



10th Anniversary Freedom Drive

9—12 September 2013
Strasbourg, France

Report





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1. Introduction

The European Network on Independent Living ('ENIL') held its sixth Freedom Drive in Strasbourg between 9 and 12 September 2013. This year marked a historical occasion for the Freedom Drivers, as ENIL celebrated the 10th anniversary of the event. The Freedom Drive is a biennial event, organised since 2003 with the aim of providing an opportunity for the Independent Living campaigners to meet Members of the European Parliament ('MEPs'), to promote Independent Living issues, exchange ideas and information, meet old and new colleagues and get inspired.

The highlight of the week, a march through the streets of Strasbourg on 11 September 2013, provided the Freedom Drivers with an opportunity to state their messages loud and clear. This year, a number of other events were organised along with the march, including a conference "The Future of Independent Living, Citizenship and Europe 2020". ENIL's President Vibeke Maroy Melstrom opened the conference by outlining the importance of continuing to advocate for the rights of disabled people and Independent Living across Europe in these times of austerity, stating:

"Our legitimate fight to be seen, heard and included in society must be fought as fiercely and intensely as before, in relation to our opportunities for education and work, our rights and obligations as citizens and our right to control our own lives."

One of the unique aspects of this year's Freedom Drive was the focus on young people's involvement, with a session on rejuvenating the Independent Living movement during the conference and a meeting of the ENIL Youth Network. Four workshops focusing on key issues that have a direct impact on the lives of disabled people - combating discrimination, hate crime, Structural Funds and the misuse of the Independent Living terminology - took place on the opening day of the conference.

The Freedom Drive 2013 was organised in cooperation with the Strasbourg Centre for Independent Living CHA and with the support of the City of Strasbourg, ULOBA and the European Commission.

2. Participation

For most Freedom Drivers, getting to Strasbourg involves overcoming many obstacles along the path. The majority of Freedom Drive participants were Independent Living activists, many of whom are a part of the national or local Centres for Independent Living (CILs) in their countries. Many came with their Personal Assistants and two were accompanied by guide dogs. The countries represented this year by organisations or individuals were: **Austria, Belarus, Belgium, Bulgaria, Bosnia and Herzegovina, Croatia, Estonia, France, Germany, Greece, Ireland, Italy, Latvia, Norway, Romania, Serbia, Slovenia, Spain, Sweden and the United Kingdom.**

Freedom Drive is open to any individuals or organisations which are supportive of ENIL's work. This year, representatives of the European Disability Forum ('EDF'), the Organisation for Security and Co-Operation in Europe ('OSCE') and the Council of Europe joined many of the Freedom Drive activities.

3. The Freedom Drive Campaign

A new Freedom Drive Campaign was launched in 2013. It replaced the Freedom Drive demands from the previous years and aimed to show the reality of disabled people across Europe, the increasing barriers they face in times of economic crisis and why so many were unable to join us in Strasbourg. For every person who made it to Strasbourg this year, there were thousands who could not join the Freedom Drive due to the barriers they face as disabled people in their own countries.

The Freedom Drive Campaign consisted of a number of personal accounts from different countries. Based on these, a campaign video was produced, which called on the European Union (EU) to take action to improve the lives of disabled people. The campaign video was played at the meeting of the Freedom Drivers in the European Parliament. It was an opportunity to demonstrate the many ways disabled people are still being discriminated and excluded from society.

The Freedom Drive Campaign video is available at: <http://www.enil.eu/category/multimedia/> The full transcript is available in the Annex to the Report.

What did the Campaign call for?

Similar to the previous Freedom Drive demands, the 2013 Campaign set out a number of actions which should be taken by the EU Member States and the EU institutions:

1. Ensure Personal Assistance for all in need
2. Safeguard support services for disabled people against the cuts
3. End segregation of disabled people in institutional care
4. Provide inclusive education for disabled children and young people
5. Grant disabled people access to employment in the open labour market
6. Give all disabled people the right to make decisions
7. Make the mainstream facilities and services available and accessible to disabled people
8. Protect the rights of disabled women

Furthermore, ENIL called on the EU Member States and the EU institutions to ensure the full ratification and implementation of the UN Convention on the Rights of Persons with Disabilities ('CRPD') and its Optional Protocol as a matter of priority.

