitions ➤ to get a better understanding about what Personal Assistance is and what it entails ➤ to get a better understanding of what Peer Support is and what it entails
3. Programme	<p>Each participant answers the questions 'What is independent living for you?' and 'To what extent do you live independently?' Answers are noted down on a flip-chart.</p> <p>A debate about the statement 'nobody is independent'. (<i>This is the argument that authority figures often use when they try to oppose to the demands of IL activists</i>).</p> <p>All participants are encouraged to contribute to the debate.</p> <p>Discussion on whether parents can be Personal Assistants</p> <p>A debate about the statement 'independent living is not a human right'. Both sides of the argument are considered. Benefits of both arguments are outlined and a conclusion is drawn.</p> <p>Discussion about Personal Assistance. Questions like 'Who chooses the Personal Assistant (the state or the disabled individual)?' are discussed.</p> <p>Transition to the topic of Peer Support. Discussion about what Peer Support is.</p>

Lunch	1 hour
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Session III

1. Title and duration	Peer supporter – role, qualities and controversial topics (1h 45min)
2. Aims and objectives	<ul style="list-style-type: none"> ➤ to provide participants with the relevant knowledge about the role of Peer Supporters ➤ to provide participants with the relevant knowledge about the qualities/characteristics of Peer Supporters ➤ to encourage participants to reflect on debatable/controversial topics within the independent living philosophy
3. Methodology	<ul style="list-style-type: none"> ➤ Group discussions ➤ Power point presentation
4. Programme	<p>Brainstorming about the translation of the term ‘peer support’ in Bulgarian and Macedonian. <i>(This is needed since there is no direct translation).</i></p> <p>Power point presentation prepared by guest lecturer – guiding materials for working in a peer counsellor centre. These include: basics about peer counselling and guidelines for counselling work. All participants are given the materials in printed form and are encouraged to read them in detail after the training. A discussion about what has been presented takes place after watching the presentation.</p> <p>Brainstorming about the qualities and/or characteristics that a Peer Supporter must have. Each participant contributes. Suggestions are written on a flip chart paper. These are discussed afterwards with the help of the trainer and the facilitator.</p> <p>Group discussion on a controversial topic – ‘Can a family member be a Peer Supporter?’ All participants are asked to</p>

	express verbally their opinion and a group discussion follows.
Coffee break	30min

Session IV

- 1. Title and duration** **Who can be a Peer Supporter?**
Basic rules of behaviour of the Peer Supporter
(1h30min)

2. Aims and objectives	<ul style="list-style-type: none"> ➤ to develop a discussion around the topic of Peer Support delivery and in particular who can become a Peer Supporter ➤ through gathering ideas and opinions to reach a conclusion about the basic rules of behaviour that the Peer Supporter must follow
3. Methodology	<ul style="list-style-type: none"> ➤ Group discussions
4. Programme	<p>Discussion on the difference between Peer support, Peer counselling and professional input (medical doctors, social workers, therapists, etc.). All participants are asked to share their understanding of the three terms. Ideas are collected and summarised on flip chart paper. Afterwards the leading trainer speaks about the real difference between the discussed terms and relates to the given answers by participants.</p> <p>Discussion about how to encourage members of National Governments to include Peer Support in its politics? Again ideas are collected and noted down. A discussion to take place. The trainer summarises the suggested ideas and then speaks about ways of achieving this goal.</p> <p>Discussion – ‘Who should provide Peer Support?’</p>

Conclusion

1. Title and duration **Conclusion**
(30min)

2. Aims and objectives	<ul style="list-style-type: none"> ➤ to recap what had been done during the day ➤ conclusions to be drawn ➤ ideas for possible follow up to be discussed
3. Methodology	<ul style="list-style-type: none"> ➤ group work
4. Programme	<p>As a final group work everybody shares his/her personal experience as a Peer Supporter who has encountered a problem. Everybody gathers in a circle and each participant shares his/her story and how s/he felt about it. The facilitator makes notes on the main areas of problems.</p> <p>Finally, the leading trainer recaps what has been done during the training, possible conclusions are drawn. Participants are asked to reflect on what they have learned, how they felt during the training, what can be improved, what they liked most about the event. Follow up ideas are discussed.</p>

Peer Support Training - 21st June 2014/ Sofia, Bulgaria: The Training Notes

11.15h – 12.00h

Session I

- Kapka (trainer) as a host welcomed the participants and briefly explained the purpose of the current event
- The participants from Macedonia then expressed their gratitude for being invited and gave a present to CIL Sofia – a bottle of Macedonian wine, a beautiful drawing made of copper and the symbol of their organization ‘Polio Plus’
- Dilyana (facilitator):
 - also welcomed the participants
 - obtained consent from participants for taking photos
 - explained that a guest speaker (Milica Mima Ružičić-Novković) was unable to come
 - briefly introduced the project which ENIL and CIL Sofia co-ordinate
 - agenda for the training was given to participants; it was read through quickly in order for participants to know what to expect
- Kapka spoke about the background of CIL Sofia’s work in DI processes – justifying the theme of the current training
 - about two years of intensive work with young disabled people in small group homes in Lukovit and Dalbok dol
 - CIL Sofia members (Nina, Maria, Mitko) are peer supporters of the residents
 - CIL Sofia has the practical experience, which has not been described in a theoretical framework yet. So, this training might be useful in this respect
- Circle with names
 - Everybody introduces him/herself and says where his/her name comes from or what it means

