



ENIL BRUSSELS FREEDOM DRIVE 2015

Independent Living – The Next Generation

September 29 – October 1, 2015

First we take Strasbourg then we take Brussels!



# ENIL FREEDOM DRIVE 2015



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## Summary

Between 29 September and 1 October 2015, the European Network on Independent Living (ENIL) held its biennial Freedom Drive. During the Freedom Drive participants had the chance to meet members of the European Parliament, promote Independent Living issues and exchange information.

The focus of the 7th Freedom Drive was “Independent Living - the next generation”. ENIL encourages young people to bring new ideas to the Independent Living movement and at the same time provides the youth with the necessary tools to defend their rights that are frequently threatened by budget cuts.

After six successful editions in Strasbourg, this seventh edition was, for the first time, organized in Brussels. As the capital of Europe and home to many European institutions and international NGO's, Brussels is the perfect place to build a strong Independent Living network and to make European decision makers aware of Independent Living issues. To strengthen our voice in Brussels ENIL recently opened a Brussels office at Rue de l'Industrie 10, near the European Parliament.

The main event of the Freedom Drive was the march to the European Parliament on the 30th of September. After the march the Freedom Drivers were invited to a meeting in the Parliament hosted by MEP Marek Plura from Poland. The day at the Parliament was concluded with a disability film festival.

Other activities organized this year included national meetings with MEP's, an Independent Living Exhibition, the ENIL Youth Network meeting, the ENIL general assembly, a celebration dinner and a conference on different aspects of Independent Living followed by discussion groups.

The Freedom Dive also provided a great opportunity to test the accessibility of the Brussels public transport network. To make sure all the Freedom Drivers could get around the city, ENIL worked out a transport plan together with the Brussels public transport provider STIB. The transport went fairly well but was partly based on segregated special transport which is against ENIL principals. ENIL hopes that this, and future Freedom Drives will keep issues on public transport accessibility high on the political agenda in Brussels.

The Brussels Freedom Drive had good national and international media coverage with a report on Euronews as one of the highlights. Other important results from this year's Freedom Drive was a meeting with Ms. Cabral, the head of the Disability Unit from the European Commission. Several productive meetings between national delegations and MEPs also took place. There was great interest for the Independent Living exhibition and good cooperation with other National and international NGOs.

The Freedom Drive 2015 was organized in cooperation with ENIL members such as ULOBA from Norway, STIL from Sweden, Grip from Brussels, Onafhankelijk leven vzw from Ghent as well as with the support of the City of Brussels, the region of Brussels, The STIB, ATM concept, and the European Commission.



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## Introduction

The European Network on Independent Living (ENIL) held its biennial Freedom Drive between 29 September and 1 October 2015. The Freedom Drive has been organized since 2003, with the aim of providing an opportunity for Independent Living Freedom Drivers to meet Members of the European Parliament, promote Independent Living issues, exchange ideas and information, meet old and new colleagues and for inspiration.

After six successful editions in Strasbourg, this seventh edition was, for the first time, organized in Brussels. As the capital of Europe and home to many European institutions and international NGO's, Brussels is the perfect place to build a strong Independent Living network and to make European decision makers aware of Independent Living issues. During the Freedom Drive Independent Living activists from all over Europe had the opportunity to meet members of the European Parliament (MEP) and representatives from the European Commission. To strengthen our voice in Brussels ENIL recently opened a Brussels office at Rue de l'Industrie 10, near the European Parliament.

The main event of the Freedom Drive was the march to the European Parliament on the 30<sup>th</sup> of September. After the march the Freedom Drivers were invited to a meeting in the Parliament hosted by MEP Marek Plura from Poland. The day at the Parliament was concluded with a disability film festival.

Other activities organized this year included a conference on different aspects of Independent Living followed by discussion groups, national meetings with MEP's, the ENIL Youth Network meeting, the ENIL general assembly (GA) and a celebration dinner.

The focus of the 7th Freedom Drive was "Independent Living - the next generation". ENIL encourages young people to bring new ideas to the Independent Living movement and at the same time provides the youth with the necessary tools to defend their rights that are frequently threatened by budget cuts.

Zara Todd, one of the leaders of the ENIL Youth Network, feels that one of the biggest challenges is to bring young disabled people together to exchange experiences and allow them to become aware of their right to live independent in societies still dominated by the medical approach to disability. This way we can overcome the medical model and the negative perceptions of disability and keep the movement relevant, accessible and inclusive for the generations to come. In general Zara is optimistic about the future because of the increasing number of disabled people who are willing to fight for Independent Living.

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## Participation

Over 400 people participated in the 7<sup>th</sup> Freedom Drive. The majority of Freedom Drivers were Independent Living activists, many of whom are a part of the national or local Centres for Independent Living (CILs) in their countries. Most came with their Personal Assistants and others accompanied by a guide dog or service dogs.

The countries represented this year, by organisations or individuals, were Belarus, Belgium, Bosnia and Herzegovina, Bulgaria, Estonia, France, Germany, Greece, Holland, Hungary, Italy, Ireland, Latvia, Lithuania, Norway, Romania, San Marino, Serbia, Slovenia, Spain, Sweden, Turkey and the United Kingdom.

The Freedom Drive is open to any individuals or organisations that are supportive of ENIL's work or the European Independent Living movement. This year, members of the European Parliament, the European Commission, the European Disability Forum and other European NGOs and DPOs joined many of the Freedom Drive activities.



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## FD Campaign and Demands

The ENIL FD campaign started in 2014. That year the European Parliament elections took place and it was vital that the candidates were made aware of the pertinent issues affecting disabled people from achieving Independent Living. Equally, eligible voters needed to acknowledge the importance of casting a vote as well as to know what the candidates, in their Member States, intended to do to improve the inclusion of disabled people within society.

In order to achieve this, ENIL drafted and finalized a Manifesto. The ENIL vision is to ensure that all disabled people, regardless of impairment or background, have the opportunity to have choice and control over all aspects of their lives. Therefore, ENIL adopted the following ten key demands, which if implemented, would 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.
2. To introduce a dedicated Directorate for Disability.
3. To ensure the use of the correct terms for Independent Living, respecting definitions established by the Independent Living Movement.
4. To have the opportunity to use the European Structural and Investment Funds to support Personal Assistance schemes.
5. To stop EU funds being invested into institutions for disabled people (regardless of their size).
6. To provide more funding for local and national non-governmental organizations led by disabled people.
7. To reverse cuts in services and benefits for disabled people.
8. To ensure that disabled people have access to mainstream services.
9. To strengthen the protection of disabled people against discrimination (in all areas) at the EU level.
10. To ensure inclusive education for all disabled children and young people.





## Events

### Independent Living Exhibition in the Bel Brussels

ENIL staged an exhibition on Independent Living during the Freedom Drive at the Bel Brussels venue reaching hundreds of persons. The exhibition, a combination of photos from the ENIL members ULOBA - Norway and Onafhankelijkleven – Ghent, Belgium as well as the ENIL/Latvian project described below allowed IL to be portrayed visually for visitors to the events.

The ENIL/Latvian exhibition created by the Latvian ENIL volunteer Gatis Caunitis, has had much success in Latvia. Persons with Disability in Latvia – What Independent Living means to you? is a series of photos portraying young disabled people living ordinary lives. This exhibition shown throughout Latvia has had three objectives: to show the importance of being active to create qualitative and independent life for disabled people in Latvia and Europe, to raise awareness in society about Independent Living's importance for the lives of disabled people and at the same time on the issue of equality for disabled people important within the different European countries and to emphasize the strong fighting attitude for independent life.

The target audience is the society in general and disabled people. The exhibition has as target to be inspirational and motivational for people not knowing how and where to start the quest of living his/her own independent life. The art exhibition has already been exhibited across 5 different Latvian regions in various local municipality buildings.

The exhibition was opened in 2014 in the Riga 'Galerija Centrs' shopping center which is located in the old town of Riga and has a long tradition of hosting expositions. The Galerija attracts hundreds of people every day that passed the exhibition when entering the Building. The exhibition is a travelling exhibition with 9 photographs and 1 main placard on which the description about the project is written. The hope is that the message of Independent Living will reach many people.



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## MEPs meetings

Freedom Drive participants from several Member States held national meetings with their MEPs, providing a chance to talk in more detail the issues relevant to disabled people in their county. It was also an opportunity to discuss future cooperation and promote continued dialogue with MEPs on disability issues. In total over 40 MEPs participated in national meetings organized by Freedom Drivers from 18 different Member States. Below some examples of MEP meetings are described in more detail.

The Estonian delegation talked with the Estonian MEP Indrek Tarand about the lack of a national control committee to monitor UN CRPD implementation in Estonia. The Estonian Freedom Drivers also expressed their concern about the absence of clearly defined Independent Living terminology in both Estonia and the EU.

