

Centres for Independent Living (CILs)

A Toolkit on the role of CILs in supporting disabled people into employment

European Network on Independent Living
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“Independent Living is a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities and self-respect. Independent Living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation. Independent Living means that we demand the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbours and friends take for granted. We want to grow up in our families, go to the neighbourhood school, use the same bus as our neighbours, work in jobs that are in line with our education and interests, and start families of our own.

Since we are the best experts on our needs, we need to show the solutions we want, need to be in charge of our lives, think and speak for ourselves - just as everybody else. To this end we must support and learn from each other, organize ourselves and work for political changes that lead to the legal protection of our human and civil rights.¹”

Adolf Ratzka, a leader of the Independent Living movement in Sweden

¹ See: <http://www.independentliving.org>

Foreword

It is with great pleasure that ENIL presents this Toolkit on establishing Centres for Independent Living (CILs) and their role in the empowerment of disabled people and supporting them into mainstream employment.

CILs are important for the Independent Living movement. They work on empowering disabled people by providing training and peer support. CILs also lobby for the right to independent living. They serve as watchdogs within our communities, making sure the authorities implement the UN Convention on the Rights of Persons with Disabilities.

There are various types of support offered by the CILs: peer support and peer counselling, support to personal assistance users to become work leaders and support for getting into employment. Unfortunately, not many CILs prioritise working with the youth, which is a shame. Our youth are, after all, our future.

ENIL and I personally want to thank all for cooperation in 2014 in collecting information for this Toolkit. This work included a survey to CILs on their role in facilitating employment, a study visit to SPECTRUM CIL in Southampton, a webinar on employment, monthly role models and our participation in the LEARNABIL project. In addition, many have provided information for this Toolkit, which we hope becomes an appreciated tool for the movement.

I especially thank: all the CILs who contributed to the survey, Vanessa Scanlon, the ENIL Communications Officer for her work on the survey, Mari Siilsalu, an ENIL intern, for her web research and Dilyana Deneva, the ENIL Youth Coordinator for her work on the webinar and with the survey on employment.

I would like to end by reminding ourselves that empowerment, provided by our CILs is key to our strength. We all need to be Strong, Proud and Visible and can find support in our local CILs!

Jamie Bolling, ENIL Executive Director

1. Introduction

This Toolkit was developed by the European Network on Independent Living (ENIL), a Europe-wide network of disabled people, with members in more than 20 countries. Our organisation promotes Independent Living and equal opportunities for disabled people and fights against discrimination of disabled people in Europe. ENIL's mission is to advocate and lobby for Independent Living values, principles and practices, namely for a barrier-free environment, provision of personal assistance support and adequate technical aids, which together make full citizenship of disabled people possible. Promoting and advocating for the implementation of the UN Convention on the Rights of Persons with Disabilities (UN CRPD) is an important aspect of our work.

The Berkeley Center for Independent Living (CIL) was the first CIL in the world. Julie Ann Racino, the then leader of the CIL, described it as "the first organisation of its type in the world" and "a visible symbol of the Independent Living movement, the international civil rights movement of disabled people". Since 1972, when a coalition of severely disabled people founded the Berkeley CIL, Centres for Independent Living have spread across the globe and this first CIL is now recognised worldwide as the inspiration and "archetype for over 300 Independent Living centers".

The mission of the first CIL was: "to create and maintain independence for disabled people through providing services, advocating for the rights of disabled individuals, and nurturing a system of support in the community." From its establishment, the CIL has combined providing support with advocacy activities, although not always in the same ratio. In its first 16 years it is said to have provided "direct services to over 140,000, built 500 residential ramps free of charge for wheelchair users, helped 1,000 people secure jobs, and assisted over 600 students to complete the Independent Living skills training program."²

