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Independent Living Manual

"We are sailing stormy waters in a shared boat"

CFCU
RUSİHAK
TÜRKİYE CUMHURİYETİ AVRUPA BİRLİĞİ BAKANLIĞI
REPUBLIC OF TURKEY MINISTRY FOR EU AFFAIRS

Independent Living Manual

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> “...I feel hopeful when I think of our struggle
> in Turkey because only after the struggle we could
> attain an independent life. I think independence and
> life are valuable separately in themselves, but
> taken together, the value increases many times.
> For a new dream, to transform, let us hit the
> bricks with our stubborn hopes.”
>
> *—Yasemin Şenyurt, Turkey—*

ENIL Freedom Drive, Brussels, 2015

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List of Abbreviations

ENIL	European Network on Independent Living
ESIFs	European Structural and Investment Funds
EU	European Union
CIL	Centre for Independent Living
DPAC	Disabled People against Cuts
DPO	Disabled People's Organisation
IL	Independent Living
ILNET	Independent Living Network: Promoting the Right to Independent Living of People with Disabilities in Turkey
NGO	Non-governmental Organisation
PA	Personal Assistance
UN CRPD	Convention on the Rights of Persons with Disabilities
UN CRPD Committee	Committee on the Rights of Persons with Disabilities
UPIAS	Union of the Physically Impaired against Segregation
US	United States

A Note on Terminology

As far as possible this document uses social model language (see Part 2). This is a terminology that argues that it is social barriers that disable people, such as negative attitudes, environment, inaccessible transport, segregated education etc., and not impairments or individual attributes. This puts the onus on policy-makers to change the life situations we face and work from a human rights and equality perspective. It also puts the onus on us, as disabled people, to educate and fight for recognition of independent living as a human right. As such the term disabled people is a political term.

Below is presented a set of disability-related terms with the social barriers terminology provided first, followed by its equivalent.

disabled people	people with disabilities
mental health users	psychosocial disabilities
learning difficulties	psychosocial disabilities/intellectual disabilities
cognitive impairments	intellectual disabilities
disabled women	women with disabilities
disabled children	children with disabilities

It is imperative to understand that in a social model or social barriers approach we do not own disabilities/disability, it is not an attribute of the person, or an element of lack, rather disability is a social condition imposed on top of our impairments. This understanding is expressed in the term ‘disabled people’, which refers to people being disabled by the environment.

We are all aware that the United Nations Convention for disabled people is titled the UN Convention on the Rights of Persons with Disabilities. It is, however, based on a social barriers understanding of disability and equality.

Introduction

A manual is usually a book giving instruction or information. This manual is written to provide tools for change through information. It does not set out to give instruction, specifically, but to offer examples of routes, histories and circumstances that have occurred in Europe. It identifies frameworks, ideas, challenges, myths and hope.

The routes for Turkey are dependent on Turkey's infrastructure, the attitudes of Government, existing legal systems and different stakeholders. These in turn are contextualised within Europe and internationally. But as with elsewhere it is for disabled people and disabled people's organisations to lead, act and work together for the future they want to see.

Change does not come because we wait for it, but because we fight for it. While we have a framework of rights, those rights must have a political will behind them so that they are implemented, monitored, shaped and improved by disabled people themselves. It is up to us to change our lives and convince others to support us in doing so until we achieve full independent living and equality everywhere for all disabled people.

Photograph © Richard Lumb | DPAC protest, London, 2012

PART 1

What is Independent Living and Why Is It Important?

“I have been involved in some NGOs voluntarily and have been a disability rights activist, but this visit made me realise that I need to work for independent living for people with different disabilities, promote IL to a wider audience and endeavour for realisation of IL in Turkey as soon as possible.”[1]

“In Turkish there is no equivalent phrase for independent living. The closest are two phrases, ‘independent’ and ‘self-sufficiency’, but independent living is not ‘self-sufficiency’.”[2]

Part 1 looks at what the term ‘independent living’ means and why it is important. It explores the philosophy of independent living, and gives a brief history of the independent living movement. Finally, it focuses on different examples of organisational frameworks with an emphasis on user-led self-directed personal assistance support, showing the ways this has been achieved in three different countries.

It is widely accepted that disabled people have fewer opportunities to participate in the activities of everyday life due to a number of social, access and attitudinal barriers. This section identifies the philosophy and actions that need to be taken to begin to remove the multiple social disadvantages that exist for disabled people and which continue to prevent us from living with the full choices, self-determination, rights and control that non-disabled people take for granted. Independent living requires a number of societal practices to be put in place which do not discriminate the life chances of an individual purely because they have an impairment (or multiple impairments), which may be sensory, physical, intellectual, related to mental health, or are labelled as having learning difficulties. We begin with the concept of independent living.

The underpinnings of the concept of independent living

Independent living is about all disabled people having the same rights and choices as everyone else. It is about the human rights of disabled people. However, independent living does not mean that an individual does everything themselves; whether disabled or not we are all interdependent. We all interact with others and depend on them in everyday life. But if one set of people are denied basics such as education, housing, support, they are at a disadvantage and have less chance to make independent choices or exercise their basic human rights. They do not have choice and control.

This is not a problem of the individual, but a problem of how societies are organised in ways that mean particular groups are not equal to others (see Part 2 on the social model of disability). It is a problem of some people’s human rights not being respected to allow them to live as and where they chose. It is a problem of policy and its implementation. It is

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[1] ILNET project participant, study visit to CIL-Sofia, April, 2015.

[2] ILNET project participant, kick-off meeting, January 2015, Istanbul.

a removal of the control from the individual. Yet, everyone should have the right to make independent choices that affect their lives, with support if necessary. Everyone should have the right to independent living.

Many have offered definitions for what independent living is:

> "The term independent living refers to all disabled people having the same choice, control and freedom as any other citizen – at home, at work, and as members of the community. This does not necessarily mean disabled people 'doing everything for themselves', but it does mean that any practical assistance people need should be based on their own choices and aspirations".[3]

A more active definition is offered by Dr Adolf Ratzka, one of the pioneers of the independent living movement:

> "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, organise ourselves and work for political changes that lead to the legal protection of our human and civil rights. As long as we feel ashamed of who we are, our lives will be regarded as useless. As long as we remain silent, we will be told by others what to do".[4]

The theme here is self-determination, to act on it, and to demand it. Some disabled people employ personal assistants to support them in everyday tasks or activities. One of the keys of independent living is that disabled people are able to employ, train and work with personal assistants to support them in a number of ways. The support can be provided at home, at work, in the community, at school or at university. What is important is that the personal assistance model is based on choice and control; that the disabled person is the boss, because disabled people are the experts on their own lives (see Part 2 for a further discussion of the personal assistance model). To understand, we need to look at the beginnings of the independent living movement where we also see the power of activism and what can be achieved.

Beginnings of the independent living movement[5]

The independent living movement philosophy was active in the United States in the 1960s and 1970s with the first well known Centre for Independent Living being established at Berkeley in 1972. It was spearheaded by Ed Roberts, a student at the University of California, Berkeley.

The University of California at Berkeley was reluctant to admit Ed Roberts when he initially applied. He had contracted polio as a teenager. He had limited functional movement and used a respirator to breathe. "We've tried cripples before and it didn't work," said the university. But, they did admit Ed in 1962 and arranged for him to live in the campus medical facility, Cowell Hall. His brother, also a student, served as an on-campus personal assistant, often pushing Ed from class to class in an old manual wheelchair. The barriers they encountered were not those of individual issues, but environmental and attitudinal barriers. It was these barriers that needed to be tackled to allow more independence.

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3. Disability Rights Commission (2002) Policy Statement on Social Care and Independent Living.
4. Ratzka, A. (2003) *What is Independent Living – A Personal Definition*, available at: http://www.independentliving.org/def.html
5. Based on 'Brief History of Independent Living', *Framework for Inclusion*, available at: http://www.frameworkinclusion.uk/resources/history-of-independent-living/

Ed Roberts, one of the pioneers of the independent living movement

In the late 1960s and early 1970s the Berkeley disabled students organised themselves into a group known as The Rolling Quads. The Rolling Quads put pressure on the university to become more accessible and to remove the environmental barriers around and in the university. The group began to look for funding to develop a student organisation to work for barrier removal. They also wanted to include support services and personal assistance services to allow disabled students to live more independently.

After establishing the campus organisation, Ed and others realised the need for an off campus, community-based organisation. In 1972, with minimal funding, the Berkeley Centre for Independent Living (CIL) was started. The core values of the Berkeley CIL: dignity, peer support, consumer control, civil rights, integration, equal access, and advocacy, remain at the heart of the independent living and disability rights movements.

Other countries were also active. Some examples are Finland, establishing the first independent living program in 1973 with 6 Centres for independent living being established in the same year. In 1975 the Union of the Physically Impaired against Segregation (UPIAS) published a manifesto in England in relation to the institutionalisation and lack of rights of disabled people. This was to be the basis for the social model of disability – a UK model popularised by Vic Finkelstein, Mike Oliver, and Colin Barnes. In the same year a group of disabled people living in a residential home in Zimbabwe organised themselves for advocacy for rights.

In 1978 Japanese disabled people organised radical self-advocacy and Switzerland held one of the first conferences on self-help or peer support for disabled people.

In the early 1980s the first Canadian CILs were founded, and the first organisation of disabled people was founded in Nicaragua, providing Independent living services and advocacy. In 1981 the British Council of Disabled People was founded (now renamed the UK Disabled People's Council), whilst in Germany a disability rights coalition staged a mock tribunal putting the country on trial for the abuse and segregation of disabled people. In the same year Project 81, which was the earliest UK form of direct payments, was funded by a local authority allowing people to employ personal assistants. It was operated by what would later become the Hampshire Centre for Independent Living in the UK[6]. It is important to recognise that these things did not just happen, but were a process of ideas, activism and battles. However the beginnings meant that a new form of support for disabled people had been established. This was not in the institutions, or the hospitals. A battle had begun, and it is fair to say that while we have made progress we are still forced to fight a continuing battle.

