

# 2023 ANNUAL REPORT



#### **Photo Description**

Cover page: People holding a flag and a banner during the ENIL

Freedom Drive saying Institution – no solution!

Page 4: A woman sitting at a desk, smiling.

Page 8: A young woman speaking into a megaphone, smiling.

Page 14: A woman and a man are in discussion with another person, who is holding leaflets.

Page 15: A young man is looking at his phone and speaking to a woman, who is holding a small microphone.

Page 17: Three panellists are sitting behind a desk in the European Parliament, with one of them speaking into a microphone.

Page 21: A group of panellists is sitting behind a desk, with roll ups and a European flag behind them, and screens in front of them.

Page 25: A group of men, one wheelchair user and a woman standing in front of a screen saying Zero Project For a world with zero barriers, and a roll up saying European Accessibility Resource Centre.

Page 27: A young man with headphones typing into his computer, with a young woman sitting next to him holding a microphone.

Page 30: A group of five people posing for a camera, with two women wheelchair users in front.

Page 34 - 35: Two screenshots from ENIL's website and Facebook, showing podcasts and a home screen with ENIL's logo and cover picture.

Page 36 – 37: Logos of Facebook, Instagram, X and LinkedIn.

Page 38: People holding a flag and a banner during the ENIL Freedom Drive saying Institution – no solution!

Page 42: One picture shows people sitting behind a desk, with laptops in front, while the other is a close up of a woman speaking into a microphone.

Page 45: Two young women smiling into the camera.

Page 48: A hand holding ENIL's publication.

Page 52: A group of people, men and women, some of them wheelchair users, smiling into the camera in a big conference room.

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Dear members, Dear readers,

Another year promoting Independent Living has closed. Sometimes, after my thirty years of activism, I wonder. I wonder how far backwards we can go? We have progressed but then cuts and poor policy draw us backwards. ENIL's activism is needed more than ever!

During 2023, ENIL used its resources in trying to influence the European Union with its work on Independent Living, with the closure of institutions throughout Europe, with the empowerment of youth, with leadership programs for the youth and in new areas including international development cooperation, networking with Ukraine and the Middle East. A collaboration with the International Labour Organisation has as a goal to increase awareness on personal assistance which is one of the most important tools we as disabled people need to carry out our activism.

ENIL knows the importance of good laws and policies that should allow us to better our situations as disabled persons living across the globe. ENIL in 2023 again advocated for the use of EU funds for Independent Living. Work was carried out to influence the EU Framework of Social Services of Excellence. We emphasize that we need support to live our lives, not to be taken care of.

As ENIL's work goes on, we lose fellow comrades one after another in our fight for our rights. For those of us who stay behind, we need all of you who want to be active to join us in all that we do to change our lives for the better.

Thank you to everyone for their commitment and support!

Sincerely,

#### **Jamie Bolling**

ENIL Co-chair and Director of the Independent Living Institute

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#### **CHAPTER 1**

# Our main achievements in 2023



## Proposal for European Guidance on Independent Living

Access to the right to Independent Living differs throughout Europe. Over a million disabled people still live in segregated settings, be it in large institutions or group homes. Many of these institutions have received funding from the European Union. This is why guidance from the European Commission to the Member States on how to improve implementation of Article 19 of the UN Convention on the Rights of Persons with Disabilities is crucial. In consultation with our members, we published our proposal on what this guidance should include. Our proposal was published on 4 May, just before the European Independent Living Day, and it was presented to the Commission officials responsible for drafting the policy document.

## Providing opportunities for young disabled people

Opportunities for young disabled people to get work experience in Brussels are limited because of the cost of living and the inability to access support services, such as personal assistance. ENIL aims to fill this gap by providing volunteering opportunities for 6 months each, as part of the European Solidarity Corps programme, funded by Erasmus+. In 2023, we recruited three young disabled people from Ireland and Italy. Our first volunteer – Fionn Crombie Angus – moved to Brussels in October 2023, to experience work in the office and receive mentoring and support from the ENIL team.

#### **Investing in new leaders**

ENIL's Youth Leadership Programme, relaunched in 2023, provides opportunities for young disabled people to get leadership skills by learning from each other and organisations advocating for the rights of disabled people. This year, four young disabled women, from Ukraine, Montenegro, Norway and Italy were given an opportunity to spend a week with the Threshold (Finland), Independent Living Movement Ireland (Ireland), Validity Foundation (Hungary) and Foundation "All Together Now" (Albania). This gave them a new perspective on the situation in their own countries and motivation for the future.

#### **Branching out into new areas**

With the right to independent living being one of the most interconnected Convention rights, there is no shortage of areas we must work on. In 2023, we started working on climate change, looking at its impact on independent living. We expanded our work in the area of international cooperation, working with organisations in Ukraine, but also in the Middle East, to ensure that independent living was at the heart of deinstitutionalisation and other reforms. We began a new collaboaration with the International Labour Organisation, focusing on working conditions of personal assistants. We also created opportunities to work on artificial intelligence and energy poverty in the future, to highlight links and remove barriers to independent living.