The work done by the CILs at the grassroots level is of fundamental importance to the continued emancipation of disabled people. For many disabled people in Europe, CILs are often the first point of contact with the Independent Living movement and philosophy. Historically, they have played a vital role in supporting disabled people to live in the community. ENIL would like to see the establishment of more CILs across the European Union and in neighbouring countries, in order to allow for more empowerment of disabled people. This is especially important at the time when austerity measures introduced by many European governments continue to disproportionately affect disabled people³. Disabled people in Europe are at a greater risk of poverty. The lack of support for disabled people seeking employment

² See Racino, Julie Ann (1991) *Center for Independent Living (CIL): Disabled People Take the Lead for Full Community Lives*; available at:

<http://www.independentliving.org/docs4/racino91.html>

³ See: http://www.enil.eu/wp-content/uploads/2012/05/Background_paper_Resolution.doc

has become a huge barrier for many disabled people in finding work and in receiving the supports needed in the work place environment.

2. What is a Centre for Independent Living (CIL)?

Defining what a Centre for Independent Living IS, and IS NOT, is very important to its establishment and work. CILs exist throughout the world in different shapes and sizes, with different missions, aims and activities. There are various ways to describe or define what a CIL is, but all these definitions include **common elements**, which derive from the principles of Independent Living: **self-determination, equal opportunity, self-respect, choice and control over services, and the right to full participation.**

Below are some of the **definitions** used by various CILs:

A Centre for Independent Living is a cross-disability organisation controlled by disabled people with a mission to promote social inclusion and mainstreaming of disabilities in all public policies. CILs should focus on personal assistance, peer support and building inclusive communities, information and training activities for both disabled and non-disabled people, policy research from the perspective of the UN Convention on the Rights of Persons with Disabilities and legal representation for disabled people who want to live independently but have no opportunities to do so. (*Centre for Independent Living Sofia*⁴)

Centres for Independent Living are community-based, cross-disability, non-profit organizations that are designed and operated by people with disabilities. CILs are unique in that they operate according to a strict philosophy of consumer control, wherein people with all types of disabilities directly govern and staff the organization.

Centres for Independent Living provide: Peer Support; Information and Referral; Individual and Systems Advocacy; and Independent Living Skills Training. (*National Centre for Independent Living UK*⁵)

The Centre for Independent Living promotes the philosophy of Independent Living and creates conditions for its implementation in Serbia. The Centre's aims include:

- Working towards the creation of conditions for independent living of disabled people in Serbia, especially including setting up a new model for non-institutional support for disabled people (personal assistant service);

⁴ <http://www.cil.bg/en/>

⁵ <http://www.ncil.org/about/aboutil/>

- Working towards the creation of an accessible environment, housing and public transport;
- Gathering and disseminating data and information on the philosophy of independent living of disabled people;
- Putting effort into and working towards the realization of basic human rights of disabled people;
- Promotion of creative potentials of disabled people and putting efforts into their self-empowerment and building of their self-confidence;
- Promotion of social model of disability, especially in the fields of economic, social and housing policy;
- Participation in the work of ENIL and cooperation with other CILs worldwide. (*Centre for Independent Living Serbia*⁶)

3. Main principles

The work of CILs, as well as that of ENIL, is based on the principles of Independent Living, adopted at an ENIL meeting in the Netherlands in 1990⁷. These are:

- Independent living is a process of consciousness raising, empowerment and emancipation. This process enables all disabled persons to achieve equal opportunities, rights and full participation in all aspects of society.
- Disabled people must be able to control this process individually and collectively. To achieve this goal we provide peer support and use democratic principles in our work.
- As equal citizens we must have the same access to the basics of life including: food, clothing, shelter, health care, assistive devices, personal support services, education, employment, information, communication, transportation and access to the physical and cultural environment, the right to sexuality and the right to marry and have children, and peace.
- The Independent Living Movement must be a cross disability movement addressing the needs of all disabled persons. In order for this to occur we must rid ourselves of any prejudice we have towards persons with disabilities other than our own and encourage the involvement of disabled women and other underrepresented groups. Disabled children should be enabled by their families and society in general to become independent adults.
- Disabled people must obtain all the requirements for equalisation of opportunities and full participation by defining their own needs, choices and degree of user control.
- The Independent Living Movement is opposed to the development and maintenance of systems which promote dependency through institutional

⁶ <http://cilsrbija.org/ser/index.php>

⁷ <http://www.independentliving.org/docs2/enildocs.html>

responses.