The Latvian delegation met four of the eight Latvian MEPs, Inese Vaidere, Artis Pabriks, Iveta Grigule and Tatjana Ždanoka. Ideas about how to improve the situation of disabled people in Latvia were exchanged and both parties agreed to stay in touch.

The Irish delegation met four MEPs and two MEP assistants. The meeting was very productive and a follow up meeting was planned for a more in-depth discussion on some issues. The MEPs expressed their concern about the low number of Irish delegates and made a commitment to help raising the number of Irish participant for the next Freedom Drive.

The Italian delegation had two meetings. First they met with MEPs Piernicola Pedicini, Eleonora Evi, Laura Ferrara and Dario Tamburrano. MEP Brando Benifei and a representative from the office of MEP Elena Gentile were present during the second meeting. MEP Pedicini informed the Italian delegation about the formation of a working-group on Structural Funds that will monitor the use of these funds in different member states including Italy. He and his assistant also expressed high interest in meeting the ENIL staff in the Brussels office. MEP Evi pointed out the importance of the petitions committee. European citizens should actively use petitions to influence the policy process because even a petition with few signatures suffices for inviting the Committee's hearing. MEP Benifei promised to follow up the Ombudsman's investigation on the use of structural funds.

The Belgian delegation from Walonia met 5 MEPs, Philippe Lamberts, Hugues Bayet, Frédérique Ries, Claude Rolin and Marc Tarabella. Both Philippe Lamberts and Frédérique Ries stressed that the EU has limited competences to enforce disability related rights. Nonetheless the MEPs agreed to follow up European initiatives in this area and several possible European actions, like the targeted use of structural funds, were discussed. Claude Rolin proposed to contact the Wallonian minister of social affairs Maxime Prévot to make sure that the European Regional Development Funds are used for the right projects.





## ENIL General Assembly

ENIL has 191 individual members, 117 Youth Network members and 56 member organizations from 39 countries. Seventy voting members (both member organizations and individual members) from 20 countries took part in ENIL's General Assembly (GA) on 29 September 2015.

At the start of the GA, Catherine Naughton from the European Disability Forum (EDF) was elected as the chair for the meeting and the minutes from the 2013 GA were approved.

The ENIL activities of 2013-2014 were presented by Dilyana Deneva. Then several changes to the ENIL Constitution were proposed, discussed, voted and adopted.



The main topic of this GA was the election of a new ENIL Board. There were 12 nominees for a place in the new board (Maria Dahl - Sweden, Tove Linnea Brandvik - Norway, Stelios Kypourpoulos - Greece, Marina Voudouri - Italy, Kapka Panayotova - Bulgaria, Mimicza Ruzicic Novkovic - Serbia, Christian Bayerlein - Germany, Paul Fagan - Ireland, Nadia Hadad - Belgium, Debbie Jolly - UK, Jean Pierre Ringler - France and Zara Todd - UK). To make sure different views from across Europe are represented in the board, board members are chosen from four regions.

The composition of the new board is as follows. Maria Dahl (new) and Tove Linnea Brandvik (re-elected) will represent the Northern Region Stelios Kypourpoulos (new) and Marina Voudouri (new) are the members from the Southern Region. The Eastern Region will be represented by Kapka Panayotova (re-elected). Finally from the Western Region Paul Fagan (re-elected), Nadia Hadad (re-elected), Debbie Jolly (re-elected) and Zara Todd (new) were elected.

After the election of the board a new Nominating Committee was proposed and approved. The new members of the Nominating Committee are Jonas Franksson - Sweden for the Northern region, Vanya Pandieva - Bulgaria for the Southern region, Gregor Fajdiga - Slovenia for the Eastern region and Mathilde Fuchs - France for the Western Region.

The GA also decided by majority vote not to reintroduce membership fees for ENIL.

The GA was concluded with a walking dinner where Freedom Drivers could meet and exchange views in an informal setting within the Bel Brussels. Bel Brussels is a very accessible, modern building providing a great place for exchange for many wheelchair users.



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## ENIL Youth Network meeting

One of the biggest outcomes of the 7<sup>th</sup> Freedom Drive was that the youth present at the event agreed unanimously, that the ENIL Youth Network should become formalized and adopted a draft memorandum of understanding that appointed an interim board. The interim board will work until the 2017 Freedom Drive, to develop the youth network and put in place the structures needed for formal elections in 2017.

The ENIL Youth Network used their time at the Freedom Drive to connect with one another and to start identifying work priorities for the network. To achieve this, Jamie Bolling (the ENIL executive director), Dilyana Deneva (Coordinator of the ENIL Youth Network) and Zara Todd (newly appointed Youth Network chair and ENIL board member) facilitated a session on how ENIL and its youth network should work together. Many issues were discussed, including for example the key issues affecting the independent lives of young disabled people, and what kind of support the Youth Network would require from ENIL. It was decided that the Youth Network will have as goal to host a monthly webinar and that the Youth Network will publish its own newsletter.

In short, the 7<sup>th</sup> Freedom Drive was particularly significant for ENIL's Youth Network. Members of the Youth Network were involved in all parts of the Freedom Drive, from discussions on the UN Convention to the impact of austerity on disabled people. Throughout the whole event young disabled people were strong, proud and visible.







## March to the Parliament

The March to the European Parliament is the main event of every Freedom Drive. More than 400 Freedom Drivers and sympathizers gathered on Wednesday morning, 30 September 2015 at the park Cinquantenaire in the center of Brussels. Journalists from across Europe were present to witness the event.



Before the march, different Independent Living activists gave motivational speeches. Peter Lambreghts, Jamie Bolling, Kapka Panayotova and Liesbeth Geldhof were a few of the speakers. At 12 o'clock the march, accompanied by a police escort, began to make its way to the European Parliament.

On the way to the Parliament the march stopped in front of the office of the European Commission. Maria-Luisa Cabral, the head of the European Commission Unit on the Rights of Persons with Disabilities, addressed the Freedom Drivers.

After Ms. Cabral's speech the march continued its way to the Parliament through the streets of Brussels. Participants were carrying banners and shouting slogans, such as: "Proud, Strong, Visible", "Institutions are NOT Solutions", "Rights, NOT Charity" and "Nothing, about us, Without us". Many journalists took part in the march and interviewed Freedom Drivers along the way.

A group of fire artists greeted the march with a spectacular show upon arrival at the EU Parliament. The march ended with the singing of the Freedom Drive anthem on the grounds off the Parliament.



After the march the participants were invited into the Parliament for a meeting and discussion with parliamentarians.



## Meeting in the Parliament

Both the Parliament meeting and the subsequent film festival were hosted by **MEP Marek Plura** (EPP) from Poland. After a short word of welcome by **Peter Lambrechts** (ENIL senior officer), **MEP Plura** opened the meeting. In his speech Plura spoke of the importance of the EU disability card that will allow disabled people to enjoy their national benefits across the EU and at the same time make use of specific benefits in each member state. **MEP Plura** congratulated the Commission for its commitment to the project and expressed his hope that concrete steps towards the disability card will be taken this year. MEP Plura also urged the EU Commission to work together with the EU Parliament for a fast adoption of the accessibility act.



In her statement the Greek **MEP Kostadinka Kuneva** said that, by being disabled, she understands what it means to live with a disability. Through her work in the Parliament she wants to take on disability issues and improve the rights of disabled people across Europe.

ENIL's President **Kapka Panayotova** looked back on the demands of the first Freedom Drive in 2003 and noticed that though there is more legal protection of disability rights through for example the UNCRPD, the demands from 2003 and 2015 are almost the same. So, despite many years of action and legal improvements there is no real improvement, to the situation of disabled people. While deinstitutionalisation should be the standard we see that community homes are often just a different name for an institution and that people still cannot live according to their own choice. Disabled people still have to use special public services instead of mainstream public services and still go to special schools. To change this a human rights + politics approach is needed and DG justice and DG employment have to work together.

**Mari Siilsalu**, an Estonian ENIL volunteer, had the following three suggestions. First, she proposed the adoption of the ENIL definitions of Independent Living concepts on the European level in order to avoid different interpretations of these concepts by the member states. Secondly she asked consultation groups on disability rights to have their own budget. Finally, she demanded society to have more faith in the next generation and let young people participate in the decision-making meetings on youth issues instead of only side events.

**Tom Rüütel** from Estonia highlighted that one of the key issues for ensuring Independent Living for young disabled people is to educate parents to make sure they allow their children to gain independence.







**Jamie Bolling** the ENIL Executive Director focused on everyday human rights for disabled persons and that we should be able to live ordinary lives. She envisioned a world where the disabled youth would no longer be among those with the lowest education, the highest level of unemployment and being amongst those who are the poorest of the poor no matter in which country they live.

**Michael Holden** from the UK emphasized the fact that disabled people are still mostly represented by non-disabled people while they should have the right, opportunity and possibility to represent themselves.