# ENIL's work in 2023 in numbers

46

Internal meetings involving the staff, volunteers and the Board

23

Trainings & capacity building events

9

Policy influencing events

4

Awareness raising events

90

Key meetings attended

15

Publications and position papers issued

**17** 

Consultations to which we contributed

10

Collaborations achieved

5

Directorate
Generals we
contacted regularly

5

Surveys disseminated

**17** 

Fundraising applications submitted

#### **CHAPTER 2**

## Highlights by work area



## INFLUENCING POLICY

# Towards strong Guidance on Independent Living

As part of its Strategy for the Rights of Persons with Disabilities 2021 – 2030, the European Commission announced new guidance to Member States on improving access to independent and inclusion in the community. This guidance is due to be published until the end of 2024.

After an extensive consultation process with the ENIL Board and membership, which started in 2022, we published **ENIL's Proposal for the Commission Guidance**.

On 4 May – on the occasion of the European Independent Living Day - our proposal was presented at an event in the European Parliament. During the event, we heard from MEPs Stelios Kympouropoulos, Katrin Langensiepen and Anne-Sophie Pelletier, a member of Commissionar Dalli's cabinet Nora Bednarski and the the Director at DG Employment, Social Affairs and Inclusion Katarina Ivanković-Knežević. Our members from Spain and Belgium spoke about barriers to Independent Living in their countries.

After the event, efforts to distribute our Proposal and to build support among MEPs and national governments started. Among other, we met with the Spanish Office for the Rights of Persons with Disabilities. The meeting took place during Spain's EU Council Presidency.

In April, we joined the Disability Platform Sub-Group on Independent Living, where we presented our expectations from the guidance. Later in the year, we gathered examples of good practice to be included in the Commission's document. We focused on the important role of Centres on Independent Living and Personal Assistance user cooperatives.

An article about ENIL's proposal was published in **Social Europe**. Another article, on Independent Living and Personal Assistance, also written by our Policy Coordinator Florian Sanden, came out in a **publication** of the Foundation for European Policy Studies (FEPS), the think tank of the Party of European Socialists. ENIL was invited to further discuss its contribution during a **webinar** on 9 September.

## **Supporting EU review by the CRPD Committee**

In 2022, we published a Shadow report on the implementation of the CRPD in the European Union and sent it to the CRPD Committee in time for the adoption of the List of Issues Prior to Reporting (LoIPR) in March 2022.

In January 2023, the European Commission held a meeting to consult stakeholders on the official report to the CRPD Committee on the implementation of the CRPD in the EU. ENIL took part in the consultation and we presented the main points from our Shadow Report. The Commission subsequently submitted its report to the CRPD Committee in April.

Unfortunately, the review of the EU report by the CRPD Committee was postponed until 2025, due to the Committee's backlog. For this reason, ENIL decided to work on the updated shadow report in 2024 and to submit it in February 2025, when the information from civil society will be collected by the CRPD Committee Secretariat.

Nevertheless, we published a **thematic briefing**, looking at the use of EU funds in relation to persons with disabilities, which was launched in December.

## Helping to shape the new Framework for Social Services of Excellence

Another flagship initiative foreseen by the Strategy for the Rights of Persons with Disabilities 2021 – 2030 is the EU Framework for Social Services of Excellence.

Throughout 2023, ENIL has been working on its Proposal for this framework, which is key to ensuring that social services support the right to Independent Living. To gather input, we consulted members and academic experts during a webinar on 26 July. We

focused on the key principles according to which all community-based services should be organised: peer support, co-production, intersectionality, and the five As (availability, accessibility, acceptability, affordability and adaptability).

The **draft Proposal** was shared with the Board and their comments were collected and incorporated. It was finalised in December, with a plan to launch it in 2024, in the European Parliament.

## **Exposing the role of state aid in funding institutions**

Having monitored the role of EU funds in maintaining institutions for disabled people for many years, we expanded our watchdog role into the area of state aid. In 2023, we began looking into the role of state aid (public procurement) in funding institutions for disabled people. We focused on two countries – Germany and Portugal – where we found evidence that state aid plays a significant role in the financing of institutions. A case study on this topic was published in December and included in the final Newsletter of the year. It will be presented to the European Commission in 2024.

## Proposing changes to the European Disability Card



Our proposals were also incorporated into a submission of the European Social Observatory, which was sent to the Belgian EU Council Presidency.

Once the Commission's proposal for the European Disability Card and the European Parking Card were published on 9 September, ENIL came out with a **quick reaction**. We also sent concrete **amendments** to a number of MEPs and national government representatives.

An article about the European Disability Card, expressing our position was also published in the **Social Europe Journal**.