- Disabled people must involve themselves in research and development, planning and decision making, at all levels, in matters concerning their lives.

4. Establishing a CIL

Below is a series of steps in the establishment of a CIL. It is not an exhaustive list, but should help get a new CIL off the ground.

Step 1: Find a group of people who have a common interest and want to start an organisation. In the case of a CIL, this is a group of disabled people who themselves want to run the organisation and advocate for their rights and services. It should be a group of people with different impairments (cross-disability), as the philosophy of Independent Living is that we are fighting for our rights as disabled people and not on the basis of our diagnosis.

Step 2: Formulate the mission and aims of the organisation. In the case of Serbia (see above), the mission was that their CIL was to promote the philosophy of independent living and create conditions for its implementation in Serbia. Today, promotion, implementation and monitoring of our most important tool, the UN Convention on the Rights of Persons with Disabilities, could and should be a part of the mission.

Next steps: Decisions need to be taken on the structure of the organisation. Key people need to be appointed as leaders. Decision-making processes need to be determined. Some other formal steps could include:

- Registration of the organisation is necessary, if it is to be able to apply for funding;
- A constitution needs to be formulated for the registration of the organisation;
- Steering committee, board or group of people may need to be elected to lead the organisation;
- An action plan should be written, with goals and objectives, planned activities, expected outcomes, timeframe and resources required;
- Funding, or volunteer resources, will need to be identified;
- Communication channels should be established;
- There may be other steps depending on the national and local legislation.

5. Survey of the CILs in Europe

In September 2014, ENIL conducted a survey targeting CILs in the following countries: Belgium, Bulgaria, France, Italy, Germany, Slovenia, Spain and Sweden

(see Annex 2 for a list of respondents). The survey looked at the benefits of setting up CILs and their role in increasing employment of disabled people, providing peer support and facilitating de-institutionalisation. The survey also considered the methods used by the CILs to build the capacity among disabled people in Europe.

The survey consisted of nine questions describing the CILs and six questions on the role of a CIL (see Annex 1). Following is a summary of the information collected through the survey.

5.1 Information about the CIL

<p>How do you define a CIL (if you have a definition)?</p>	<p>All the definitions were based on the promotion or defending of Independent Living. CIL Sofia gave the following definition: “A CIL is a cross-disability organisation controlled by disabled people with a mission to promote social inclusion and mainstreaming of disabilities in all public policies. CILs should focus on personal assistance, peer support and building inclusive communities, information and training activities for both disabled and non-disabled people, policy research from perspective of the UN Convention on the Rights of Persons with Disabilities and legal representation for disabled people who want to live independently but have no opportunities to do so.”</p>
<p>Does your organisation have a programme to assist and support disabled people to access employment in the open labour market?</p>	<p>Projects carried out by the CILs varied. All the CILs worked on personal assistance (incl. in the workplace) in one way or another. Four of the nine organisations also worked in other ways on facilitating employment of disabled people. One CIL had a separate organisation promoting and supporting individuals in the field of employment.</p>
<p>Does your organisation provide peer support?</p>	<p>Peer support was provided by all but one organisation – the Institute for Independent Living (ILI) in Sweden - which is not organised as an ordinary CIL. Instead, ILI focuses on research, providing information on personal assistance in Sweden and on implementing national and international projects, together with other CILs. In the future, ILI plans to produce a curriculum for peer support in order to promote this type of support.</p>
<p>Does your organisation run any other programmes to promote Independent Living and community-based</p>	<p>CIL Sofia provides training on Independent Living to people in institutions, as a specific activity to empower them to move out.</p>

