

FREEDOM DRIVE 2011

What it's all about



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The Demands of the Strasbourg Freedom Drive 2011: Background and introduction

Purpose of this document

This document provides some background to the Demands of the Freedom Drive 2011. The nine demands represent the main objectives of the Freedom Drive and they reflect the priorities of members of the Independent Living movement.

In order to fully understand the demands some definitions and explanations are provided.

The demands are listed at the end of this document.

Table of Contents

Centre for Independent Living.....	4
Independent Living.....	5
Personal Assistant.....	7
Independent Living and the Social Model of Disability.....	8
Direct Payments.....	9
European Citizens & Freedom of Movement.....	10
Disability and the European Union.....	11
The European Charter of Fundamental Rights.....	11
European Disability Strategy 2010-2020.....	12
UN CONVENTION on the Rights for People with Disabilities.....	14
Article 19 of the UN Convention on the Rights of Persons with Disabilities.....	16
Community living.....	17
Deinstitutionalisation.....	17
The Role of Europe.....	18
Separation of buildings and support.....	19
Access to the same options as everyone else.....	19
Choice and control.....	19
Deinstitutionalisation & Rights.....	20
The European Union & Deinstitutionalisation.....	20
Development funds.....	22
1 Million for disability and the proposed disability specific directive.....	23



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Centre for Independent Living

The Centre for Independent Living (CIL) was established in Ireland in 1992. It is an organisation run by people with disabilities for people with disabilities. Today CIL has a network of 23 organisations throughout the country. We seek the full development of rights based choices to enable Independent Living for all people with disabilities. Our motto is “nothing about us without us” and our mission statement is:

“The Centres for Independent Living in Ireland are committed to all people with disabilities being recognised as equal citizens and achieving equal membership of mainstream society, to make informed decisions about our own lives according to individual needs and lifestyle choices, to design and develop our own services, to achieve equality of experience through consensus, respect and value for all.”

“Independent Living” is further explained below.

Workshops

In order to ensure that the views, concerns and opinions of the Centre for Independent Living members throughout Ireland are articulated in Strasbourg, CIL held regional workshops, one in each of the four European constituencies; Dublin, the Northwest, Leinster and Munster. The workshops heard from previous Freedom Drivers and a presentation was also given on the European Institutions.

The workshops took place between 16th June and 23rd June 2011 in CIL offices in Dublin (Carmichael House), Galway city, Tullamore

and Waterford city.

Independent Living

Independent Living forms the basis of our movement and of the Freedom Drive. The Independent Living philosophy emerged from the civil rights movement in the USA in the 1960s and has spread throughout the world, the latest CIL having recently opened in Addis Ababa, Ethiopia.

The IL Movement works at replacing the “special education” and “rehabilitation” approach with a new paradigm developed by people with disabilities themselves. The first Independent Living ideologists and organizers were people with extensive disabilities. The movement represents people that are most exposed to custodial care, paternalistic attitudes and control by professionals.

According to Adolf Ratzka, a leading member of the IL Movement in Europe “Independent Living is the right of all persons regardless of age, type or extent of disability to live in the community, as opposed to living in an institution; to have the same range or choices as everybody else with regard to housing, transportation, education and employment, to participate in the social, economic and political life of their communities, to have a family, to live as responsible respected members of their communities with all the duties and privileges that this entails, and to unfold their potential”.

Ratzka goes on to explain that “it is about creating choices and identifying solutions. It is a way of life that grows as you grow and develops as you develop”.



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Essentially, Independent Living is a philosophy and a movement of people with disabilities who work for self-determination and equality. Independent Living does not mean that we want to do everything by ourselves or that we want to live in isolation. We demand the same choices and control in our every-day lives that others take for granted. We want to be included in community life. Since we are the best experts on our needs, we wish to influence decision makers that make decisions that impact our lives. Therefore we work for political changes that lead to the legal protection of our human and civil rights.

As long as we regard our disabilities as tragedies, we will be pitied. “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”.
Adolf Ratzka 2005

There are daily activities that are essential for all humans. The freedom in carrying out these activities should not be denied to people with disabilities, as they are basic freedoms.

