

European Network

on

Independent Living



2014 Manifesto



Implemented in the framework of the project "Proud, Strong and Visible – Promoting the Choice, Control and Participation of Disabled People in Europe", supported by the European Commission 2014 Action Grant and by ULOBA, Norway.

ENIL – Ground Floor, Chase House, City Junction Business Park, Northern Cross, Malahide Road, Dublin 17, Ireland, T +3531 525 0700 E <u>secretariat@enil.eu</u> W <u>www.enil.eu</u>



Chair's Foreword

"Freedom, equality and democracy...

Any nation which excludes a section of its citizens will enjoy neither freedom nor equality – and can barely be called a democracy. For those excluded, it is of little consequence whether the exclusion is based on ideological differences or



disguised and excused as compassionate care. Furthermore, you can always rise up and fight against your known opponents, but you can often be left feeling powerless against those who profess to have your best interests at heart.

Those of us, who remain excluded in most European countries, have found good solutions to become active participants within society. The Independent Living Movement, established and developed by disabled people, is based on the fact that all humans are equal. Disabled people, like their non-disabled peers, want to contribute to society. We want to pay taxes and help in the development of our countries. Inclusion and participation is no more expensive than exclusion; we need to strive to be seen, heard and included in society; to ensure we have opportunities to access education and work, realise our rights and obligations as citizens and our right to control our own lives. We need to fight for our rights. Changing society's perception of disabled people means we will all have to work together and ensure people listen to disabled people, especially politicians in power.

When we build our nations together, we build a better society for everyone. Whenever certain groups are excluded, history shows that we are all the poorer for it.

This is why the European Network on Independent Living's rallying cry is 'Nothing about Us without Us'.

The UN Convention on the Rights of Persons with Disabilities is a major step in the right direction for us - but each Member State must work to make the articles within the Convention a reality. Ahead of this year's EU elections, ENIL has prepared 10 demands which together, and individually, will make the European countries better places to live in – for everyone."

Vibeke Marøy Melstrøm Chair, European Network on Independent Living



About the European Network on Independent Living

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

ENIL promotes equal opportunities for disabled people and fights against discrimination in Europe. ENIL addresses the under-representation of persons with extensive disabilities in European disability and social politics, as well as in mainstream society. ENIL's mission is to:

- Promote the Independent Living philosophy among disabled people, general public, national policy makers, government administrations, as well as among regional bodies (e.g. European Union and the Council of Europe).
- Develop the concept, principles and definition of Independent Living. Promote the development of Centres of Independent Living throughout Europe and enhance solidarity and networking among them.
- Carry out training and awareness raising activities at the European level.
- Represent Independent Living Organizations and the Independent Living movement at the European level.
- Combat social exclusion and discrimination through policies which promote Independent Living of disabled people.
- Embrace the social model of disability in acquiring independence and self-determination by overcoming the barriers of the medical and attitudinal models.

About the Manifesto

With the upcoming European Parliament elections (May 2015), it is vital that the candidates are aware of the pertinent issues affecting disabled people achieving Independent Living. Equally, disabled people, their organisations and allies can use this manifesto to be aware of ENIL's demands and, subsequently, ask their local candidates to support them.

What are our Demands?

Our vision is to ensure that all disabled people, regardless of their impairment or background, have the opportunity to have choice and control over all aspects of their lives. By adapting societal policies and services, disabled people will have their



needs met; in order to do this, Governments and those in decision-making positions need to recognise that disabled people want and need personalised support services (such as: personal assistance), a right to an inclusive education, meaningful employment opportunities and a life that is void of any harassment, discrimination and abuse.

We have ten key demands, which if implemented, will improve disabled people's life chances and support us to achieve our goals and aspirations:

1. A legal right to live independently and be a valued member of society:

As set out in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities, we expect all disabled people to have the freedom to make their own choices and have independence and autonomy within all aspects of their lives. To recognise that all disabled persons can fully enjoy all human rights and fundamental freedoms. Furthermore, disabled people and their families need to be aware of the Convention and provided with adequate support, which is tailored to their needs in order to achieve Independent Living; by doing so, societal attitudes will change and disabled people will be perceived as valuable members of their community, with roles and responsibilities to help with the functioning of our society.