12.00h – 12.30h

Coffee break

Session II

- Discussion – **What is independent living? Do we live independently?**
 - The discussion began with the interesting and often cited statement that nobody lives independently. We are all dependent on something and/or somebody (Zvonko)
 - Lyudmila – *“I try to do it on a daily basis. I work and study and this helps me”*
 - Veselka – *“To me independent living is to do whatever I want, whenever I want and with whomever I want. For the time being I have achieved the first two. However, I can’t be with whoever I want since my mother is my personal assistant”*
 - Liza – *“To do whatever I want and with whomever I want”*
 - Petko – *“IL is to depend on yourself”*
 - Mitko – *“IL is when I make the decisions concerning my life”*
 - Vanya – *“In the context of the IL philosophy and not in in terms of general philosophy – IL means everybody to govern your life and to take their responsibilities”*
 - Stefan – *“To be able to go out when I want”*
 - Nina – *“The environment has an impact on leading independent life. I’ve adjusted my home according to my needs and can live independently there. But when I go out I can’t as the city environment is totally inaccessible”*
 - Elena – *“The term ‘independent’ can be defined by each individual in a different way. For some this might include access with ramps, for somebody else this might be related to taking decisions”*
 - Dilyana – *“IL is a human right. It is not something special, not a luxury”*
 - Zvonko – *“IL is a matter of personal choice”*
- A debate around the statement that **nobody is independent**. This is the argument that authority figures often use when they try to oppose to the demands of IL activists. The response from the side of the IL movement is that it is true that we all live in mutual inter-dependence. But disabled people often cannot make decisions themselves.

- The topic of parents as personal assistants was touched upon
- Petko – wanted to share a moment when he felt independent. He had gone by himself in a nearby forest to pick up mushrooms. Then he cooked them and finally ate the dish with his friends. He concluded that such moments of independence bring him satisfaction.
- A hot debate around the statement of one of the Macedonian participants (with juristic education), Tomas, that **IL is not a basic human right**. He argued that IL is a right of a separate group of people and therefore it cannot be universal human right. *“Human rights do not recognise IL”* – he says, to which Kapka responded that the UN CRPD does recognise it. According to Tomas IL is a right, which needs people to fight for; the basic human right is the right of choice and from this the IL right comes from. The ENIL definitions were read out and eventually some sort of agreement was achieved. It was agreed that IL complements the concept of the right of freedom of choice. It is helpful and even necessary to regard it as a human right because this way the State would be obliged to take it into consideration.
- There is no separate **definition of ‘Peer Support’** in ENIL’s definitions. Why is this? It is included for the first time in the definition of ‘Personal Assistance’. Is its place there? Discussion follows:
 - Personal Assistance is an instrument for living independently
 - Peer Support includes all elements necessary for Personal Assistance
 - Nina – *“Peer support is a kind of personal assistance. The concepts overlap to some extent”*
 - An example was given with the ‘distorted’ regulation for personal assistance in Sofia; 95% of the people who were approved to have an assistant for IL eventually hired a person from their family and thus the benefits turned into addition to the social pension. Apparently people could not break the dependency from their families and the consequence was as follows: the income did not support IL!
 - The Peer Support concept is included in the PA definition because PA makes you an employer, manager; it makes you feel more confident in your own abilities and thus contributes to your IL

- Debate – whether everything is about the money; is the lack of financial resources the only reason for not living independently??
- PA means a compensation for what your disability does not allow you to do
- The suggestion that there should be a certain limitation about who can become one’s PA was discussed. It was proposed a maximum of 15% of the time allocated for this service to be taken by a family member
- Discussion – **who chooses the Personal Assistant?**
 - The state or the disabled person?
 - The state should give the money to the disabled person and s/he should be able to spend it only for hiring a PA. Neither in Bulgaria, nor in Macedonia this is the situation
- Transition to the **topic of peer support**
 - The moment when a disabled person receives the grant for PA, s/he needs to have the capacity and confidence to deal with this – to train the assistant, to report the allowance, etc.
 - Elena – “One needs to have peer support from childhood and a personal assistant from emerging adulthood. These need to be separately regulated.”
 - Peer support is not a service solely for disabled people, but we consider it in this context
- Does peer support need to be paid?
 - Peer support (not paid) vs. peer counselling (paid service, e.g. at ULOBA)
 - Peer counselling in institutions – Lyusi: “These are needed in institutions because people seek support.” She gave an example with herself as a peer supporter – people in the institution where she lives approach her constantly, asking for advice
- Discussion about the difference between the residents of the institutions in Lukovit and Dalbok dol
 - One is governed by the state, the other one – by NGOs
 - Residents of the former lack motivation, aspirations; the other ones have dreams and goals