**Raffaello Belli** from Italy pointed out that art. 1 of the EU Charter of Fundamental Rights guarantees Human dignity. To uphold this article it is the EU's obligation to adopt a human rights approach towards disability in order to make sure that all disabled people can lead a decent life.

**Aleksandra Surla** from Slovenia focused on the difficulties blind people still face today when doing everyday things like watching television or visiting a website. The rights of blind people must also be taken into account.

**Zara Todd**, a leader of the ENIL Youth Network accentuated the challenging future for the Independent Living movement. The new generation will have to change the mindset about disability and at the same time protect the accomplishments of the previous generation of Independent Living activists in the context of austerity.

The impact of personal assistance was highlighted as well. Thanks to his personal assistant one Freedom Driver said that he can live independently from his parents though he has an intellectual disability. This example undermines immediately the myth that personal assistance is only a desire of the stubborn physically disabled.

The gap between the accessibility law and the reality in Belgium was brought up. Belgium has longstanding legislation intended to make for example the public transport accessible but as was seen during the Freedom Drive this is still not the case.

**MEP Helga Stevens from Belgium** closed the meeting welcoming the work of ENIL and future cooperation.





## Film festival

MEP Marek Plura hosted the European Film Festival 'Integration You and Me' in the EU Parliament during the Freedom Drive having it become one of the week's events. This film festival talks about disability and barriers to be broken. From 2003-2014 over 400 films from around the world have been presented, portraying the daily lives of disabled people. Each edition has had its unique theme including sport, sexuality or parenting. Concepts like 'integration', 'barriers' and 'tolerance' are presented for discussion and examination. The festival works towards the integration of disabled people in society, promoting human rights and Independent Living. The organisers gave a short presentation in the European Parliament to introduce the festival. Many of ENIL's Freedom Drivers attended the festival.



As a response to this film festival, ENIL asked members to send in films they have made on personal assistance or other relevant IL issues. A complete list of the collected videos can be found in annex to this report.

## Celebration dinner

To celebrate the ENIL 25<sup>th</sup> birthday and the first Freedom Drive in Brussels ENIL organized a celebration dinner on the 30<sup>th</sup> September 2015. The dinner was also a suitable end for the successful day with the march. The Brussels minister of equal chances Ms. Bianca Debaets offered the dinner and was represented by Ms. Veronique Peeters and two others colleagues. In her delivered speech, given in 3 languages, the minister reaffirmed her commitment to remove obstacles and barriers in order to make sure that all citizens can live and participate in an inclusive Brussels region.

The city of Brussels was represented by Mr. Mohamed Ouriaghli, Councilor for Equal Chances and a parliamentarian. The city of Brussels provided the necessary subsidies to rent the BEL Brussels, the venue for the Freedom Drive activities. In his speech Mr. Ouriaghli promised to work together with disabled persons to improve the accessibility of the city. He considered cooperation with disabled people important for the city of Brussels and looked forward to increase and extend the scope of the cooperation in the future.

After the speeches ENIL thanked the City of Brussels, the region of Brussels, The STIB, ATM concept, Bel Brussels, ULOBA and the European Commission for making the Freedom Drive possible in Brussels. A glass was raised up and the party started. The environmental friendly catering company Biorganic provided excellent food and drinks. After the dinner the music band "50 no's and a yes means yes" started the Freedom Drive party that went on until late evening.



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## Conference

ENIL organized the Freedom Drive conference on October 1<sup>st</sup> with focus on Independent Living. The conference consisted of three parallel panel discussions, each followed by a mutual exchange session.

*The first session moderated by Peter Lambreghts, ENIL Senior Officer, focused on the question “How can we advance the right on Independent Living via the EU policy level?”.*

The panel consisted of **MEP Helga Stevens** and **MEP Richard Howitt** -both Co-chairs of the Disability Intergroup, **Maria-Luisa Cabral** - head of the Unit on the Rights of Persons with Disabilities at the DG Employment and **Marie-Anne Paraskevas** from the unit ESF and Cohesion Policy at DG Employment.

The first topic was deinstitutionalisation and community living.

**MEP Richard Howitt** stressed the importance of a European definition of institutions to avoid misinterpretation. He also mentioned that even though several big institutions were already closed we should not forget the smaller ones; the FRA is currently working on this.

**Peter Lambreghts** followed up by pointing out that ENIL has been promoting its Independent Living definitions for years and that he is happy that the EU is making progress on this topic (the ENIL definitions can be found in annex to this report).

**MEP Helga Stevens** talked about the recent “revolution” in the Belgian system. New legislation is being implemented allowing people to move from institutions to community living without losing benefits. However the long waiting lists remain a problem.

**Maria- Luisa Cabral** announced that the Commission is organizing trainings for their desk officers in the member states to improve understanding of the need for deinstitutionalisation. As a result of these trainings the attention for disability issues in the country reports increases each year.

**Marie-Anne Paraskevas** said that ESF budgets are not always used as intended. To make sure the EFS budgets are used for the right purpose an active complaint system is needed but the Commission also needs more information from civil society about how the money is used at the national level. To achieve this, the stakeholders should be involved in the monitoring committee work.





**Tove Linnea Brandvik**, member of ULOBA and ENIL board member asked how ENIL can help improve the representation of disabled people in the European governments and raise the issues of disabled people on the political agenda. **MEP Helga Stevens** answered that the disability movement could learn from the women's rights movement becoming more radical to overwhelm decision makers. **Tove Linnea Brandvik** replied that many disabled people cannot participate because of the physical inaccessibility of the decision making process.

The second topic was the effects of the cuts and austerity measures on disabled people.

**Peter Lambrechts** started by stating that due to austerity measures previous success in achieving social inclusion of disabled people is at risk. To counter this ENIL has been very active on the topic with its proposed resolution to the European Parliament on the effect of cuts. The resolution got support from all political groups but in the end did not succeed due to lack of time for getting it to the agenda for voting. ENIL then established the Alliance Against Cuts in cooperation with other DPOs, organizations contributing also to work against the austerity measures. ENIL will attempt to set in action a new parliamentary resolution. Peter asked if the Disability Intergroup would support the new resolution with a meeting on the issue of cuts before the end of this year.

**MEP Richard Howitt** said he wants to support the ENIL demand. **MEP Helga Stevens** was also supportive but emphasized that the European Parliament has no power to influence the member states directly with a resolution. Therefore she proposed to look for a more effective way to get the message to the Member States.

**Peter Lambrechts** asked if disability issues would be higher on the political agenda in the future. **Maria- Luisa Cabral** answered that things will not change from one day to another but the issues are heading in the right direction as can be seen in the country reports.

The session was wrapped up with concluding observations:

**Marie- Anne Paraskevas** emphasized first of all the need for more disabled people in the civil service. Secondly, she called for more personal stories about barriers and solutions to mobilize the public opinion and identified good practices.



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**MEP Helga Stevens** called upon the EU and its members to remember that one of the founding principles of the EU was human dignity in a social Europe. To uphold this principal the EU and the Member States have to work together on for example disability rights.

**Peter Lambrechts** concluded that, as advised by the panelists, the disability movement had to become more radical and engage in more structural lobby work.

*The second session moderated by Agnes Sarolta Fazekas (ENIL Youth Network) was about ways to monitor the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD).*

The panel consisted of **Nadia Hadad** and **Patrick Vandelanotte** from Grip VZW, the ENIL president, **Kapka Panayotova** and **Rados Keravica** from the ENIL Youth Network

**Kapka Panayotova** started by giving information on how to collect data and to establish benchmarks for a shadow report. Data has to be obtained through proven methodology and come from reliable sources as comparison with legislation or national statistics. When writing a shadow report it is important to base it on the official government report by building arguments around the data. It is also essential to have the support, and use the expertise, of other organizations because shadow reports by single organizations are taken less seriously.

**Rados Keravica** from Disability Rights Promotion International (DRPI) gave more information about different ways of data collection and sampling. He also clarified some key concepts like discrimination and inclusion. DRPI uses a Holistic Monitoring approach to collect data. This means that individual experiences, legislation and social attitudes about disability are brought together to monitor the progress in disability rights and the implementation of the UNCPD. DRPI's monitoring projects are also designed to be sustainable so that disabled persons and their organizations are able to gather, on an on-going basis, evidence-based information about disability rights. Costs are kept low and monitoring capacity is built and fostered so that monitoring activities, led by disabled persons and their organizations, are able to continue into the future.

**Rados** concluded by highlighting the importance of holistic monitoring. Holistic monitoring provides the information necessary to start conversation between the different levels of government and members of the disability community about laws, common policies and programs to make society more accessible and inclusive for all.





**Nadia Hadad** and **Patrick Vandelanotte** talked about the drafting of the Belgian shadow report by Grip in 2011. To write the report Grip founded a project group that consisted of full members, advisory members and free advisers. Full members were responsible for drafting and finalizing the report. The advisory members provided advice on specific topics without necessarily agreeing with the full report. The free advisers were all people who wanted to give input, based on their knowledge or experience.