4. ENIL Proposal for a Resolution of the European Parliament against cuts in public spending

As a reaction to the cuts in Independent Living services for disabled people that are taking place across Europe, 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 Proposed Resolution outlined measures that should be taken by the Member States, the European Council and the European Commission to ensure that cuts in public spending do not lead to further social exclusion and institutionalisation of disabled people. ENIL has argued that doing so is everyone's responsibility under the CRPD.

Since the launch of the Resolution at the 2011 Freedom Drive, ENIL has continued with a series of activities in order to get the needed support from the MEPs. These included working with a number of European and national organisations over the past 18 months, as well as with some MEPs, in order to ensure an adequate response of the European Parliament. In February 2012, a successful hearing took place in the European Parliament, organised by ENIL in cooperation with the GUE/NGL Parliamentary Group. As a result of the hearing, a debate on an oral question on the impact of austerity on the living conditions of disabled people took place at a plenary meeting in the European Parliament on 12 March 2013. Unfortunately, the discussion was not followed by a vote on the Proposed Resolution; demonstrating the lack of understanding by MEPs for the precarious situation of Europe's disabled citizens brought on by the cuts in public spending. The oral question had been debated and adopted by the Employment and Social Affairs Committee at the European Parliament in February 2013 and was based on a proposal by ENIL and cooperating European organisations.

Although the Proposed Resolution was not adopted by the Parliament, ENIL has continued its efforts by relaunching the campaign at the 2013 Freedom Drive. This will involve another oral question put forward by the European Parliament, to establish what concrete measures are being taken by the European Commission to fulfil EU's obligations under the CRPD, the EU Charter of Fundamental Rights and the European Social Charter, as well as the European Disability Strategy 2010-2020.

The first campaign activity, carried out during the Freedom Drives was successful, with nearly all the MEP signatures needed for the oral question collected by the Freedom Drives. Some delegations, such as the Irish one, succeeded in obtaining signatures from all of the countries' MEPs.



Meeting in the European Parliament ©ENIL



5. Events

5.1 The Future of Independent Living, Active Citizenship and Europe 2020

The opening conference, entitled "The Future of Independent Living, Active Citizenship and Europe 2020", took place on 9 and 10 September 2013.

The introductory speeches were delivered by ENIL's President **Vibeke Maroy Melstrom** and **John Evans**, a member of ENIL's Advisory Board. In his words, "the Freedom Drive had become a call for action, where everyone can come together and unite to campaign for our right to independent living to be respected in Europe". John also pointed out the importance of acknowledging all that has been achieved through the course of the last 10 years in the Independent Living movement throughout Europe.

First Session- The Future of Independent Living

During the first session, **Lena Mari Steinfjell Karlsen** from Uloha, Norway, read out a speech prepared by ENIL's Executive Director Jamie Bolling, who could not make it to Strasbourg. Jamie's message was:

"We are all needed in our drive for freedom; in our drive for full participation; in our drive for the full implementation of the UN CRPD in all of our countries. A drive for us to be seen as individuals that can contribute to society, not where we are hidden from the view! We are PROUD, STRONG and VISIBLE!"

Gerd Anden, Founder of JAG, attended the Freedom Drive as a legal representative for her son Magnus Anden, the Chairman of JAG's Board. JAG is a non-profit cooperative of users of personal assistance. In Sweden, persons with high support needs have the right to personal assistance paid for by the State (through the National Insurance Agency). Gerd outlined how she, along with other parents of children with intellectual disabilities, coordinated the establishment of the organisation. In 1992, they decided to help their children start their own organisation (Foreningen JAG), and succeeded in moving the power away from the parents to the service users. The importance of including persons with intellectual disabilities within the Independent Living movement was one of the key points made in her speech.



Participants at the conference ©ENIL

Adolf Ratzka, STIL, went back in his speech to 1989, when almost all people with extensive disabilities lived in parental homes or residential institutions, when there was very poor access to housing, public buildings and transportation, and poor self-representation. Comparing this to 2013, he said that although significant changes have happened, very few people still have real Personal Assistance, and most depend on family or institutional care. While access to housing, public buildings and transportation has gotten somewhat better, there are still organisations run and controlled by non-disabled people, which claim to know what is in the best interest of disabled people. He argued that with the advent of the CRPD, disabled people's rights have been made explicit and it is time these are turned into reality.

