



Ten Years Closer to Freedom?



Celebrating the
10th Anniversary
of the Strasbourg
Freedom Drive



European Network on Independent Living

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of the Strasbourg Freedom Drive**



European Network on Independent Living

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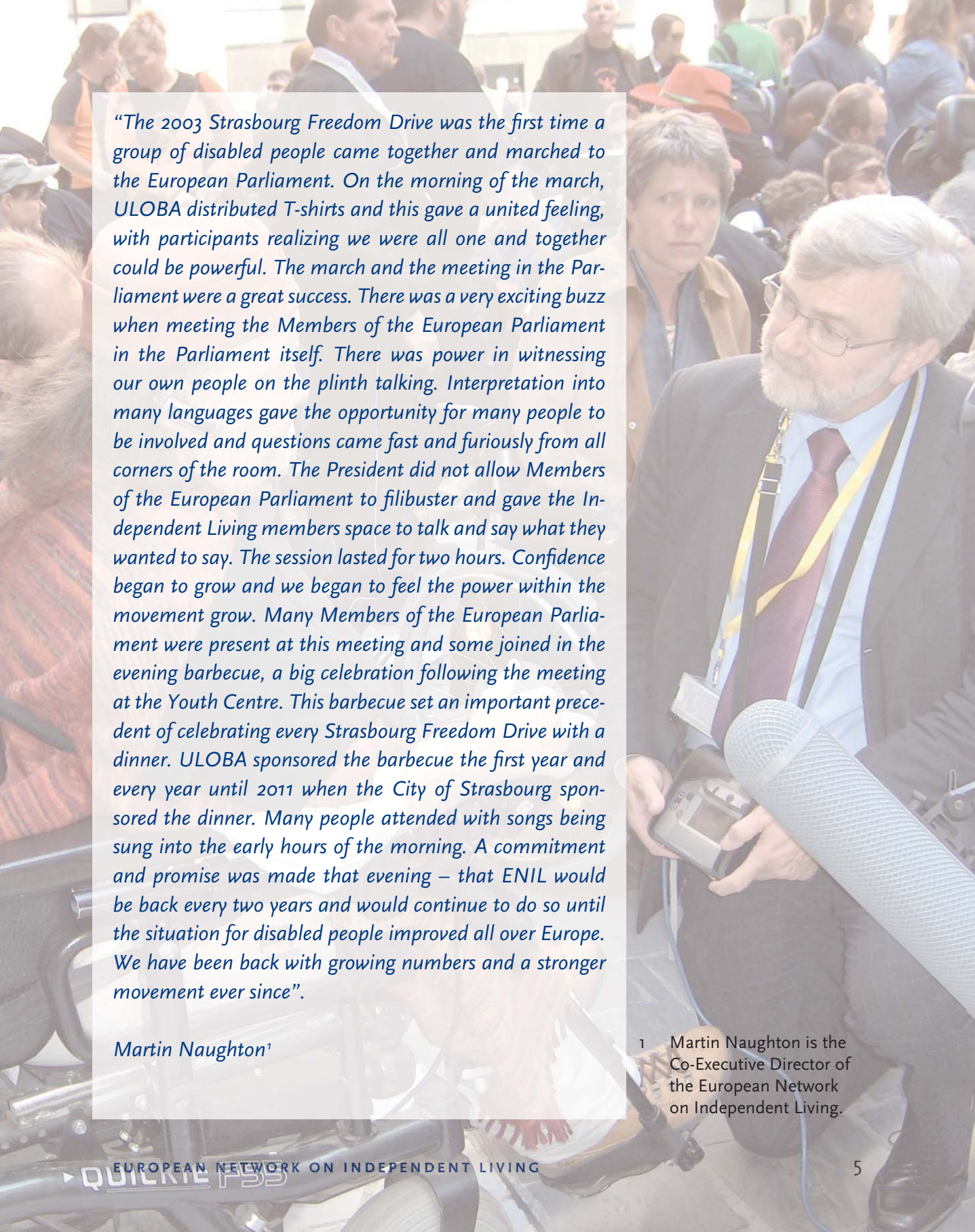
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The Road to Freedom



“The 2003 Strasbourg Freedom Drive was the first time a group of disabled people came together and marched to the European Parliament. On the morning of the march, ULOBA distributed T-shirts and this gave a united feeling, with participants realizing we were all one and together could be powerful. The march and the meeting in the Parliament were a great success. There was a very exciting buzz when meeting the Members of the European Parliament in the Parliament itself. There was power in witnessing our own people on the plinth talking. Interpretation into many languages gave the opportunity for many people to be involved and questions came fast and furiously from all corners of the room. The President did not allow Members of the European Parliament to filibuster and gave the Independent Living members space to talk and say what they wanted to say. The session lasted for two hours. Confidence began to grow and we began to feel the power within the movement grow. Many Members of the European Parliament were present at this meeting and some joined in the evening barbecue, a big celebration following the meeting at the Youth Centre. This barbecue set an important precedent of celebrating every Strasbourg Freedom Drive with a dinner. ULOBA sponsored the barbecue the first year and every year until 2011 when the City of Strasbourg sponsored the dinner. Many people attended with songs being sung into the early hours of the morning. A commitment and promise was made that evening – that ENIL would be back every two years and would continue to do so until the situation for disabled people improved all over Europe. We have been back with growing numbers and a stronger movement ever since”.