## Advocating for disability inclusive youth policies

In January, ENIL met with the Youth Department of the Flemish Government, leading on youth affairs during the Belgium Presidency of the EU Council in 2024. Our expertise on how to organize accessible events and which priorities to set when it comes to disability inclusive youth policies was shared. We followed up by sharing further guidance in writing.

In October, we provided input to the Commission on how to make the European youth programmes more inclusive. Our Policy and Movement Support Officer Kamil Goungor shared his experience as a former EVS volunteer. He also spoke about ENIL's experience in organising accessible and inclusive European Solidarity Corps volunteering projects, and the challenges we face.

#### Resisting the care agenda

There was a large number of developments at the European and international level when it comes to the so-called Care Agenda – a threat to Independent Living and the social model of disability. As ENIL, we undertook many activities to promote the right to support, rather than being cared for.

With the support of the Maltese Government, we submitted a number of ENIL **amendments** to the Council Conclusions on the transitioning of care systems, as well as the Council Conclusions on **social economy**.

In January, we attended a debate on the European Care Strategy at the Section for Employment, Social Affairs and Citizenship (SOC) of the European Economic and Social Committee. In her panel contribution, our Co-Chair Nadia Hadad highlighted the need to move ahead with the process of deinstitutionalisation and the expansion of community-based services.

In February, ENIL was represented at the Zero Project Conference in Vienna, which was dedicated to the topics of "Independent Living and Political Participation". Kamil Goungor spoke in a session on personal care and care-taking and chaired a session on self-advocacy.

In July, the United Nations Office of the High Commissioner for Human Rights (OHCHR) published a call for good practices on support systems for disabled people, for a report mandated by A/HRC/RES/49/12. ENIL submitted a **response**, with input from some of our members.

After the submission, ENIL (represented by Nadia Hadad) and ENIL Youth Network (represented by Nicolas Joncour) attended a formal consultation. Following the consultation, Nicolas Joncour was interviewed by UN OHCHR, providing his experience as a young person using support services.

In July, the UN General Assembly adopted the UN Resolution for the International Day for Care and Support on 29 October. ENIL published a **position** in relation to this day, highlighting the importance of support.

In October, our Policy Coordinator Florian Sanden spoke at an event of the Foundation for European Progressive Studies on the EU agenda in the field of long-term care.

A recording is available here.

#### Voting rights for all

ENIL has been working together with our member, the Validity Foundation, and the law firm Covington & Burling to find disabled people who are discriminated against in their right to vote or be elected. To raise awareness of this initiative, we organised a webinar on 3 October. **The recording is available here**.

Also in October, our Policy Coordinator Florian Sanden spoke at an event of the National Disability Agency Ireland on the topic of political participation.

To expand our Independent Living Map, a **survey** on political participation was launched. Based on this survey, a summary report, focusing on participation in the European elections, was published in December.

A selection of other policy files we worked on is presented below:

European Parliament Resolution "Towards equal rights for persons with disabilities" — We promoted this Resolution, adopted at the end of 2022, which quotes ENIL: "whereas according to the European Network on Independent Living's 2020 survey on independent living, 24 out of 43 countries represented in the Council of Europe do not have a deinstitutionalisation strategy".

Covid-19 - In February, we presented insights from our research during a consultation meeting on the impact of COVID-19 on disabled people, organised by MEP Katrin Langensiepen.

Commission's Proposal for cross border protection of vulnerable adults – We joined efforts with the European Disability Forum, Mental Health Europe and other organisations to oppose the Commission's draft proposal on cross border protection of vulnerable adults. We also provided comments for discussions in the Council, focusing on the lack of compliance with Articles 12 and 19 CRPD.

Civic space - In July, we took part in a focus group organised by the EU Fundamental Rights Agency (FRA) on participation of marginalised groups in EU policy making. We then provided specific input for the FRA report on the topic, as part of their **research on the EU civil society space**.

Rights, Equality, Citizenship and Values programmes - In September, we submitted a contribution to the public consultation on the Rights, Equality, Citizenship and Values programmes (REC, EfC and CERV) – evaluation report. Our contribution asked for more funding to be allocated to disability rights and for more consideration of the need for reasonable accommodations for organisations employing disabled people.

Marrakesh Directive - In August, we contributed to a consultation on the evaluation of the Marrakesh Directive. In our response, we raised concerns about the high costs of accessible materials and the difficulty to access them for many people, particularly in low and middle-income countries.

#### **AWARENESS RAISING**

#### **European Independent Living Day**

The 10th edition of the European Independent Living Day - 5 May was marked by our members, other disabled people's organisations (DPOs), service providers and governments across Europe. Those who shared information about their events with ENIL were featured on our social media. We also organised two events – in Brussels and online.

On 4 May, we presented our Proposal for the EC Guidance on Independent Living in the **European Parliament**, at an event with participation of high level Commission officials.

On 5 May, we organised a **webinar** to present the Independent Living survey findings on access to personal assistance to the policy and the disability community.