As we have seen it takes one person to argue and fight for change. One voice that can articulate how things can be done differently, that voice is soon joined by others, groups and organisations are then formed to effect change. As

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6. See Jolly, D. (2015) 'The Disability Movement'. In James D. Wright (editor-in-chief), *International Encyclopaedia of the Social & Behavioural Sciences*, 2nd edition, Vol 6. Oxford: Elsevier, pp. 462–466.

noted, one of the effective forms of organisation can be a Centre for Independent Living[7] or a different type of non-governmental organisation run and controlled by disabled people, another can be a co-operative. They are each based on the ideas of being led by disabled people for self-determination and are formed on the basis of that first CIL in Berkeley. Before moving on to look at examples of different constructs of organisational types, we need to look at the ways the independent living movement evolved in Europe and how the European Network on Independent Living was formed.

The foundation of the European Network on Independent Living

In April 1989 the first European Independent Living Conference was held at the European Parliament in Strasbourg, France. It was attended by disabled people from the Netherlands, UK, Denmark, Italy, Switzerland, Sweden, France, Austria, Finland, Belgium, USA, Hungary, the former Federal Republic of Germany and Norway. The conference resulted in the founding of ENIL: The European Network on Independent Living. Although the conference focused on personal assistance as a key theme of independent living, other issues such as housing, transport, access, education, employment, economic security and political influence were recognised as explicitly linked with independent living and self-determination.

Adolf Ratzka presented the keynote speech and went on to become the founding chair of ENIL. Adolf was previously student at Berkeley, German born and living in Sweden. He spoke of the impending entry into a European Community and market, due to happen in 1992. This was seen as both an opportunity and a threat to disabled people. An opportunity, because there was a chance to influence policy at the European level, and a threat because at country level professionals and those who claimed to 'know best', were still making decisions on disabled people's lives. It was possible that this would be continued at the European level, unless action was taken. Below we reproduce the Strasbourg resolutions arrived at that meeting, which still have merit today.

Strasbourg Resolutions

1. Access to personal assistance service is a human and civil right. These services shall serve people with all types of disabilities, of all ages, on the basis of functional need irrespective of personal wealth, income or marital and family status.
2. Personal assistance users shall be able to choose from a variety of personal assistance service models which together offer the choice of various degrees of user control. User control, in our view, can be exercised by all persons, regardless of their ability to give legally informed consent.
3. Services shall enable the user to participate in every aspect of life such as home, work, school, leisure and travel and political life. These services shall enable disabled people to build up a family and fulfil all their responsibilities connected with this.
4. These services must be available long term for anything up to 24 hours a day, 7 days a week, and as a short term, or emergency basis. These services shall include assistance with personal, communicative, household, mobility and other related services.
5. The funding authority shall ensure that sufficient funds are available to the user for adequate training of the user and the assistant, if deemed necessary by the user.

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[7] For further information on CILs and a survey of CILs in Europe see ENIL (2014) *Centres for Independent Living: a Toolkit on the role of CILs in supporting disabled people into employment*, available at: http://www.enil.eu/wp-content/uploads/2012/06/CIL-Toolkit_FINAL.pdf

6. Funding must include assistants competitive wages and employment benefits, and all legal and union required benefits, plus the administrative costs.
7. Funding shall come from one guaranteed source, and to be paid to the individual wherever he/she chooses. Funding shall not be treated as disposable taxable income, and shall not make the user ineligible to other statutory benefits of services.
8. The user should be free to appoint all personal assistants, whoever he/she chooses, including family members.
9. Lack of resources, high costs, substantial or non-existent services shall not be used as a rationale for placing an individual in an institutionalized setting.
10. There shall be a uniform judicial appeals procedure which works independently of the funders, providers or assessors, and is effected within a reasonable amount of time and enables the claimant to receive legal aid at the expense of the statutory authority.
11. In furtherance of all the above disabled people and their organizations must be decisively involved at all levels of policy-making including planning, implementation and development.[8]

In the final section we look at examples of successful organisations based on the CIL and co-op models in Sweden, England and Norway with an emphasis on self-directed personal assistance support.

Organisational forms for personal assistance

There are many variations of organisations led and run by disabled people to deliver personal assistance. Those below have been chosen because each emphasises a different group focus, business model or legal framework. The Hampshire CIL example also explains escape from institutionalised settings.

JAG Co-operative

Set up in Sweden, Jag means ‘I’ in Swedish. It is a reminder that the members of JAG are individuals, not objects of care. The name JAG is also formed of the first letters of the Swedish alphabet for the words Equality, Assistance and Inclusion. These three things represent important aims for its members. It is a co-operative for those with learning difficulties and multiple impairments, many of whom may not have speech. JAG membership includes those who may be considered as needing a high level of support. Members explain:

> “For us who have intellectual impairments it is on occasion difficult to express wishes, needs and priorities. It can also be difficult to understand the consequences of a decision. Almost every adult member in JAG has the help of a legal representative who interprets and conveys his or her wishes. For minors, the parents are legal representatives. All representatives must work towards the goals as stated in the statutes of JAG”.

JAG also has around a third of personal assistance users who are children. It is the users of the personal assistance that decide on the personal assistants they want and on their tasks. The users are in charge of the support that allows them independent living. While the members of JAG remain in control of choosing their personal assistants and the tasks they will perform, JAGs structure also provides a service guarantor appointed in consultation with each member’s legal representative. The guarantor acts as a guarantee that members receive the support they need. The JAG user co-operative has a contract with the service guarantor and provides training for them to take on the

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[8] Available at: http://disability-studies.leeds.ac.uk/files/library/DPI-ENIL89.pdf

ULOBA Disability Pride Parade

employment responsibilities and bureaucracy regarding the employment of personal assistants, as well as counselling, if needed. Guarantors are responsible for the personal assistant following the users intentions concerning the way members want to live their lives. The service guarantor commits to JAGs ideological aims of personal assistance, of human dignity and integrity, is prepared to take charge should personal assistance not be running properly, helps the member select assistants, schedule work plans, and provides monthly figures needed by the co-operative on salaries, administration and employment costs.

Assistants are employed on a full-time, part-time or hourly paid basis within the dictates of national employment law and union requirements. JAG informs newly hired personal assistants of their professional roles, employment conditions and the goals of personal assistance. This is done at hiring and on special information days organised by JAG. However, only the user and service guarantor can give information on specific tasks and duties the personal assistant will perform.[9]

Hampshire CIL

Hampshire CIL was the first CIL set up in England. Its history draws on both Berkeley and an institutional setting. Its genesis documents how liaison with local authorities can be used to support, yet not control disabled people's self-determination. At this time many disabled people were living in institutions. While the large institutions had been closed down in the 1960s, small institutions still remained and if a person was disabled this was likely to be where they lived. The exception was if they were wealthy and could afford their own support, or if they were, or wished to be supported by their families. While the roots of independent living in the United States (US) came from the universities, in England they came from people trying to get out of the institutions and live independently.

It was a group of people who became known as Project 81 who would come to spearhead the development of independent living. This was a group of people living in Le Court Cheshire residential home in Hampshire in 1979. They used the name Project 81 because 1981 was the United Nations year of Disabled People. Some of their number had visited Berkeley and brought the principles of independent living back, but as England had a different social and legal system they needed to fit solutions into that context – although the principles of independent living remain the same globally, systems within each country are different and need to be negotiated to ensure the principles of independent living develop effectively. The local authority was paying for them to live in institutions, so negotiations begun so that the same money the authority were paying for the institutions could be used to help the residents pay, instead, for personal assistants and live in the community.

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[9] Based on JAG (2011) *The "JAG-model"*, available at: http://enil.eu/wp-content/uploads/2012/02/Pa-manual_ENG.pdf

However, due to the false stereotypes of disabled people needing to be 'cared' for and somehow saved from 'risk' and 'danger', the process took three years. It was a process that was methodical and residents needed to undertake both extensive research and provide convincing arguments to sceptics, professionals and social workers. Over the same period residents researched what was happening with other disabled people and discovered a project called The Grove Road Scheme in Derbyshire. The Grove Road Scheme had also been set up by disabled people who were previously in institutions, in 1976. The scheme was that a set of apartments with three apartments downstairs and two apartments upstairs was used as a living arrangement. Disabled people lived in the downstairs apartments, while non-disabled people lived in the upstairs apartments and acted as personal assistants in exchange for living there, although they were also paid a small sum. Part 2 will come back to what those disabled people went on to do.

When the Project 81 pioneers had achieved their freedom from the institution, they wanted to share and spread the message to other disabled people and help them achieve the same things. They set up Hampshire CIL in 1984. It was based on the principles of US CILs with a focus on the independent living principles and the main themes of personal assistance and accessible housing. This was because at that time, and to an extent now, accessible housing in which wheelchair users could live was difficult to find.[10]

ULOBA user-led co-operative

In 1991 ULOBA, a user-led co-operative, was formed in Drammen, Norway by five disabled entrepreneurs 'with the goal of achieving equality for disabled people by providing them with personal assistance and the opportunity to live independently and join the work force on an equal basis with others'[11].The formation came after several years of planning work. ULOBA, or Uavhengig Liv Oslo og omegn (meaning independent life), came about through the work of Bente Skansgård and others who were influenced by the US example, and work that was already happening in Sweden and in Denmark. The five co-founders, all of whom were disabled, and wished to be personal assistance users realised that the municipality services could never offer independent living. The limited home help services meant people needed to stay at home, and wait for times set by the municipality. In addition, no support was available outside the home, unless it was from family members. Presentations on the alternatives of independent living and personal assistance, with the personal assistance user as the employer, were made by the co-founders to municipalities and national Government. In an interview Bente shared that officials saw their ideas like science fiction. She recalled, 'They wondered how anyone who couldn't get dressed by themselves would be able to employed anyone!'[12].

The arrangement was that the local authority or municipality transferred to ULOBA the funds for the home service for those who wanted to use ULOBA for personal assistance. In the first two years only four local municipalities were signed up. However, ULOBA grew to sign up 150 Norwegian municipalities with almost 6,000 personal assistants on the ULOBA payroll. Personal assistant users train and chose their assistants with support from ULOBA. Half of the administrative staff employed by ULOBA are also disabled people.

ULOBA has developed the 'assisted work leader scheme' for those who may need additional support in running their personal assistant schemes, for example those described as having social and intellectual impairments, to have the same access to independent living. Crucially, ULOBA has played a key role in pushing through a personal assistance law in Norway for those needing more than 25 hours of support per week. It also runs the Disability Pride festival each year in Oslo where disabled people come together from many different countries.

Like all examples given, the ULOBA model has great transferability to other countries where disabled people are fighting for equality and independent living. Personal assistance incurs no extra expense but is a matter of shifting funds from institutions and home services to user-led personal assistant models, aiding work and education, and allowing disabled people to live lives as full citizens with choice and control over their lives. In addition, such schemes save public administration costs in terms of in-employment support, training, and peer support.