Judith Heumann, Special Advisor for International Disability Rights at the US State Department, addressed the participants via Skype. Judith stated that all over the world disabled people face the same type of discrimination, and that what the Independent Living Movement can do is offer a place for people with all sorts of experiences to come together. She emphasised the importance of people working collectively, collaborating and advancing the movement, and the need to work with all levels of governments, both local and national. Judith focused on the importance of young people participating in the Independent Living movement and of knowing their rights, arguing that inclusion begins with disabled children being educated with their non-disabled peers. One of Judith's key points was that the CRPD shows a commitment to removing barriers, but there is much more work that needs to be done to fully remove all the barriers and to ensure equal opportunities for all.

Second Session- Rejuvenating the Independent Living Movement

The second session, planned by members of ENIL's Youth Network, highlighted ENIL's commitment to including young disabled people in the Independent Living Movement..

Miro Griffiths, ENIL East Regional Coordinator (and newly elected Board member of ENIL), presented some of the barriers that prevent young people from being part of the Independent Living Movement. He argued that young people will often focus on a national issue or become active in an organisation which works at the national level. In his opinion, this is a good place to start, because while everyone's rights should be respected and implemented globally, it is important to start at a local level.

Dilyana Deneva, ENIL South Regional Coordinator, used her personal experience of getting involved in the Independent Living movement to highlight the importance of events such as the Freedom Drive in making a positive and meaningful difference in people's lives. Dilyana's involvement with ENIL started at the ENIL Study Session in Strasbourg in 2012, which she described as "life changing". Meeting the participants of the study session inspired her "to become a successful professional in my area and to live a life with dignity no matter what my physical condition is."

Gatis Caunitis, ENIL Latvian Coordinator, focused on the role of the ENIL Youth Network in

expanding the knowledge of young disabled people and giving them an opportunity to share their experiences. He also pointed out how being a member of the ENIL Youth Network is a very good starting point to gain the tools necessary to take the first steps in changing the Government's attitude towards disabled people and influencing legal and policy decisions.

Mari Siilsalu, Estonian National Coordinator (a voluntary post), spoke of her own personal fight for personal assistance to support her to live an independent life. She told the audience about how, until a few years ago, she could not get out of bed and could not get personal assistance. Mari spoke of her realization about having two choices: "to fight, or to start existing instead of living". She chose to fight. Mari was successful in securing personal assistance and, once her health began to improve, realised there was a lot to do for many people. This is how she became actively involved in advocacy work with her local Estonian organisation, which eventually led her to become involved in ENIL.

Third Session – Independent Living, disability and politics

Paul Murphy, Irish MEP (GUE/NGL Parliamentary Group) began his speech by stating that disabled people have been disproportionately impacted by the austerity policies of the European Union. He outlined that, even before the crisis, disabled people have had to endure underfunded and inadequate public services and have faced discrimination. Paul noted how he himself has been inspired by the self-organisation of disabled people and by events such as the Freedom Drive. He attended the first Freedom Drive in 2011 and has been involved with ENIL since, especially in the working group against the cuts. He concluded by saying that Independent Living is a basic human right that should and can be guaranteed for all.



P. Lambrechts, G. Caunitis and M. Tomassoni ©ENIL

Mirko Tomassoni, MP, San Marino relied on his personal experience to explain the necessity of the presence of disabled people in public life and in politics. This is a precondition for being able to contribute and to fully enjoy all the rights and freedoms on an equal basis with others. Mirko called for increasing participation of disabled people in political life to become a priority.

Gordana Rajkov, CIL Serbia and former MP, spoke of how even though politics are not "pretty", they influence everyone's life. She therefore argued that, if disabled people wish

to achieve Independent Living, their participation in politics is essential. Based on her own experience as the first Serbian MP with a disability, Gordana made suggestions on how disabled people can get involved in politics. During her time as a politician, she had to fight to make the Parliament recognise her need for accessibility and for additional support. She outlined the impact this has had on the Parliament and the policy, and how it raised awareness of her fellow MPs, the Government and the public. Therefore, Gordana's key message was: *"To change the system, you have to get inside the system"*.

Virginia Atkinson, International Foundation for Electoral Systems (IFES), presented the work of the IFES, which focuses on increasing and improving access of disabled people to voting and elections. One of the good practice examples given was the Philippines, with a designated Commissioner for disability inclusion and voter registration weeks. During this process, information is recorded on what type of accommodation a voter may need. The importance of Article 12 of the CRPD was also highlighted, as one of the factors to be looked at when increasing access of disabled people to voting and standing for elections.