services for disabled people currently in institutional care or at risk of institutionalisation?	
Does your organisation run any youth programme to build the capacity of young disabled people to become more active in the community?	Only one of the nine organisations works specifically with the young people.
Are there any other activities/programmes which you carry out?	<p>Support with personal assistance is a common activity. This can be provided by mail and telephone or through individual coaching and accompanying of persons needing support when meeting authorities. Home coaching was provided by one CIL, which also had a help-desk providing answers to questions and support in all areas of life.</p> <p>Other projects carried out by the CILs vary in character. CIL Sofia works on strategic litigation in order to advance the rights of disabled people. One CIL, besides providing personal assistance, has a tradition of organising a cooking course several times per year, in order to build the skills of its members and as a team building activity. Another CIL wants to provide breathing training for their members, especially “frog breathing”. Training on Independent Living for refugees with trauma was the focus of one project run by a CIL.</p>
Do you work with any particular group of disabled people, such as people with intellectual disabilities, or is your work cross-disability?	Two of the nine organisations targeted only people with physical impairments. The other CILs work from a cross-disability perspective.
Are your activities carried out at a local, regional or national level?	The CILs all work on a local level, but eight of them also run activities on the national level. Four of the CILs carry out activities on the international level.
How is your work funded?	The way CILs are funded varies. The national authorities have been funding all the CILs participating in the survey. The European Social Fund (ESF) was used by two of the CILs. Membership fees, fundraising, donors and applying for tenders were other ways of obtaining the needed funding.

5.2 On the role of CILs in general

<p>What do you think is the key role of a CIL?</p>	<p>The role of a CIL was seen as one to promote and defend Independent Living. CIL Sofia advocated for CILs to act as watchdogs for the rights of disabled people. The provision of services was seen as a natural role: services of personal assistance, including within the employment field, and peer support.</p>
<p>How do you think CILs could better facilitate the employment of disabled people?</p>	<p>For the promotion of employment, facilitating internships or apprenticeships was seen as essential. Promotion of accessible workplaces is considered crucial, as well as working on improving the attitudes of employers towards disabled people.</p>
<p>What do you think are the benefits of providing peer support to disabled people in local communities?</p>	<p>Peer support is important for the empowerment of disabled people. It raises self-esteem and self-confidence. Peer support allows people to live independent lives with full participation.</p>
<p>What role do you think CILs play in the deinstitutionalisation process?</p>	<p>CILs were of the opinion that they are important for the deinstitutionalisation process. They can be outreach organisations providing coaching and training. They are needed to ensure that housing becomes accessible and can even provide housing services. Their members can be seen as role models, showing that living independently is possible. Violations of human rights in institutional/residential care can, and are, revealed through the work of some CILs.</p>
<p>What do you think are the essential steps to establishing a CIL?</p>	<p>These have been summarised under point 4.</p>
<p>How can ENIL better promote or support the work of the CILs?</p>	<p>ENIL is seen as a bridge between the local or national CILs and the EU level. ENIL advocacy at EU level is appreciated along with its publications and comparisons between the situation in different Member States. ENIL campaigns are considered to be important. ENIL is expected to push for a personal assistance directive and should work on the twinning of CILs. ENIL as a funding agency is a vision of several of the CILs.</p>

6. Supporting disabled people into employment

Three core methods that are essential tools in supporting disabled people into employment were identified from the survey. These core tools are: **peer support**, **personal assistance** and **independent living training**.

6.1 Peer Support

“Results of peer support can be empowering, emotional relief, the realization of own potential and better awareness.” (Elena Pečarič, YHD Slovenia)

Peer support was identified through the survey as one of the crucial services that CILs provide to their members. Indeed, providing peer support has been the reason why many CILs were established.

Peer support is the term used to describe the help and support that people with lived experience are able to provide to another individual similarly situated: for example, it can be referred to as the support provided by somebody who has lived in an institution to other disabled people living in institutions. This support may be social, emotional or practical (or all of these)⁸.

Peer support can be used to increase a person’s awareness of their rights—the right to full participation in society. It can also help a disabled person identify instances where they have been discriminated against and empower them to take action. Peer support can also help disabled people to acquire new skills to manage their social and physical environment or to apply for a job.