We strongly demand a review of current legislation by Member States, detailing how they are ensuring Independent Living becomes a reality for *all* its citizens and what European countries are doing to ensure they work together and enable disabled people to move across Europe without fear of losing their independence. We expect Member States to change their policies, which affect Independent Living, and move from institutional care to community-based support; this includes disabled people accessing personal budgets and other forms of self-directed support. By working with ENIL, we can provide you with guidance on how to transform traditional, marginalising services and ensure disabled people's aspirations of achieving Independent Living becomes a reality.

2. To introduce a dedicated Directorate for Disability:

The importance of this role would be to ensure that the rights of disabled people receive the needed attention across all the policy areas, equality and diversity is promoted, equality law is enforced and discrimination is eliminated within all areas of an individual's life. At the 2013 Freedom Drive, It was strongly expressed that disability should get a higher priority within the European Union (EU) and therefore a dedicated directorate should be created. There is documented evidence demonstrating support for this from within the European Parliament, including a submission of a written declaration to the EU Parliament, requesting a European Commission Directorate for disability.



We call on Political Groups and MEPs to act on our demand, acknowledge the support from within the European Parliament as well as the Independent Living Movement and work with us to ensure we have a powerful voice championing and working to improve our lives.

3. To ensure the use of the correct terms, respecting how they are defined by the Independent Living Movement:

This allows all members of society such as community members, professionals and policy makers to be aware of the correct terminology to use when discussing and thinking about disabled people's situations and experiences. Too often, concepts of choice and control, independence and personalised support have had their original definitions hijacked by those in decision-making positions, altering their meaning and using the 'new' definitions to justify the reductions in services and to obtain EU structural funds. Local and national decision-makers need to recognise that disabled people developed the principles and terms that promote and call for our full inclusion within society.

To realise this demand, we call on all statements and policy documents to reflect and promote the 'original' concepts of Independent Living (which can be found here: http://www.enil.eu/policy/), acknowledging their 'true' principles; the notion of choice and control needs to be embedded firmly within all aspects of a disabled person's life. Allow us to work with Member States so that they understand what our Movement has been demanding and why the terms are vital for our existence.

4. To have the opportunity to use the European Structural and Investment Funds to support Personal Assistance schemes:

Centres for Independent Living and Disabled People's Organisations (organisations controlled *by* disabled people *for* disabled people) must have a real and authentic opportunity to receive this funding to further promote choice and control within disabled people's lives. Furthermore, the European Structural and Investment fund aims to promote 'smart, sustainable and inclusive growth' (The Development and Delivery of European Structural and Investment Funds Strategies, 2013) and this can be achieved by ensuring services and schemes are designed, developed and delivered by those who use them. Disabled people want choice and control and personal assistance is a tool that, when coordinated by the individual, gives people a route towards inclusion and self-empowerment.



Work with us to ensure the Funds are delivering on what disabled people across Europe are demanding – a right to access personal assistance.

5. To stop EU funds being invested into institutions for disabled people (regardless of their size):

It is important that EU funds are invested in the development of community-based services for disabled people. Institutions deny disabled people the opportunity to have choice and control in their life choices. We must eradicate the segregated initiatives which hinder community development, promote discrimination and sometimes leads to the horrendous abuse and death of disabled people. Hundreds of thousands of disabled people live in closed institutions and this cannot continue to be a reality for the current and future generations of disabled people. By investing in more community-based services, we will reduce social exclusion and promote disabled people's rights.

We call on Member States to implement the European Structural and Investment Funds Regulations, which references the transition from institutional to communitybased care. By committing to this and ensuring it becomes a reality at an operational and grass-root level, you must work with disabled people and their organisations to improve self-directed support initiatives and provide people with support services that raise aspirations, improve inclusion and are aligned with human rights agendas.

6. To provide more funding for local and national nongovernmental organisations led by disabled people:

Whether it is a redirection of existing funding or an increase, it must be made available to organisations run by disabled people and they must have a fair and realistic opportunity to bid and succeed in securing the funding; if this becomes a reality, it will improve growth and sustainability of services for disabled people. Organisations led by disabled people also ensure that disabled people have their voices heard at every level and that practical improvements are being made in the lives of disabled people and their communities. Furthermore, Governments and those with decision making power need to agree that disabled people are experts by experience. By giving them funding to provide services or advocate on behalf of disempowered disabled people, there will be recognition that disabled people are best placed to identify and find solutions to barriers.