14.15h – 15.15h

Lunch

15.15h – 17.00h

Session III

Brainstorming about a **translation of the term ‘peer support’** in Bulgarian and Macedonian

- Подкрепа от опит
- Подкрепа от равен
- Подкрепа чрез опит
- Подкрепа от познат
- Равнокрепа
- Дружеска подкрепа
- Лична подкрепа
- Житейска подкрепа
- Пиър-подкрепа
- Взаимна подкрепа
- Mima sent a power point presentation and with the translation help from the Macedonian participants it was read out
- Not too useful for the purpose of the current training
- More useful were the materials sent by Mima prior to the training – guidelines to peer support counsellors; these were printed out and a copy was given to each participant
- Brainstorming about the **qualities/characteristics that a peer supporter must have:**
 - To be patient
 - To be a good listener
 - To be able to articulate his/her experience
 - To be able to predispose for sharing
 - TRUST – agreed that this is among the first and foremost
 - To be ready and willing to share
 - To be open

- Education has nothing to do with peer support! Peer supporter's character and his/her life experience are of crucial importance
- To be able to empathize

Discussion – **can a family member be a Peer Supporter?**

- One of the participants shared her feeling that at times she's a Peer Supporter for her own children. The rest of the group did not agree this is possible since the parent figure can never be a 'peer', i.e. equal in status.
- Another participant gave an example of a situation where the mother of a disabled child contacted her with a request for help. It turned out that the mother of the participant was the one who managed to provide effective help to the mother seeking help. This supported the argument of the majority of the trainees that only people equal in status (or in similar life situations) can be Peer Supporters
- An example was given with one of the residents of the small group home in Lukovit. She seeks support from two of the CIL Sofia members for different things. One is close to her age, but is not disabled. And the other one shares the status of a disabled person, but is much older than her. So, this is an interesting peer support relationship.

17.00h – 17.30h

Coffee break

17.30h – 19.30h

Session IV

- Difference between **Peer support, Peer counselling and professional input (medical doctors, social workers, therapists, etc.)**
 - These are three different things
 - Are they mutually exclusive or complementary?
 - Peer counselling and professional input – formal; peer counselling – non formal
 - PEER SUPPORT – awareness raising; change of attitudes
 - PEER COUNSELING – professional service
- Discussion about **how to make the State to include Peer Support in its politics?**

- **Personal accounts of providing Peer Support**
 - Vanya spoke about her own experience with role models and peer supporters. She realises now that there is a danger the disabled person to admire so much his/her peer supporter, that s/he can become dependent on him. The peer supporter should keep this in mind.
- **Discussion – who should provide Peer Support?**
 - Who should train Peer Supporters?
 - There's a danger such trainings to make the service 'professional', which would spoil the idea of peer support as such.
 - IL activists should provide such training. So, only disabled persons should be eligible for this.

Conclusion:

- Despite the many controversial topics discussed during the day, the main topics were covered and many interesting insights were obtained
- As a final group work everybody shared his/her personal experience as a Peer Supporter who has encountered a problem. As Peer Supporters people found problematic:
 - Parents and family members
 - Professionals, experts
 - Environment
 - Lack of setting clear boundaries between the Peer Supporter and the person seeking advise
 - Lack of motivation from the side of the person seeking advice. The Peer Supporter should not feel guilty about this
 - Several people shared that they have helped persons to become independent, but afterwards these 'newbies' betrayed the IL philosophy and now even work against its progress. Conclusion was drawn that the peer supporter cannot keep control over the behaviour of the person they support. They are responsible for their actions, but should not feel discouraged by such misfortunes.
 - One can be a Peer Supporter without knowing this. There might be people who look up to him/her without the admired person to suspect this

- Another conclusion was that it is possible a person's support to become effective only after a while, when the person seeking advice is ready for it

Peer Support Training - 21st June 2014 / Sofia, Bulgaria: Personal Reflections

“As a summary of the event I can say that the international peer support training in Bulgaria achieved the following: (1) the experience in supporting disabled people of three different countries was shared; (2) the definitions about independent living, peer support and community living were clarified; (3) a great deal of techniques for providing peer support needed for working with disabled people of different kinds were discussed; and last but not least – young disabled people were trained how to provide peer support themselves to other young disabled people. It could be said that we all agreed on the statement that there is a great need such trainings to be held in different EU countries.”

(Mitko Nikolov, participant at the training)

“In my opinion the training was very useful for both sides – trainees and trainers. The quality of organization was at high professional level, the whole process run succinctly and effectively. It was really nice to see people who are interested in becoming good and helpful supporting figures for other people who need this. I liked that I saw passion in the Macedonian colleagues’ eyes, that I was convinced that they will do a great job on the local level when they go back to their country. It was useful to share thoughts and experience, as well as writing down the agreed decisions, because as the wise man has said – only what is written on a paper remains.”

(Nina Zhisheva, participant at the training)

“Discussing peer support, independent living, peer counseling, who has the right to live independently and to receive support was more than useful and fascinating for me as a pioneer in the field. This training provided me with the opportunity to get to know about practices and personal accounts, which will help me in my future work as a peer supporter.”

(Mariya Dimitrova, participant at the training)

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