As described above by Elena Pečarič, from YHD Slovenia, peer support can be provided on an *individual basis*, which involves a (confidential) conversation between a peer advisor and a user. *Group peer support* means that there are several users and several peer advisors at one time and often the topic is decided beforehand. Many CILs provide training for their peer counsellors, but the core element of being a peer counsellor is to actively listen to the person and empower them to find their own solutions.

The relationship between a peer counsellor and a user is a unique relationship. As described by the Berlin CIL: “The counsellors live with disabilities themselves and can establish a particularly trustful relationship with the clients because of their own experiences”.

Currently, CIL Sofia works with a group of young disabled people in two small

⁸ ENIL (2014) *Peer Support for Independent Living—A training manual*; available at: http://www.enil.eu/wp-content/uploads/2012/06/Peer-Support-Training-Manual-Final_281014.pdf

residential settings (group homes), providing them with peer support to become empowered and move into other independent living arrangements. The CIL staff and volunteers (activists) established an especially strong relationship with several residents of the small group home and are helping them move into the mainstream community. The next step is to search for accessible and affordable housing, personal assistance and to ensure that their funding is redirected from the residential care to supporting community living (which involves working with the relevant authorities). It is an informal relationship, based on shared values and principles.

6.2 Personal Assistance

“Personal Assistance is a tool which allows for Independent Living. Personal Assistance is purchased through earmarked cash allocations for disabled people, the purpose of which is to pay for any assistance needed. Personal Assistance should be provided on the basis of an individual needs assessment and depending on the life situation of each individual. The rates allocated for personal assistance to disabled people need to be in line with the current salary rates in each country. As disabled people, we must have the right to recruit, train and manage our assistants with adequate support if we choose, and we should be the ones that choose the employment model which is most suitable for our needs. Personal Assistance allocations must cover the salaries of personal assistants and other performance costs, such as all contributions due to the employer, administration costs and peer support for person who needs assistance.” (ENIL Definitions)

The need for personal assistance has been a common vision of many of the CILs and a reason why many were established. ULOBA, for example, is one of the biggest employers of personal assistants in Norway. The Stockholm Co-operative for Independent Living (STIL) in Sweden, also a provider of personal assistance services, was the founder of Independent Living in Sweden and the initiator of personal assistance services. This has led to the renowned Swedish reform of services for disabled people in 1994, making personal assistance a civil right for those in need. Händikapp from Estonia benefited from training on personal assistance from the CIL Threshold in Finland, in order to provide and lobby for personal assistance services in their own country.

OVI-Madrid also provides personal assistance for its members. The service targets all areas of activity, but the majority of people use personal assistance to access the labour market. By the end of 2013, 34 members of the CIL were in employment thanks to personal assistance.

6.3 Independent Living Training

“Independent Living is 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 our 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. It is necessary to point out that Independent Living is for all disabled persons, regardless of the level of their support needs.” (ENIL Definitions)

One of the key types of training found essential for employment and provided by CILs is training in relation to Independent Living. YHD in Slovenia explained that such training is designed for disabled people who want to live independently, i.e. to live in their own home, outside institutions, nursing homes, residential communities and other special settings for disabled people. The training prepares participants to accept responsibility and obligations that they will face. One key element of the training is in relation to the obligation of the disabled person to their personal assistant; by assuming the role of an employer, the disabled person takes on different obligations and duties towards their employee.

The Berlin CIL has run a number of projects supporting young disabled people when they leave school, helping them to formulate future goals and providing them with information and support to find apprenticeship placements or work in the open labour market.

7. Disabled people’s experiences of employment

During 2014, ENIL cooperated in a project on vocational training and rehabilitation called *Learnabil-IT: Mutual Learning on skills for the ICT labour market for people with disabilities*. Learnabil-IT aimed to promote the cooperation and mutual learning between the worlds of work and vocational education and training in the ICT sector, supporting a better labour skills match and a greater employability of people with disabilities in the open labour market.