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10. Adapted from Evans, J. (2002) *Independent Living movement in the UK*, available at: http://disability-studies.leeds.ac.uk/files/library/evans-Version-2-Independent-Living-Movement-in-the-UK.pdf
11. Innovative practice for 2015: Norway/ULOBA, *Zero Project*, available at: http://zeroproject.org/practice/uloba-norway/
12. See http://www.enil.eu/news/bente-skansgard-the-mother-of-the-norwegian-independent-living-movement/

Protest of disabled people in Germany

PART 2

The Social and the Individual/Medical Models: Why We Need to Re-make Social Policy

“…as a social worker in a municipality, I was impressed once more by CIL [Sofia’s] advocacy-based approach, instead of a care-based one. Unfortunately, we all know that in Turkey the work of municipalities is care-based. I would like to emphasize that this perspective needs to change.”

“Living in institutions together and being isolated from society (being imprisoned) is no longer good for us. In the past, this idea seemed to be attractive, yet we understand from our painful experiences that this is just an illusion. Now, we have to fight against institutionalization. Disabled people need awareness raising about their rights and to get education in any field they like.”[13]

Part 1 examined the concept and roots of independent living along with examples of actions taken by disabled people. **Part 2** will look at the social and medical models. It will examine why the concept of care can often debilitate us. While looking in more detail at the personal assistance model, it also expands to examine other factors of independent living, and some of the myths surrounding it within the context of the situation in Turkey. Finally, it gives examples of advocacy and direct actions by disabled people. We begin by looking at the social and medical or individual models of disability.

The social model

> “…the social model of disability – a focus not on the individual and impairment as the problem but on the need to address social, economic and environmental barriers. This approach means recognising that it is these barriers, rather than functional impairments, which get in the way of individual autonomy and self-determination, creating disadvantage and social exclusion. It also means that disabled people should have choice and control over how any assistance they might need is provided – in order to enable autonomy and self-determination. Most importantly, since independent living is a necessary component of full citizenship for disabled people, it should be provided as a right, and not dependent on charity or professional discretion”.[14]

The social model or social barriers approach was developed by disabled sociologist and activist Mike Oliver as a training tool for social workers and professionals. The social model was an attempt to move away from individual and medical ways of viewing individual impairments (whether physical, sensory, or cognitive) as issues of an individual to be fixed, towards a focus on social barriers, social policy and de-professionalisation. Crucially the focus moves away

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13. ILNET project participants, study visit to CIL – Sofia, April 2015.
14. Morris, J. (2011) *Rethinking Disability Policy*, p.11, available at: https://www.jrf.org.uk/report/rethinking-disability-policy

from the individual being perceived as an example of personal tragedy, an object of care or charity, or something for medical professionals to fix, towards a focus on the barriers that serve to disable people. In this way we are disabled not by our impairments, but by attitudes, environments, professionalism, a lack of effective social policy and medicalisation.

The social model came into being through a letter from Paul Hunt, who was incarcerated in an institution, to the Guardian (a British newspaper) calling for the creation of a consumer group to put forward the views of the people in residential institutions. It is based on the early work of the Union of the Physically Impaired against Segregation – a manifesto 'Fundamental Principles of Disability', written by Vic Finkelstein and other activists, arguing that they were disabled by society, not by their bodies. They were institutionalised in a Leonard Cheshire[15] institution. The UPIAS document and its premise were taken forward in the 1980s and 1990s by disabled activists and academics including Mike Oliver and Colin Barnes. The social model of disability was also taken forward by activists, campaigners and those who set up some of the first Centres of Independent Living. Disability activists, using the social model perspective, argue it is the ways that society treat disabled people that creates the main problem. The experience of disability is not exclusively about the individual or the individual's attitudes. The experience of disability is an interaction with actions of non-disabled people, planners, governments, employers and others. People need educating on what it is really like to be disabled and the many barriers that disabled people face in their everyday lives. They need to understand those barriers which prevent disabled people having the same opportunities and life chances as their non-disabled peers, including institutionalisation.

The social model does not focus on disabled people as victims of their medical diagnoses, whether physical, cognitive or otherwise, nor as vulnerable, helpless individuals but as people who are disabled by attitudes, the environment, design, working patterns and by those who see disabled people as unworthy or purely as objects of care. The social model also offers a way to organise politically against the principles of social and economic exclusion in disabilist societies. It gives a critique of all that has gone before based on individualism, 'care', institutionalisation, charity and medicalisation. It also argues that disabled people must be at the centre of voicing their own experiences. The social model was constructed by disabled people, not medical 'experts', not policy-makers, not disability charities, not service providers, not care agencies, not governments, nor private companies profiting from disability. We do not want to be cared for as objects of pity by professionals, but cared about in policy, in universal design, and as a political voice arguing for our human rights and our self-determination. The table below outlines these principles.

Two models of disability

Individual model	Social model
Personal tragedy	Social oppression
Personal/individual problem	Social problem
Individual treatment	Social action
Professional dominance	Collective peer support
Professional expertise	Life experience
Medical identity	Collective political identity
Object of care	Rights
Control	Agent of choice and self-determination
Individual adjustment	Social change

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[15] Leonard Cheshire is a charity for disabled people in the United Kingdom.

Part 1 showed how the Hampshire CIL (England, UK) had been developed by some of those who formed Project 81. They had successfully moved out of institutions and convinced the local authorities that the money being used to institutionalise them should be used to allow them to employ personal assistants and live in the community. We also saw the example of the Grove Road Scheme in Derbyshire (England, UK) through which disabled people also left institutions by sharing an apartment with non-disabled people who were providing informal personal assistance. Those in the Grove Road Scheme later decided to move into their own homes, and while Hampshire CIL focused on personal assistance and accessible housing, those from the Grove Road Scheme went on to set up the Derbyshire CIL. They still promoted personal assistance, but also identified other social issues. In 1981 they developed a list of seven needs for independent living, including but not exclusive to personal assistance. The Seven needs were developed with their members. They were based on the five core services developed at Berkeley and became a guide for the setting up of CILs at the time. They are outlined below.

Derbyshire CIL: Seven Needs of Independent Living[16]

1. **Information**
   Disabled people require accessible information on what is available to assist with independent living.
2. **Peer Support**
   Disabled People need the support of other disabled people to discuss how to make best use of the information obtained and for ongoing support.
3. **Housing**
   Disabled People need accessible housing. This may mean wheelchair access or support and advice to enable some disabled people to live in their own homes.
4. **Equipment**
   Many disabled people need practical equipment to assist them in living independently.
5. **Personal Assistance**
   This is the one-to-one support that some disabled people need to live in their own home and be part of the community.
6. **Transport**
   This includes physical access to public transport, accessible information about the routes, assistance for passengers and routes which take into account the needs of disabled people. It also includes access to personal transport such as cars.
7. **Access**
   This covers physical access such as dropped kerbs, level entrances to buildings and accessible toilets. It also covers access to all aspects of mainstream life involving the removal of barriers caused by systems, practices and attitudes which prevent disabled people from participating.

The thinking at the time was that once these were in place policy would develop to include issues such as access to education and employment. A new set of criteria came in in 2010 which were ‘the twelve pillars of independent living’, sometimes called ‘the twelve pillars of full citizenship’. The seven needs remained, but were added to include: an adequate income, inclusive education and training, equal opportunities for employment, appropriate and accessible health and social care provision, meaning that instead of a professionals telling us what is right for us as disabled people, we identify our choices from a framework of options that fit with our lives.

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[16] See http://www.frameworkinclusion.uk/2015/05/25/seven-needs-of-independent-living/

The social and the national in Turkey

The Manual has focused on examples from different countries to look at the history of independent living and the various solutions that have been put in place by disabled people from CILs, and co-ops. However, it is clear that although the philosophy and actions towards self-determination and independent living are global, in that they have the same goals, different countries have different infrastructures, policies and attitudes towards disabled people. It is really no surprise that independent living as a concept came to life in the US, with a highly individualistic culture. However different countries need to take different routes towards their goals, depending on the context of the particular country, its history and its current situation regarding the treatment of disabled people (via institutionalisation in large or small institutions), family cultures, legal frameworks, current government policies and policy-makers.

Currently in Turkey the charity model prevails instead of the rights model and the medical and care model – instead of the social model. The Turkish Social Rights and Research Association (TOHAD) identifies the following social and attitudinal barriers to independent living in Turkey:

- Disability is seen as an individual, not social, problem, which could be addressed by people with special knowledge and authority. Disabled people are not treated as persons but as 'invalids', which devalues their ability to perform as citizens.
- Disabled people are seen as needing special treatment (e.g. children with special needs need special education) instead of mainstream.
- Charity instead of human rights model: Activities done for disabled people are seen as a blessing not as a right. Few NGOs promote rights-based approach, the majority provide charity.
- Disabled people's attitude and perception about their disability and the lack of knowledge of their rights.
- Fiscal concerns
- Social marginalisation[17]

A survey carried out by the General Directorate of Services for Disabled Persons and Elderly and the Turkish Statistical Institute in 2010, titled Survey on Problems and Expectations of Disabled People had a definition of disabled people as:

> "Disabled individuals are unable to ensure by theirself, wholly or partly, the necessities of a normal individual and/or social life, as a result of deficiency, either congenital or not, in their physical capabilities". [18]

While certainly not adopting a social model definition, the survey appeared to make some effort to identify problems of disabled people in the societal realm, although identifying and having the political will to solve issues are two different things. Issues covered included income, assistance, support, employment, education, environmental barriers and transport barriers – all of these can fit into a social barriers approach.

The survey identified expectations from governmental institutions and organisations of 'people with visual disability, hearing disability, language and speech disability, mental and emotional disability, orthopaedic disability, intellectual disability, chronic illnesses and multiple disability'. It showed the biggest issue was that social assistance and support needed to increase (87.5%), followed by the need to improve health services (77%) and to improve and extend care services (40.4%). Lower on the scale were the increasing possibilities of finding a job and increasing educational opportunities – at 28.7% and 25.6%. Lowest of all, were arrangements of the physical environment and transport facilities.

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[17] Polat, G., personal communication, 2015; Akbulut, S. (2015) 'Disability Rights and the Current Situation in Turkey regarding Independent Living', presentation at the ILNET kick-off meeting, 21 January 2015, Istanbul.