Martin Naughton¹

¹ Martin Naughton is the Co-Executive Director of the European Network on Independent Living.

The Road to Freedom

The year 2013 marks the 10th Anniversary of the Strasbourg Freedom Drive, and on this historical occasion we take a look back on how this event began, the achievements over the last number of years and how it is set to develop into the future. From humble beginnings, this week-long event has grown in both strength and numbers and has become the flagship campaign of the European Network on Independent Living (ENIL).

The aim of the Strasbourg Freedom Drive is to provide an opportunity for disabled people from across Europe to come together and exchange their experiences in an informal way, as well as to facilitate further development of the Independent Living movement.

Those who attend the Strasbourg Freedom Drive are examples of the Independent Living philosophy in action. They are people who lead self-directed lives. Many travel great distances and overcome immense barriers to participate in one of the most unique events in the world.

The Strasbourg Freedom Drive has become one of the most recognised events in Europe. The event has had a profound impact on the development of disability policies at the local, national and European level, and has played an important role in progressing the Independent Living movement across Europe over the last ten years.

What is the Strasbourg Freedom Drive?

The Strasbourg Freedom Drive is a biennial event organised since 2003, with the aim of providing an opportunity for Independent Living campaigners to meet Members of the European Parliament, to promote Independent Living issues, exchange ideas and information, and meet with old and new colleagues.

Every two years, hundreds of disability activists from all across Europe travel to Strasbourg, France to take part in the Freedom Drive. Through the events organised throughout the week, the situation of disabled people in Europe is brought to the attention of Members of the European Parliament, the Council of Europe, the media and the general public.

The Strasbourg Freedom Drive provides an opportunity for Independent Living campaigners to meet each other and exchange experiences of their life situations in the different countries across Europe. The Strasbourg Freedom Drive engages people from many different areas of life and highlights the positive aspects of Independent Living and the work that must be done to progress the right to Independent Living for all disabled people. The Strasbourg Freedom Drive inspires and motivates all those who participate to continue to campaign for Independent Living for all disabled people.



Every Great Journey
Begins with a
Single Step

Every Great Journey Begins with a Single Step

In 2003, campaigners from across Europe began a journey to the heart of Europe – the European Parliament, the Council of Europe and the European Court of Human Rights. Their goal was the freedom to live independently for disabled European citizens. Historically, this aim seemed impossible to achieve. Europe has a dark, sinister history in relation to disabled people. Institutionalisation, eugenics, oppression, segregation and forced poverty are a tragic fact of European history, some of which remain today. The Freedom Drive sought a new era in the status of disabled people in Europe.

During the first Freedom Drive, campaigners articulated their aims in eight key demands:

1. A European-wide policy on personal assistance.
2. The right to gain personal assistance services regardless of cost.
3. The right to retain personal assistance funding when travelling.
4. Action to address the growing number of people with disabilities being institutionalised.
5. More effective representation of people with disabilities in European inclusion strategies.
6. Promotion of the appropriate implementation of the Independent Living philosophy.
7. Allocation of 5% of overseas development aid to people with disabilities in developing countries.
8. Action to address the significant human rights abuses.

In 2003, the Freedom Drivers arrived in Strasbourg with a clear human rights agenda. In what was the European Year of People with Disabilities, they demanded action rather than rhetoric. At the time, their demands appeared to be on the periphery of the European agenda. It would be another three years until the adoption of the UN Convention on the Rights of Persons with Disabilities (CRPD) and seven years until the European Union ratified the CRPD. The demands of the Freedom Drive have evolved over the past 10 years to reflect these changes. However, what remains core to the campaign is the demand for Independent Living, human rights and equality. It is a journey to freedom, one which has not yet reached its destination.

History of the Strasbourg Freedom Drive

The year 2003 was designated as the European Year of People with Disabilities. This was the catalyst which sparked the idea for the first ever Strasbourg Freedom Drive.

The origins of the Strasbourg Freedom Drive were born out of a desire of a small group of disability activists to revive and renew the Independent Living movement in Europe. Cathal Ó'Philibin (an Irish disabled activist living in England and a user of personal assistance services) gathered together disability activists from across Europe at a meeting in Southampton, England. This meeting inspired and lifted the spirits among those in attendance about the future of the Independent Living movement. They set out on a mission to engage more disabled people across Europe. As a result, in early 2003, the European Network on Independent Living held a Board meeting, where it was decided to organise one big event to spread the message of Independent Living. This big and seemingly crazy idea was the Strasbourg Freedom Drive.

The Strasbourg Freedom Drive, as conceived in 2003, intended to bring together disabled people and the leaders of the Independent Living movement from across Europe, to share life experiences and to encourage each other to take control over one's lives.