The Independent Living Day continues to be an important day in the calendar and, while the right to independent living should be respected every day of the year, it is important to use this day to raise awareness.



#### **Independent Living and climate change**

The impact of climate change on the right to Independent Living is a new topic for ENIL. A key activity for 2023 was the drafting of a Position paper on Independent Living and climate change, which will form the basis of ENIL's future activities on this issue.

As part of the work on this Position paper, we attended meetings of the Disability Climate Coalition, led by our member Disability Rights UK.

Our staff and Board also attended several other climate related events:

- the Disability and Climate Action Caucus preparatory meeting for COP28, led by the International Disability Alliance;
- a meeting between the regional and global stakeholder focal points of the UN Office for Disaster Risk Reduction regional and global mechanisms of stakeholder engagement. We shared the perspective of disabled people, who are among the first ones left behind when a disaster occurs;
- the European Climate Stocktake, where we learned about the EU and global progress towards the goals of the Paris Agreement;
- the event organised by the EU Agency for Fundamental Rights (FRA), titled "Fundamental Rights and the EU Green Deal". Our Policy and Movement Support Officer Kamil Goungor spoke about the impact of climate change on disabled people and explained why we should be involved in all the discussions.

Following the EDF training for members on disability inclusive humanitarian action, ENIL joined the European Alliance for a Just Transition, led by SOLIDAR.

## Supporting Independent Living advocacy in Ukraine

Thanks to our new Human Rights Officer Rita Crespo Fernandez, who joined in April, we were able to intensify our activities in relation to Ukraine, focusing on deinstitutionalisation. We listened to the needs of our partner organisations working in Ukraine and supported their efforts.

We had a number of meetings - with the European Disability Forum, the DG for European Civil Protection and Humanitarian Aid Operations (DG ECHO), the DG for European Neighbourhood Policy and Enlargement Negotiations (DG NEAR), the UN Human Rights Mission in Ukraine and Save the Children.

In April, we collaborated with Disability Rights International and UK activists to support the Study Visit of the Ukrainian government to the UK to learn more about deinstitutionalisation projects. Our aim was to ensure that DPOs were part of this visit.

Fight for Right, a Ukrainian DPO working for the rights of disabled people and supporting the emergency response, visited our offices in Brussels. We exchanged about our organisations' visions, our work on Ukraine, the potential for future collaboration on deinstitutionalisation in Ukraine and the accession process to the European Union.

We continued having regular online meetings with Fight for Right, as well as Disability Rights International, DRI – Ukraine and Validity Foundation. The aim of the meetings was to update each other on developments, assess support needs and strategise.

We followed closely the developments with the EU's Ukraine Facility, with the aim to ensure that deinstitutionalisation is part of the recovery efforts, without investing in large institutions, small group homes or other segregated settings. We released a joint statement with Disability Rights International, DRI - Ukraine, Validity Foundation, and Fight for Right, calling for deinstitutionalization reforms in Ukraine to be supported by the European Union, in consultation with DPOs.

## Mainstreaming the right to Independent Living

In January, ENIL representatives spoke at the "Forum for Exchange Experience of Montenegrin and European organisations of persons with disabilities" in Podgorica, Montenegro, organised by the "Association of Persons with Disabilities of Montenegro - AYDM".

In April, our Policy Coordinator Florian Sanden gave a lecture on the work of ENIL in front of political science students at the Free University of Brussels. The lecture explored the work of ENIL from the political science point of view, comparing two lobby campaigns and analysing the factors which contributed to our activities having political influence or a lack thereof.

In June, together with our Board members Suela Lala and Elena Kochoska, we took part in an event organised by the First Lady of North Macedonia, on independent living. We explained the basics of Independent Living and answered questions from the participants.

In October, our team met with the Disability Unit at DG Employment, Social Affairs and Inclusion at the European Commission. We met with the Head of Unit Alison Crabb and the Policy Officer Olga Brionez. We discussed ENIL's work and the ongoing work of the Unit, in particular the forthcoming Guidance on Independent Living.

In early November, ENIL contributed to a workshop organized by the Belgian Ministry on Social Affairs on disability and employment.

We helped select good practices on independent living for the Zero Project and the European Social Network's European Social Services Award, by being part of their peer review/jury. Kamil Goungor was a reviewer for the Zero Project, while Florian Sanden was on ESN's Jury. Our Board member Elena Kochoska spoke at the ESN Conference in Zagreb, Croatia where the winners of the ESN awards were announced.

We provided input into the following surveys: EDF's external evaluation and a survey on members' needs; questionnaire on passenger rights in bus and coach transport, by PWC; EU Youth Strategy evaluation survey; EASPD's report on social innovation.

As a member of the Disability Platform, established by the Commission to monitor the implementation of the European Disability Rights Strategy 2021 - 2030, we participated actively in the meetings and in the subgroup on Independent Living.

Finally, we re-joined the Facing the Facts network on hate crime, led by CEJI (A Jewish Contribution to an Inclusive Europe), and plan to participate in various initiatives in the coming years.