[18] Turkish Statistical Institute, http://www.turkstat.gov.tr/PreTablo.do?alt_id=1017

Given that income from social assistance and support is important, if such income is in the hands of others (for example, guardians) there are obvious problems. At an initial ILNET meeting organised by RUSIHAK, one Turkish man told of his frustration at his family holding his support income, as a middle age man he believed that it should be payable to him directly. The legal guardian system, still existing in Turkey, is very problematic. Guardianship can be used by family members and friends to place disabled person in an institution against their will or to take over their property and possessions. For example, at the ILNET meeting one man's story concerned a friend becoming a legal guardian, the man had had a house bequeathed to him by an aunt, but the legal guardian took possession of it. The guardianship system is clearly in the medical model of disability and presents a problem for human rights and independent living. Those under guardianship are viewed as 'persons with limitations'. This goes against the UN CRPD provisions, which are discussed in **Part 3**.

The improvement and extension of care and support services is also essential for the independent living of disabled people. The Roadmap on the Implementation of Article 19 in Turkey[19], developed as part of the ILNET project, finds that the existing support services are limited in range and scope, dominated by residential and traditional institutional type of care and with provision generally based on a medical model, which segregates disabled people and denies their right to make decisions for themselves. A change in the policy is required to move towards development and provision of services based on the social model, supporting disabled people's independent living and full participation in society.

Finally, improved opportunities for quality education and employment are also important for disabled people's independent living. Currently, 41.6% of registered disabled people[20] are illiterate, 18.2% are literate but have not completed any schooling and only 7.7% have attended college and higher education. The access to quality mainstream education is needed to improve employability of disabled people. This should go hand in hand with measures to put in place the relevant infrastructure, such as accessible physical environment and transportation, support services, including personal assistance, equipment, etc.

The issues described above are not isolated to Turkey by any means, but set the scene for what needs to change. While all key social and attitudinal barriers need to be challenged and changed, two of the key issues are guardianship and the structures of financial support not following the disabled individual[21]. Changes here could enable choice, control and personal assistance.

Hope houses and personal assistance

Hope houses are residential services for disabled people, which are currently being developed in Turkey as a community-based alternative to large-scale institutions[22]. Hope houses provide people with a place to live, but the home undertakes guardianship, which is fundamentally against the independent living philosophy.

While the problems outlined are based on examples and policy 'solutions' in Turkey, they are not specific to Turkey. Ratzka explains why:

> "Social policy is rarely made by the people whose lives depend on it. For that reason we often see legislation, programs and practices that make people with disabilities more dependent rather than more independent. In most countries, policies or lack of policies drive people who need help of others in the activities of daily living into dependence on their families or exclude them from the life of the community by forcing them to live in segregated residential facilities or to stay in their parental homes beyond the customary age."[23]

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19. See http://ilnet.enil.eu/resources/
20. The research included 280 014 people who were registered on the National Database of People with Disabilities, created by the General Directorate of Services for Disabled Persons and Elderly.
21. Further recommendations for actions that need to be taken to ensure that disabled people in Turkey can live independently could be found in the Roadmap on the Implementation of Article 19 in Turkey.
22. As of March 2015, the number of Hope houses in Turkey is 94. See http://eyh.aile.gov.tr/kuruluslarimiz/kuruluslarimiz-engelli/umut-evleri (in Turkish)
23. Ratzka, A. (ed) (2004) *Model National Assistance Policy*, available at: http://www.independentliving.org/docs6/ratzka200410a.html

The funds used for the Hope Houses could be used differently to ensure choice and control. Adolf Ratzka's personal assistance model is relevant here, as are the examples of the structuring of the co-operatives and CILs given in Part 1. These ensure that the disabled person, whatever their impairment type, is in control, but also that any funds are paid directly to the disabled person themselves to undertake independent living in the ways they want, with them having the control.

As noted, the term personal assistance user refers to a disabled person choosing a personal assistant to aid them in everyday tasks and in negotiating environmental, transport and other social barriers. Not all disabled people may want or require personal assistance, but all disabled people, including those that use or wish to use personal assistance, want to exercise choice, control and self-determination over their own lives. ENIL supports the personal assistance model by Dr Adolf Ratzka and the European Centre for Excellence in Personal Assistance which sets key principles in place.

Ratzka's Employment Model of Personal Assistance

The funding of [personal assistance] services follows the person and not the service provider.

Personal assistance users are free to choose their preferred degree of personal control over service delivery according to their needs, capabilities, current life circumstances, preferences and aspirations.

Their range of options includes the right to custom-design their own services, which requires that the user decides who is to work, with which tasks, at which times, where and how. Therefore, a policy for "personal assistance", among other solutions, enables the individual to contract the service of his or her choice from a variety of providers or to hire, train, schedule, supervise, and, if necessary, fire his or her assistants. Simply put, "personal assistance" means the user is customer or boss.[24]

Personal assistance is NOT the assistance of nurses, social workers, charities or medical professionals. It is not a volunteer visiting a disabled person and having tea or coffee with them, nor should it be the assistance of family members as this is less likely to support self-determination and independence than a personal assistant distinct from the family with set tasks organised and overseen by the personal assistance user. The exception would be where a disabled person has a special requirement for a person from their own family due to religious or other cultural criteria which cannot be satisfied by other eligible persons. Personal assistance is certainly not something offered by staff in residential homes or institutions (including day centres), nor should it be described in translations of Article 19 of the UN CRPD as "personal support" or by any other term. Personal assistance is something controlled and managed by the disabled person to ensure their self-determination and independence on their own terms – anything else contravenes the aims and philosophy of the original concept developed by the independent living movement.

Definitions to support development of Independent Living Policies

Charities, service providers, policy-makers and others have sometimes hi-jacked the independent living philosophy for their own profit, so they offer something with the name of independent living without its underlying philosophy or outcomes. Presenting small group homes (such as Hope houses in Turkey) as community-based services are just

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[24] Ratzka, A. (ed) (2004) *Model National Assistance Policy*, available at http://www.independentliving.org/docs6/ratzka200410a.html

one of many examples. Bearing this in mind, ENIL has produced an important set of definitions of key terms based on independent living philosophy. These definitions are intended for use in the development of policy and legislation at the European Union level, Member State level and local level. Their aim is to give decision-makers clear guidance for the design and implementation of disability policy. They have been developed to prevent the manipulation and the misuse of our language for the development of policies that are counter-productive to independent living.

The concept of independent living is much older than the UN Convention on the Rights of Persons with Disabilities. It has played a key part in the drafting of the Convention, especially Article 19, but is also underpinning other articles, none of which can be realised without independent living. Article 19 sets out the right to choose where, with whom and how to live one's life. This allows for self-determination upon which independent living is based. There is a continuous debate on independence vs. interdependence; ENIL considers that all human beings are interdependent and that the concept of independent living does not contravene this. Independent living does not mean being independent from other persons, but having the freedom of choice and control over one's own life and lifestyle.

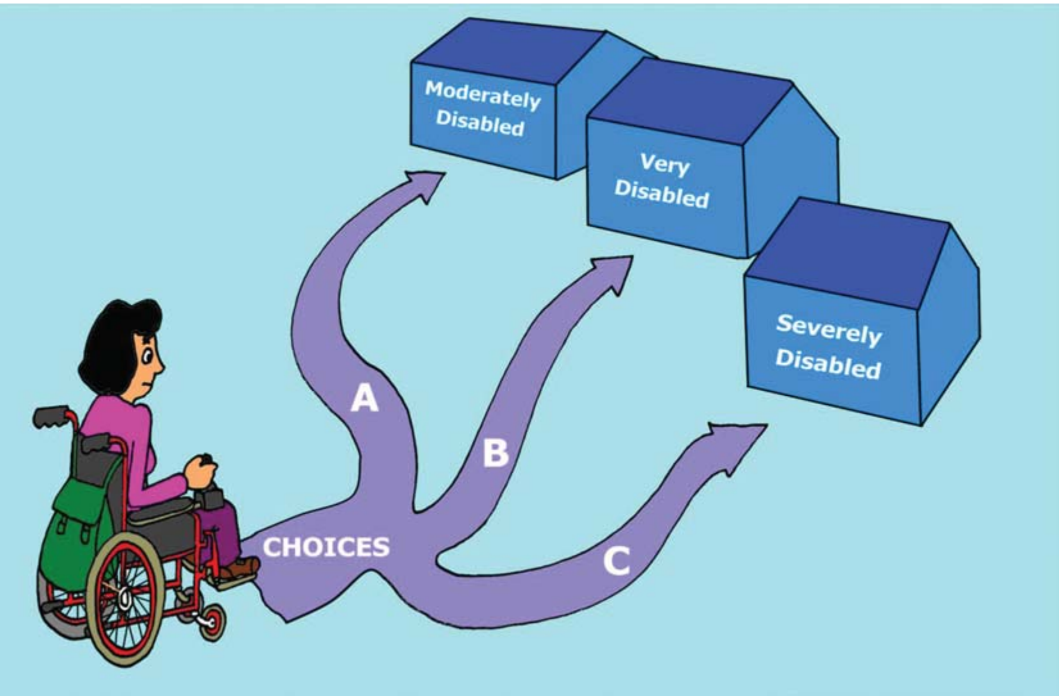
Independent Living (IL): IL is the daily demonstration of human rights-based disability policies. IL is possible through the combination of various environmental and individual factors that allow disabled people to have control over their own lives. This includes the opportunity to make choices and decisions 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. IL 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 IL is for *all* disabled persons, regardless of the level of their support needs.

Personal Assistance (PA): PA is a tool which allows for IL. PA is purchased through earmarked cash allocations for disabled people, the purpose of which is to pay for any assistance needed. PA 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. PA allocations must cover the salaries of personal assistants and other performance costs, such as all contributions due by the employer, administration costs and peer support for the person who needs assistance.

Deinstitutionalization (DI): DI is a political and a social process, which provides for the shift from institutional care and other isolating and segregating settings to IL. Effective DI occurs when a person placed in an institution is given the opportunity to become a full citizen and to take control of his/her life (if necessary, with support). Essential to the process of DI is the provision of affordable and accessible housing in the community, access to public services, personal assistance, and peer support. DI is also about preventing institutionalization in the future; ensuring that children are able to grow up with their families and alongside neighbours and friends in the community, instead of being segregated in institutional care.