The shadow report was drafted from May to December 2011. In May the announcement on the writing of the report was made. In June the project group met for the first time, the second meeting took place in September. In October open input sessions were organized. In November the project group met for the last time and in December the report was published.

In 2013 the Grip shadow report was submitted to the UN Human Rights Committee in Geneva. In 2014 Grip was invited to the 12th session of the Committee.

**Nadia** and **Patrick** explained that when one presents a shadow report it is vital to build a strong case and go to Geneva personally to explain it. Press coverage is also very important. After the presentation of the report and the recommendations of the Committee it is important to inform the press of the results and continue to emphasize those results in all ways of communication. Finally, after the publication of the UN recommendations new legislation should be monitored to make sure it takes into account the UN recommendations.





*The third session moderated by Dilyana Deneva (ENIL- EC Program) focused on Ways for young disabled people to engage in advocacy for Independent Living at the local, national and European level.*

The panel consisted of **Zara Todd**, **Gatis Caunitis** and **Alexandra Surla** all members of the ENIL Youth Network. They shared their experience on advocacy to encourage other young disabled people to use this powerful tool to influence the political process. Some of the main conclusions are described below:



The Independent Living movement needs to be accessible and inclusive, communicate what Independent Living means, listen and respond to calls from society and create opportunities to engage. To do this young disabled people need to say what they want without fear, explain what works and what does not, offer solutions, be proud and work together.

To advocate on the local level disabled people need to identify the issues, provide peer support, speak at schools, institutions and community centres and show the difference by challenging patterns. To advocate at national level disabled people first of all need to create opportunities by being present and relevant. When visible they can give input and demand feedback. At the European Level young advocates for Independent Living need to cooperate across borders and impairments to find and promote common issues.

### *Conclusion of the conference*

To wrap up the conference the moderators Peter Lambrechts, Kapka Panayotova and Zara Todd each presented the conclusions of their mutual exchange groups. Jamie Bolling closed the conference, and with it the 2015 Freedom Drive by thanking all the Freedom Drives for their enthusiastic support and inviting them for the next Freedom Drive in 2017.



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## Transport

When the first Freedom Drive was held in Strasbourg in 2003 the public transport in the city was not very accessible. The Freedom Drive was however a great incentive for the city to improve the accessibility and during the 2013 edition of the Freedom Drive, the Freedom Drivers were delighted to see that the public transport in Strasbourg was almost completely accessible.

Moving the Freedom Drive from Strasbourg to Brussels provided a great opportunity to challenge the inaccessibility of the Brussels public transport network. ENIL leaders knew from the start that the Brussels public transport is far less accessible than the public transport system in Strasbourg and that it is time to claim our rights in the capital of Europe. ENIL and STIB, the Brussels public transport provider, worked together on a solution and decided that the regular public transport would be used as much as possible but supplemented with Taxi busses and door-to-door transport when necessary.



The STIB provided extra support to make a number of metro stations and bus stops more accessible during the Freedom Drive. They deployed extra personnel to make it easier for the Freedom Drivers to board or get off the buses or metro. Taxi busses were available from Bel Brussels to the hotels in the evening for door-to-door transport when needed.

Thanks to the cooperation with the STIB, transport during the Freedom Drive went fairly well. Nevertheless the taxi busses were segregated transport limiting the flexibility and autonomy of the Freedom Drivers. The use of segregated transport is against ENIL's principles of Independent Living. Some have complained saying that the Freedom Drive should return to Strasbourg but the ENIL board recognizes the importance of keeping the Freedom Drive in Brussels to amongst other reasons, highlight the shortcomings of the public transport system amongst other reasons. Like in Strasbourg the number of disabled people and the media coverage during the Freedom Drive will pressure local, national and European decision makers to improve the accessibility of our capital. First we took Strasbourg now we take Brussels!





## Press coverage

In order to ensure the Freedom Drive had good coverage ENIL issued two Press Releases and provided regular updates on the FD preparations. A press map was distributed among Belgian journalists while the EU press was contacted directly by the ENIL Brussels office. The efforts proved successful with the Freedom Drive being covered both by the local press and the Belgian press agency Belga. A number of journalists from different Member States interviewed Freedom Drivers during the march. An overview of the press coverage can be found in the annex to this Report together with some examples.

## FD Booklet

ENIL published the Freedom Drive booklet entitled “First we take Strasbourg, Then we take Brussels!”. The booklet, disseminated during the Freedom Drive, outlined the history of the event, the evolution of the Freedom Drive demands, the achievements of the previous Freedom Drives and the road ahead in the fight for Independent Living and equal rights. The booklet paid tribute to many leaders of the Independent Living movement having contributed to its worldwide growth.



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## Summary of ENIL Brussels Freedom Drive 2015

A summary of some of the results from the 2015 Freedom Drive:

- Being on Euronews and having large media coverage both nationally and internationally.
- Meeting the European Commission during the Freedom Drive march – Ms. Cabral head of the Disability Unit met and addressed the Freedom Drivers on the street during the March.
- Many meetings with MEPs took place with a good response from the MEPs.
- Several MEPs personally supported Freedom Drivers by paying for travel and hotel costs and/or hosting meetings in the Parliament.
- There was a good participation from allied NGOs. Belgian DPOs but also International NGOs including: The European Disability Forum (EDF), Mental Health Europe (MHE), The European Union of the Deaf (EUD) and The International Federation for Spina Bifida and Hydrocephalus (IF)
- The ENIL IL exhibition attracted many visitors.
- A collection of good examples of IL was launched to be followed-up in the next years.

## Useful links

- ENIL Website Freedom Drive: <http://www.enil.eu/campaigns/freedom-drive/>
- ENIL Facebook Page: <https://www.facebook.com/ENILsecretaria/>
- ENIL Resolution against the Cuts: [http://www.enil.eu/wp-content/uploads/2012/05/ENIL\\_EP\\_Resolution\\_Proposal\\_FINAL\\_Jan2013.pdf](http://www.enil.eu/wp-content/uploads/2012/05/ENIL_EP_Resolution_Proposal_FINAL_Jan2013.pdf)
- The ENIL youth network: <http://www.enil.eu/about-enil/enil-youth/>



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## Annex I. Overview of press coverage and examples

DATE	MEDIA	TITLE/Web link
28/09/2015	Rtbf.be (Belgium French)	<a href="http://www.rtbf.be/info/societe/detail_des-personnes-atteintes-d-un-handicap-a-bruxelles-mercredi-pour-faire-entendre-leurs-voix?id=9093076&amp;utm_source=rtbfinfo&amp;utm_campaign=social_share&amp;utm_medium=fb_share">http://www.rtbf.be/info/societe/detail_des-personnes-atteintes-d-un-handicap-a-bruxelles-mercredi-pour-faire-entendre-leurs-voix?id=9093076&amp;utm_source=rtbfinfo&amp;utm_campaign=social_share&amp;utm_medium=fb_share</a>
29/09/2015	Radio 1 (Belgium Dutch)	<a href="http://www.radio1.be/hautekiet/vlot-aan-de-slag-met-een-handicap">http://www.radio1.be/hautekiet/vlot-aan-de-slag-met-een-handicap</a>
30/09/2015	De redactie (Belgium Dutch)	Freedom drive march <a href="http://deredactie.be/cm/vrtnieuws/binnenland/1.2456474">http://deredactie.be/cm/vrtnieuws/binnenland/1.2456474</a>
30/09/2015	Journaal VRT (Belgium Dutch)	Freedom Drive march <a href="http://deredactie.be/cm/vrtnieuws/videozone/nieuws/binnenland/1.2456530">http://deredactie.be/cm/vrtnieuws/videozone/nieuws/binnenland/1.2456530</a>
30/09/2015	Radio Studio Brussel (Belgium)	Report about the Freedom Drive march during the radio news
30/09/2015	Radio MNM (Belgium Dutch)	Report about the Freedom Drive march during the radio news
30/09/2015	Radio Q-Music (Belgium Dutch)	Report about the Freedom Drive march during the radio news
30/09/2015	Euronews + Euronews Italia + Euronews France + Euronews Spain	<a href="http://www.euronews.com/2015/09/30/disabled-people-protest-for-more-rights/">http://www.euronews.com/2015/09/30/disabled-people-protest-for-more-rights/</a> + <a href="http://it.euronews.com/2015/09/30/disabili-in-marcia-a-bruxelles-per-chiedere-pari-opportunita/">http://it.euronews.com/2015/09/30/disabili-in-marcia-a-bruxelles-per-chiedere-pari-opportunita/</a> + <a href="http://fr.euronews.com/2015/09/30/les-personnes-handicapees-portent-leur-message-a-bruxelles/">http://fr.euronews.com/2015/09/30/les-personnes-handicapees-portent-leur-message-a-bruxelles/</a> + <a href="http://es.euronews.com/2015/09/30/los-discapacitados-europeos-reclaman-sus-derechos-en-bruselas/">http://es.euronews.com/2015/09/30/los-discapacitados-europeos-reclaman-sus-derechos-en-bruselas/</a>

