



Freedom Drive Report

February 2020

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Freedom Drive Report

Introduction

The 2019 Freedom Drive, organised by the European Network on Independent Living (ENIL), took place on 1 – 3 October in Brussels, under the motto “Loud and Proud”. The 9th edition of ENIL’s main campaigning event was special in two respects – it marked the 30th Anniversary of the European Independent Living movement and attracted a record number of participants from all corners of Europe, and from Japan.

Participants

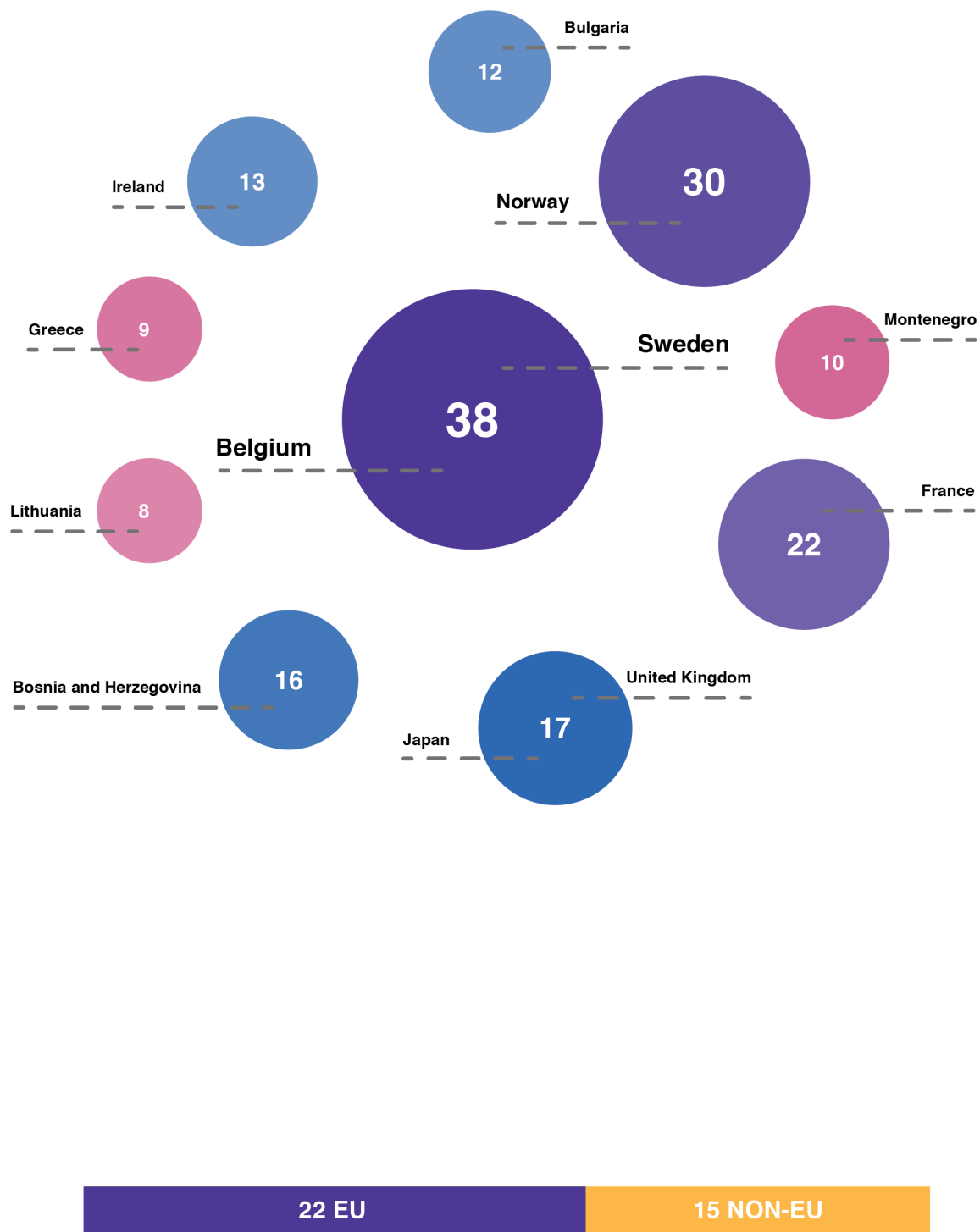
Most of around 300 participants in the Freedom Drive were disabled activists and their personal assistants. In addition, we also had representatives of other NGOs that advocate for the rights of disabled people, family members and EU-level officials from the European Commission and the European Parliament. At least 500 people joined the march through Brussels, which carried a loud message against institutionalisation of disabled people.