These basic freedoms include:

- Getting up when you want in the morning
- Going to bed when you want at night
- Being able to drink and eat when you are thirsty or hungry
- Going to the toilet whenever it is necessary
- Meeting with family, friends & neighbours when you decide
- Going out for a walk, to the cinema, a cafe etc., when you have time
- Falling in love and having children

- Getting an education, having a job
- Bringing your personal assistance with you wherever you go

Independent Living is based on the principles of:

- Empowerment
- Control
- Choice
- Options
- Equality

Without these basic rights people are imprisoned and do not have access to Independent Living.

“People who are disabled by society's reaction to physical, intellectual and sensory impairment and to emotional distress have the right to assert control over their lives.” (Morris, 1993)

The key service in advancing these rights is the provision of personal assistance. The role of a personal assistant is to assist the person with disability (the 'leader'). It is the leader, and the leader alone, who instructs the personal assistant. The provision of PAS strengthens our democracy; it allows the disabled community to live their lives with dignity and equality as full and free participants in our society.

Personal Assistance Service (PAS)

PAS is carried out by a personal assistant. A personal assistant, whilst he/she is on duty, only takes instruction from the person with disability who is known as the “leader”. A personal assistant can be legally employed by a service provider, but does not take any instruction from any of the service provider's personnel while on



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duty with the leader. A personal assistant does not report a leader's activities to service provider personnel. Nor does a personal assistant write in any ledger or notebook, information about their leader to be viewed by others unless instructed by the leader to do so.

Personal assistants do not work in day centres or nursing homes or any other similar establishment where they are responsible only to management of the said establishment.

We believe the above distinguishes a personal assistant from a carer or care assistant. We recognise and respect carers and the need for them in certain circumstances, but the role of a carer is very different to the role of a personal assistant, and therefore carers should not be called personal assistants.

Independent Living and the Social Model of Disability

The IL philosophy promotes a “social model” of disability, recognising that people with disabilities are prevented from achieving their full potential by society's attitudes and/or environmental restrictions in accessing public transport, entertainment, public places, education and employment etc.

Prior to the IL movement, the predominant understanding of disability came from a “medical model” whereby people with disabilities were viewed purely as patients to be rehabilitated or at least helped to adapt in order to fit in with society. In other words they were seen as having a problem and society would endeavour to fix that person's problem to enable the person to fit in with society. This medical model resulted in the majority of disabled people living passive, dependent lives, quite often in institutionalised settings.

The “social model” approaches it from a different angle. It is society that disables the person with disability and it is society that needs to adapt in order to include all. The social model recognises that the real experts, when it comes to designing services, are those with the most experience of disability issues – people with disabilities themselves. For this reason we believe that organisations representing people with disabilities in relation to Independent Living must be peer led by people with disabilities, as they understand the reality of Independent Living first hand.

Direct Payments

Direct Payment is where the payments for services required by people with disabilities are given to disabled person him/herself, and that person then administers the payment. By transferring financial control to the disabled individual they are afforded greater control over their own life. Direct Payments empower service users by giving the opportunity to choose and to manage the services they use to meet their needs. Each person is given an amount of money which they are to manage themselves. They may use this budget to purchase supports to facilitate the complexity of direct payments and Independent Living if they wish.

It is envisaged that the role of service providers would be adapted to offer supports around recruitment, tax, employment law and other technical aspects of being an employer. This allocated personal budget may be used to purchase any service or services that meet the person's assessed needs. As the money given to the person is given in lieu of the local authority providing the care, the money remains public money belonging to the local government who makes the payments. Service users must account for their expenditure so that



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those administering the budgets, local authorities in some countries, potentially the HSE in Ireland, are able to meet auditing requirements.

There is, however, no requirement for a person to receive the entirety of their care needs through direct payments. People are free to mix direct payments for some of their needs with traditional methods of care provision. Direct Payments can be used to directly employ a personal assistant (in this case the Direct Payments recipient may legally be classed as an employer with all the responsibilities this entails) or hire care workers from a private domiciliary care agency. As an alternative to care services, the recipient may be able to use his or her Direct Payments to fund other local services that enable their independence within their own home and community, such as 'meals on wheels', taxi cabs and social clubs.

European Citizens & Freedom of Movement

The Single European Act established freedoms of movement in terms of:

- Goods
- Services
- People
- Capital

In terms of Independent Living for citizens of Europe, we question if these freedoms are available to us in the same way that they are available to citizens that do not have disabilities.