Through the support of ULOBA and the efforts of the Centers of Independent Living in Ireland, enough momentum and energy were gathered to turn this idea into reality.



The Journey

The Journey

A movement is only as strong as the individuals it is made up of. The Freedom Drive comprises a collective of individuals from countries across Europe, with different cultures, languages, political persuasions and economic situations. One of the great strengths of the movement is the unity of individuals from diverse backgrounds, brought together by the goals and aims of the Independent Living movement. In 2011, Freedom Drivers travelled to Strasbourg from as far and wide as Austria, Belgium, Bulgaria, Bosnia and Herzegovina, Croatia, France, Germany, Iceland, Ireland, Italy, Latvia, Lithuania, Montenegro, Norway, Poland, Serbia, Slovenia, Spain, Sweden and the UK.

Freedom Drive Demands


The Freedom Drive demands have become an advocacy tool and have evolved to reflect the current situation of disabled people in Europe and outline issues that the Freedom Drivers want the European institutions to act upon. In 2011, the central theme of the Freedom Drive was *Free our People Now!*, with nine new demands drafted and presented to the European Parliament. They were to address the everyday discrimination and barriers to participation in society faced by disabled people.

1. Independent Living central to all relevant EU policies.
2. Respecting the UN Convention on the Rights of Persons with Disabilities, with provisions on non-discrimination, accessibility, right to live in the community and personal mobility as the minimum benchmarks for European Union Law and policy.
3. Inclusion of disabled people through universal design and the abandonment of special solutions.
4. De-institutionalisation – closure of institutions by 2020.
5. Personal Assistance for all in need.
6. Freedom of Movement.
7. Independent Living in international development programs.
8. Full ratification and implementation of the UN Convention on the Rights of Persons with Disabilities.
9. Disabled People's Organisations in policy making.

The demands have evolved to encompass the changing laws and policies in relation to disability, including the UN Convention on the Rights of Persons with Disabilities. All of the demands call for deinstitutionalisation, personal assistance services for all those who need them and the freedom of movement. The evolution of demands since 2003 shows that although much progress has been made, there is still much more to be done to ensure the equal rights of disabled people in all European countries.



Driving Change



"This year I met Swedish men and women who travel to Strasbourg to campaign for deinstitutionalisation and a right to personal assistance in Europe. This provided a valuable insight into individual motivations for making the journey to Strasbourg. I was struck by the lengths to which many people went to participate in the Freedom Drive. They travelled 1,700 kilometres from Stockholm to Strasbourg by bus or car. Some people prepared months in advance of the Freedom Drive, determined to get their message across. For instance, some people did not use verbal speech as their primary method of communicating. Instead, they undertook a complex process, with the support of their personal assistants, to get their message across. One woman trained her assistants to interpret what she wanted to say and to translate a speech into English alongside photos depicting her life with personal assistance. It cost them a great deal of money, effort and personal sacrifice to travel to Strasbourg. All campaigners shared similar experiences of the Freedom Drive. Each person had the opportunity to express their views at the very top level in Europe. Each person I spoke to was motivated by a clear goal, solidarity with other European citizens who do not have the opportunity to live independently with personal assistance. All campaigned for the closure of all institutions and an end to oppression of disabled people. The numbers of Swedes participating in the Freedom Drive, with the support of personal assistants, reflects the inequalities that remain between European countries when it comes to the right to live independently on an equal basis with other citizens. Swedes have had an individual right to personal assistance since the enactment of legislation in 1994. Swedes who have benefited from personal assistance have not forgotten about the majority of Europeans who do not have such opportunities. In fact, the people I spoke to were motivated by the extent to which their lives have improved since they have the right to assistance. Their lack of complacency and solidarity with others was very uplifting. They were determined to keep fighting until everybody is out of institutions, with equal rights to all European countries."

Ciara Brennan²

- ² Ciara Brennan is a PhD candidate based at the centre for Disability Studies, University of Iceland. Her doctoral thesis focuses on advancing the right to live independently in Europe, with a focus on the experiences of people in Nordic countries. For more information or to contact Ciara please email at: csb1@hi.is

Driving Change

The achievements of the Freedom Drive campaigners demonstrate the power of ordinary citizens mobilising to fight for change. The issues brought to the European Parliament and the Council of Europe emerge from the grassroots, from the lived experiences of individuals throughout Europe. Participants in the Freedom Drive have the opportunity to highlight their concerns prior to and during the event. They have the opportunity to voice their concerns to Members of the European Parliament (MEPs) attending the meetings and conferences. In 2011, a large number of MEPs responded to individual issues. This illustrates the powerful voice of the campaigners and the extent to which the MEPs are willing to sit up and take notice. Rarely in European politics is there such an example of a direct link between the civil society and the policy and decision makers.