DATE	MEDIA	TITLE/Web link
30/09/2015	Het laatste nieuws(Dutch Belgian newspaper)	<a href="http://www.hln.be/hln/nl/922/Nieuws/article/detail/2473627/2015/09/30/Honderden-rolstoelen-palmen-Europese-wijk-in-Brussel-in.dhtml">http://www.hln.be/hln/nl/922/Nieuws/article/detail/2473627/2015/09/30/Honderden-rolstoelen-palmen-Europese-wijk-in-Brussel-in.dhtml</a>
30/09/2015	Belga (Belgium)	Hundreds of wheelchairs take Brussels.  See Below
30/09/2015	AFP (French)	Disabled people protest for the right on Independent Living in Brussels.  See Below
30/09/2015	De redactie / (Belgium French)	Hundreds of wheelchairs take Brussels. <a href="http://deredactie.be/cm/vrtnieuws.francais/videotheque/1.2456665">http://deredactie.be/cm/vrtnieuws.francais/videotheque/1.2456665</a>
01/10/2015	De redactie (Belgium Dutch)	Euro Commissioner Marianne Thyssen has received 50 NGOs in the margin of the Freedom Drive march. <a href="http://m.deredactie.be/#!/snippet/560d28020cf21322eaf42250/533abaeb0cf26c7fa37c46ca">http://m.deredactie.be/#!/snippet/560d28020cf21322eaf42250/533abaeb0cf26c7fa37c46ca</a>
01/10/2015	Het Laatste Nieuws/de Ring-Brussel (Dutch Belgian newspaper)	Freedom Drive March in Brussels  See Below
01/10/2015	Metro (French Belgian newspaper)	Freedom Drive March <a href="http://fr.metrotime.be/2015/09/30/spotlight/freedom-drive-march-400-personnes-en-chaise-roulante-defilent-a-bruxelles/">http://fr.metrotime.be/2015/09/30/spotlight/freedom-drive-march-400-personnes-en-chaise-roulante-defilent-a-bruxelles/</a>
01/10/2015	Le Soir (French Belgian newspaper)	Freedom Drive March <a href="http://www.lesoir.be/1003610/article/actualite/fil-info/fil-info-belgique/2015-09-30/freedom-drive-mars-des-centaines-chaises-roulantes-dans-quartier">http://www.lesoir.be/1003610/article/actualite/fil-info/fil-info-belgique/2015-09-30/freedom-drive-mars-des-centaines-chaises-roulantes-dans-quartier</a>



DATE	MEDIA	TITLE/Web link
01/10/2015	handicap.fr	Vie autonome : les handi se fâchent à Bruxelles ! <a href="http://informations.handicap.fr/art-bruxelles-marche-libertes-63-8282.php">http://informations.handicap.fr/art-bruxelles-marche-libertes-63-8282.php</a>
28/09/2015	Superando.it (Italy)	<a href="http://www.superando.it/2015/09/28/in-marcia-a-bruxelles-per-la-vita-indipendente/">http://www.superando.it/2015/09/28/in-marcia-a-bruxelles-per-la-vita-indipendente/</a>
29/09/2015	Sociale.it (Italy)	<a href="http://www.sociale.it/2015/09/29/freedom-drive-per-la-vita-indipendente/">http://www.sociale.it/2015/09/29/freedom-drive-per-la-vita-indipendente/</a>
01/10/2015	Èlive (Italy)	<a href="https://www.facebook.com/593681394038262/videos/946428782096853/">https://www.facebook.com/593681394038262/videos/946428782096853/</a>
06/10/2015	video-interviews by Èlive agency (Italy)	<a href="https://www.youtube.com/watch?v=uoSyvdSIW0o&amp;feature=youtu.be">https://www.youtube.com/watch?v=uoSyvdSIW0o&amp;feature=youtu.be</a>
28/09/2015	West-info/it (Italy)	<a href="http://www.west-info.eu/it/prima-edizione-della-freedom-drive-a-bruxelles/">http://www.west-info.eu/it/prima-edizione-della-freedom-drive-a-bruxelles/</a>
28/09/2015	Superabile.it (Italy)	<a href="http://www.superabile.it/web/it/canali tematici/qui europa/news/istituzioni ue ed europee/info-176807578.html">http://www.superabile.it/web/it/canali tematici/qui europa/news/istituzioni ue ed europee/info-176807578.html</a>
29/09/2015	Smtvsanmarino.sm (San Marino)	<a href="http://www.smtvsanmarino.sm/cultura/2015/09/29/disabili-liberi-volare-lavorare-europa">http://www.smtvsanmarino.sm/cultura/2015/09/29/disabili-liberi-volare-lavorare-europa</a>
01/10/2015	Av-avis.no (Norway)	<a href="http://www.av-avis.no/aktuelt/-Institusjonene-ma-avvikles-371381.html">http://www.av-avis.no/aktuelt/-Institusjonene-ma-avvikles-371381.html</a>
07/10/2015	Wablieft krant (Belgian printed newspaper in easy read language)	<a href="http://www.wablieft.be/krant/archief/2015-10-07/2015-10-07/0/0/">http://www.wablieft.be/krant/archief/2015-10-07/2015-10-07/0/0/</a>
01/10/2015	Standard.be (Dutch Belgian newspaper)	<a href="http://www.standaard.be/cnt/dmf20150930_01896323">http://www.standaard.be/cnt/dmf20150930_01896323</a>

DATE	MEDIA	TITLE/Web link
30/09/2015	Deredactie.be (Belgium Dutch)	<a href="http://deredactie.be/cm/vrtnieuws/binnenland/1.2456474">http://deredactie.be/cm/vrtnieuws/binnenland/1.2456474</a>
30/09/2015	Brusselstimes.com (Belgium)	<a href="http://brusselstimes.com/brussels/4185/hundreds-of-wheelchairs-in-brussels-s-european-quarter">http://brusselstimes.com/brussels/4185/hundreds-of-wheelchairs-in-brussels-s-european-quarter</a>
07/10/2015	m.staburags.diena.lv (Latvia)	<a href="http://m.staburags.diena.lv/novadu-zinas/gatis-caunitis-no-bebriem-piedalas-briseles-brivibas-brauciena-2015-122356?from-full">http://m.staburags.diena.lv/novadu-zinas/gatis-caunitis-no-bebriem-piedalas-briseles-brivibas-brauciena-2015-122356?from-full</a>
02/10/2015	Inf.lt (Lithuania)	<a href="http://www.inf.lt/index.php/apie-Inf/apie-Inf-2/756-eitynes-savarankiskumo-link-ispudziai-is-freedom-drive-renginiu-briuselyje">http://www.inf.lt/index.php/apie-Inf/apie-Inf-2/756-eitynes-savarankiskumo-link-ispudziai-is-freedom-drive-renginiu-briuselyje</a>
30/09/2015	Post from MEP Vilija Blinkeviciute (Lithuania)	<a href="https://www.facebook.com/vilijablinkeviciute/posts/1697015997177580">https://www.facebook.com/vilijablinkeviciute/posts/1697015997177580</a>
01/10/2015	Post from MEP Petras Austrevicius (Lithuania)	<a href="https://www.facebook.com/PetroAustreviciausbiuras/posts/1655387734699496">https://www.facebook.com/PetroAustreviciausbiuras/posts/1655387734699496</a>
24/09/2015	Radio NRK Hordaland (Norway)	<a href="https://radio.nrk.no/serie/distriktsprogram-hordaland/DKHO02019115/24-09-2015#t=2h1m9s">https://radio.nrk.no/serie/distriktsprogram-hordaland/DKHO02019115/24-09-2015#t=2h1m9s</a>
28/09/2015	Strilen (Norway)	<a href="http://www.strilen.no/nyheiter/Til-Brussel-for-a-aksjonera-369905.html">http://www.strilen.no/nyheiter/Til-Brussel-for-a-aksjonera-369905.html</a>
05/10/2015	2 Greek radio broadcasts with FD mentioned	<a href="http://takisalexandrakis.blogspot.gr/2015/10/alpha989-26-27-3-4.html">http://takisalexandrakis.blogspot.gr/2015/10/alpha989-26-27-3-4.html</a>
08/10/2015	Local newspaper (Lithuania)	<a href="http://darbs.lt/2015/10/08/neigaliuju-balsai-europos-sajungos-sostineje">http://darbs.lt/2015/10/08/neigaliuju-balsai-europos-sajungos-sostineje</a>





# – Institusjonene må avvikles

Askøyværingene Magne Hetlevik og Tore Dale har demonstrert for rettighetene til funksjonshemmede i Europa.