Fourth Session- Disability and Austerity

Peter Lambregts, ENIL Board Member and West Regional Coordinator, presented the effect of the economic crisis on disabled Europeans and ENIL's work against the cuts. Peter presented the European Foundation Centre (EFC) report "Assessing the impact of European Government austerity plans on the rights of people disability", which concluded that disabled people have been disproportionately affected by the cuts. The impact of austerity measures is visible in many areas, including: cuts in direct Independent Living support, budget restrictions for service providers, impact on education and employment support, standardisation, institutionalisation, lack of innovation and decreased availability and affordability of services.

Debbie Jolly, Disabled People Against the Cuts UK (DPAC) focused on the effects of the crisis and the cuts to services for disabled people in the UK. She outlined how DPAC had come into existence in 2010, as a direct response to the planned cuts to services. Today, DPAC has over 15,000 supporters and members, plus other anti-cuts groups and organisations. Debbie has highlighted the following effects of austerity measures in the UK: the re-assessment of everyone on incapacity support through private contractors Atos, an increasing number of suicides and premature deaths amongst disabled people and those 'assessed' by Atos as 'fit for work'; also, cuts to support provided by the local authorities and the closure of the Independent Living Fund.

Thorsten Afflerbach, Head of the Social Cohesion and Integration Division at the Council of Europe (CoE), was among those who welcomed the first Freedom Drivers in 2003. Since then, there have been a number of developments, most notably the adoption of the CoE Disability Action Plan 2006-2015. Mr. Afflerbach expressed his concerns about the trend



towards re-institutionalisation of disabled people, mainly fuelled by the economic crisis. He relayed the importance of informing and educating policy and decision makers about alternatives to institutional care, and the important role that the ENIL has in this.

All presentations are available on www.enil.eu/campaigns/freedom-drive/

Workshops

The workshops were a new addition to the Freedom Drive programme, and have given the participants an opportunity to ask questions and discuss different issues with experts in that field.

Workshop 1: Discrimination and the processing of disability-related cases (Berit Vegheim, Uloba and Professor Lisa Waddington, European Disability Forum Chair in European Disability Law, Maastricht University) - What kind of Equality Bodies do we need? What powers should they have? What type of discrimination is prohibited by EU law and how is it enforced? What impact does it have at the national level?

Workshop 2: Disability hate crime and independent living (Joanna Perry, Hate Crime Officer, OSCE - Office for Democratic Institutions and Human Rights)- What is disability hate crime? What are the links between tackling hate crime and Independent Living? How can we raise awareness about disability hate crime?

Workshop 3: Hijacked definitions and disability policy (Kapka Panayotova, ENIL Board Member) - What are the most important concepts for Independent Living? What definitions has ENIL developed and what is their role? How can we promote them?

Workshop 4: Using the EU Structural Funds to support Independent Living (Ines Bulic, ENIL Policy Officer and Coordinator of the European Coalition for Community Living) - How can Structural Funds support Independent Living? What is the relevant legal framework? How were they (mis)used during 2007 – 2013? What can we do to ensure Structural Funds are used more effectively in 2014 – 2020?

All workshop presentations are available at: <http://www.enil.eu/campaigns/freedom-drive/>



Workshop participants ©ENIL

6. March to the European Parliament

The march from the centre of Strasbourg to the European Parliament is the central event of every Freedom Drive. Freedom Drivers gathered at Place de la Republique, where motivational speeches were given by Independent Living activists, including Peter Lambreghts, Martin Naughton and Kapka Panayotova.

Led by Gary Lee of the CIL Carmichael House in Dublin, the Freedom Drivers made their way to the European Parliament, carrying banners and shouting slogans, such as: Our lives, Our rights", "Institutions are NOT Solutions", "Rights, NOT Charity" and "Nothing about us, Without us". Despite the downpour of rain, the spirits of all those on the march were lifted by these slogans. Along the route, many Freedom Drivers handed out flyers to the people of Strasbourg, which explained Independent Living and the importance of the implementation of the CRPD. Many gave interviews to the local and international journalists who attended the march.

After the march, the Freedom Drivers made their way into the European Parliament for a meeting with the MEPs. Despite initial concerns that places for wheelchair users would be limited, everyone was allowed to take part (although banners had to be left outside the building). Upon arrival in the Parliament, the 200-strong crowd sang a poignant rendition of "Do you hear the people sing" from the musical Les Misérables, which had been adopted as the anthem for the 2013 Freedom Drive.