Altogether 37 countries were represented at the Freedom Drive – among those, 22 were EU Member States and 15 were from other parts of Europe and the rest of the world. The largest number of participants came from Belgium and Sweden, followed by Norway and France. The breakdown of the countries with the largest number of participants is available on the next page.

Over the years, the Freedom Drive has become a truly cross-disability event and there were wheelchair users, autistic advocates, people with intellectual disabilities and others – all united in their conviction that all disabled people have a right to live independently and should not be locked away in any type of institution.

A dossier for participants can be downloaded from this link: https://enil.eu/wp-content/uploads/2019/09/Loud-and-Proud_web2409.pdf

Graph 1: Breakdown of participants by country



Freedom Drive Demands

For the 2019 Freedom Drive, we agreed on three main demands, which we presented to the newly elected members of the European Parliament. These demands formed the basis of our European elections manifesto and will continue to drive our advocacy work at the European level. They are:

1. Mainstream disability in all policy areas and ensure that the future European Disability Strategy is fully aligned with the UN Convention on the Rights of Persons with Disabilities and its general comments.
2. End institutional care and promote access to community-based services and Personal Assistance for all those in need.
3. Promote the freedom of movement for all by working towards a common European Social framework.

The demands, with their explanatory text, can be downloaded from this link: https://enil.eu/wp-content/uploads/2019/09/Freedom-Drive-Demands-2019_Print_and_web.pdf

ENIL's 30th Anniversary

ENIL was founded in April 1989 during a meeting in the European Parliament in Strasbourg. The meeting was sponsored by the Greens and called for a world-wide network of organisations and individuals that subscribed to the Independent Living ideology. We celebrated our 30th birthday with a party, where one of the founders – Adolf Ratzka – reflected on ENIL's beginnings and the journey until now. Adolf was joined by ENIL's outgoing President Kapka Panayotova and former Director Jamie Bolling, as well as two representatives of ENIL Youth – Marijeta Mojašević, from Montenegro, and Marianne Knudsen, from Norway. Vibeke Maroy Melstrom from ULOBA in Norway – ENIL's main funder and long-term supporter – also spoke about the importance of keeping the network alive.

Our 30th Anniversary timeline, with key events from our history and background information can be downloaded from this link: <https://enil.eu/wp-content/uploads/2019/09/ENIL-Timeline-Final-Front.pdf>



Freedom Drive Highlights

Workshops: We organised six workshops during the first day of the Freedom Drive, with the number of participants ranging from 15 to 60 per workshop. Among the most popular workshops was that on co-production and campaigning for Independent Living in one of the London boroughs, led by Tara Flood and Kevin Caulfield, a workshop on Sustainable Development Goals, led by Nadia Hadad, and a workshop on personal assistance and the PA Checklist developed by ENIL, led by Dr. Teodor Mladenov. We also had successful workshops on communication and campaigns to raise awareness about the rights of autistic people in Belgium, led by Tess Van Deynse, a workshop presenting Independent Living Institute's Disabled Refugees Welcome project, led by Jamie Bolling, and a workshop on using EU Funds for Independent Living, led by Nataša Kokić and Ines Bulić Cojocariu.

Three of the workshops were web streamed, and these recordings, as well as all the presentations, can be downloaded from this link: <https://enil.eu/campaigns/freedom-drive/9th-enil-fd-sept-2oct-2019/>

Meetings with MEPs: Many Freedom Drivers took the opportunity to meet with their newly elected Members of the European Parliament (MEPs). Considering that many MEPs were new to Brussels, this was an opportunity to inform them about the barriers and human rights violations faced by disabled people in their constituencies, and to suggest what they should be doing to promote Independent Living in the European Parliament.

Freedom Drivers coming from Belgium, Estonia, Greece and Cyprus, Ireland, Poland, Portugal, Slovenia, Sweden and the UK (Northern Ireland) reported to ENIL about their successful meetings, and we have agreed to jointly follow up with those MEPs to ensure we have allies in the European Parliament.

March: This year, the march started by gathering in Parc du Cinquantaire, where we were joined by several media crews that reported about the protest. A team from Al Jazeera, working on the

documentary “Europe’s Recurring Shame”, also followed the march. Starting in the park, and armed with banners, megaphones and whistles, we moved past the main EU institutions - the European Council and the European Commission – finally ending up in front of the European Parliament. There, we were joined by several MEPs who accepted our demands, but the heavy rain meant that the protest had to end.

As the march passed by the seat of DG Employment, Social Affairs and Inclusion, we met one of the Freedom Drivers sitting in a cage, with a sign: *Funded by the European Union*. The cage was set up by ENIL to bring to attention the continued investment of EU Funds into the segregation of disabled people in institutions across the EU.

Throughout the entire march, our demand for an end to institutionalisation of disabled people was loud and clear, and was heard by those making decisions about policies, laws and funding that affect disabled people’s ability to live independently.