There is no real freedom of movement in the EU for people with disabilities. Someone could have employment in Ireland yet may not

be able to move to France because of the difficulty of transferring one's PAS from one country to another. There is also no standardization of PAS in the EU, so PAS varies dramatically according to the country one is in. For example; compare and contrast Sweden and Romania.

Disability and the European Union

According to an EU Labour Force Survey some 80 million people in the EU have a disability.

The EU Motto “United in Diversity” is at the heart of the Freedom Drive. The Freedom Drive aims to unite European citizens with disabilities in Europe to campaign for justice and equality for people with disabilities.

The European Charter of Fundamental Rights

The European Union Charter of Fundamental Rights sets out in a single text, for the first time in the European Union's history, the whole range of civil, political, economic and social rights of European citizens and all persons resident in the EU.

These rights are divided into six sections:

- Dignity
- Freedoms
- Equality
- Solidarity
- Citizens' rights
- Justice



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They are based on the fundamental rights and freedoms recognised by the European Convention on Human Rights, the constitutional traditions of the EU member states, the Council of Europe's Social Charter, the Community Charter of Fundamental Social Rights of Workers and other international conventions to which the European Union or its member states are parties.

Article 26 - “Integration of persons with disabilities”

The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.

European Disability Strategy (EDS) 2010-2020

The goal of the EDS is a society open and accessible to all. For this, barriers need to be identified and removed. This approach, to some extent, has been stimulated by the UN standard rules on Equalisation of Opportunities for Persons with Disabilities.

The EDS reiterates the strong mandate that the EU and its member states have to improve the social and economic situation of people with disabilities.

It sets out the legal basis for this and in particular it repeats the obligations that member states have under the UN Convention and restates the central role people with disabilities and their organisations have under Article 33 of the Convention.

The EDS states that its overall objective “is to empower people with disabilities so that they can enjoy their full rights and benefit fully

from participating in society and the European economy.” This is to be achieved through “eliminating barriers”.

The EDS identifies the eight main areas for action as follows:

- Accessibility
- Participation
- Equality
- Employment
- Education and Training
- Social Protection
- Health
- External Action

In implementing the EDS the EU is committed to the following:

- Raising awareness of disability issues amongst the disabled community and society in general
- Financially supporting policy programs with particular emphasis placed on funding research programmes
- Collecting statistics and data through social surveys

Given the above it is somewhat disappointing that our application to Europe for funding to assist our delegates to attend the Freedom Drive and ENIL General Assembly was rejected. In 2009 we secured funding through the Europe for Citizens Programme. This enabled 450 delegates throughout Europe to attend. This year, as a direct result of the lack of funding, our numbers are significantly down. Where members have attended many are subsidising the costs themselves.



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UN CONVENTION on the Rights for People with Disabilities

Described by Kofi Annan as the “dawn of a new era”, the convention is international and comprehensive so as to promote and protect the rights and dignity of persons with disabilities. The treaty is the product of an overall shift in the attitude of the international community and society in general towards people with disabilities.

The UN Convention on the Rights of Persons with Disabilities, adopted by the UN General Assembly on 13 December 2006, is designed to change the political landscape and focus attention on inclusive development.

This UN Convention may be used to uphold the rights of persons with disabilities. Article 32, the International Cooperation Article, gives, for the first time, legal recognition to the principle and practice of inclusive development – development cooperation inclusive of persons with disabilities.

Article 12 and Article 19 identify the shift from the medical approach to the social model with an emphasis on self-determination.

Clarity on the different theoretical models of disability is also needed. As we noted earlier, the traditional medical approach sees disability as a problem residing in the individual; one deals with disability through rehabilitation of the individual, charity handouts and other services. The human rights based approach of the social model, on the other hand, no longer views people with disabilities as victims or patients but as people with rights and a role to play in

society. It is the unaccommodating environment that disables a person's life rather than a physical impairment.

There are some 650 million people with disabilities throughout the world. The UN convention has been a work in progress for a number of years. The push began in the 1980s when the UN inaugurated a world decade of action on disability in 1982. By 1987 there was a general consensus that a convention was a crucial and logical next step. The General Assembly, however, opted for a soft law approach (non-binding) with the enactment of the UN standard rules on the Equalisation of Opportunities for Persons with Disabilities. Although there are many other existing human rights treaties that cover persons with disabilities in theory, the problem is the failure in practice. So the convention, therefore, does not create rights in and of itself, but rather outlines actions that state and non-state bodies must take to ensure that those with disabilities are afforded their basic human rights on an equal basis.