ENIL, as a partner organisation, contributed with a survey among young disabled people. The purpose of the survey was to collect experience from different European countries in the field of employment and to outline the main problems and good practices. The summary below is based on the answers received to the survey from 7 persons (5 females and 2 males) from six European countries – Greece, Spain, Estonia, Georgia, Bosnia and Herzegovina and Austria. Six of the seven respondents are young disabled people and members of the ENIL Youth Network.

Most of the respondents shared the view that it was far from easy to get a job placement. Those who did not experience great difficulties work in the disability field and currently have a job placement supported by the EU project funding. Physical and attitudinal barriers exist, with the first obstacle being accessibility. Accessibility either makes working difficult (e.g. lack of accessible toilets) or impossible - when there are no lifts in a building. However, some of the respondents shared that after working for a while and proving their potential, skills and capacities as employees, adaptations to the working environment were made. Another problem faced by the disabled people in regard to job placement are the fears and preconceptions of the potential employer. The lack of portability of services, including personal assistance (i.e. losing your right to have an assistant when you move abroad), also causes significant difficulties when trying to find a suitable job.

Half of the survey respondents had not heard the term 'vocational education training' (VET) and hence had not received any such training. Some reported seeking additional qualifications or help, including attending online seminars and trainings at their own initiative, without support from the government. Local and European NGOs (e.g. CILs and ENIL) have been the sources for inspiration and in some cases provided peer counselling, which is considered a positive step towards the wanted professional realization.

It was revealed that the initial negative preconceptions of the employers have afterwards been replaced by good relationships. It was found that as long as the employer is well informed about the access needs of the disabled employee and the needed adaptations are made, there is no reason for the employee's disability to interfere with the working process. Respondents to the survey suggested that an equal position and attitude is the best strategy an employer can take towards able-bodied and disabled employees. One of the most common myths should be debunked – that hiring a person with disability is a financial burden for the employer or their company. Resources allocated for adapting the working environment need to be seen as an investment.

It was evident from the survey that disabled people consider employment as their right. In order to achieve full inclusion, crucial changes need to take place at all levels, starting with the change of paradigm – from the medical model of disability (being too 'sick' to work) to a human rights model. This should result in the adoption of effective policy strategies, investing in capacity building and awareness-raising.

In addition to the *Learnabil-IT* survey, ENIL collected 12 personal experiences of disabled people from across Europe, published as Role models in the ENIL Newsletter and the website. All the role models were asked about their experience in

accessing employment or education, and many came from minority backgrounds. All the role models can be accessed on the ENIL website.⁹

8. Case study: Study Visit to the SPECTRUM CIL in Southampton, England

On 9 - 11 September 2014, ENIL organised a two-day study visit to the SPECTRUM CIL¹⁰ in Southampton, England. Several young Independent Living activists from five European countries were selected to take part. The specific objective of the study visit was to discuss the role of CILs in promoting active citizenship of disabled people, especially employment. The participants were either already working for a CIL in their country or were planning to establish one.

During the study session, participants had an opportunity to learn about the ground-breaking “Project 81”, which was the start of the Independent Living movement in the UK. There was also information provided on the history of the Independent Living Movement in Europe during the early 1980s up until the present day. The presentation was made by one of the leading Independent Living pioneers and a member of the ENIL Advisory Board — John Evans from the UK.

The SPECTRUM staff - Ian Loynes and Lesley Long-Price - gave an overview of the SPECTRUM structure and introduced the philosophy and methods of their organisation. They emphasized that disabled people controlling the organisation and the development of sustainable user-led services are key for running a sustainable Centre for Independent Living. It is also important that disabled people themselves are employed in a professional capacity.

Other factors which are key to running a successful CIL, and which were stressed during the study visit, are as follows:

- The majority of employees and especially experts and decision makers in the organisation should be disabled people themselves.
- There needs to be a wide range of fundraising sources, including project funding, grants and business sponsorship.
- Selling services provided by the CIL, such as consultancy, training or accessibility assessments, can be a goal.
- A CIL should have a wide range of activity including, for example, peer support, training, provision of services, policy advocacy and capacity building for user led personal assistance.
- It is important to have allies and cooperate with other organisations in the

⁹ See: <http://www.enil.eu/category/news/role-models/>

¹⁰ See: <http://www.spectrumcil.co.uk/>

same field, in order to reach the desired outcomes.