Hearing in the European Parliament: For this year’s hearing in the European Parliament, which was hosted by MEPs Julie Ward and Petra de Sutter, we chose to focus on the “Freedom of movement in the European Union”. With the support of Prof. Lisa Waddington from the Maastricht University, we prepared a background paper, discussing the reasons why disabled people in the EU are unable to enjoy this fundamental right – to live and work in a Member State of their choice. Importantly, we put forward some recommendations on how to make it easier for people to move around. The hearing was used to launch the paper and to hear personal experiences of the barriers faced by disabled people in the EU. We were also able to show a French documentary showing police brutality and heavy fines imposed on disabled people exercising their right to peaceful protest.

Conference on Independent Living: The half-day conference was organised at the Charlemagne Building and focused on the past and the future of Independent Living. It was inspired by ENIL’s 30th anniversary, but also the fact that the current European Disability Strategy is coming to an end and that a new one will come into its place in 2021. Speakers from

the Independent Living movement were asked to reflect on personal assistance, austerity, institutionalisation and older people and Independent Living. We heard from young people, as well as two MEPs and representatives of the European Commission. It was a short but lively debate, which provided an opportunity to think about new strategies to counter resistance to Independent Living by governments, service providers and others.

General Assembly: During the General Assembly, we adopted a number of changes to our Constitution, in order to better reflect the work that we are doing and to ensure that all our members comply fully with Article 19 of the UN Convention on the Rights of Persons with Disabilities and the General Comment 5. The new Board was also elected, with Nadia Hadad, Vibeke Maroy Melstrom, Michael Holden, Suela Lala, Jukka Kumpuvuori and Tess Van Deynse appointed for a period of four years, and joining Jamie Bolling, Radoš Keravica and Armen Alaverdyan. We used the GA to thank our outgoing President Kapka Panayotova for her leadership and commitment to fighting for Independent Living in Bulgaria and elsewhere.

World Independent Living Network (WIN) Meeting: Thanks to ENIL's involvement in WIN, which was established in 2017, we were able to welcome a large delegation of activists from Japan at the Freedom Drive. The WIN meeting, although held after an already long day, was used to inform Freedom Drivers about the purpose of WIN and how our members can contribute to the world-wide efforts to promote Independent Living.

Youth Network General Assembly: There was a good representation of young people at the Freedom Drive, and even though not all were members of the ENIL Youth Network, they decided to take part in the Youth GA. As a result, despite not having quorum to elect its new Board, there was a successful meeting and a lively discussion about the work being done by young people in different countries and the opportunities to work together. The Board elections were postponed and eventually took place in December 2019.



Media coverage

In cooperation with our Belgian member GRIP, we planned our communications work and prepared several materials that were posted on our social media, the website and were distributed to journalists . This included personal stories of six participants, one of which is featured below. On the day of the march, we published a press release, which was picked up by a number of news outlets: <https://enil.eu/news/enil-press-release-hundreds-demand-end-to-segregation-of-disabled-people/>

As mentioned earlier in the report, Al Jazeera released a two-part documentary as part of its series People & Power, some of which was filmed during the Freedom Drive. The programme was aired at the beginning of December 2019.

“Europe’s Recurring Shame”, Part I and II, can be watched here:

<https://www.youtube.com/watch?v=DSL0tqMsE8g> and here:

https://www.youtube.com/watch?v=Ou-O8YQfq_0&feature=youtu.be



“My name is Nicolas Joncour. I’m a French non speaking autistic student (in Law). I’m almost 20 years old. In France, only 20% autistic children go to school, sometimes only for some hours a week but most of them are in an institution or in a psychiatric hospital with no education. But, I have fortunately always been at school, mainstreamed or home schooling. I would like to get a degree in disability rights. I am a member of the ENIL Youth Network, Clé-autisme (an association of autistic people who are against the medical model of disability) and CHA (the French independent living association). I was 16 when I joined ENIL’s Youth Network, because I started to realise how much we have to fight for our rights.” (Nicolas Joncour, France)

A selection of the press coverage:

- Euronews:
<https://twitter.com/jackeparrock/status/1179322370433138690>
- Europost:<https://europost.eu/en/a/view/we-don-t-want-to-be-a-burden-to-our-families-26397>
- Brussels times: <https://www.brusselstimes.com/belgium/71270/protesters-in-brussels-demand-greater-inclusion-for-people-with-disabilities/>
- The bulletin: <https://www.thebulletin.be/marchers-demand-end-disabled-apartheid>
- Nieuwsblad: <https://www.hln.be/in-de-buurt/brussel/400-mensen-met-een-handicap-en-hun-begeleiders-protesteren-voor-meer-inclusie~a00460d4/>
- De wereld morgen: <https://www.dewereldmorgen.be/artikel/2019/10/02/we-have-a-dream/>
- Wikipedia: https://fr.wikipedia.org/wiki/Exclusion_des_personnes_autistes
- 7 Sur 7: <https://www.7sur7.be/belgique/des-personnes-handicapees-defilent-a-bruxelles-pour-plus-d-inclusion-dans-la-societe~a5e6f736/?referrer=https://www.google.be/>
- Bruzz: <https://www.bruzz.be/samenleving/mensen-met-handicap-trekken-door-brussel-voor-inclusie-de-maatschappij-2019-10-02>