AV: Jan Erik Storebo

Publisert: 01.08.2015 19:00 Oppdatert: 02.08.2015 07:37

Rettighetsaksjonen Freedom Drive arrangeres denne uken i Brussel, Belgia.

Onsdag gikk Tore Dale og Magne Hetlevik i tog sammen med 300 funksjonshemmede fra hele Europa, til EU-parlamentet med krav om å sikre funksjonshemmedes rettigheter. Askøyværingene er med i et følge på totalt 17 nordmenn.

I tillegg til protestmarsjen har de deltatt på flere konferanser.

- Dagene har nådd har gitt mye. Opplevelsen har vært todelte. For det første har det vært veldig lærerikt, men samtidig har det vært mye urokkende som har kommet frem. Forskjellene i Europa er store når det kommer til muligheter og rettigheter, sier Magne Hetlevik til Askøyværingen torsdag.

## Rettighetsfestet BPA

Tore Dale er i Brussel som fungerende arbeidsleder i assistanseordningen til sin sønn. Det betyr at sønnen hans har borgerstyrt personlig assistanse. Dale administrerer assistansen.

Magne Hetlevik er BPA-konsulent i Uloba – Independent Living Norge SA. Den ideelle organisasjonen jobber for at dem med assistansebehov skal få leve et fritt og selvstendig liv med borgerstyrt personlig assistanse (BPA).

I tillegg er Hetlevik fungerende arbeidsleder. Dette har gitt ham erfaringer som han bruker i sin rådgivning til andre fungerende arbeidsledere.

## - Skummel utvikling

Parallelt med at BPA fra 1. januar 2015 ble en rettighet for funksjonshemmede i Norge, også dem som ikke kan lede assistansen selv, opplever Uloba at det bygges nye institusjoner for funksjonshemmede.

- Dette er en skummel utvikling, både hjemme og ute i Europa. Derfor er ett av kravene fra årets Freedom Drive at institusjonene må avvikles og at flere må få BPA, sier Magne Hetlevik.

- Mange land tilbyr ikke borgerstyrt personlig assistanse i det hele tatt. Og i de landene som tilbyr det, har finansieringen blitt mye dårligere assistanseordningen, sier Tore Dale.

## Første gang i Brussel

Freedom Drive har vært en årlig aksjon i Europa siden 2003. Tidligere har aksjonen vært holdt i Strasbourg, men man har kommet frem til at Brussel er en mer riktig arena.

- Det er her de store politiske beslutningene i Europa tas, påpeker Hetlevik.

Han håper at funksjonshemmede blir tatt mer på alvor i fremtiden.

- Det er som regel ikke mangel på ord, men heller handling. Mange er enige om kravene som blir satt frem. Likevel skjer det lite. I Norge har vi det forsviddt ganske bra sammenlignet med mange andre land i Europa, men vi har en lang vei å gå når det gjelder å håndheve FN-konvensjonen for mennesker med nedsatt funksjonsevne, sier han.



## BORGERSTYRT PERSONLIG ASSISTANSE

Borger- eller bruker-styrt personlig assistanse (BPA) skal bidra til å gi mennesker med assistansebehov mulighet til å leve et aktivt og mest mulig uavhengig liv til tross for sin funksjonsnedsettelse.

Ble rettighetsfestet fra 1. januar 2015, når som gir brukerne fleksibilitet og valgfrihet.

Den eneste måten funksjonshemmede selv kan velge hvem som skal assistere dem, hva de skal assisteres med, når og hvor.

Med BPA skal man i størst mulig grad kunne ivareta plikter, interesser, behov og ønsker som alle andre samfunnsborgere. Når praktisk bistand og opplæring organiseres som en BPA-ordning, er det brukeren selv, eventuelt med bistand, som organiserer og leder arbeidet med assistentene.

Arbeidslederen har det daglige lederansvaret for assistentene. Det er et krav at arbeidslederen blir forsvart i hvert sitt.

Kilder: Helsedirektoratet

## LES OGSÅ



## - Brage er sjefen!

En ny verden har åpnet seg for familien Midtøy. Noe helt nytt etter at Brage fikk sine to assistenter.



## Friluftsforkjemperen

Annenhver uke er Jan Kåre Stura på reise. Det hadde ikke gått uten personlig assistent.



## SISTE NYTT

10:51	Kast maska!
07:13	Basketgutta vil opp i år
18:55	Jente (3) lettere skadet i fallulykke
16:14	Drømmedag på Ullevaal
13:22	Jeanette er best i Norden - neste stopp VM
11:59	–Bussen svikter fremdeles elevene på Fauskanger
09:07	Ringer for regnskogen
07:36	Stakk av fra politiet, ble funnet halvtime senere
07:20	Pensjonist dømt etter ruskjøring

SISTE 100

## EUROPEAN AFFAIRS

Brussels bureau

# Disabled people protest for more rights

30/09 16:10 CET



Hundreds of people with disabilities have protested outside the EU institutions in Brussels.

The protest was organised by the European Network on Independent Living.

It wants to make European decision makers aware of the obstacles disabled people face on a daily basis.

"The situation is quite different from one country to another. For example, here in Belgium, we have waiting lists, to have right on personal assistance. In other countries it doesn't even exist. They don't have personal assistance budgets," said Nadia Hadad, a spokesperson from the European Network on Independent Living (ENIL)

It is the seventh-ever 'Freedom March', although this is the first time that it has been held in the Belgian capital.

"Research has shown that we are the hardest hit in society because we are the lowest fruit to pick of the tree. It's not acceptable and we need to stop it now," said Paul Fagan, an Irishman who suffers from spina bifida, a spinal condition which causes damage to the central nervous system.

More than 1 out of 5 people with disabilities (21.1%) are at risk of poverty in the EU, according to a 2012 report by the European Foundation Centre.

## DISABILI: liberi di volare e lavorare in Europa



## all'EUROPARLAMENTO

Evento organizzato da ENIL (la rete europea per la vita indipendente e i disabili) prima per 6 anni a Strasburgo e ora a Bruxelles per sensibilizzare le rappresentanze parlamentari europee sui problemi e le necessità dei disabili: mezzi, supporti e bisogni, per rendere attive le differenti capacità di chi non è normodotato e possiede abilità esprimibili come diversità fonte di ricchezza per la società.

Essere come tutti è un diritto di tutti: avere una famiglia e vivere in casa, andare a scuola normalmente e quotidianamente come gli altri, studiare, soffrire e amare, per poi lavorare per vivere. Mezzi di trasporto e strumenti di lavoro senza barriere e con supporti alternativi capaci di rendere le condizioni di partenza paritarie tra disabili e non-disabili.

Giovedì 1 ottobre conferenza generale sulla VITA INDIPENDENTE con diverse sessioni di lavoro a cui partecipa SAN MARINO presente Mirco Tomassoni.

fz

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## Freedom Drive, per la Vita indipendente

Publicato 29 settembre 2015 | Da Riccardo Fanale



Freedom Drive

### Le persone con disabilità si uniscono per i loro diritti in Europa

La **Freedom Drive**, appuntamento biennale promosso a Strasburgo da **ENIL (European Network on Independent Living)**, per la prima volta si terrà a Bruxelles dal 29 settembre al 1 ottobre.

Sarà un'opportunità per tutte le persone con disabilità dei Paesi europei per riunirsi e per sfilare tutte assieme fino alla sede del Parlamento, per incontrare alcuni suoi membri e altri rappresentanti delle più importanti istituzioni dell'Unione Europea.

ENIL è una rete europea di persone con disabilità e non che lavorano sulle questioni fondamentali della Vita Indipendente, per l'attuazione della **Convenzione ONU sui Diritti delle Persone con Disabilità** ed una legislazione centrata sulla de-istituzionalizzazione, l'assistenza personale e il sostegno alla pari.

### Il Programma di Freedom Drive

Secondo il programma, martedì 29 i partecipanti al Freedom Drive hanno incontrato i Parlamentari europei delle proprie nazioni, e si sono riuniti per l'Assemblea Generale di ENIL ed ENIL Giovantù.

Mercoledì 30, centinaia di persone con disabilità provenienti da oltre venti Paesi europei, sfileranno per le strade di Bruxelles con poster, megafoni, tamburi e bandiere, per raggiungere la sede del Parlamento Europeo, con l'obiettivo di consegnare le richieste di ENIL ai decisori europei.

Giovedì 1, infine, ENIL ospiterà una conferenza sulla Vita Indipendente, con diverse sessioni su vari argomenti, guidata da relatori esperti, tra cui Maria-Luisa Cabral, che presiede l'Unità per i Diritti delle Persone con Disabilità nella Commissione Europea.