#### CAPACITY BUILDING

## Providing technical assistance on deinstitutionalisation

ENIL provided technical support to the Government of Malta on personal assistance and deinstitutionalisation, as they began working on closing down institutions and moving towards independent living.

In March, our office in Brussels was visited by Julia Farrugia Portelli, the then Minister for Inclusion, Voluntary Organisations, and Consumer Rights (currently the Minister for Inclusion and Social Wellbeing) and Ms. Nancy Caruana, the Permanent Secretary. The Minister and the ENIL team engaged in an in-depth **discussion** on how to set up a quality personal assistance scheme and other alternatives to institutions.

In September, we met again with the Minister, as well as representatives of Agenzija Sapport and the Maltese equality body, to discuss the process of deinstitutionalisation in Malta and ENIL's concerns about a large investment in an institution. We stressed the importance of prohibiting all investments into institutional care and resisting the calls for new beds (even when they come from disabled people or their families).

In January, we learnt that a project for a deinstitutionalisation network in Lebanon and Palestine, which we supported, received funding from the UK Research Council. We are represented in this network by our Co-chair Nadia Hadad, who attended several meetings during the year.

In July, we joined a strategic meeting organised by USAID to discuss language in their calls on deinstitutionalization of children. Together with our allies, we made it clear that no funds should go to residential care providers, even if they commit to closure.

Also in July, we discussed independent living and deinstitutionalisation with the Spanish EU Council Presidency. **More information is available here**.

On 9 November, ENIL published an **Open letter** about abuses in Slovenia's institutions for disabled people, which was sent to the relevant Ministries and contacts at the European Commission and in the European Parliament. Only the European Commission sent a response.

In October, we published and disseminated an **Explainer** on the Guidelines on deinstitutionalisation, including in Emergencies. It simplifies the most complex aspects of the document, making it accessible and easy to navigate. In addition to the Explainer, we coordinated the translation of the Guidelines on deinstitutionalisation into German, in cooperation with the German Human Rights Institute. This translation, along with the others, is available from the **Committee's website**.

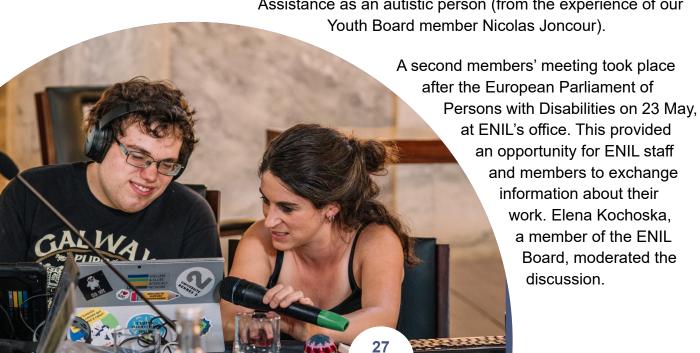
#### Regional members' meeting in Portugal

On 14 – 15 September, with the support of our Portuguese members from the **Centro de Vida Independente (CVI)**, we organised our annual Regional Members Meeting. The first day of the meeting took place at the Matosinhos City Hall, in Porto, and the second at the Matosinhos public library.

Matosinhos municipality (adjacent to Porto) serves as a good practice example when it comes to the right to independent living. Among other, we heard about the actions taken by the municipality to ensure that disabled people can work, move freely and be active members of the community.

Members from 11 countries from Southern and Western Europe - Albania, Belgium, France, Germany, Greece, Italy, Malta, North Macedonia, Portugal, San Marino, Spain, plus Norway - came together, shared the developments from their countries and had the opportunity to learn about ENIL's work from our staff and provide suggestions for future activities.

Day 2 of the members' meeting focused on personal assistance. We heard about the Portuguese and Greek Personal Assistance pilots, as well as about having Personal Assistance as an autistic person (from the experience of our



## DI Guidelines training for the CRPD monitoring body

In cooperation with the Center for Independent Living Innsbruck, ENIL delivered a **training** for the Tyrolean CRPD Monitoring Committee, based on the UN Guidelines on deinstitutionalisation, including in Emergencies.

On 14 – 16 June, ENIL Director Ines Bulić Cojocariu delivered a presentation and moderated a workshop during a one-day open event for members of the CRPD Monitoring Committee in Innsbruck. The meeting was well attended, not just by members of the Committee, but also other disabled people, survivors of institutionalisation and service providers. The meeting was fully accessible, with translation English – German and into Easy to Read.

In addition to the training, we visited CIL Innsbruck and some of the institutions renovated with EU funding in the area around Innsbruck. We were only able to see the institutions from the outside, as we did not have permission to enter.

## Mutual exchange webinars on deinstitutionalisation

We organised three mutual exchange webinars, in an effort to improve the governments', service providers' and disabled people's capacity to implement deinstitutionalisation reforms that are CRPD compliant.