The dedication of the campaigners has impacted Europe at the very highest level. For instance, one of the demands of the Freedom Drive has been the EU's ratification of the UN Convention on the Rights of Persons with Disabilities, which finally happened on 23 December 2010. Article 19 of the CRPD (Living independently and being included in the community) reflects the original demands of the 2003 Freedom Drive. It calls for the right to live independently in the community, on an equal basis with other citizens, with access to personal assistance services.

The determination of campaigners often triumphed in the face of financial barriers and opposition from vested interests. Recent reports from Europe revealed how austerity and investment in services that deny disabled people the right to Independent Living are very much alive in Europe. Reports highlighting the "investment" of EU Structural Funds in the building and renovation of institutions are a devastating reminder of the roadblocks to Independent Living. A dreadful paradox is found in the fact that while austerity measures are taking place across Europe, Member States are investing large amounts of EU Funds in services that are not in compliance with the CRPD. This serves as a stark reminder that there is still a lot of work to be done in the fight for the initial eight demands of the movement. ENIL has responded to these challenging times with calls for action from the European

Parliament. *ENIL's Proposal for a Resolution of the European Parliament on the effect of cuts in public spending on persons with disabilities in the European Union* was launched at the 2011 Freedom Drive.

The Freedom Drive has generated advancement within the disability and Independent Living movement. Over the years, it has created new, creative mechanisms for capacity building and exchange of knowledge amongst disabled people and their allies. For instance, interactive workshops and conferences, and meetings of personal assistance co-operatives have been incorporated into the programme. It has nurtured new, young leaders of the Independent Living movement throughout Europe and facilitated exchange of knowledge between the participants, who have successfully returned to create change in their home countries. For example, participants from Iceland who took part in the 2011 Freedom Drive have successfully lobbied for the right to personal assistance, which is expected in 2014.

Apart from disability organisations, the Freedom Drive has successfully raised awareness among the European policy makers and has recruited some powerful political allies. One of the issues highlighted to MEPs has been the need for freedom of travel with personal assistants (for education, work or leisure). Another area where campaigners have made a significant impact is the issue of overseas development aid for disabled people in developing countries. This is now an issue high on the agenda of the UN and the development aid agencies. The Freedom Drive has also targeted the national and European media. Images and media depictions of the Freedom Drive have created strong, powerful imagery of disabled people as active campaigners for human rights.

Achievements of the Freedom Drive

European Level

The Strasbourg Freedom Drive plays an important role in awareness raising at the European level. It provides an opportunity for disabled people to share their lived experience and their concerns directly with Members of the European Parliament (MEPs), who can then pass these on to the local politicians. The Strasbourg Freedom Drive also provides an opportunity for Freedom Drivers to discuss issues at the European level, which also have a huge impact on the lives of disabled people in individual countries. These issues include deinstitutionalisation, the use of EU Structural Funds and the issue of non-transferability of personal assistance services in Europe. Communication between the Freedom Drivers and their MEPs continues once they leave Strasbourg, which makes it possible to further discuss important issues in an open dialogue.

UN Convention on the Rights of Persons with Disabilities

Over the years, we have seen a movement away from the medical model of disability towards a social model and a human rights based approach to disability. In 2003, the Freedom Drive called for “a right to gain Personal Assistance services regardless of cost”. Ten years on and this is one of the key issues that the UN Convention on the Rights of Persons with Disabilities (CRPD) addresses. Article 19 of the CRPD states that disabled people have a right to choose their place of residence, and that they should have access to a range of support services in the community, including personal assistance “necessary to support living and inclusion in the community”. The Freedom Drive and the demands of the campaigners no doubt influenced the drafting of this Convention. In 2010, the CRPD was ratified by the EU and ENIL now calls for its full implementation in every Member State.

Fight Against the Cuts

The Freedom Drive has become a very important platform where ENIL can launch campaigns to respond to issues which are facing disabled people across Europe. As a reaction to the cuts in Independent Living services for disabled people, at the 2011 Freedom Drive, ENIL launched a *Proposal for a Resolution of the European Parliament on the effect of cuts in public spending on persons with disabilities in the European Union*. The Resolution calls on the Member States and the European Commission to take action, in order to stop further cuts to community-based services, such as direct payments and adequate financial support for the extra living costs of disability and





Independent Living. It also calls for the re-introduction of those services which have been recently abolished and the better use of the EU Structural Funds, which could be used to fund some of the community-based services in the Member States in times of imposed financial austerity. To date, the resolution has attracted support from a number of MEPs.

ENIL Allies

The Strasbourg Freedom Drive is also open to all individuals and organisations in agreement with ENIL's objectives and work on Independent Living. In 2011, representatives of the EU Fundamental Rights Agency, the Assembly of European Regions (AER), the Organisation for Security and Co-operation in Europe (OSCE) and the European Disability Forum (EDF) joined in the activities of the Freedom Drive. The Freedom Drive is an opportunity to develop the cooperation with different organisations and to engage more people in the work that ENIL is undertaking. In 2012, as a result of the Freedom Drive, ENIL worked with the Office for Democratic Institutions and Human Rights (ODIHR) at OSCE to organise a workshop on hate crime against disabled people. At this year's Freedom Drive, this will be followed up with another workshop on Hate Crime and Disability.