In tale occasione saranno organizzati vari gruppi di discussione sui diritti delle persone con disabilità, al fine di scambiare esperienze e buone pratiche che saranno illustrate e presentate agli organismi competenti nei diversi Paesi Membri.



IZVĒLNE

Novads ziņas

### Gatis Caunītis no Bebrim piedalās "Briseles brīvības braucienā 2015"

www.staburags.lv • 2015. gada 7. oktobris 11:32 • 2411 reizes



Skatīt galeriju

Tikšanās ar Inesi Vaideti, Gatis Caunītis — citrā no kreisās

No šīgada 29. septembra līdz 1. oktobrim Briselē norisinās ENIL (Eiropas Tīkla par neatkarīgu dzīvi) organizētais "Brīvības brauciens 2015", kura piedalījās invalīdītes jomas aktivisti ar dažādu invaliditāti no vairāk kā 20 Eiropas valstīm, tajā skaitā arī Gatis Caunītis no Bebrim.

Pateicoties Eiropas Parlamenta deputātes Ineses Vaideres, AS "SEB banka", AS "Latvijas Finieris", AS "Olanfami" un biedrības "YIP" atbalstam, Latviju šajā Eiropas līmeņa pasākumā pārstāvēja ne tikai Gatis Caunītis (ENIL jauniešu tīkla valdes loceklis, "Brīvības brauciena" koordinators Latvijā), bet arī Inga Baltiņa un Anna Treļone.

Pasākums sevī ietvēra ENIL Ģenerālā Asambleju, konferenci, tikšanos un diskusijas ar sociālās un invalīdītes nozares pārstāvjus, kā arī tikšanos ar Latvijas deputātiem Eiropas parlamentā. Noslēgumā dalībnieki devās gājienā līdz Eiropas Parlamenta ēkai ar mērķi pievērst sabiedrības un EP deputātu uzmanību aktuālajām problēmām invalīdītes jomā.

"Uz 'Briseles brīvības braucieni' ieradās vairāk kā 250 personu ar dažādu invaliditāti no vairāk kā 20 Eiropas valstīm, kā arī to asistenti. Viens no šī pasākuma mērķiem ir nodrošināt iespēju EP deputātiem tikties ar cilvēkiem ar invaliditāti no visās Eiropas un apspriest jautājumus, kas skar personu ar invaliditāti dzīves. Diskusijas sevī ietver jautājumus, kas saistīti ar personālo asistentu, dezinstitucionalizāciju, uzglābību, nodarbinātību, pieejamību videi un servisiem, kā arī pārvietošanās brīvību Eiropas Savienībā," stāsta Gatis Caunītis. "Latvijas pārstāvis bija iespēja personiski tikties ar četrām no astoņiem Latvijas EP deputātiem — Inesi Vaideti, Anu Pabiku, Ivetu Ogiņu un Tānu Žanču. Eiropas Parlamenta deputāte Vaidere kundze ne tikai izrādīja interesi, lai tiktos, bet sniedza daļu finanšu atbalstu, sedzot organizēto naktsmītni Briselē pārstāvjiem no Latvijas. Jāzīmē, ka Vaidere kundze arī līdz šim ir izrādījusi interesi, atbalstot Gata Caunīša aktivitātes. Karņa kungs veselības problēmu dēļ tikšanos atcēla, bet pārieja trīs Latvijas deputāti EP dienā par šo Eiropas līmeņa pasākumu interesi neizrādīja. Mūsu ieguvums no šīm sarunām un diskusijām — atbalsta, vērtīgi padomi un lielāka motivācija turpmāko mērķu sasniegšanai."

"Pasākuma spilgtākais notikums — gājienā no Armijas muzeja parka pa Briseles ielām līdz Eiropas Parlamenta ēkai," atceras Gatis Caunītis. "Dalībniekos ne mirkli neizsīka enerģija izteikt savu ziņu skaj un skaidri ar dažādu saukļu palīdzību, piemēram, "Institūcijas nav mūsu mājums", "Tiesības nav zēlīdība", "Nekas par mums, bez mums". Pēc gājiena Eiropas Parlamenta ēkā norisinājās tikšanās ar Eiropas Parlamenta deputātiem, debatējot par pašreizējo situāciju invalīdītes jomā, kā arī rosinot deputātus to uzlabot. Ceram, ka pēc notikušās diskusijas kāds no zālē sēdošajiem deputātiem tomēr ieklausīs un izteiktie solījumi nepaliks tikai Parlamenta ēkas sienās, bet atspoguļosies arī nāšajās dzīvēs."

Gatis Caunītis atzīst — kopumā pavadītais trīs lieliskais dienas ar cilvēkiem, kas spēja iedvesmot apkārtējos un ir noskaņoti cīnīties par savām tiesībām un vienlīdzīgu dzīvi sabiedrībā. "Mūsu mērķis — daudz lielāka Latvijas grupa nākamajā 'Brīvības braucienā' pēc diviem gadiem," viņš saka.

"Brīvības Brauciens 2015" laikā tika izstrādāta Gata Caunīša organizētā ceļojuma fotoizstāde "Lepns. Stips. Pamanāms.". Fotoizstāde ir atspoguļota divu cilvēku ar invaliditāti videoklipā par to, "Ko man nozīmē neatkarīga dzīve?". Tādējādi akcentējot neatkarīgas dzīves nozīmi ikdienas dzīvē. Projektā piedalās cilvēki ar invaliditāti no dažādām Latvijas novadēm. (Vairāk informācijas fotoizstādes Facebook lapā, Lepns. Stips. Pamanāms.)

"Pateicoties atbalstītājiem, dalībniekiem no Latvijas bija iespēja piedalīties šajā invalīdītes un sociālajā jomā tik nozīmīgajā pasākumā un dalīties savās zināšanās un pieredzē ar apkārtējiem. Lielas palīdzības atbalstītājiem" saka Gatis Caunītis.

## Honderden rolstoelen palmen Europese wijk in Brussel in

Aanbevelen 54 Delen 54 Tweet 0 G+ 0

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GERELATEERD NIEUWS

Door: redactie  
30/09/15 - 14u28 Bron: Belga

BEWAAR ARTIKEL



Morgen volgt een ontmoeting met Marianne Thyssen. © photo news.

Zo'n 400 mensen hebben vandaag deelgenomen aan de Freedom Drive Mars, een optocht van mensen met een beperking die vragen actief te kunnen deelnemen aan de samenleving. Tijdens de tweedaarlijkse Freedom Drive komen mensen met een beperking uit heel Europa samen om ervaringen uit te wisselen en aandacht te vragen. Het evenement vond voor de eerste keer in Brussel plaats.

Na zes edities in Straatsburg komt de Freedom Drive nu voor het eerst langs bij de hoofdzetel van de Europese Commissie. De mars is een initiatief van ENIL, het Europese netwerk voor Onafhankelijk Leven in samenwerking met de Vlaamse vzw Onafhankelijk Leven. De driehonderd internationale deelnemers werden bij de start in het Jubelpark vergezeld door een honderdtal Belgen.

Om 12 uur vertrok de mars richting Schumanplein voor een meet&greet met Brendan Sinnott, het hoofd van de Disability Unit van de Europese Commissie. Die valt onder de bevoegdheid van Europees Commissaris Marianne Thyssen. Daarna gaat het naar het Europees parlement voor een debat in aanwezigheid van verschillende parlementsleden. Morgen volgt nog een ontmoeting met Marianne Thyssen.

### "Niet zomaar in apart circuit stoppen"

De initiatiefnemers vragen de uitvoering van het VN-verdrag voor de rechten van personen met een beperking. "We mogen deze mensen niet zomaar in een apart circuit stoppen, of het nu om scholing of leefomgeving gaat", zegt Peter Lambrechts van ENIL. "Wij willen actief deelnemen aan de maatschappij, kunnen keuzes maken en niet geleefd worden."

Concreet pleit de organisatie ervoor de mensen zelf te laten beschikken over persoonlijke assistentiebudgetten en de toegankelijkheid van gebouwen en openbaar vervoer te verbeteren. Daarnaast staan ook inclusief onderwijs en participatie in de gewone arbeidsmarkt op de agenda.

### HLNbe-nieuws in je facebook nieuwsfeed?

517.244 personen vinden dit leuk. Registreren om zien wat je vrienden leuk vinden.



Organisatoren doelen tentenkamp op: "Wij zijn niet het alibi van de regering"

Sterrenchef opent nieuw restaurant in hartje Brussel

Man zonder rijbewijs scheurt met 100 km/u door Brussel

Meer over Politiek, Brussel, België, Brussels Hoofdstedelijk Gewest

### MEER VAN HLN

Dronken student (22) kritiek na val van 15 meter hoog

Koen De Graeve: "Ik wou dat ik niet zoveel ambitie had"

Vin Diesel reageert met deze opvallende foto op commotie omtrent 'bierbuik'

Doop loopt seksueel serieus uit de hand: studentencub meteen opgedoekt

aangeboden door @utbrain

### HLNBE NIEUW

12u31 Nieuwe spoorstakingen volgende ...