Two SPECTRUM initiatives were introduced by Gerry Zarb and Robert Droy, which gave the participants a closer look at how Spectrum has been influencing the UK Government policy through working with equality bodies. SPECTRUM's campaigning for direct payments and helping new user-led organisations establish themselves has had a strong impact on the current services in the UK and in influencing other human rights advocacy organisations.

All the participants were asked to complete action plans on how they would set out to establish a CIL in their country. The Latvian participant planned to set up a CIL focused on personal assistance, as he and his colleagues felt the current legislation was lacking and should be changed. He felt that personal assistance was important if more of his peers were to access employment. The Greek participant also planned to start a CIL with several colleagues and has managed to do so (see the case study below). Two participants from the Netherlands were already working in an established CIL, but wanted to learn how they could improve their work in order to focus more on employment of young disabled people.

9. Case study: Setting up of a CIL in Greece

One of the main outcomes of the SPECTRUM study visit was the establishment of a new CIL in Greece, called "i-Living". The CIL was opened symbolically on 10 December, the International Human Rights Day, at the initiative of Stelios Kypouropoulos, a young psychiatrist working at a hospital, and five of his university colleagues and friends.

How is the CIL organised?

"i-Living" was established by six founding members (all of whom are disabled people), who for the moment all contribute in their voluntary capacity. They agreed on the following positions: president, vice president, secretary and cashier. Although the CIL is based in Athens, it plans to work nationally, as there are no other CILs active in Greece at the moment. The six founding members have disseminated promotional materials and plan to have meetings open to other disabled people, in order to attract additional members to the Independent Living movement. "i-living" is currently funded from the contributions of its founding members, but in the future plans to apply for funding available in Greece, as well as EU funding.

What issues will it be focusing on?

The new CIL will carry out both advocacy activities and will provide support to other disabled people. Their focus will be on promoting the implementation of the UN

Convention on the Rights of Persons with Disabilities, especially Article 19 (Living independently and being included in the community), but also Article 9 (Accessibility). Given that disabled people are not entitled to personal assistance, which for the moment they have to pay for themselves, “i-living” will advocate for the introduction of personal assistance and direct payments into legislation and their provision across the country. Support will also be provided to disabled people who employ their assistants, but also to those who do not, in order to promote the benefits of independent living among disabled people.

“i-Living” also plans to focus on awareness raising among the general public, and changing how disabled people are viewed in Greece. Emphasis will be on active citizenship and participation, as opposed to charity and pity, which is the case at the moment.

The new organization has and will continue to increase contact with political parties in order to raise awareness. During the ongoing election campaign, “i-Living” has been handing out brochures on the right of disabled people to independent living. Letters were sent to all the parties from left to right, informing them about the CIL and independent living, in the hope that it will soon be high on the Greek political agenda.

What was necessary to establish the CIL?

One of the founding members took part in the ENIL Freedom Drive in 2013 and the study visit to the SPECTRUM CIL in Southampton, England. There, he was able to speak to colleagues from other countries and learn from their experiences. It was also where the idea to set up a CIL in Greece came from. Particularly inspiring were the experiences from England in the 1970s, where Project 81 paved the way for personal assistance and direct payments for disabled people, as an alternative to institutional care.

10. Conclusions

Centres for Independent Living (CILs) are crucial for keeping the Independent Living movement alive and for advancing the right to independent living across Europe and beyond. Peer support, Independent Living training and advocacy/support around personal assistance are some of the key activities CILs can offer to their members and users. The three together empower disabled people and allow us to participate fully in our societies.

Disabled people who do not have a local CIL to go to, are therefore encouraged to start one. As the first step - gather a group of people interested in defending our right to Independent Living, making sure that people of all ages and backgrounds are

welcome. It is especially important to involve young people, to ensure that the issues of relevance to them are reflected in the CIL's activities and that the CIL has a future.