Youth Engagement

The Freedom Drive plays a very important role in engaging young people in the Independent Living movement. It gives young disabled people an opportunity to meet with leaders of the movement, to hear their experience and to understand the importance and significance of the Independent Living movement in improving the lives of disabled people. It also recognises and credits our new young leaders and their ideas. As a result of the success of ENIL's week-long study session for young people in 2012, at this year's Freedom Drive there will be a conference session with a panel comprised of young disabled people and a meeting of the ENIL Youth Network.

ENIL Development

The Freedom Drive has had a significant impact on the way in which ENIL has progressed and developed. Membership by both organisations and individuals of ENIL has increased significantly as a direct result of the Freedom Drive, as more and more people become engaged with ENIL and the Independent Living movement. In the last ten years, ENIL has developed from a small group of activists in 2003, to a Europe-wide network





with four Regional teams (currently based in Sweden, Slovenia, Belgium and Bulgaria) and the Secretariat based in Dublin. ENIL's Regional Coordinators expand the network and bring the message of Independent Living to many people across Europe. ENIL has developed to be a true pan-European organisation with strong links to the grassroots.

People Power

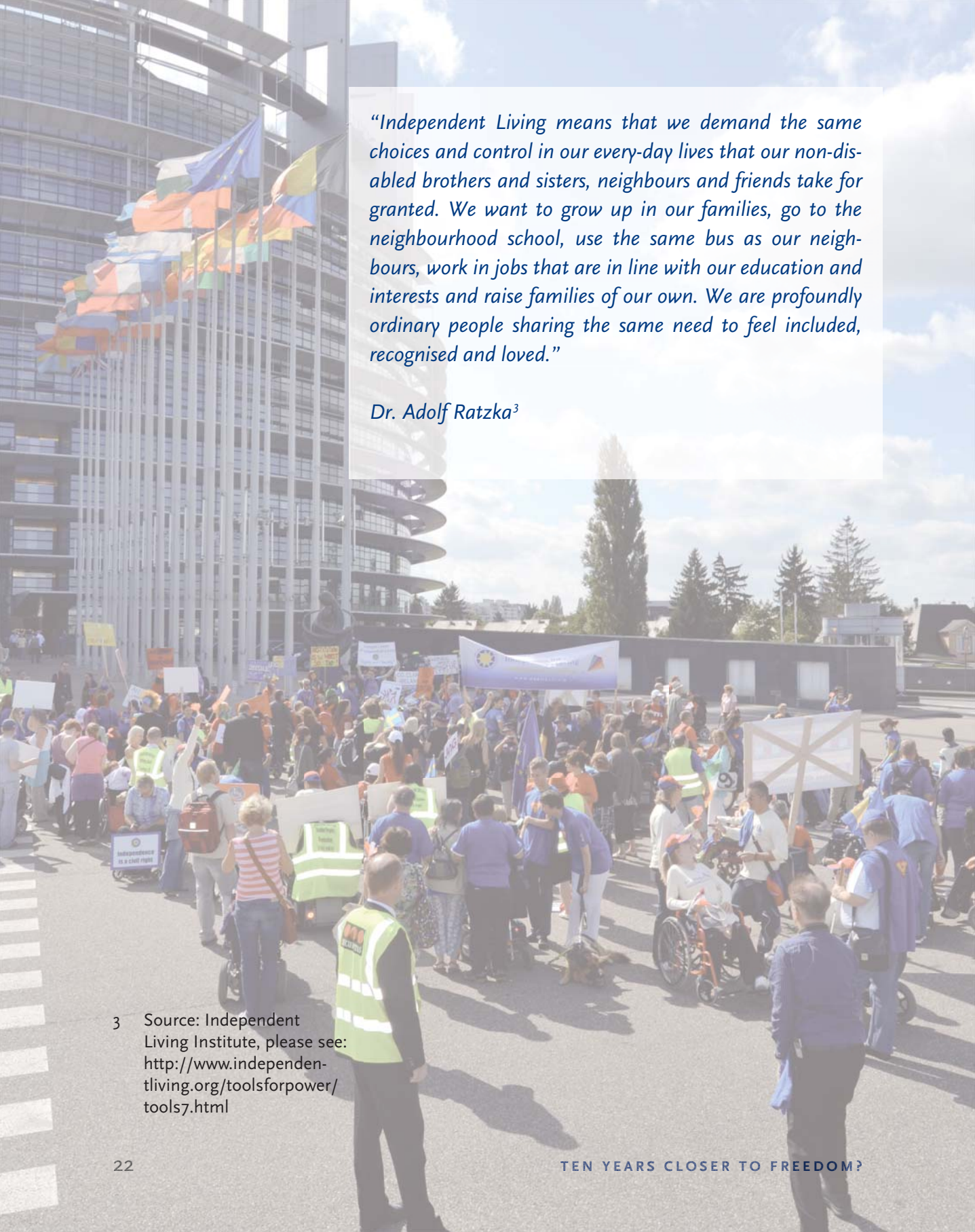
The most important achievement of the Freedom Drive is its ability to bring together a great number of people mobilising for positive change. Across Europe, there are many disability organisations and activists who work tirelessly to advocate for the rights of disabled people and inspire others to live self-determined lives. The Freedom Drive would not be possible without these people working at the grassroots level. Moreover, the Freedom Drive provides an opportunity to acknowledge and highlight this important work done in local communities across Europe. Once the Freedom Drive events finish, the campaign for equal rights for all disabled people is carried forward by these individuals. Participants return home and take with them the spirit and enthusiasm of the Freedom Drive. They continue to spread the message of Independent Living through their local Centres of Independent Living and disability organisations. This exchange of knowledge at a grassroots level has resulted in the continuing growth of the movement. Links between disabled people's organisations across national boundaries created at the Strasbourg Freedom Drive are developed and this results in advancing the Independent Living Agenda across Europe. The power of a gathering of disabled people who are champions of the Independent Living movement and who are representative of many thousands cannot be underestimated.