12u27 "Inzittenden MH17 waren enkele ...

12u19 Student in Gent kritiek na val ...

12u18 Zaak tegen 'horrormann' ...

12u14 Duits parket onderzoekt of ...

Student in Gent kritiek na val van dak

Koen en Jili zien een prachtige zonsverduistering

Fraai versierde trucks in Le Mans

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## Belga

# Honderden rolstoelen palmen Europese wijk in Brussel in

Belga - 30 Sep. 2015

Pagina 0

(BELGA) = Zo'n 400 mensen hebben woensdag deelgenomen aan de Freedom Drive Mars, een optocht van mensen met een beperking die vragen actief te kunnen deelnemen aan de samenleving. Tijdens de tweejaarlijkse Freedom Drive komen mensen met een beperking uit heel Europa samen om ervaringen uit te wisselen en aandacht te vragen. Het evenement vond voor de eerste keer in Brussel plaats.

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## Belga

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AFP

## Des personnes handicapées défilent à Bruxelles pour une “vie autonome”

AFP - 30 Sep. 2015

Pagina 0

Une centaine de personnes handicapées issues d'une vingtaine de pays européens, accompagnées de leur assistants personnels, ont manifesté mercredi à Bruxelles pour réclamer le droit de mener une existence “autonome”, loin des institutions spécialisées qui les “isolent” du reste de la société.

“Ce que nous voulons ? La liberté. Ce dont nous avons besoin ? De l'assistance”, ont scandé sous les fenêtres de la Commission et du Parlement européens les manifestants, qui avaient répondu à l'appel du Réseau européen pour la vie autonome (Enil).

Baptisée “marche des libertés”, la manifestation a lieu tous les deux ans, mais c'est la première fois qu'elle se déroulait dans la capitale européenne.

“Je suis une femme, une maman de deux enfants et j'ai le droit de vivre comme n'importe qui”, a déclaré à l'AFP Corinne Lassoie, une Belge de 52 ans qui défilait en fauteuil électrique, sous le soleil.

Très dépendante depuis un accouchement catastrophique survenu alors qu'elle avait 24 ans, pratiquement aveugle, Mme Lassoie réclame un “changement de mentalité” et des moyens financiers pour que “les personnes en situation de handicap vivent au sein d'une société plus inclusive et non dans des institutions qui les isolent”.

“Les personnes handicapées doivent être des citoyens à part entière et pouvoir vivre selon leurs propres aspirations”, abonde Mathilde Fuchs, venue de Rennes, dans l'ouest de la France. Cette jeune femme de 32 ans, qui se déplace également en fauteuil roulant, a “étudié l'électronique”, mais “personne ne (l')a engagée”, regrette-elle.

“C'est un combat permanent pour essayer de vivre normalement, les choses banales demandent beaucoup d'énergie”, confie Sidney Bozec, un Bordelais de 28 ans, qui bénéficie d'un soutien financier de l'Etat français pour que six assistants puissent se relayer afin d'assurer une présence 24 heures sur 24 à ses côtés. Mais il se dit “inquiet” que ces aides diminuent.

“Personne ne doit vivre dans une institution. Les personnes handicapées doivent pouvoir vivre en famille, mais pour cela il faut des moyens”, résume la présidente du réseau Enil, Jamie Bolling, en se réjouissant de la présence de manifestants venus notamment du Bélarus, de Bulgarie, d'Allemagne, de France ou encore d'Espagne.  
siu/mla/amd

AFP

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Het Laatste Nieuws/De Ring Brussel

## Freedom Drive Mars trekt door stad

Het Laatste Nieuws/de Ring-Brussel - 01 Okt. 2015

Pagina 17

Zo'n 400 mensen hebben woensdag deelgenomen aan de Freedom Drive Mars, een optocht van mensen met een beperking die vragen actief te kunnen deelnemen aan de samenleving. Driehonderd internationale deelnemers werden bij de start in het Jubelpark vergezeld door een honderdtal Belgen. Om 12 uur vertrok de mars richting Schumanplein voor een meet&greet met Brendan Sinnott, het hoofd van de Disability Unit van de Europese Commissie. Daarna ging het naar het Europees parlement voor een debat. De mars is een initiatief van ENIL, het Europese netwerk voor Onafhankelijk Leven, dat de hulp kreeg van de Vlaamse vzw Onafhankelijk Leven. De initiatiefnemers vragen de uitvoering van het VN Verdrag voor de rechten van personen met een beperking. "We mogen deze mensen niet zomaar in een apart circuit stoppen, of het nu om scholing of leefomgeving gaat", zegt Peter Lambreghts van ENIL.

(AMG)

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## Annex II. ENIL key definitions as adopted by the ENIL board in November 2012

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 (UN CRPD) but it has played a key part in the drafting of the CRPD. This is especially true for Article 19, but is also other articles cannot be realized without a clear understanding of 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 neighbors 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.



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### Annex III. Overview of videos on PA and IL collected by ENIL

1) Two documentaries from Bulgaria:

- The Price of Non-Freedom - (movie\_Cenata\_na\_nesvobodata)  
[https://www.dropbox.com/s/7x0d3a7ssit3vw7/movie\\_Cenata\\_na\\_nesvobodata.flv?dl=0](https://www.dropbox.com/s/7x0d3a7ssit3vw7/movie_Cenata_na_nesvobodata.flv?dl=0)
- Moonstruck Sonata -  
<https://www.dropbox.com/s/wzscs3i82wqy4wx/MOONSTRUCK%20SONATA.mp4?dl=0>

2) A film about the development of IL movement in Slovenia and about what PA means to disabled people.

- Part 1:  
<https://www.youtube.com/watch?v=aqSHnju71Pc&index=35&list=UULR7gGUCrykBDBv9aqcuWBA>
- Part 2:  
[https://www.youtube.com/watch?v=11ur6GF\\_z\\_g&index=34&list=UULR7gGUCrykBDBv9aqcuWBA](https://www.youtube.com/watch?v=11ur6GF_z_g&index=34&list=UULR7gGUCrykBDBv9aqcuWBA)

3) Three videos for the promotion of employment in regular environments for people with disabilities.

- <https://www.youtube.com/watch?v=AdZ0DSyz9ds&index=36&list=UULR7gGUCrykBDBv9aqcuWBA>
- <https://www.youtube.com/watch?v=ETe7OhWhoTU&index=37&list=UULR7gGUCrykBDBv9aqcuWBA>
- <https://www.youtube.com/watch?v=eZTKzLLMdJ4&index=38&list=UULR7gGUCrykBDBv9aqcuWBA>

4) A funny and a sad video about the need for PA

- Funny: <https://www.youtube.com/watch?v=qp6AFOUg79A>
- Sad: <https://www.youtube.com/watch?v=q7VDhtEsc68>

5) An animated video from the Greek Independent Living Organization "i-living". It shows the everyday life of people with disabilities with (first part) and without (second part) the possibility of Independent Living.

- [https://www.youtube.com/watch?v=rPzy0M5su\\_k](https://www.youtube.com/watch?v=rPzy0M5su_k)





- 6) A video about the disability cuts in the U.K.
- <https://vimeo.com/106278113>
- 7) Independent Living Fund (ILF) Protest video: people challenge the Department for Work and Pensions (DWP) decision to abolish the ILF in the U.K.
- <https://www.youtube.com/watch?t=1&v= K0mINi0UJ4>
- 8) Video's about what the closure of ILF means to disabled people
- Kevin's story: <https://www.youtube.com/watch?v=KTeMUwsy II>
  - Penny's story: <https://www.youtube.com/watch?v=nRQNUXqma2s>
- 9) BBC report about disabled protestors who storm the U.K. Parliament.
- <https://drive.google.com/file/d/0B37vGQoIDyPrVU9wTnA1emNIZTA/view>
- 10) The speech of Liz Carr and the song of John Kelly at the anti-austerity march from 20 June 2015
- Liz: [https://www.youtube.com/watch?v=A\\_UgGha9-2c](https://www.youtube.com/watch?v=A_UgGha9-2c)
  - John: <https://www.youtube.com/watch?v=mh9JpBCtwts>
- 11) A video from STIL about living with PA
- <https://www.youtube.com/watch?v=amTvUJGYpt0>
- 12) The video "Independent Living Norway" from ULOBA
- <https://www.youtube.com/watch?v=GB2ukcnCdmA>
- 13) A Spanish video about PA
- <https://vimeo.com/4364969>
- 14) The Freedom Drive 2013 campaign video
- <https://www.youtube.com/watch?v=h9efDYTa4JU>
- 15) The Freedom Drive anthem "Do you hear the people sing"
- <https://www.youtube.com/watch?v=Tm4uID8xYil>