March through Strasbourg ©CIL Dublin

7. Meetings

7.1 Delegations' meetings with MEPs

Freedom Drive participants from a number of countries - Spain, Slovenia, Belgium, Estonia, Sweden, the United Kingdom, Bulgaria, Belgium, Ireland, Germany and Italy - held national meetings with some of their MEPs, providing a chance to discuss in more detail the issues relevant to disabled people in their own countries. It was also an opportunity to discuss future cooperation and promote continued dialogue with MEPs on disability issues. The meetings proved to be especially successful this year, as Freedom Drivers succeeded in getting nearly forty MEPs to sign a form seeking an oral question on the effect of the austerity measures of the European Union on the lives of disabled people in Europe.

7.2 10th Anniversary Meeting in the European Parliament

A meeting of the Freedom Drivers with the MEPs was held on 11 September 2013. Emer Costello, MEP for Ireland, opened the meeting by outlining the importance of the CRPD, the



ratification of which she is promoting in Ireland. Mairead McGuinness, another MEP for Ireland, stressed the importance of working to ensure that Structural Funds do not go into the building or maintaining of institutions for disabled people.

Unfortunately, not many members of the Disability Intergroup at the Parliament attended the meeting, although ENIL had sent an invitation to all the MEPs. Martin Naughton, ENIL's Co-Executive Director, therefore called on members of the Disability Intergroup, in particular its President, to come forward and introduce themselves to the Freedom Drivers, adding that Freedom Drivers would not leave until they do so.

After e-mails and messages were sent to all members of the Disability Intergroup by fellow MEPs, a small number of MEPs did join the meeting. However, the President of the Disability Intergroup, Adam Kosa (Hungary) sent a message to say that, as there was no sign language interpretation, he would not attend the meeting. In response, Martin Naughton called

for the resignation of Mr. Kosa from his position as the Intergroup President.

One of the Vice-Presidents of the European Parliament, Edward McMillian-Scott (UK) also joined the meeting and invited some of the Freedom Drivers to attend the meeting of the Plenary Session. He supported ENIL's call for a Commissioner on Disability and invited everyone to engage with this issue.



Meeting in the European Parliament ©ENIL

Issues raised by the Freedom Drivers

A number of speeches were made by Independent Living activists, including John Evans, who spoke about the negative impact of the cuts and called on all MEPs to sign the oral question. Kapka Panayotova explored whether we are really ten years closer to freedom, and Miro Griffiths highlighted the issues affecting young disabled people. Pierre Gyselink of EDF spoke about the importance of bringing EU policies and laws in line with the CPRD, and the important role that the European Parliament can play in this.

A number of MEPs took to the podium to speak about issues affecting disabled people. Phil Predergast, MEP for Ireland, spoke about the research showing that the austerity measures produce small savings for the Government, but have a big impact on the lives of people. Together with Emer Costello, she agreed to send a question to the European Commission, asking for the endorsement of ENIL's Independent Living definitions.



After the interventions, the floor was open for questions, giving participants the opportunity to address the MEPs present. Below is the summary of the discussion:

- A participant from **Slovenia** expressed that although the meeting is in the European Parliament, there are not many MEPs to hear what the Freedom Drivers have to say. She stated how every two years the same basic demands are made, but all that is received are empty promises and patronising speeches, not real support. She suggested that it was time to change the strategy and become more radical, in order to make MEPs understand that disabled people have a right to personal assistance.
- A participant from **Spain** argued that one day disabled people will have their freedom, but that not many of those attending the 2013 Freedom Drive will live long enough to witness this.
- A **Swedish** participant stated the necessity for MEPs to understand the CRPD and argued that disability should get a higher priority within the European Union. He suggested that everyone present should work together to achieve this, and called for a dedicated Commissioner for Disability.
- One participant from **Serbia** acknowledged the important role that the European Union has in setting the standards for neighbouring countries.
- A delegate from **Norway** stated that they were there in solidarity with other European countries and asked the MEPs what they can do to make sure that Europe stops investing in institutions.

As a result of this discussion, there were a number of answers from MEPs which are summarised here:

- **Paul Murphy** (Ireland), stated that there are 750 MEPs elected to the European Parliament, and it is not acceptable that so few of them could attend this meeting. He stated that the EU puts economic interests before human rights, but that it is up to everyone present to use their power to instigate change and not to underestimate the power that everyone has.
- **Maureen Harkin** (Ireland) spoke about how she had put a number of amendments in favour of disabled people through the Parliament, and would raise the issue of Structural Funds spending. She also suggested that everyone present should lobby for a Commissioner on Disability.
- **Richard Howitt** (UK) acknowledged the effects that the austerity measures are having on the lives of disabled people and suggested that people should not vote on 22 May 2014 for any MEP who has ignored them.
- **Jean Lambert** (UK) spoke about the report of the Employment and Social Affairs Committee on the impact of the crisis on vulnerable groups.