Community-based Services (CBS): The development of CBS requires both a political and a social approach, and consists of policy measures for making all public services, such as housing, education, transportation, health care and other services and support, available and accessible to disabled people in mainstream settings. Disabled people must be able to access mainstream services and opportunities and live as equal citizens. CBS should be in place to eliminate the need for special and segregated services, such as residential institutions, special schools, long-term hospitals for health care, the need for special transport because mainstream transport is inaccessible and so on. Group homes are not IL and, if already provided, must exist alongside other genuine, adequately funded IL options.

Independent Living Myths[25]



MYTH: Living independently is not for everyone. We will always need institutions.

FACT: If given the right support, everyone can live in the community.

MYTH: Independent Living can be achieved by building Group Homes and Day Care Centres for disabled people.

FACT: Disabled people are often placed in group homes and day care centres due to lack of other supports and services available.

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[25] ENIL (2014) Myth Buster. Independent Living. Available at: http://www.enil.eu/wp-content/uploads/2014/12/Myths-Buster-final-spread-A3-WEB.pdf

Advocacy and protest

We have looked at the underpinning of the independent living model and the social model and have explored some of the past actions that disabled people have taken. It is important to state that collective actions are crucial for raising awareness, for collective empowerment and for uniting disabled people and our allies in the cause to promote change and the fight we are all involved in. All the problems outlined here can be changed by social pressure by disabled people and their organisations to push the political will for change.

> "I would like to give a quote from Don Quixote: 'One people need to be woken up. One needs to turn their ways of perception upside down and let them know that they live in a pretty unreliable and weird world, that they are not in the kind of world they suppose."
>
> "Leaving aside all difficulties experienced by the one, who is already alone, for the other issues such as education, healthcare, employment and social environment, individuals with or without disabilities need to act together in order to provide everyone with humane and equal conditions".
>
> "Several things remained in my mind from all the conversations, tools and people. For ILNET in Turkey, people with disabilities... need to face the realities – because spreading and promoting this concept here in Turkey must be the most important endeavour for people with disabilities."[26]

One of the well-known direct actions at EU level is the ENIL Freedom Drive, which is held every two years. Disabled people attend from all over Europe to march to the European Parliament, speak to their national Member of the European Parliament and to meet and share their collective ideals[27]. Yet there are many protests and direct actions at national levels too. Sadly, we only have space for a few examples here.

When Nothing Else Works – CIL-Sofia in Action, Bulgaria

In the summer of 2015 CIL-Sofia organised a mock tribunal against the Bulgarian Government for crimes against disabled people.

In most national languages tribunal is a special jurisdiction, usually in post-war situations and outside the regular court system. The 1945 Nurnberg Tribunal marked the start of special courts for crimes against humanity.

In the middle of 20th century a System, somewhere in Europe, is the major perpetrator for institutionalisation of disabled people. On the 27th August 2015 this System experienced the Citizens' Tribunal – Disabled People vs. the System.

Bulgarian disabled people are left for years to stay isolated, uneducated and poor, pushed to the margins of society with no opportunities to choose and decide who to have a cup of coffee with. The Centre for Independent Living in Sofia runs the battle for years to see a change, to have respect for the human dignity of hundreds of thousand disabled Bulgarians. This battle is hard and unjust: "hard" as it aims at destroying the long lasting status quo – maintained with the support of passive disabled people – that lasts due to the tragic situation of disabled people; "unjust" as the System operates a wide range of means for oppression and huge

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[26] ILNET participants, study visit to CIL – Sofia, April 2015.

[27] See http://www.enil.eu/

When Nothing Else Works – CIL-Sofia in Action, Bulgaria *(continued)*

public resources to keep the System going. The System screams at us quietly but ominously, shows its teeth, puts disabled people against other disabled people; it kneels down to all governments to keep it unreformed in order to continue to destroy human lives placed in its care.

We have lost many friends and supporters on the long way of the battle. The cruel System did not spare the 22-years old Lora from a small group home in Pleven who starved to death. The System spends money to buy surveillance cameras and install them in the bedrooms of SGHs residents.

The System keeps its built environment inaccessible, spends money for accessible buses with bus-stops in the middle of the road; it does not care about the schools and individual supports at all. The System says that disabled people are sick and does not recognise their needs for participation – technical aids, personal assistance, etc. It locks up innocent people, girls and boys in institutions and takes their future away – once they get into the System they are simply forgotten until money is to be collected for every single 'personal individual number' on the list of residents.

So, enough is enough! This is nothing but a crime against humanity and we put the System on trial before the Citizens' Tribunal. There was a Grant Jury, judges and a Themis – all principles of a due process and fair trial were hundred percent observed. and lots of eye-witnesses…

The indictment was clear enough to get the jury decide

GUILTY AS CHARGED!

The Bulgarian Government is in violation of UN CRPD Art. 19, depriving disabled Bulgarians of their right to choose where and with whom to live, to participate in communities of their choice, to use public services as all other citizens do by having access to reasonable housing, personal assistance, technical aids and peer support. This situation makes disabled people apply for institutional placement where they are badly treated, misused and oppressed. The so called deinstitutionalisation represents a simple move of large cohorts of people from large, old and worn-out facilities to newly built small houses with institutional type of management. The approach applied is still the one of isolation and referrals of disabled people to special places while mainstream environment is left full of barriers. Instead of providing for personal assistance Government authorities keep hiring social workers, doctors and other professionals to take care of the disabled residents who are not given a chance to enjoy peer support and become empowered in order to move some day to effective community living arrangement. The situation gets even worse given the restricted access of disabled children to decent education in mainstream classes.

Given the circumstances presented in the indictment, the Court urges the Government to start immediate action and pass a new disability legislation, mainstreaming disabilities in all public policies and changing the approach to representation of disabled people in the policies process.[28]"

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28. Zhisheva, N. (2015) When Nothing Else Works – CIL – Sofia in Action, available at: http://www.enil.eu/news/when-nothing-else-works-cil-sofia-in-action/

Citizen Tribunal, CIL – Sofia

Demonstrations against Austerity by Disabled people in Turkey

In spring 2015 demonstrations against austerity policies were held by disabled people in thirteen Turkish provinces. Protests were around a cut in 'home care' payments paid to the families of disabled people. The home care payments for a third of the 76,000 people in Istanbul who received that money in 2014 have already been cut and the figure was expected to continue to increase. The anger of people was directed at the fact that such payments were now based on the income of the family, which was not previously the case. The fact that payments for disabled people are paid to family members instead of directly to the disabled person is bad enough, but the focus on family income is another problem that identifies disabled people as a perceived burden.

The deputy head of the Association of Handicapped Persons stated, "This is not a social state. The family or relatives cannot stand between the state and the individual. This is a very dangerous approach. It will lead relatives to see the disabled person at home as someone who impoverishes the family and impedes its development. This could spur an undercurrent of animosity against that person within the family."[29]

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[29] Cetingulec, T. (2015) 'Disabled Turks protest benefits cuts', *Al Monitor*, 16 April, available at: http://www.al-monitor.com/pulse/originals/2015/04/turkey-disabled-people-protest-their-curtailed-rights.html#ixzz3lYi0qgm4

Protest of disabled people in France, 2014

PART 3

The European and International

> *Disability and mental health are human rights issues, Article 19 [of the UN Convention on the Rights of Persons with Disabilities] shows all services should be revised, yet essence of the UN CRPD is not fully understood by civil society.*[30]

Part 1 and **Part 2** looked at the philosophy and beginnings of independent living, the practical structures to set up cooperatives and CILs, the social barriers approach, why context matters and similarities and differences in different countries. **Part 3** will focus on the UN Convention on the Rights of Persons with Disabilities and the European Disability Strategy 2010–2020. It will examine different routes to strengthen our rights and the key problems we face. Both documents are important in the European and international context as tools through which to strengthen our human rights.

The United Nations Convention on the Rights of Persons with Disabilities

The spirit of independent living is enshrined in the UN Convention on the Rights of Persons with Disabilities. The Convention has 50 Articles in all, setting out disabled people's human rights and the obligations of the State Parties to promote, protect and ensure these rights. At the time of writing there were 154 ratifications to the Convention and 86 ratifications to the Optional Protocol[31].

To ratify the UN CRPD means a country agrees to implement the UN CRPD. If a country ratifies the Optional Protocol, it means that individual citizens and non-governmental organisations can present cases to the UN CRPD Committee. This provides a route to challenge limitations imposed on disabled people by central governments. The signing of the Optional Protocol and its ratification by a country means that it agrees to individual and group petitions from disabled people to the UN Committees (after all national legal mechanisms have been exhausted). The signing of the Optional Protocol therefore offers two procedures which can strengthen the Convention's implementation:

1. an individual communication procedure, allowing individuals to bring petitions to the Committee with breaches of their rights;
2. an inquiry procedure, giving the authority to the Committee to make inquiries into violations of the convention[32]

The UN CRPD has the potential to be a strong tool for independent living and disabled people's human rights. However, it is up to us to chase governments to make sure they implement, to take court cases against governments at local and national levels, and to make the UN CRPD work by making use of it. A study carried out in 2010 by ENIL and covering 31 countries, showed a mixed response to how the UN CRPD was being implemented. The purpose of the study was to try and understand how people thought the UN CRPD was working and how they believed their governments were implementing, or not implementing it.

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[30] ILNET participant, kick-off meeting, January 2015, Istanbul.

[31] Turkey ratified the Convention on September 28th 2009 and the Optional Protocol on March 26th 2015.

[32] United Nations (2006) From Exclusion to Equality: Realizing the Rights of Persons with Disabilities, available at: http://www.un.org/disabilities/documents/toolaction/ipuhb.pdf

ENIL Pilot Study on UN CRPD

Most respondents described their governments' knowledge of the CRPD as poor. Over half (56.4%) believed that their government's knowledge of the CRPD was poor or very poor.

Sixty-four percent of respondents said that their government had ratified the CRPD. Almost 15% did not know if their government had ratified it or not.

Fifty percent said that there had not been any changes for disabled people in their country since their government signed or ratified the CRPD. Twenty three percent did not know and almost 27% said there had been changes.

Changes were described as poor or very poor by almost 20%, just 6.2% described the changes as good with almost 22% describing changes as 'average'.

Just 10% saw a positive will from their government to make changes in relation to Article 19. Thirty-two percent believed there was 'a little' will, but a further 32% saw no will at all from their government to make any positive changes in relation to independent or community living.

Twenty-four percent said that their government had begun to monitor the Convention. Yet the largest majority did not know if their government had begun to monitor or not.