Experiences of the Freedom Drivers

After the Freedom Drive, we asked the participants for their experience of the event and received 45 responses. The majority responded very positively:

“Great experience with many things learned about other EU countries.”

“It has been an unforgettable experience for me. Thank you so very much for organizing this. All of my feedback on more interactive workshops, more "mingle time", more accessibility for visually impaired delegates, must be understood as a genuine wish to be

able to get the maximum out of this unique opportunity. I really hope to be back again in the future!"

"Enlightening and interesting event, would love to come back!"

"You've given me strength and it was inspiring meeting so many people and seeing their work."

"I felt very proud to have participated in such an important event of solidarity between disabled people of different countries from Portugal to Japan and all fighting for such important causes as our human rights against discrimination and for an independent life with personal assistants help."

In addition, one of the participants from Japan reflected on taking part in the Freedom Drive march and visiting Europe for the first time:

"We, all of Japanese delegates, also join the Freedom Drive. It was so passionate that we could blow our coldness away! "We don't need institutions! We need Freedom!", freedom drivers shouted out these powerful words and they gave us courage. We have peers who fought for same target. We have different nationality but same IL blood /spirits. These facts encourage us. We can't bring Independent Living movement forward by alone. Our great senior leaders have strong leadership/conviction and colleagues who can share/act ideas. For these reasons, they could have spread IL philosophy to all over the world. We are based in different areas, Europe and Tokyo, but we can make giant steps towards our SOLIDARITY. I would love to express my pleasure and gratitude from bottom of my heart."

We also received some suggestions on how to improve the Freedom Drive, which we will take into account when planning the next edition.

"Even though personally I am very happy to make a small financial contribution for the organisation of the Freedom Drive through the participation fee, I think 30 or 50 Euro can be a considerable amount for some people who would like to participate but don't have the financial means. So, it might be helpful to consider a way of ensuring that this is not an additional barrier to people's participation. ENIL team is always great! :) Great work!"

“Brussels is too inaccessible. I couldn't go the whole march because of the cobble stone. More or less impossible to find an accessible restaurant.”

In addition to these, we received comments about the lack of translation from English into other languages, the need for audio description, the lack of clear information during the event, long days, and the relevance of the workshops and conference presentations. We thank everyone who took the time to provide feedback, which helps us make sure that the next event is even better. While some things are out of our control, others we can try to address.

Freedom Drive Budget

The organisation of the 2019 Freedom Drive has been made possible thanks to the funding or support in kind from: ULOBA, STIL, GIL, Bente Skansgårds Independent Living Fund, European Commission, the City of Brussels, Microsoft, Oslo Region European Office and Michael Holden - Mobiloo Ireland. The summary of income and expenses is included below.

Graph 2: Income and expenses

Summary Freedom Drive 2019



Budget

Income
€ 28.000
Costs
€ 30.600
ENIL own contribution
€ 2.600

Income

Description	Amount
Subsidy Bente Fund	€ 13.300,00
ENIL 30th birthday Uloba Donation	€ 3.000,00
Participants donations	€ 7.200,00
Other income (t-shirts & gadget sales)	€ 1.500,00
Brussels City Subsidy	€ 3.000,00

Costs

Description	Amount
Travel costs Staff and Speakers	€ 12.700,00
Costs for promotional material	€ 6.700,00
Costs for services (catering, text to speech, rent of rooms)	€ 11.200,00

Acknowledgements

We would like to thank all our volunteers, supporters and sponsors for helping us organise the 2019 Freedom Drive. In particular, we would like to thank GRIP, our member in Flanders, and the European Disability Forum for helping us with the media work and for providing volunteers. We also wish to thank Marie-Anne Paraskevas and Peter De Visscher for their support.



We look forward to seeing you at the next Freedom Drive, on 21 - 23 September 2021!

For all the updates, please follow our dedicated Freedom Drive page on ENIL's website <https://enil.eu/campaigns/freedom-drive/9th-enil-fd-sept-2oct-2019/>, the Freedom Drive Facebook page <https://www.facebook.com/ENIL-Freedom-Drive-124127045055/>, or contact us at secretariat@enil.eu