- **Kinga Goncz** (Hungary) suggested to use the Petitions Committee and to vote for those MEPs that listen to disabled people.

After the meeting in the European Parliament, a buffet dinner sponsored by the City of Strasbourg was held for all the Freedom Drivers.

7.3 Regional Exchange Meetings

On 10 September 2013, each region organised smaller meetings pertaining to the situation in their region. The aim of these meetings was to foster greater communication throughout the regions. Unfortunately, due to a tram strike in Strasbourg, these meetings had to be cut short.

7.4 ENIL Youth Network Meeting

The final event on the programme was an informal ENIL Youth Network meeting at the CoE European Youth Centre. At this evening get together, participants shared their own experiences, advice and ideas. Through this exchange, they discovered that in every country there are difficulties that young disabled people face, including access to personal assistance, education, employment and accessibility.



Meeting in the Parliament ©ENIL

8. ENIL General Assembly

A total of 32 voting members (including member organisations and individual members) took part in the General Assembly. Several changes were adopted to the ENIL Constitution, and three new ENIL Board members were elected - Miro Griffiths from the UK, Nadia Hadad from Belgium, and Paul Fagan, from Ireland. They have replaced Javier Arroyo from Spain, Sue Bott from the UK and Wassilios Katsioulis from Greece.

After the General Assembly, an ENIL Allies Development meeting was held with Cor Van Damme from Onafhankelijk Leven in Belgium presenting his road trip across Europe. Mari Siilsalu presented ENIL's work of the INNOSERV Project and the importance of innovative social services.

In 2013, ENIL gave an opportunity to all of the participants to give feedback on the events throughout the week with an Evaluation Session. Some of the positive feedback included: the quality of the documents distributed, the energy of the youth panel and that the week was well-organised. There were also a number of suggestions for improving the Freedom Drive, including better translation, better accessibility for people with visual and hearing impairments, and others, a shorter programme of events and more time for informal networking.

9. Press Coverage

A Save the Date (dated 16 August 2013) and two Press Releases (6 and 16 September 2013) were issued by ENIL, in order to ensure that the Freedom Drive gets the coverage it deserves. Our local partner CHA was responsible for contacts with the French press, while the EU press was contacted by the ENIL Secretariat. As a result of our efforts, the Freedom Drive was covered by the local press and a number of journalists covering stories of interest to different Member States. A press conference was also held in the European Parliament on 11 September 2013, with Vibeke Maroy Melstrom, ENIL's President and Peter Lambreghts, ENIL Board member and West Regional Coordinator. The press conference was organised with the support of the GUE/NGL Parliamentary Group of the European Parliament. Some of the press coverage and the link to the video of the press conference can be found in the annex to the report.

10. Freedom Drive Booklet

To commemorate the 10th Anniversary of the Freedom Drive, ENIL published a booklet entitled "Ten Years Closer to Freedom? - Celebrating the 10th Anniversary of the Strasbourg Freedom Drive". The booklets, disseminated during the Freedom Drive, outlined the history of the event, the evolution of the Freedom Drive demands, the achievements of the Freedom Drive and the road ahead in the fight for Independent Living and equal rights. The booklet also paid tribute to the many leaders of the Independent Living movement who have contributed to its growth worldwide. Some of them were with us at the 2013 Freedom Drive, including Adolf Ratzka, John Evans and Judith Heumann (via Skype).

11. Useful Links

ENIL Website Freedom Drive: <http://www.enil.eu/campaigns/freedom-drive/>

ENIL Facebook Page: <https://www.facebook.com/ENILsecretariat>

ENIL Facebook Freedom Drive: <https://www.facebook.com/pages/Strasbourg-Freedom-Drive/124127045055>

EFC Study: <http://www.enil.eu/wp-content/uploads/2012/12/Austerity2012.pdf>

ENIL Resolution against the Cuts: http://www.enil.eu/wp-content/uploads/2012/05/ENIL_EP_Resolution_Proposal_FINAL_Jan2013.pdf

Videos from the Freedom Drive

ENIL Press Conference Campaign for the Right to Independent Living - European Parliament: <http://www.guengl.eu/media-channel/video/press-conference-campaign-for-the-right-to-independent-living>

ENIL Youth Network Meeting: <http://www.enil.eu/multimedia/youth-meeting-at-the-strasbourg-freedom-drive/>

Annex I: Selected press coverage

Accueil > News > Alsace 20 Reportage

Alsace 20 Reportage

Partager

Tweeter 1

Like 87



6ème édition de la Freedom Drive !