The convention is the first in 16 years, it does provide a new concept of disability and has a wide variety of rights related to changing attitudes, provisions for women and children, accessibility, personal autonomy, employment, health, legal capacity, freedoms on an equal basis with all others, and home and family.

The guiding principles are:

1. Respect for inherent dignity and individual autonomy including the freedom to make one's own choices and live independently
2. Full and effective participation and inclusion in society
3. Respect for, and acceptance of, persons with disabilities as active



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participants in broader society and an integral part of overall human diversity

Change was needed due to the level of injustices in the past under the impairment focused medical model. When disabled persons are placed in an environment ill equipped to practically accommodate their impairment, their rights and equal opportunities are impeded. There is now a growing sentiment amongst the general public that disabled persons should be allowed to fully control their own destiny.

The real work on the convention is its implementation and monitoring. Article 33 of the Convention gives people with disabilities a central role when it comes to monitoring implementation.

In January of this year (2011) the EU, in an historic move which was welcomed by CIL, ratified the Convention; however eleven member states, including Ireland, have yet to do so. CIL calls upon these member states to ratify the Convention, the excuses put forward for delaying ratification simply do not stand up to scrutiny.

Under the Convention there is a reporting system established where signatories report on their “compliance”. Only states can report other states for failure to comply. Under the optional protocol individuals are allowed to make complaints only after all domestic channels have been exhausted.

Article 19 of the UN Convention on the Rights of Persons with Disabilities

This article sets out the right of all disabled people to “live in the community, with choices equal to others” and requires states to

enable disabled people to be fully included and participate in society.

According to Article 19, people with disabilities should:

- Have the opportunity to choose where and with whom they live
- Have access to a range of in-home, residential and other community support services, including personal assistance
- Have access to community services and facilities for the general population

Community living

The term “community living” refers to people with disabilities being able to live in their communities as equal citizens, with the support that they need to participate in every-day life, such as living in their own homes with their families, going to work, going to school and taking part in community activities. It also means having choices and living with dignity.

To support individuals to live an ordinary life they need access to mainstream opportunities and services available to the general population, and also to tailored individual support.

Deinstitutionalisation

Deinstitutionalisation is the “replacement of institutions by services in the community”. It is about bringing people out of institutions and helping them to live in the community by creating the necessary support mechanisms. Deinstitutionalisation is also about recognising the variety of needs of people with disabilities and supporting them



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to live an ordinary life in the community.

Deinstitutionalization represents fundamental change in support and housing arrangements for the disabled community. In Europe, residential institutions have been the typical response to the needs of disabled people needing accommodation and assistance with daily living since the early 19th Century. Often established to relieve suffering and with humane ideals, institutional care gradually became an instrument of segregation and control, in which poor standards of care became accepted. Following the Second World War, some countries began to move away from large residential institutions. Governments in these countries began to develop policies for the shift from institutional care to the provision of care and support in local communities. This was prompted by different factors in different countries. Changing ideology and the rise of normalisation, the occurrence of scandals in institutions and the rise of lobbying organisations have each played important roles in different countries, with the respective influence of the three factors varying between countries.

The Role of Europe

Increasingly the goal of services for people with disabilities is seen not as the provision of a particular type of building or programme, but as the provision of a range of supports and resources which can be assembled and adjusted as needed to enable all people with disabilities to live their lives in the way that they want but with the support and protection that they need. The approach is characterised by several features:

Separation of buildings and support

The organisation of support and assistance for people is not determined by the type of building they live in, but rather by the needs of the individual, what they need to live, and where and how they choose to live. High levels of support can be provided in ordinary housing in the community, for example. This approach involves treating the person as an individual and providing sufficient support to meet their needs and promote a good quality of life, not trying to fit the person to the already existing services.

Access to the same options as everyone else

This means that people have access to the same range of options as everyone else with regard to where they live and receiving the support they need wherever they may choose. This principle is closely allied to the principle of universal design, by which facilities available to the general public are designed so as not to disadvantage disabled people.

Choice and control

People with disabilities should have as much control as possible over services they use and how they are delivered. Where people are not able to exercise control over all aspects of their life, arrangements are made for a representative or advocate to protect their interests and support decision-making to preserve the individual's quality of life. This approach is referred to as “supported living”, entailing the separation of support from the provision of accommodation. People own or rent their own home and support is provided to them accordingly.