We demand recognition that organisations led by disabled people are best placed to provide individuals with the right level of support, facilitate inclusive practices and work to improve the lives of disabled people. This recognition must be reinforced



through the availability of funding, allowing such organisations to be sustainable and develop positive legacies.

7. To reverse cuts in services and benefits for disabled people:

As a result of the economic crisis in Europe, disabled people are becoming increasingly marginalised from society. Disabled people already face many barriers to employment, education and to full inclusion in the community but now, because of the cuts to support related to independent living and other disability-related services, disabled people face further isolation. Reducing benefits and services for disabled people negatively impacts an individual's right to independent living and their freedom. It is vital that Member States realise how the current level of reductions are impacting on the lives of disabled people, who now face further isolation and exclusion from society, are grounded further into poverty and have led some to commit suicide.

We demand an immediate stop to the cuts and reverse all decisions that have stripped disabled people of their benefits and services. Member States must recognise their responsibility to provide services to all human beings and realise that disabled people have a right to access holistic support, which meets all their needs. Furthermore, by providing the right level of support and not targeting disabled people as a way of reducing Government expenditure, it prevents the escalation of higher costs to meet unsupported and crisis-related needs. We expect the European Union to provide strong guidance and additional legislative initiatives to pressure the Member States to safeguard disabled people's support services and benefits from the imposed cuts.

8. To ensure that disabled people have access to mainstream services:

Member States must focus on removing the barriers within mainstream services, which will bring us closer to an inclusive society. To achieve this, it will require all aspects of societal life to meet the needs of the individual at every stage; yet, mainstream society is void of authentic, continuous opportunities to engage and participate in public and private life. Participation is essential for the development and maintenance of our society; disabled people should have the opportunity to influence the destiny of their communities and that is why it is vital that mechanisms exist to ensure there are opportunities for participating in mainstream activities and accessing services, now and in the future. In particular, the right to meaningful employment is also imperative as many disabled people are not provided with support to aid the process of getting and staying in employment. Whilst a smooth



transition between education and employment is necessary, those in powerful positions need to make reference to disabled people when agreeing on policies and services which promote employment opportunities.

We demand a review of the barriers within mainstream services and expect resources and funding to be allocated in order to remove the disabling barriers that explain disabled people's marginalisation, exclusion and isolation from community life.

9. To strengthen the protection of disabled people against discrimination (in all areas) at the EU level:

All forms of discrimination must be eradicated by improving the inclusion of disabled people within society, removing discriminatory practices as a result of policy implementations and working to protect disabled people when encountering discrimination. This also includes disability hate crime, which is considered the most extreme form of discrimination and is on the increase in countries where research has been conducted. It infringes the human rights of those affected, stopping them from being able to enjoy the full benefits of the society.

We call for Member States to do more to promote the rights of disabled people so individuals are made aware of their rights and how they can challenge discrimination. Furthermore, we demand the EU to tackle discriminatory practices instigated by those in positions of power and influence and remind them of their obligations, as outlined in the United Nations Convention on the Rights of Persons with Disabilities.

10. To ensure inclusive education for all disabled children and young people:

It is vital that all disabled learners have the right to inclusive education which in turn strengthens and promotes an inclusive society. All schools must ensure that disabled pupils are not at a disadvantage when learning and participating within the educational environment. Inclusive education benefits all pupils, as it can strengthen a school community and ensure that all students are valued for who they are. Therefore, the right to an education needs to be realised with the education system providing better continuous support, which is streamlined at every stage within the educational process; furthermore, if we want disabled people to be valued, respected citizens with skills then we need to ensure mainstream schools are fully inclusive of all disabled students and we no longer promote a segregated approach to any aspect of our life.



We demand an approach to education that enables all students to achieve their potential, whilst ensuring their needs and access requirements are supported. Furthermore, we expect all learners to be educated together, regardless of their background or circumstances, within their local communities.

European Network on Independent Living, 2014 Manifesto



Implemented in the framework of the project "Proud, Strong and Visible – Promoting the Choice, Control and Participation of Disabled People in Europe", supported by the European Commission 2014 Action Grant and by ULOBA, Norway.

ENIL – Ground Floor, Chase House, City Junction Business Park, Northern Cross, Malahide Road, Dublin 17, Ireland, T +3531 525 0700 E <u>secretariat@enil.eu</u> W <u>www.enil.eu</u>