On 29 March, the **first ENIL-ECCL webinar** focused on ways to promote deinstitutionalisation. We heard from Cool Crips from Greece, who organise successful social media campaigns, and a journalist from the Slovenian national broadcaster that provides information in accessible formats.

During the **27 October webinar**, we learned about the "Stay Up Late Campaign" from our ESC volunteer Fionn Crombie Angus. This was followed by a presentation on the supported decision making pilot in Norway, presented by Kristin Torske from ULOBA. Finally, we heard a presentation of the Personal Assistance Handbook from our member YHD from Slovenia.

The **third webinar**, entitled "Getting People Out", focused on Japan's action plan on deinstitutionalisation, followed by experiences of closing an institution in Slovenia and finally by a presentation from Starfire Council about creating alternatives to day care centres in the US.

At the end of the year, we also published a **recording of the 2021 webinar**, organised with MDRI-Serbia, about personal assistance for adults with intellectual disabilities. There is a lot of interest in how personal assistance works for persons with intellectual disabilities and this webinar recording includes practical examples from Sweden, the Netherlands, Belgium and the UK.

#### Peer support for personal assistance users

Monthly meetings of the Personal Assistance Users Club (PAUC) were held online during the year, led by Alessandra Grotta and regularly attended by a group of about ten disabled people who use Personal Assistance from across Europe. The meetings dealt with various aspects of being a PA employer, such as recruitment, conflict resolution, advertising etc.

In September, the meeting focused on the question "Do we have/need standards of peer counselling for PA users?", while in October, the group watched and discussed movies from the Superfest Disability Film Festival. In addition, we contributed an article on PAUC and ENIL's work on peer support for the **Disability Rights Defenders newsletter**, which featured many articles by Independent Living activists from around Europe.

#### **Capacity building on personal assistance**

As a leading organisation on personal assistance and the right to independent living, ENIL continued to receive requests, queries and study visits.

On February 23 – 24, Misako Yasuara from the Independent Living Center in Osaka, Japan, visited ENIL's office in Brussels. Our team presented ENIL's work in the Global Coalition on Deinstitutionalisation (GC-DI), ENIL's history and key results of the Independent Living Survey.



- On 21 March, we met with the delegation of Eudajmnia Foundation from Poland, the House Under the Nuts and the Norwegian organisation Fonix. Among them were three self-advocates. The aim of the meeting was to share information about ENIL and the Freedom Drive.
- On 28 March, Kamil Goungor spoke at the European expert meeting "Inclusive Education for an Inclusive Europe", organised by COFACE Families Europe in Monza, Italy. His intervention was titled "Inclusive higher education and mobility from practice to policy" and covered the aspects of formal and non-formal education.
- On 26 April, Kamil Goungor gave a guest lecture for the Maynooth University of Ireland, invited by the ENIL Youth Board member Peadar O'Dea. He spoke about independent living, ENIL, i-living Greece and our advocacy.
- ENIL Co-chair Nadia Hadad and Kamil Goungor shared experiences, highlighting barriers and positive examples, when it comes to employment of disabled people during the launch of the EDF Human Rights Report on employment on 27 April.
- On 25 May, Flora Kalemi, from the Albanian Disability Rights Foundation, visited ENIL's office in Brussels. This meeting was an opportunity to discuss their work and potential collaboration in the future, particularly on the EU accession process.
- We supported our French member CHA in organising an **all-day online conference** on Personal Assistance in France. The conference took place on 26 June, with Ines Bulić Cojocariu presenting on the implementation of Article 19 and the situation in Europe. With ENIL's support, the conference could be held in English and French.
- On 1 October, Kamil Goungor represented ENIL at the EAMDA International Conference on Neuromuscular Disorders, in Bucharest, Romania. He delivered a workshop on personal assistance and how it is important for people with neuromuscular disorders.

- On 5 October, the ENIL team held an online workshop titled "Armenia: Advocacy for Disability-Led Independent Living Policy. European Models of Personal Assistant Services (PAS)" organised by Mobility International USA (MIUSA). The workshop was aimed at two Armenian Independent Living Centres, which are being supported by MIUSA. In two hours, we were able to explain what personal assistance means, to introduce some PA models from Europe and pilot project examples. We also presented ENIL's "Personal assistance Checklist", spoke about the role of CILs and about personal budgets.
- On 3 November, our Co-Chair Jamie Bolling and Kamil Goungor spoke at OVI Valencia's conference on personal assistance in Valencia, Spain. They presented the Swedish Personal Assistance model and EU laws and policies relevant to Independent Living and Centres for Independent Living in Europe.
- On 20-26 November, Ines Bulić Cojocariu and Kamil Goungor were in Yerevan, Armenia, for an Independent Living/Personal Assistance Expert Technical Assistance Visit, as well as a Training of Trainers (TOT). During their visit, Ines and Kamil met with numerous stakeholders, including the Armenian government, UN bodies and DPOs, and co-facilitated (with a team from the US and Armenia) a 3-day workshop on the fundamentals of Independent Living and Personal Assistance.
- On 29 November, Kamil Goungor spoke at EDF's event for youth with META in Brussels, talking about the Freedom Drive and how technology and social media help youth disability activism.
- On 11 December, we organised a webinar on the opportunities provided by Erasmus+, entitled "Advancing Independent Living with Erasmus+", for our members. We heard from several members who have successfully implemented Erasmus+ projects and shared ideas on how to apply for funding.
- Our Policy Coordinator Florian Sanden has been supporting our member, the European Council of Autistic People EUCAP, in setting up a policy working group, with the aim to help improve their advocacy at EU level. He also spoke to Kenneth Westberg from the Independent Living Institute about the work of ENIL at the European level. Several articles were subsequently published on ILI's website.