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Programmes where disabled persons are involved in planning their support, such as where they live and who supports them, and have autonomy over how their allocated money is spent, are usually referred to as “self-directed support”. These services support people to enjoy the full rights of citizens.

Deinstitutionalisation & Rights

Supporting disabled people to live in the community as equal citizens is an issue of human rights. The segregation of disabled people in institutions is a human rights violation in itself. Furthermore, research has shown that institutional care is often of an unacceptably poor quality and represents serious breaches of internationally accepted human rights standards. The European Parliament's 1996 Resolution on the Rights of Disabled People called on the European Commission and member states to promote the social inclusion of people with disabilities and advocated non-discrimination and non-violence against people with disabilities. It proposed that disability rights be treated as a civil rights issue, that institutionalization should be avoided and that no-one with disabilities should be institutionalized against their will.

The European Union & Deinstitutionalisation

The Charter of Fundamental Rights of the European Union (2000) prohibits discrimination on grounds of disability and says that the European Union should respect the right of persons with disabilities to benefit from measures designed to ensure their independence, integration and participation in the community. The United Nations Convention on the Rights of Persons with Disabilities (which the European Community and member states have signed) includes the

right to Independent Living and participation in the community (Article 19).

Given this, community-based services should be developed around the following principles:

- They should be person-centric
- They should support family and community life
- They should adopt a social model of disability
- They should address all of people's lives to promote a good quality of life
- They should ensure these principles are expressed in the day-to-day assistance provided to the individuals they support

The European Commission identifies supporting member states making the transition to community-based services, including managing the costs of doing so. The common challenge across Europe is how to organise community services for disabled people so that their independence, integration and participation in the life of the community is successfully achieved. One of the main challenges is managing the transition from institutionally-based systems of care to new models in the community.

This project was developed to reinforce the European Union's capacity to anticipate and manage change, acting as a catalyst to bring about policy developments contributing to the elimination of discrimination on the grounds of disability.



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It is essential to stimulate policy development in the reallocation of financial resources to best meet the needs of people with disabilities, through a transition from large institutions to a system of community-based services and Independent Living. Housing plays a major role in social inclusion as de-institutionalization contributes to the end of social exclusion.

Development funds

There are more than 650 million people with disabilities worldwide and 70-80% of them live in developing countries. Many are trapped in poverty and, based on their disability, are denied their basic human rights. Persons with disabilities are largely excluded from most development activities of the international community. 82% of disabled people live below the poverty line in developing countries (UN). 98% of children with disabilities in developing countries do not attend schools (UNESCO). Mortality for disabled children is as high as 80% even in countries where under-five mortality is below 20% (DFID 2000).

The European Union, as the biggest donor of development funds, is responsible for the distribution of 60% of development aid in the world. It is essential that projects funded through Europe are inclusive of persons with disabilities.

The European Development Fund (EDF) is the main instrument for providing community aid for development cooperation in the ACP States (African, Caribbean and Pacific states) and OCT (overseas countries and territories). The 1957 Treaty of Rome made the provision for its creation with a view to granting technical and financial assistance initially to African countries, which at that time

were still colonized and with which some member states had historical links.

Even though a heading has been reserved for the Fund in the Community budget since 1993, following a request by the European Parliament, the EDF does not yet come under the Community's general budget. It is funded by the member states, is subject to its own financial rules and is managed by a specific committee.

The development aid provided by the EDF forms part of a broader European framework. Within the European Union the funds of the Community's general budget may be used for certain types of aid. In addition to managing part of the EDF's resources (loans and risk capital), the European Investment Bank (EIB) will contribute a total of 1.7 billion from its own resources for the period covered by the ninth EDF. The tenth EDF covers the period from 2008 to 2013 and provides an overall budget of EUR 22 682 million.

1 Million for disability and the proposed disability specific directive

In recent years campaigning and lobbying on behalf of people of disabilities has been growing and gained ground in challenging both legal and social barriers. An example of this building of solidarity may be seen in the success of the 1million4disability campaign. The campaign aimed to address discrimination, direct and indirect, against people with disabilities in Europe. Also, under European Law a petition of 1 million signatures from the citizens of Europe will force the European Commission to act on the issue in question. Over 1.3 million signatures were obtained.