Access to employment is also key, if disabled people are to play an active role in society. In the process, a number of barriers have to be challenged: lack of accessibility, employers' prejudice, need for reasonable accommodation, disempowered job seekers, portability of independent living support within the EU and many more. Given the EU's drive for more and better jobs, and targets for increasing the number of people in employment, it would be important for the European Social Fund (ESF) in particular to support the work of CILs on facilitating the employment of disabled people.

As a European organisation bringing together a number of CILs from different countries, ENIL will continue to facilitate exchange of information and skills among those involved in running CILs and those interested in establishing one. There are still many countries without CILs, or other types of independent living organisations, therefore encouraging and supporting their establishment and work will continue to be our priority.

For further information about the work of CILs, and to share your experiences or questions with other organisations from the Independent Living movement, please e-mail secretariat@enil.eu.

Annex 1: Survey on the Centers for Independent Living in Europe

The aim of this survey by the European Network on Independent Living is to gather information on the role of Centers for Independent Living (CIL) in facilitating access to employment of disabled people and in facilitating deinstitutionalisation throughout Europe. This survey also aims to review the benefits of establishing a CIL and to review the methods used by CILs, such as the provision of peer support, to build capacity among disabled people in Europe.

The results of the survey will be compiled and attached to a Toolkit on establishing and running a CIL, aimed at disabled people across Europe. The Toolkit and the survey will be available for free on the ENIL website.

Please complete this table:

Question	Answer
Name of Center for Independent Living	
Address	
Number of Members	
Is your organisation controlled by disabled people	

Please answer the following questions about your Center for Independent Living (CIL):

1. How do you define a CIL (if you have a definition)?
2. Does your organisation have a programme to assist and support disabled people to access employment in the open labour market? If yes, please provide examples.
3. Does your organisation provide peer support? If so, could you please explain (formal/non-formal)
4. Does your organisation run any other programmes to promote Independent Living and community-based services for disabled people currently in institutional care or at risk of institutionalisation? If yes, please explain.
5. Does your organisation run any youth programme to build the capacity of young disabled people to become more active in the community?
6. Are there any other activities/programmes which you carry out?

7. Do you work with any particular group of disabled people, such as people with intellectual disabilities, or is your work cross-disability?
8. Are your activities carried out at a local, regional or national level? Please explain.
9. How is your work funded?

Please also share your views on some or all the following questions (optional):

1. What do you think is the key role of a CIL?
2. How do you think CILs could better facilitate the employment of disabled people?
3. What do you think are the benefits of providing peer support to disabled people in local communities?
4. What role do you think CILs play in the deinstitutionalisation process? (local/national level)
5. What do you think are the essential steps to establishing a CIL?
6. How can ENIL better promote or support the work of the CILs?

Thank you for answering the questionnaire! Please return it to Vanessa Scanlon at vanessa.scanlon@enil.eu by 12 September 2014.

Annex 2: List of survey respondents

Organisation	Contact person	Website
Onafhankelijk Leven vzw	Peter Lambregts	http://www.onafhankelijkleven.be
CHA – Vie Autonome France	Jean-Pierre Ringler	http://coordination-handicap-autonomie.com/
La Sfida Cooperative Sociale Onlus	Info@lasfida.org	http://www.lasfida.org/
Berliner Zentrum für Selbstbestimmtes Leben e. V. (Berlin Centre for Independent Living)	beratung@bzsl.de	http://www.bzsl.de/startseite.html
Independent Living Institutet	Adolf Ratzka	http://www.independentliving.org
Zentrum für Selbstbestimmtes Leben Behinderter e.V. Erlangen	Dinah Radtke	http://www.zsl-erlangen.de
Oficina de Vida Independiente (OVI- Madrid)	Javier Arroyo	http://www.federacionvi.org/
Centre for Independent Living Sofia	Kapka Panayotova	http://www.cil.bg
YHD - Association for Theory and Culture of Handicap	Elena Pecaric	http://www.yhd-drustvo.si/

For more information, please contact:

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