Almost half (45%) did not know if the government had involved a Disabled People's Organisation in the monitoring process. Only 21.3% claimed that a DPO was involved in the monitoring of the CRPD.

Just 22.2% of those who knew a DPO were involved in the monitoring said that they believed the DPO involved was an organisation working from the social model perspective with an understanding of independent living values.[33]

While all articles of the UN CRPD are significant Articles 19 and 12 are of particular significance to hold governments to account and to educate others on our rights

Article 19 of the UN CRPD

Article 19 of the UN CRPD is at the heart of independent living and sets out the independent living philosophy and aims clearly.

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[33] See Jolly, D.(2010) Pilot Study: The UN Convention on the Rights of Persons with Disabilities, available at: http://disability-studies.leeds.ac.uk/files/library/jolly-pilotCRPD-final.pdf

Article 19 – Living independently and being included in the Community

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

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

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

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

> "By encapsulating independent living in international law, it becomes not just available but a requirement in widely differing political and cultural settings around the world. Whether or not it achieves its emancipatory potential will depend on many factors, not least the ability of disabled people to retain ownership of its meaning, its interpretation and its application." [34]

A survey on personal assistant services in 22 countries in Europe, carried out by ENIL in 2013, showed that countries with national legislation were Denmark, France, Germany, Latvia, Norway, Serbia, Slovakia, Spain, Sweden and the United Kingdom. However, not all countries covered all impairment types, for example, those with learning difficulties, or intellectual impairments, in legislation, or in proposed legislation.

Taking the example of England, direct payments that could be used for personal assistance were first given to those with physical and sensory impairments, but were later widened to include those with learning difficulties, mental health issues and children. This was because pressure was applied on government at local and national levels. Yet, both England and the UK had to overcome the 'care' criteria, set in place by local authorities, that were focused on notions of 'risk'.

Currently, budgets for personal assistance are being cut and a new Health and Social Care Act is being implemented. It is correct to say that currently, the central government do not understand the UN CRPD or treat it as anything but 'soft law'. However several court cases have been fought using the UN CRPD Article 19 along with domestic legislation. In addition to the two court cases on the closure of the Independent Living Fund (see Part 2), there have been a number of court cases on assessment procedures by grass-root user-led mental health networks, and there are cases going forward on the Mental Health Capacity Act. While legal routes are not always successful and are time consuming their power to change things cannot be underestimated. These actions became part of wider campaigns in awareness raising creating new pressures on government and freelancers in media. Of course this route is not specific to the UK alone.

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[34] Collingbourne, T. (2009) The UN Convention on the Rights of Persons with Disabilities and the Right to Independent Living Paper (written for ENIL) cited in Jolly,D. Personal Assistance and Independent Living page 2 http://disability-studies.leeds.ac.uk/files/library/jolly-Personal-Assistance-and-Independent-Living1.pdf

> “Here in Sofia, CIL is doing this, making a big struggle and made a great progress. It was really important to hear the experiences (personal assistance, legal processes, empowerment, etc.) of people with or without disabilities supporting the cause. This is why the societies have to come together, share experienced and eliminate the obstacles. Your presence empowers and supports us.”[35]

The problem of institutions

While institutions, large or small, remain, Article 19 remains unfulfilled. ENIL offer several useful definitions:

An institution is any place in which people who have been labelled as having a disability are isolated, segregated and/or compelled to live together. An institution is also any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size. Institutional care refers to any residential care where: users are isolated from the broader community and/or compelled to live together; these users do not have sufficient control over their lives and over decisions which affect them; the requirements of the organisation itself tend to take precedence over the users’ individualised needs.

A residential care setting is terminology used by service providers to denote settings specifically designed for disabled people (such as group homes, service apartments, protected/sheltered homes and living centres), where people are grouped together depending on their labelled type/severity of disability. Such settings can cater for children and adults, and can be smaller (for example, for 6 people) or bigger (for example, for 30 people). It is a model of service which links the supports a person requires with a particular type of housing, thereby restricting people’s choices about where and with whom they will live. Residential care settings, despite being physically placed in a city neighbourhood or a suburb, are often based on a ‘one size fits all’ model and can be as isolating as an old-style institution. Residential care and institutional care are often used interchangeably by Independent Living activists.[36]

Part 1 showed how both Hampshire CIL and Derbyshire CIL were set up by people leaving institutions and using the funds to pay for personal assistance support. But the existence of different institutional structures can mean that funds do not follow the person. This is a significant factor in the state’s contribution to preventing independent living and living in the community. Funds being tied to buildings, rather than people, means that in most countries there is little choice between personal assistance or institutionalisation, or being supported by families.

Funding from the EU – the European Structural and Investment Funds[37] (ESIF) and the Instrument for Pre-accession Assistance[38] (IPA) – can play a crucial role in supporting the transition from institutional care to life in the community. However, reports have shown that during the 2014–2020 financing period some countries have used ESIF investments to renovate, and/or build new, long-stay residential institutions.[39] In some cases the projects clearly stated that they are for renovation and expansion of such institutions, whereas other projects that appear to be for the development of community-based alternatives create replicas of institutions in smaller settings. CIL-Sofia highlights this as a particular concern in Bulgaria, noting that services called “community-based” were established on the grounds of large long-stay residential institutions.

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[35] ILNET participant, study visit to CIL – Sofia, april 2015.

[36] ENIL (2014) Myth Buster: Independent Living, available at: http://www.enil.eu/wp-content/uploads/2014/12/Myths-Buster-final-spread-A3-WEB.pdf

[37] The European Structural and Investment Funds are financial tools set up to implement the regional policy of the European Union.

[38] IPA supports reforms in the enlargement countries, including Turkey, with financial and technical assistance.

[39] See ENIL/ECCL (2013) *Briefing on the Structural Funds Investments for People with Disabilities: Achieving the transition from Institutional Care to Community Living*, available at: http://www.enil.eu/wp-content/uploads/2013/11/Structural-Fund-Briefing-final-WEB.pdf; ENIL/ECCL (2015) *Briefing on the Use of European Structural and Investment Funds to Support the Transition from Institutional Care to Community Living for People with Disabilities*, available at http://www.enil.eu/wp-content/uploads/2015/05/ENIL/ECCL_Briefing_SF_300415.pdf

ENIL Freedom Drive March

Investment in institutions is against the priorities of the European Disability Strategy 2010–2020[40].The Strategy builds on the principles of the UN CRPD. It has eight key areas, one of which is participation where the goal is: '[to] remove barriers to equal participation in public life and leisure activities; promote the provision of quality community-based services'. The other areas are: accessibility, equality, employment, education and training, social protection, health and external action. "Transition from institutional to community-based care" has been identified as one of the priorities in the European Disability Strategy, with Structural and Investment Funds identified as key to supporting "the development of community-based services and raising awareness of the situation of people with disabilities living in residential institutions".

The European Expert Group on the Transition from Institutional to Community-based Care has published two documents offering practical guidance to national politicians, policy-makers and EU officials on how to make sustained transition to community-based services and how to the use of Structural and Investment Funds to support this process – Common European Guidelines on the Transition from Institutional to Community-based Care and Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care[41]. Both documents are designed in reference to key standards agreed at international and European level, including UN CRPD, European Disability Strategy, Europe 2020 Strategy, etc.

Article 12 – legal capacity, guardianship and supported decision-making

Article 12 has been one of the most contested Articles of the UN CRPD. The issue of guardianship and supported decision-making remains an area that has sparked most debate. On the 19th May 2014 the UN Committee released a General Comment on Article 12 emphasizing that supported decision-making must be actualized in reality. It called for the abolishment of guardianship and the recognition of legal capacity for all disabled people by national governments:

> "28. In its concluding observations on States parties' initial reports, in relation to Article 12, the Committee on the Rights of Persons with Disabilities has repeatedly stated that States parties must "review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person's autonomy, will and preferences".

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[40] See European Disability Strategy 2010–2020: A Renewed Commitment to a Barrier-Free Europe, COM(2010) 636 final

[41] The two documents are available in English and other languages at: http://deinstitutionalisationguide.eu/

> 29. Substitute decision-making regimes can take many different forms, including plenary guardianship, judicial interdiction and partial guardianship. However, these regimes have certain common characteristics: they can be defined as systems where (i) legal capacity is removed from a person, even if this is in respect of a single decision; (ii) a substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against his or her will; and (iii) any decision made by a substitute decision-maker is based on what is believed to be in the objective "best interests" of the person concerned, as opposed to being based on the person's own will and preferences.'
>
> 30. States parties' obligation to replace substitute decision-making regimes by supported decision-making requires both the abolition of substitute decision-making regimes and the development of supported decision-making alternatives. The development of supported decision-making systems in parallel with the maintenance of substitute decision-making regimes is not sufficient to comply with Article 12 of the Convention." [42]

While Article 12 does not offer disabled people anything they had not already believed, it does offer more of a base to challenge national governments. It sends a strong message that guardianship and substitute decision making is a policy issue. While information and new routes offer us hope, so does the history of the independent living movement and the strength of campaigns. Such as the EU PERSON's '#RightToAct' Campaign.

EU PERSON's #RightToAct Campaign

PERSON (Partnership to Ensure Reforms of Supports in other Nations) has been supported by the European Commission since 2012 to increase competences of civil society organisations in the Balkan states and Turkey to strategically advocate for and monitor reforms on the legal capacity. The PERSON network includes organisations from Albania, Bosnia and Herzegovina, Croatia, Kosovo, Serbia, Turkey and the UK[43]. RUSIHAK is the partner from Turkey.

Legal capacity refers to being both recognised as a person before the law with equal rights compared to others, and as having the right exercise that claim to equality – that is, having the 'right to act.' Equality before the law for disabled people is a cross-cutting issue that goes to the heart of disability human rights violations in law, policy and practice. These violations include restrictions on voting, financial decision-making, rights to liberty, education and other core rights. These restrictions are based on outdated and discriminatory views of disabled people[44].

The 'Right to Act' campaign[45] is based around the inconsistencies of national policies with the UN CRPD, in particular Article 12 issues of legal capacity and guardianship. Countries involved have signed and ratified the UN CRPD meaning that these countries are required to act to reform their laws to protect the right to act for disabled people. Yet, there are no laws or reforms in place that ensure the right to act for those deprived of their legal capacity. A scenario repeated across the world.