Égalité pour tous ! C'est un des slogans de la sixième édition de la Freedom Drive, le défilé de la liberté qui a vu plus d'une centaine de personnes handicapées, venues de toute l'Europe, manifester dans les rues strasbourgeoises.

Reportage du 11 septembre 2013.

demonstrated in Strasbourg for independent living

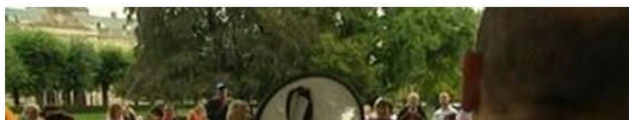
Being independent, dignified life, or just to take public transport, these are the dreams of people with physical disabilities. Dreams they would like to see become reality. That's why they showed this morning in Strasbourg.

Posted on 09/11/2013 | 12:09, updated on 09/11/2013 | 24:09



Event Wednesday in Strasbourg

This Sept. 11, people with disabilities over 20 countries paraded in the streets of Strasbourg with crutches, wheelchairs, and guide dogs headed for the European Parliament. The goal put the European Parliament and the Commission claims ENIL (European Network for Independent Living - European Network for Independent Living) for Independent Living.



Costello hosts disability activists at the European Parliament

12 September 2013



Statement by [Emer Costello MEP](#)

Dublin MEP Emer Costello hosted participants of the tenth *Freedom Drive* at the European Parliament in Strasbourg yesterday. Mrs Costello said: "Hundreds of disability activists come together from across Europe every two years for the bi-annual *Freedom Drive* organised by the European Network for Independent Living.

"The purpose of this conference is to promote issues relating to independent living and raise awareness amongst Members of the European Parliament. During their time in Strasbourg they will be exchanging views and information not only with MEPs, but also with each other as old and new colleagues.

"Participants reminded MEPs that the rights of disabled people continue to be denied on a daily basis. This is in spite of the fact that the European Union is a member of the Convention on the Rights of Persons with Disabilities. The EU was in fact the first 'supra-national' entity to become an official party to the Convention, thereby assuming the duties and obligations it entails.

"Not all Member States have yet followed through on their commitment to ratify the Convention. Regrettably, Ireland is among this group of countries. The Commission has been pushing these Member States, including Ireland, to now ratify the Convention as promised.

"Irish participants in the *Freedom Drive* included well-known disability campaigner and Dublin Support Officer with the Disability Federation, Martin Naughton, Michael McCabe, Chairperson of The Centre for Independent Living and Gary Lee, Chief Executive of The Centre for Independent Living.

"Issues raised by the Irish participants included their fears about cuts in Personal Assistant Hours, the need for continued support to ensure that people with a disability can live independently in the community make their contribution to society and to achieve their full potential, and the failure of successive governments to ratify the UN Convention on Disability. The participants highlighted cases which show that if existing resources were better deployed, there could be significant improvements in service with little or no additional cost.

In touch with Minister of State for Disability, Equality and Mental Health, Kathleen Lynch TD in these concerns. The Minister has reassured me that the Government will prioritise the ratification of the Convention in the forthcoming Dáil session."

Strasbourg

Les personnes handicapées défilent dans la capitale de l'Europe



Les manifestants ont défilé jusqu'au Parlement européen. Photo DNA - Michel Frison

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Une centaine de personnes handicapées venues de toute l'Europe se sont réunies ce matin à Strasbourg, dans le cadre de la sixième *Freedom Drive* (Marche pour la liberté) organisée par l'ENIL, le Réseau européen pour la vie autonome. Rassemblés place de la République – sous la pluie –, les manifestants ont crié des slogans en faveur de la liberté pour les personnes handicapées. « Rien pour nous sans nous », ont-ils notamment scandé, en dénonçant les placements forcés dans des centres spécialisés. Le cortège de manifestants a ensuite pris la direction du Parlement européen.