## COMMUNICATION AND DISSEMINATION

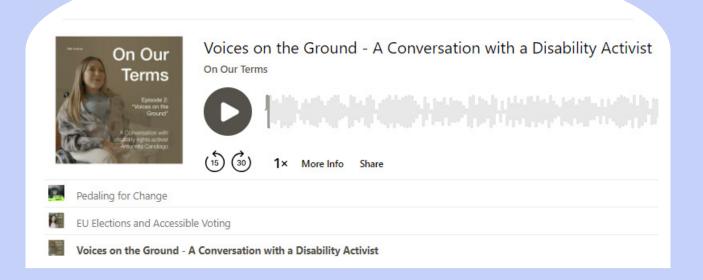
#### Membership campaign

The membership campaign had as its objective to increase knowledge about ENIL and the benefits of joining. It took the form of social media posts, in the following languages: English, German, French, Spanish, Italian, Romanian, Hungarian, Slovak and Croatian. A link where organisations and individuals can click to join accompanied all posts.

#### **Storytelling**

We created a number of powerful short videos to raise awareness about Independent Living through the stories of disabled people. The videos were filmed and edited by our Communications Officer and Digital Organiser Michael Goossens.

- Empowering Independence: A Day in the Life of a Personal Assistance User: click here to watch.
- Interview with the Rhoda Garland, the Maltese Commissioner for the Rights of Persons with Disability: click here to watch.
- Disabled People protest in Belgium for Personal Assistance: click here to watch.
- Pleading for Independent Living: click here to watch.
- MEP Katrin Langensiepen: I want more people in the European Parliament: click here to watch.



#### **Podcasts**

We have recorded three new podcasts on the topic of EU elections, scheduled for June 2024. They include a conversation with a Member of the European Parliament Stelios Kympouropolous, and with two disability activists – Niamh Ni Hoireabhaird and Antonella Candiago. **They are available here**.

The podcasts were created jointly by our Communications Officer Michael Goossens and our Policy Coordinator Florian Sanden. They were launched in December.

#### Members' mailing

Twelve issues of the Member's mailing were published in the middle of each month. All the staff have contributed content for the Members' mailing, which was coordinated by Michael Goossens. Member's mailing was distributed to 872 email addresses each month.

Out of these, 49% recipients were female, 42% male, 0,1% another identity and 9% unknown. The most common age range was 35 – 44, with the next being 25 - 34.

The opening rate of the Members' mailing is 39% (those who open it frequently), with the top locations being the Netherlands, Bulgaria and Greece.

#### **ENIL Newsletter**

Twelve issues of the Newsletter were published and disseminated, at the end of each month. The Newsletters were edited by Michael Goossens, with the articles submitted by the staff, Board, members and outside contributors. The Newsletters were distributed to 1,088 email addresses each month. Out of these, 47,5% recipients were female, 38,2% male, 0,1% another identity and 14,3% unknown. The most common age range was 45-54, with the next being 35-44.

The opening rate of Newsletter was 40% (those who open it frequently), with the top locations being the Netherlands, Ireland and Bulgaria.



#### Social media

ENIL has been very active on social media – in particular Facebook, Instragram and LinkedIn, as well as X (formerly Twitter). The posts ranged from those covering ENIL events and meetings, to awareness raising posts about issues ENIL is focusing on – such as institutionalisation, social model of disability, personal assistance, independent living etc.

#### **Facebook**



62.490 persons rea 8.222 profile visits 62.490 persons reached 235 new likes

#### **Instagram**



20.492 persons reached2.024 profile visits 216 new followers

#### X



92.112 persons reached 124 new followers

#### LinkedIn



717 reactions591 page views328 new followers

# TOP CAMPAIGN: EU FUNDS FOR OUR RIGHTS

The campaign EU Funds for Our Rights has continued, led by our new Human Rights Officer Rita Crespo Fernandez, who took over from Nataša Kokić. Throughout the year, we collected information from our members about the use of EU funds – whether for the building of institutions, or to expand access to personal assistance, for example. We have received new information about EU funds being used to finance institutions in Spain and Poland and have started to work on complaints.