Active Citizenship

At the core of the Strasbourg Freedom Drive is a magnificent display of active citizenship. Those who attend the Strasbourg Freedom Drive send a strong message that disabled people are not willing to be passive citizens but are active and fully participating members of society.



Knowledge Is Power!



"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 raise families of our own. We are profoundly ordinary people sharing the same need to feel included, recognised and loved."

Dr. Adolf Ratzka³

³ Source: Independent Living Institute, please see: <http://www.independentliving.org/toolsforpower/tools7.html>

Knowledge Is Power!

Besides the CRPD, many new policy documents have been adopted at the European level that enhance the knowledge of how to advance towards Independent Living in the countries across Europe. Most policy documents have been driven by members of civil society organisations, including ENIL. In 2009, a landmark report was published by the European Coalition for Community Living (ECCL) – an initiative of ENIL – entitled “Wasted Time, Wasted Money, Wasted Lives...a Wasted Opportunity?”⁴. The report outlined the investment of EU Structural Funds into institutions for disabled people. In 2012, the Council of Europe Commissioner for Human Rights published a seminal paper entitled “The Right of People with Disabilities to Live Independently and be Included in the Community”.⁵ The paper outlined 15 coherent steps that should be taken by countries in Europe to advance towards Independent Living for all citizens. A very detailed legal analysis was published for the Office of the High Commissioner for Human Rights at the UN (Regional Office for Europe) in 2012. The report outlined EU’s obligations for allocating Structural Funds in light of Article 19 of the CRPD.⁶ In addition to these reports, ENIL has been active in disseminating the lived experiences of individual European citizens, their struggles and triumphs across Europe. The ENIL Newsletter publishes the stories of role models and brings to attention the human rights violations occurring throughout Europe. These stories are testament to the fact that disabled European citizens will not passively have their rights removed and to the solidarity that exists throughout Europe.

4 To read the full report, please follow the link: <http://www.community-living.info/documents/ECCL-StructuralFundsReport-final-WEB.pdf>

5 To read the full report, please follow the link: <https://wcd.coe.int/ViewDoc.jsp?id=1917847>

6 For the full report see http://www.europe.ohchr.org/documents/Publications/getting_a_life.pdf.

Freedom Drive Campaign 2013

This year, our campaign focuses on the rights of disabled people as outlined in the UN Convention on the Rights of Persons with Disabilities ('the CRPD') and features personal accounts from across Europe of how these rights are being violated. This campaign has replaced the Freedom Drive Demands from the previous years, and aims to show the reality of disabled people, the increasing barriers they face in the times of economic crises and why so many are unable to join us in Strasbourg.

The CRPD aims to ensure that disabled people can enjoy their rights on an equal basis with all other citizens. It sets out minimum standards for protecting and safeguarding a full range of civil, political, social, economic and cultural rights for persons with disabilities. The CRPD has been ratified by 24 EU Member States and by the European Union, making it the first regional integration organisation which became a formal party to the Convention.

However, there is a widening gap between the rights of disabled people as guaranteed by the CRPD and the reality. That is why, on the occasion of the 2013 Strasbourg Freedom Drive, ENIL has collected a number of personal accounts from different countries. Each person's story correlates to an article of the CRPD and shows how adversely the lives of disabled people are being affected because the CRPD is not being fully upheld and implemented in all the Member States. Through this campaign, we tell their stories.