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[42] Committee on the Rights of persons with Disabilities (2014) *General comment on Article 12 ,* available at: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/1&Lang=en

[43] For information in Turkish see: http://www.madde12.org/personverusihak/ and in English: http://www.eu-person.com/about-us/partners/

[44] Country reports describing the situation in PERSON partner countries are available in English at: http://www.eu-person.com/publications/

[45] See http://righttoactcampaign.com

PERSON

I WILL ACT.

#TheRightToAct

#RightToAct Campaign

In Serbia, the use of guardianship has increased dramatically in recent years. In 2012, more than 17,000 people were deprived of their legal capacity through guardianship proceedings. People who are deprived of their legal capacity are automatically stripped of their rights to enter into contracts, marry, vote, exercise parental rights, join political parties, or make decisions on medical proceedings, including termination of pregnancy. In Bosnia-Herzegovina, where an estimated 6,500 people have been placed under court-ordered guardianship, deprivation of legal capacity also deprives a person of the right to vote. A survey of professionals working with people with disabilities in 2013 found that, although 89% of respondents had been involved in depriving a person of legal capacity, only 24% had ever been involved in returning legal capacity. In Turkey, the appointment of a guardian due to “mental illness” strips a person of the right to vote, and subjects any marriage to the scrutiny of a guardian, who may object to the validity of the marriage.

Together the partnership has achieved considerable change, including amending legislation in Croatia, holding the first ever conference in Kosovo focused on mental disability rights, initiating self-advocacy groups in Bosnia-Herzigovina, training judiciary on CRPD issues in Serbia, drawing together civil society organisations in Turkey to raise awareness on legal capacity law and policy**.** In Turkey, a blog in Turkish was launched which focused on Article 12 of CRPD[46] – The blog contains resources including law reform strategies, information about common rights violations of equal recognition before the law for people with disabilities in Turkey, and links to various civil society organisations campaigning on this issue.

What does the right to act mean and why is it important? Worldwide, people with disabilities are denied the right to make decisions about how they want to live their lives. Guardianship and other mechanisms of substitute decision-making replace person’s own wishes, decisions, and preferences with the decisions of someone else. When a person is placed under guardianship, they are denied the legal capacity to act. If a person lacks legal capacity to act, another person can make major and minor life decisions without that person’s consent. The guardian can decide what clothes a person wears, whether and how the person can spend their money, where they can live, what kind of medical treatment they will receive, and even whether or not they can be in a relationship. The person who makes decisions on behalf of someone else may be a stranger, and may not know anything about the person’s wishes, interests, or desires.

Such campaigns are effective in raising issues, generating and maintaining peer support, and pushing national governments. They are also important at the EU level. The latest List of Issues directed to the European Commission makes interesting reading. Passed at the thirteenth session of the Committee of the UN CRPD (23rd March–17th April 2015), it raises pertinent questions related to the EU’s implementation on the Convention.[47] While it does not mention

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[46] See http://www.madde12.org/

[47] All parties on the Convention are required to submit regular reports on its implementation. The EU report can be found at: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fEU%2f1&Lang=en

Article 12 it tackles Article 19 on independent/community living and a host of other issues tied to gender, education, and access to justice. On Article 19 it says:

> "Please explain how European funding, especially the European Structural and Investment Fund (ESIF), is used to ensure, protect and promote the inclusion of persons with disabilities in their local communities? How are representative organisations of persons with disabilities involved in the policy-making, implementation, monitoring and evaluation of the use of that funding?"

This shows how campaigns at national and European levels can make use of the tool of the UN CRPD. ENIL's shadow report on Article 19[48] also gives information on implementation from different European countries and the problems. Having such tools available only serve disabled people if we use them in our fight for human rights and equality. We also need to engage young people, as they are the future of the movement. ENIL's growing youth network is one such example, but there are examples across Europe too. The training manual 'Young People with Disabilities as Future Leaders of the Independent Living Movement'[49] is particularly relevant here for developing the youth movement across Europe. There are other things we can do to ensure that the UN CRPD has relevance for national and local governments.

Making the UN CRPD work

In some countries the translation of the UN CRPD has been lacking, particularly on Article 19. To address this reference should be made to the ENIL definitions (see Part 2), The wording of translations should also be monitored to avoid terms like "personal help" or "personal support" appearing in place of the term personal assistance. In addition, we should ensure that government bodies responsible for misleading translations are educated on issues of independent living by organisations *of* disabled people. There are further options for the European community to improve the application of the UN CRPD.

- Develop a stream of European core funding support for organizations dealing with issues of independent living and personal assistance on a cross-disability basis. These organisations should be run and controlled by disabled people. This means having at least 75% representation of disabled people with lived experience of independent living in decision-making positions.
- Ensure that key organisations are consulted as "experts". This means organisations *of* disabled people running personal assistant schemes and adhering to the illustrated independent living principles.
- Develop a European database of organisations *of* disabled people with experience of both the practical application and knowledge surrounding independent living with personal assistance.
- Ensure that organisations *of* disabled people are fully involved in monitoring the implementation of the Article 19 at national levels as full and equal partners entering into full dialogue with national governments and decision-making bodies.
- The monitoring activities should include a monitoring process of existing national law and policies. The process should include an identification of how such laws are, or are not, implemented effectively in achieving the aims of independent living. Monitoring processes should also include an identification of personal assistance opportunities for all disabled people including those with mental health issues, learning difficulties and those with so called complex support needs. If there are no opportunities for people to access personal assistance – this situation needs to change. There should be an appropriate remuneration system for the active participation and knowledge of disabled people and their organisations in carrying out the processes of implementing and monitoring the UN CRPD.

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[48] ENIL–ECCL(2014) *Shadow report on the implementation of Article 19 of the UN Convention on the Rights of Persons with Disabilities in the European Union*, available at: http://www.enil.eu/wp-content/uploads/2012/06/Shadow-Report-11-04-2014-final-WEB-1-1.pdf

[49] ENIL (2012) *Young People with Disabilities as Future Leaders of the Independent Living Movement*, available at: http://www.enil.eu/wp-content/uploads/2012/06/Training-Manual-03-04-2013-WEB.pdf

- Putting a penalty system in place for national governments that fail to make progress on Article 19 within a specified time period.[50]

Recommendations for disabled people and DPOs:

Collaborate with other disabled people's organisations and national human rights organisations: A coalition of organisations is always stronger than a lone organisation and much can be gained from collaboration in terms of learning and developing new frameworks and perspectives. Many human rights organisations have already developed their own tools and strategies for specific international human rights treaties. Disabled people represent a large group facing multiple discriminations incorporating issues of race, gender, sexuality, age, and poverty. Therefore building coalitions with other human rights groups can develop useful gains on a number of different levels. In addition, wider alliances can promote new funding opportunities to raise greater awareness of the complexity of disability issues.

Compile Shadow Reports: Even when disabled people's organisations have been actively involved in the completion of a report on the implementation of the Convention, governments may not always produce a report that is felt to properly identify the situations. It is useful to develop shadow or alternative reports[51] as soon as the national report becomes available. However such reports work better if they are presented by a coalition of national organizations. The impact of such a document would be more powerful if it reviewed cross-disability issues rather than concentrating on one particular impairment group, at the same time people with learning difficulties, psychiatric survivors, children and women's issues should be included and these groups must have representation in any coalition.

Monitor legal and policy frameworks and their implementation: The existence of a law or policy does not guarantee rights nor does it guarantee successful implementation. Similarly redress through the national legal system or the opportunities at European levels may not result in successful outcomes. Key steps in monitoring involve the collection of examples of cases where rights enshrined in the UN CRPD have been violated through the lack of application or a lack of laws or policies in place at the national level. Careful monitoring of systems by disability organisations can produce a set of materials that can be publicised to raise media awareness of the UN CRPD and the application of rights in particular countries and on a wider basis.

Monitor government practices and applications: Do governments ensure that all material is accessible to all people? Do their offices ensure that information is provided in easy read, Braille, large print or other formats to make it accessible? Do they ensure that public bodies and companies apply the rule of accessible information? If not, then these practices need to be highlighted**.** Use the Articles of the UN CRPD to target any practices and policies in areas that may not have been considered by governments: provision of accessible information is just one of many options.

Develop training materials: Disabled people's organisations are the organisations with a wealth of knowledge on the situations of disabled people and this should be exploited. The UN Convention represents an opportunity to spread that knowledge to other civil society and human rights organisations as well as government bodies at the local, national, European and international levels and to inform them of the processes of discrimination and the barriers that disabled people face to achieving dignity, equality and autonomy.

Use media to raise awareness: The media is a powerful resource in developing awareness of the importance of the UN CRPD and the importance of disabled people's human rights. In addition, internet resources can be used to post news and to recruit allies to the cause of monitoring or to present examples of the injustices that are happening to disabled people on a global and local basis.

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[50] The recommendations for the European Community are based on Jolly, D. (n.d) *Personal Assistance and Disability: Article 19 of the UN Convention on the Rights of Persons with Disabilities*, available at: http://disability-studies.leeds.ac.uk/files/library/jolly-Personal-Assistance-and-Independent-Living1.pdf

[51] For examples of alternative reports see ENIL's Shadow Report on Article 19, available at: http://www.enil.eu/wp-content/uploads/2012/06/Shadow-Report-11-04-2014-final-WEB-1-1.pdf and EDF's Alternative Report on the Convention, available at: http://bit.ly/1ERMe6H

Partner with universities in collecting statistical and other relevant sata: Universities have access to a range of databases and knowledge of statistical resources as well as resource databases for funding opportunities. Therefore partnering with a local university could prove beneficial in a number of ways.

Monitor media and social media: Examples where disabled people's rights or dignity have been violated by prejudiced representations can often be found in the media. In addition, the ways media represent disabled people can be problematic. For example, as tragic individuals needing care, as burdens or even as inspiring heroines and heroes overcoming tragedy. All such representations concentrate on the individual rather than on the social barriers which need to be removed and which the UN CRPD treaty seeks to change. Keep a dossier of examples for making complaints to the relevant bodies, for research and for potential training purposes.[52]

Use the Optional Protocol: If your government has signed and ratified the Optional Protocol – use it, if it has not – campaign for its signing and/or ratification. The Optional Protocol allows for individual complaints to be submitted to the UN CRPD committee if all domestic remedies have been exhausted, that is, if national court mechanisms have failed. It also allows for a state party inquiry under Article 6 of the Protocol. See the box below for how Disabled People against Cuts initiated the first ever inquiry of this kind against the UK government in 2015. This example is illuminating because this was done by three people from the disabled people led grass roots campaign group DPAC without funding, rather than a well-funded traditional disability organization or big disability charity.