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The campaign called for:

1. Comprehensive non-discrimination legislation to protect persons with disabilities and to remove existing barriers to achieve equal opportunities and equal participation
2. A swift signature and ratification of the UN Convention
3. Concrete measures, targets and objectives ensuring equal treatment in education
4. Equal treatment in employment
5. National reforms aiming at deinstitutionalisation of persons with disability and provision of alternatives for independent and community living
6. Basic standards of accessibility and non-discrimination requirements in all funding instruments including at EU level to avoid creating new barriers
7. Facts and figures provide sound basis for development of legislative measures and initiatives to effectively protect rights
8. Common standards and legislation to ensure full access to products and services across Europe

While no disability specific directive has been drafted, the European Commission has decided to come forward with a horizontal directive concerning the equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation. The aim of the proposed directive is to set out a legal framework for the prohibition of discrimination on these grounds outside the labour market and complement the Council Directive 2000/78/EC establishing a general

framework for equal treatment in employment and occupation (the Employment Directive).

This legislation will have effect on issues such as discrimination, equal treatment, social protection and access to goods and services but does not provide the level of sweeping changes called for in the original campaign and is even seen by some as a possible hindrance to future progression. The directive also does not appear to have any particular state to champion it and as a result could even be put aside altogether.

Europe has made many advances in the past two decades in terms of the advancing of the rights of people with disabilities. A lot more needs to be done at a European level, however, to ensure that all the citizens of the EU, including those with disabilities, can enjoy equality. Central to this has to be PAS and freedom of movement.

CIL Carmichael House 2011



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APPENDIX

FREEDOM DRIVE 2011 DEMANDS

1. Independent Living central in all relevant EU policies: ENIL calls on the European Union to continue the process of shifting the disability paradigm from care and welfare to human rights issues, and to ensure that Independent Living as a human rights issue is central in all relevant policies of the European Union, as required by the UN Convention on the Rights of Persons with Disabilities, concluded by the EU in 2010. ENIL calls for the European Parliament to require the European Commission to develop and distribute guidelines for disability policy based on the ENIL definitions of Independent Living, Personal Assistance, Universal Community Based Services and De-Institutionalisation.

2. Respecting the UN Convention on the Rights of Persons with Disabilities: ENIL calls for the immediate shift in interpreting the EU law and policy in light of the UN Convention on the Rights of Persons with Disabilities. The Convention provisions on Non-discrimination, Accessibility, the Right to Live in the Community and Personal Mobility must become the minimum benchmark applied by the EU and its agents in all legislative and policy initiatives.

3. Inclusion of people with disabilities: ENIL calls for full inclusion of disabled people through the application of the CRPD principle of Universal Design and therewith the abandonment of special solutions in all areas including education, transport, housing, public services and employment. Special solutions lead to segregation.

4. De-institutionalisation – closure of institutions by 2020: ENIL calls for the European Union to continue to assist the development of universal community-based services to achieve de-institutionalization across Europe before 2020 through the stipulation of Independent Living in

the EU budget and Structural Funds and with the ear-marking of funding for Independent Living. No European funding should go into the support of traditional or institutional forms of living for disabled people. If funding is spent in such a way, sanctions must be applied.

5. Personal Assistance for all in need: ENIL calls for the implementation of our human right to personal assistance for Independent Living in all EU member states. The lack of personal assistance constitutes the violation of basic human rights of disabled people.

6. Freedom of movement: ENIL calls for the opportunity to equally enjoy the right to freedom of movement with the portability of personal assistance services. ENIL calls for the adoption of the EU Mobility Act.

7. Independent Living in International Development Programs: ENIL calls for an earmarking of 5% of EU development funding to go to the development of Independent Living programs in developing countries.

8. Full ratification and implementation of the UN CRPD: ENIL calls on the EU to sign and ratify the optional protocol of the UN Convention on the Rights of Persons with Disabilities and for the European Union to call on its member states for full ratification and implementation of the UN Convention on the Rights of Persons with Disabilities and of the Optional Protocol.

9. Disabled People's Organisations in policy-making: ENIL reminds the European Union that it is required under Article 4(3) of the UN Convention on the Rights of Persons with Disabilities, to actively involve the organisations of disabled people and Independent Living organisations at all levels of disability policy-making including planning, producing and implementation.

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