The personal accounts featured in the campaign relate to the following articles of the CRPD, **calling on the European countries and the European Union to take a number of actions:**

- Safeguard support services for disabled people against the cuts (Article 4: General Obligations)
- Protect the rights of disabled women (Article 6: Women with disabilities)
- Make the mainstream facilities and services available and accessible to disabled people (Article 9: Accessibility)
- Give all disabled people the right to make decisions (Article 12: Legal Capacity – Equal Recognition before the Law)





- End segregation of disabled people in institutional care (Article 14: Liberty and Security of Person)
- Ensure Personal Assistance for all in need (Article 19: Living Independently and being included in the Community)
- Provide inclusive education for disabled children and young people (Article 24: Education)
- Grant disabled people access to employment in the open labour market (Article 27: Work and Employment)

Now is the time to close the gap between the rights set out in the UN Convention on the Rights of Persons with Disabilities and the reality. ENIL therefore asks the European countries and the European Union institutions to ensure that these rights are fully upheld for all disabled people and for the CRPD to be fully implemented across Europe.

To watch the Freedom Drive Campaign Video, please visit our website: <http://www.enil.eu/category/multimedia/>



The Road Ahead

The Road Ahead

This year marks the 10th anniversary of the first Freedom Drive. The Freedom Drive will take place on 9–12 September 2013. Ten years on and the demands of campaigners are as critical as ever. Despite all that has been achieved, Europe has reached a crossroads which will determine the future of millions of citizens. This year, Freedom Drivers will give personal accounts of the reality facing disabled Europeans and the gap between the CRPD and the reality. Although the situation is a difficult one, it is time to keep going, to keep moving along the road. The landscape has changed since 2003 - whilst many negative developments have occurred, others have reinvigorated the drive for Independent Living. None have been so crucial as the UN Convention on the Rights of Persons with Disabilities. While it would be easy to dismiss the CRPD as a document which does not have a real impact on the realities of disabled citizens, it is a powerful political tool giving us the framework to continue to contest our rights as disabled people.

By ratifying the CRPD, the EU and countries across Europe have committed to a human rights agenda. They have committed to actively involve disabled people's organisations and civil society organisations at all stages of policy development. If they take this obligation seriously, they need not look far for guidance on how to implement it. The Freedom Drive has nurtured the leaders of Independent Living in Europe. Expertise on Independent Living has grown from the grassroots, and it is the campaigners who hold the knowledge.

The journey over the past 10 years has no doubt been a bumpy one, but many strides have been made since the starting point in 2003. The Roman philosopher Lucius Annaeus Seneca said: "It is a rough road that leads to the heights of greatness". It is important to reflect on the achievements of the past 10 years, achievements that have surfaced in the face of adversity. The Freedom Drive hits the road to Strasbourg 2013 with new leaders, experts, allies, with advanced knowledge, with legal tools, and with dedicated and determined campaigners, united by guiding principles and solidarity with others who may not have the opportunity to campaign in Strasbourg. It is a stunning example of people power.

Overcoming Obstacles

Even with growing numbers and greater accessibility of transport and accommodation, ENIL recognises that for many people it is impossible to attend the Strasbourg Freedom Drive. For most Freedom Drivers, getting to Strasbourg involves overcoming many obstacles along the path. The cost of travel and accommodation can be a huge deterring factor and in these times of economic austerity, ENIL understands that the cost is increasingly the reason why many people cannot attend. For others, a long journey may simply be too difficult and arduous a task. Therefore, the Freedom Drivers who do attend are also a living proof of the obstacles that exist. In ENIL's view, the Freedom Drive must go on until there are significant changes and improvements in the attitudes toward disabled people and their life situations – until reaching Strasbourg is not riddled with so many barriers.



The Independent Living Movement and ENIL

The Independent Living Movement and ENIL

The Beginnings of the Independent Living Movement

The Independent Living movement grew out of the Disability Rights movement which began in the United States in the 1960's. Over the last number of decades, the Independent Living movement has spread from North America across the world. Led by Ed Roberts, who is often referred to as the father of Independent Living, the first Center for Independent Living (CIL) was founded in Berkeley, California. Centers of Independent Living are run and controlled by disabled people, provide peer support and support disabled people to achieve Independent Living, choice and control over their lives and full participation in society as equal citizens.

The history of the Independent Living movement in Europe is intertwined with the history of the European Network on Independent Living. In 1989, over eighty disabled persons and supporters coming from the Independent Living movement gathered in Strasbourg, France for a conference on personal assistance. As a result of this meeting, the European Network on Independent Living was founded. Many disabled people have dedicated their lives to promoting and strengthening the Independent Living movement both in Europe and globally.

Adolf RATZKA Adolf Ratzka was one of the founding members of the Independent Living movement in Europe and one of the founders of ENIL. He became the first President of the organisation. He was born in 1961 in Germany. At the age of 22 he won a scholarship to University of California. At this time, the United States was the only country with personal assistance services. In 1973, he moved to Sweden where facilities for disabled people were limited at that time. Ten years later in 1984, he founded STIL. STIL – the Stockholm Cooperative for

Independent Living – has become an international model of user-run personal assistance services based on a direct payment system. Adolf is now a Director of the Swedish based ThinkTank the Independent Living Institute Sweden, which formulates policy in the field of disability. We are honoured to have him speak at this year's Freedom Drive Conference in the first session on the future of Independent Living.⁷