Tags

- Édition de Strasbourg
- Ville de Strasbourg
- Faits divers
- Actualité
- À la Une

Notez l'article

★★★★★

Annex 2: The 10th Anniversary Freedom Drive Campaign Video Transcript

Every two years, hundreds of disability activists from across Europe travel to Strasbourg to speak to Members of the European Parliament, to promote Independent Living issues, exchange ideas and information and to meet with old and new colleagues.

However, for every person who makes it to Strasbourg, there are thousands that cannot join the Freedom Drive due to the barriers they face as disabled people in their countries.

The Freedom Drive Campaign introduces you to disabled people who will not make it to Strasbourg this year. It aims to show that the human rights of disabled people are still being violated, despite the fact that 38 European countries and the European Union ratified the UN Convention on the Rights of Persons with Disabilities.

Reinhart, from Belgium, needs support with daily household tasks and to be able to work, but he has been on a waiting list for a Personal Assistance Budget for five years.

What can Europe do? Ensure Personal Assistance for all in need

Mary, from the United Kingdom, will lose funding which gave her the freedom to live her life as she chose to and to contribute to her community. Without the Independent Living Fund – scrapped by the Government – Mary will be dependent on the local authority funding and will be confined to her home.

What can Europe do? Safeguard support services for disabled people against the cuts

Valentin, from Romania, spent his whole life in institutional care. He died at the age of 18, shortly after being moved from a children's institution to a psychiatric hospital. Intellectually disabled and with HIV, he died of severe neglect and denial of medical treatment.

What can Europe do? End segregation of disabled people in institutional care

Menno, from the Netherlands, was not admitted to a mainstream secondary school because of his intellectual disability. His only alternative was a 'special school'.

What can Europe do? Provide inclusive education for disabled children and young people

Jaka, from Slovenia, receives job coaching for disabled people to help him get into work, but despite his university level education, he has not been able to secure employment in the past two years.

What can Europe do? Grant disabled people access to employment in the open labour market



Danijela, from Serbia, lives with her partner and leads an active life, but cannot get a full-time job or a salary because she is under guardianship. Her ability to make important decisions, such as to work or to vote, has been taken away from her.

What can Europe do? Give all disabled people the right to make decisions

Mareks, from Latvia, uses an electrical wheelchair, but cannot leave his apartment because he lives on the fifth floor of a high rise building without an elevator. His local authority will not provide him with alternative housing.

What can Europe do? Make the mainstream facilities and services available and accessible to disabled people

Tanya, from Bulgaria, has a university degree, but has been paid less than her male colleagues. She has struggled in an inaccessible environment, which her employer refused to adapt.

What can Europe do? Protect the rights of disabled women

The UN Convention on the Rights of Persons with Disabilities was ratified by 38 countries in Europe and the European Union.

Article 19 of the Convention recognises the “equal right of all persons with disabilities to live in the community, with choices equal to others”. State Parties to the Convention must “take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community”.

ENIL calls on the European countries and the European Union to ensure the full ratification and implementation of the UN Convention on the Rights of Persons with Disabilities and its Optional Protocol as a matter of priority.

Annex 3: ENIL's key definitions on Independent Living

These definitions are intended for use in the development of guidelines, policy and legislation at the European Union level, Member State level and local level. Their aim is to give decision makers clear guidance for the design and implementation of disability policy. They have been developed to prevent the manipulation and the misuse of our language for the development of policies that are counter-productive to Independent Living.

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

Independent Living (IL):

IL is the daily demonstration of human rights-based disability policies. IL is possible through the combination of various environmental and individual factors that allow disabled people to have control over their own lives. This includes the opportunity to make choices and decisions regarding where to live, with whom to live and how to live. Services must be accessible to all and provided on the basis of equal opportunity, allowing disabled people flexibility in our daily life. IL requires that the built environment and transport are accessible, that there is availability of technical aids, access to personal assistance and/or community-based services. It is necessary to point out that IL is for all disabled persons, regardless of the level of their support needs.

Personal Assistance (PA):

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



Deinstitutionalization (DI):

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

Community-based Services (CBS):

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

Adopted November 2012 by the ENIL board

ENIL is inviting organisations and individuals to support these definitions, in order to help prevent the manipulation and the misuse of our language for the development of policies that are counter-productive to Independent Living.

To support the definitions, please click here: www.enil.eu/il-definitions/

The European Network on Independent Living (ENIL) is a cross-disability organisation, working across the European Union and neighbouring countries to promote independent living and the implementation of the UN Convention on the Rights of Persons with Disabilities. 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, all of which make full citizenship of disabled people possible.

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