DPAC triggers UN Inquiry into Grave and Systematic Violations of Disabled People's Rights[53]

The UN Inquiry and UN visit to UK to examine the grave and systematic violations of the UN Convention on the Rights of Persons with Disabilities (UN CRPD) was initiated by DPAC.

This inquiry is the first of its kind-it has great historic importance. It means the UN will examine the vicious and punitive attacks on disabled people's independent living as well as the cuts which have seen so many placed in inhuman circumstances and has led to unnecessary deaths.

In May 2013, after 3 years of onslaught against disabled people by the Condem government, DPAC made a formal submission under the UN CRPD Optional Protocol which establishes an individual complaints mechanism for the Convention.

There was less information and statistics than now on the impact of the Welfare Reform and loss of a right to independent living on disabled people. However the evidence DPAC presented to the CRPD Committee was extremely strong.

DPAC's evidence presented the regression of disabled people's convention rights and the grave and systematic violations of disabled people's rights under the UN CRPD. It was accepted by the UN CRPD Committee.

After an initial response from the government responding point by point to the DPAC submission, DPAC made a second submission, supported by further evidence of the disproportionate impact of all cuts on disabled people.

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52. The recommendations for disabled people and their organisations are based on Jolly, D. (2009) *ENIL Position Paper 2009/1. The UN Convention on the Rights of Persons with Disabilities*, available at: http://www.enil.eu/wp-content/uploads/2012/06/Personal-Assistance-and-independent-living-art-19-final2.doc

53. Press release published on August 31st 2015, available at: http://dpac.uk.net/2015/08/

This submission was partly based on firmly sourced statistical and other factual evidence, and also on the hundreds of personal testimonies that DPAC has received from individuals who have been affected adversely by the governments' welfare reforms.

The UK government sent a second response to the UN about DPAC's submission but by then the CRPD Committee had decided that there was enough evidence to open an inquiry into the violations of disabled people's rights by the UK government.

The Committee also told DPAC that the inquiry was totally confidential and could be jeopardised and called off if any news of an UN inquiry was leaked.

It was the indiscretion of an ex-member of the CRPD Committee which brought the inquiry into the open, but DPAC kept its side of the non-disclosure agreement. The further leak in newspapers on Sunday 30th August convinced us that disabled people needed to know the full extent of the process.

This inquiry is an unprecedented move and unchartered territory for the UN CRPD Committee. It is also another route of hope for disabled people who have been abused by the UK government, ignored by most of the opposition and betrayed by the big Disability Charities.

The tools are there as is the political will of disabled people, it must translate in the political will of the policy-makers, it must translate to continue the changes that the international independent living movement has made, and the gains that have been made. Different countries are at different stages in implementing independent living, this does not mean that some are better than others, or that there are mysterious secret ingredients. It means that different countries have different battles according to context, but the war is the same.

The Independent living model cannot be bettered, it has provided a template along with the social barriers approach. We have the tools, including the UN CRPD and the European Disability Strategy. We have the people and we have the passion, it is a passion that must be long lasting because gains can be reversed. Working together is our best prospect to learn from each other, to share experiences, routes and goals. As one participant in the Sofia CIL study visit said*:* 'We are in a shared boat on stormy seas', but working together we will get to the shore. Independent living is a fight at the local level, at the national level, at the European and Global levels – it is the fight for our human rights, and we will win!

ILNET Summer school, Istanbul, 2015

ILNET study visit to CIL-Sofia, 2015

Protest of disabled people in Greece, 2015

PART 4

A Summary and an Independent Living Check List

Part 4 provides a summary of previous parts and ends with a suggested check list of steps towards independent living and removing social barriers.

Part 1 looked at what independent living means and why it is important. It explored the concept of independent living and presented a brief history of the independent living movement. Finally, it focused on different examples of organisational frameworks with an emphasis on user-led self-directed personal assistance support, showing the ways this has been achieved in three different countries. Some of the key points included:

- Recognition that independent living does not mean an individual doing everything themselves because we are all interdependent – but the recognition of the right to self-determination.
- The recognition that if one group of people are denied basics, such as education, housing, support, they are at a disadvantage and have less chance to make independent choices or exercise their basic human rights.
- The recognition that lack of choice and control is not a problem of the individual, but a problem of how societies are organised in ways that mean particular groups are not equal to all. It is a problem of some peoples' human rights not being respected to allow them to live as and where they chose.
- The recognition that everyone should have the right to make independent choices that affect their lives, with support if necessary and that everyone should have the right to independent living.
- The values of dignity, peer support, consumer control, civil rights, integration, equal access, and advocacy, are at the heart of the independent living movement and disability rights movements.

Part 2 looked at the social and individual/medical models and the policy of dependence in national context. It examined why the concept of care debilitates us, while looking in more detail at the personal assistance model. It also expanded to examine other factors of independent living, and some of the myths surrounding it within the context of the situation in Turkey. Some of the key points included:

- How the social model was an attempt to move away from individual and medical ways of viewing individual impairments (whether physical, sensory, or cognitive) as issues of an individual to be fixed, towards a focus on social barriers, social policy and de-professionalisation.
- How we need to educate on the movement away from the individual being perceived as an example of personal tragedy, an object of care, or something for medical professionals to fix towards a focus on the social barriers that serve to disable people.
- How we are disabled not by our impairments, but by attitudes, environments, the lack of effective social policy and medicalisation. The two models of disability – the social and individual – identified how disabled people can educate themselves and others to think differently about the issues of disability as a political and human rights issue.
- How and why social policy is often constructed to make disabled people dependent, rather than to encourage and support independent living.
- How the 12 needs of independent living mean that instead of a professionals telling us what's right for us as disabled people, we identify our choices from a framework of options that fit with our lives. The 12 needs include: accessible information, peer support, accessible housing, equipment and aids, personal assistance, accessible transport and environmental access, adequate income, inclusive education and training, equal opportunities for employment, appropriate and accessible health and social care provision.

Part 3 focused on the UN Convention on the Rights of Persons with Disabilities and the European Disability Strategy 2010 – 2020 with examples and routes to strengthen each instrument. It examined the key problems we face and different routes to strengthen our rights:

- The institutionalisation and the difficult transition to community-based services were examined, showing problems and solutions in the context of the implementation of Article 19 of the UN CRPD, the European Disability Strategy 2010 – 2020 and the European Structural and Investment Funds.
- The implementation of Article 12 of the UN CRPD was examined showing on-going problems related to guardianship and deprivation of legal capacity.
- A set of objectives for European bodies on ways user-led disabled people's organisations and the independent living movement could be strengthened and developed to strengthen the processes and national implementation of the UN CRPD were outlined.
- A set of practical guidelines were outlined for user-led disabled people's organisations to strengthen the monitoring and implementation of the UN CRPD at the national and European level.

A new framework for Independent Living: A check list

Based on the issues outlined so far, an initial basis for a new framework for independent living is provided.

What needs to be in place?

- A focus on independent living and self-determination.
- A focus on human rights instead of care or charity.
- A focus on social barriers and negative attitude removal instead of individualised personal tragedy.
- A focus on social barriers and negative attitude removal instead of professionalised and medicalised dominance.
- A focus on community-based living and the closure of institutions (large and small) as per Article 19 of the UN CRPD.
- The removal of substitute decision-making to be replaced by supported decision-making as per Article 12 of the UN CRPD along with the removal of guardianship.
- Personal assistance and support for user-led organisations to run such schemes based on the core principles of independent living.
- An income paid directly to the disabled individual, which follows the individual enabling them to leave institutions and engage in independent living, allowing choice, control and support.
- New national and European policies that enable the independence rather than dependence of all disabled people.
- Local, national and European authorities to involve disabled people in policy formation and implementation of the European Disability Strategy 2010-2020 and the UN CRPD.
- Strict monitoring and legal and human rights challenges to be made by disabled people using domestic, European and United Nations instruments via various legal channels.
- The realisation of the full human rights of disabled people.

About the European Network on Independent Living

The European Network on Independent Living (ENIL) is a Europe-wide network of disabled people. It represents a forum intended for all disabled people, Independent Living organisations and their non-disabled allies on the issues of independent living. ENIL's mission is to advocate and lobby for Independent Living values, principles and practices, namely for a barrier-free environment, deinstitutionalisation, provision of personal assistance support and adequate technical aids, together making full citizenship of disabled people possible. ENIL has participatory status with the Council of Europe and is represented on the Advisory Panel to the EU Fundamental Rights Agency's Fundamental Rights Platform.

About RUSIHAK

RUSIHAK is Turkey's first grassroots organisation by people with mental disabilities and their relatives. RUSIHAK challenges inhumane treatment by defining people with mental disabilities as full human beings, who are equal citizens in every way. RUSHIAK runs advocacy campaigns, organises free vocational and empowerment trainings for its stakeholders, and creates monitoring groups to inspect institutions to ensure they are compliant with legal and health regulations.

About the Centre for Independent Living-Sofia

The Centre for Independent Living-Sofia is a Bulgarian non-governmental, non-profit organisation of disabled people. CIL-Sofia has been working for a change in the governmental policy in the area of disability since 1995 by actively promoting the values of Independent Living and the application of the Social Model of Disability.

CIL-Sofia is a member of ENIL and has worked together with ENIL as the South Regional Coordinator (2013–2014), covering 11 countries, including Turkey. This role has helped CIL-Sofia make contacts with disabled individuals and organisations in Turkey and identify key issues in the disability rights area.

Website: **www.enil.eu**

This Manual was developed as part of the project ‘Independent Living Network: Promoting the Right to Independent Living of People with Disabilities in Turkey’ (ILNET), implemented by the European Network on Independent Living in partnership with the Centre for Independent Living – Sofia (Bulgaria) and RUSIHAK (Turkey) between October 2014 and January 2016. The overall aim of the project was to ensure that disabled people in Turkey are better informed and able to advocate for the right to independent living, by learning from the experience of the Independent Living movement in Europe and by using international and European human rights legislation and policies, and good practice. Project activities included study visits of Turkish activists to organisations of disabled people in Bulgaria and Belgium, international Independent Living summer school in Istanbul, conference on the right to community living in Ankara, development of a Roadmap on the right to live independently and an Independent Living Manual.

INDEPENDENT LIVING is the daily demonstration of human rights-based disability policies. It 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.

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