Judith Heumann grew up in the United States of America. In 1970, Judith along with several friends with disabilities founded Disabled in Action, an organisation that focused on securing the protection of disabled people under civil rights laws. In 1983, she co-founded the World Institute on Disability with Ed Roberts and Joan Leon and served as its Co-Director until 1993. Judith then served in the Clinton Administration as Assistant Secretary of the Office of Special Education and Rehabilitation Services at the US Department of Education from 1993–2001. Between 2002 and 2006, she worked as the World Bank Group first Advisor on Disability and Development. She then went on to become the Director of the Department of Disability Services for the District of Columbia. In 2010, she became the Special Advisor on Disability Rights for the US State Department under President Obama. We are both honoured and delighted that Judith Heumann will be speaking at this year's Freedom Drive about Independent Living and Development Cooperation.⁸

Judith HEUMANN

7 Source: Independent Living Institute, please see: <http://www.independentliving.org/docs5/time.html>

8 Source: Wikipedia, please see: http://en.wikipedia.org/wiki/Judith_Heumann

John EVANS John Evans, OBE was one of the first people to set up an Independent Living scheme in the United Kingdom with funding to organise his own Personal Assistance. He has now been running his own scheme for over 25 years. He is a Disability Rights, Equalities and Diversity Consultant, Trainer and Researcher in the United Kingdom, specialising in Independent Living, Direct Payments, Disability Equality, Disability Rights and Human Rights. He commissioned the first piece of research on Direct Payments in the UK with BCODP (British Council of Disabled People). This was called “cashing in on independence” which was carried out by the Policy Studies Institute. He is a founding member of the European Coalition for Community Living (ECCL) and a member of the ENIL’s Advisory Group. In 2001, he was awarded the Order of the British Empire (OBE) for his services and work in Disability Rights and Independent Living. We are delighted that John Evans is one of the speakers at this year’s Freedom Drive.

Source:
Independent Living Institute,
please see:
[www.independentliving.org/](http://www.independentliving.org/25years2008evans)
25years2008evans

Bente SKANSGÅRD Bente Skansgård is one of the founding members of both the European Network of Independent Living and ULOBA (co-operative on personal assistance with self-direction). Bente graduated with a degree in Sociology in 1980 and began working at the Norwegian Building Research Institute where she researched housing issues. In 1985, she won a scholarship to study the Independent Living Movement in the United States and travelled through twenty-five states visiting Centers of Independent Living. In 1989, she was one of the founders of ENIL and went on to serve on the Board of ENIL as its President. This year, Bente was awarded the prestigious Pride Prize in recognition of the work she has done on the development of personal assistance services in Norway.

The European Network on Independent Living: Nothing About Us Without Us

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 barrier-free environment, de-institutionalisation, provision of personal assistance support and adequate technical aids, together making full citizenship of disabled people possible. ENIL's activities target European, national and local administrations, politicians, media, and the general society. ENIL works to strengthen the empowerment of disabled people of all ages, mainly through providing resources for peer counselling and peer training.

ENIL works directly with disabled individuals, organisations (mainly Centres of Independent Living), politicians, social actors, media, universities, the business world and any individual or organisation interested in learning about Independent Living history, values, principles and its practical application. The organisation also has a good working relationship with the disability units at the European Commission, the Council of Europe and is represented on the Advisory Panel and the Fundamental Rights Platform of the EU Fundamental Rights Agency.

ENIL has two initiatives – the European Coalition for Community Living (ECCL) and the ENIL Youth Network. ECCL (www.community-living.info) is a Europe-wide initiative working towards the social inclusion of disabled people by promoting the provision of comprehensive, quality community-based services as an alternative to institutionalisation. The ENIL Youth Network is an informal network, giving the opportunity to young disabled people to voice issues of concern to them within ENIL and to participate and feed-in to the organisation's activities at the European level.

Connect with us on Facebook

European Network on Independent Living

<https://www.facebook.com/EuropeanNetworkonIndependentLiving?fref=ts>

ENIL Youth Network

<https://www.facebook.com/groups/enilstudysession2012/?fref=ts>

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To All the Freedom Drivers – Thank You!

In these challenging times, the Strasbourg Freedom Drive is more important than ever. On this 10th Anniversary of the Freedom Drive we would like to acknowledge and thank all of the Freedom Drivers who have been a part of this journey with us. We hope that you continue to join with us to fight for the equal rights of disabled people in every European country.

The road to Strasbourg has no doubt been a bumpy one, but this has not deterred the growing number of campaigners travelling thousands of miles to Strasbourg from every corner of Europe. The determination of members of the Independent Living movement and their allies has impacted on the way in which Europe views disability. The Freedom Drivers have driven forward a rights agenda.

In 2013, the Freedom Drive takes to Strasbourg for the 10th anniversary of the campaign. Freedom Drivers will bring their lived experiences of disability and the barriers they face straight to the heart of Europe – the European Parliament and the Council of Europe. This publication reflects on the last 10 years of the Strasbourg Freedom Drive – the triumphs, the roadblocks and the road ahead.