We also worked with other organisations - across different equality streams - to find common challenges and to come up with joint strategies to challenge the misuse of EU Funds.



#### **Cooperation with other stakeholders**

On 27 September, we helped organise the **first webinar** 'Stop discrimination in EU Funds', with Bridge EU and other NGOs. We shared our experience of taking action against the misuse of funds at EU level. On 8 November, we co-organised the **second webinar**, titled "Stop discrimination in EU funds: the role of fundamental rights bodies". In a joint presentation with Steven Allen from the Validity Foundation, Ines Bulić Cojocariu spoke about ENIL's experience of working with the national human rights institutions within our complaints on the use of EU funds.

We provided input to the EU Fundamental Rights Agency, which published a report on the fundamental rights compliance of EU Funds in December 2023. We joined EU FRA's Fundamental Rights Platform annual meeting, where we spoke during the workshop on EU Funds. ENIL Director Ines Bulić Cojocariu also spoke at EU FRA's first annual CharterXChange event, in a parallel session 1: 'Mainstreaming fundamental rights in the EU funds – The role of National Human Rights Institutions and Equality Bodies'. She shared ENIL's reaction to FRA's new report on the topic.

Key takeaways can be found here.

On 16 November, ENIL was invited to intervene at a conference on deinstitutionalisation organized by EQUINET, attended by representatives from National Human Rights Institutions from across Europe. Rita Crespo Fernandez delivered a joint presentation with the Validity Foundation on the role of EU funds in supporting deinstitutionalisation.

As a member of the Common Provisions Regulation (CPR) Expert Group, we took an active part in its work. On 15 June, the CPR partners were invited to a dialogue at the European Commission, for a day full of presentations from EU officials and discussions among partners. There was an interactive dialogue with Normund Popens, Acting Director-General at DG REGIO at the European Commission, where ENIL expressed concerns about the financing of institutions for disabled people with EU funding. On 13 December, during the second annual meeting, we delivered a presentation on obstacles for DPOs to access Monitoring Committees. The minutes of the Expert group meetings are available here.

We also participated actively in the work of the European Community of Practice of the European Social Fund - the Social inclusion and the Partnership principle sub-groups, where independent living was one of the key topics. During the two webinars organized by the Community of Practice on Social Inclusion, our members from CIL Portugal and the Croatian Union of Associations of Persons with Disabilities (SOIH) presented the positives and challenges of Personal Assistance schemes funded from the European Social Fund. During the planning session for 2024, which focused on future activities and new taskforces, ENIL agreed to lead a taskforce on ecosystem mapping, to identify "unusual" partners across EU countries, as an opportunity to bring in DPOs.

In an effort to work with other stakeholders, ENIL has joined the Advisory Group of the EU Funds Helpdesk Project, led by EASPD. Among other, we attended three workshops, where we provided suggestions on how to ensure EU funds are used to support independent living.

#### **Complaints and requests for information**

Following our complaint, submitted in 2022 to the European Commission about funding being used for institutions for children in Austria, we received a negative decision (no violation of EU Fundamental Rights Charter) at the end of March. At the end of April, we submitted additional information from recent human rights reports and challenging problematic statements made in the decision. However, the appeal was unsuccessful, and the complaint was closed. In November, we submitted a Freedom of Information request, asking for correspondence between the EC and the Managing Authority, which we received.

In November, we submitted another freedom of information request on how the European Commission evaluates the fulfilment of enabling conditions. We have not received a response until the end of 2023.

#### **Providing input to the European Commission**

We sent responses to two European Commission consultations in June - one on the Resilience and Recovery Fund, and the other one on funding outside of the EU.

In October, we submitted a response to a consultation on the mid-term evaluation of the Regional Development Fund. We included evidence of investments into institutions under this fund and expressed our alarm about potential investments currently planned for this financial framework. We recommended stronger safeguards in policy documents and for the European Commission to better guide Member States, and to take action when necessary, in order to ensure full compliance of the EU and Member States with the UN CRPD.

**GLOBAL FOCUS** 

# Promoting independent living globally

In July, Esma Gumberidze, a member of the ENIL Youth Network, represented ENIL at the High-Level Political Forum in New York and brought the **perspective of disabled youth**.

ENIL submitted a written statement to inform the High-Level Segment of the Economic and Social Council. In our statement, we highlighted the impact of COVID-19 on disabled people, calling attention to recovery efforts after the pandemic that financed segregation instead of inclusion.

Our Co-chair Nadia Hadad spoke at the 75th Anniversary of the Universal Declaration of Human Rights, organised by the UN OHCHR Brussels Office in the Brussels City Hall.

In December, ENIL was invited by the Disability Rights Fund/ Disability Rights Advocacy to a strategic meeting in New York 'Nothing without us: Building strength through solidarity". We were represented by Kamil Goungor and were one of the two invited DPOs from Europe, alongside the European Union of Deaf Youth.

We have been elected to chair the OPD Task Force in the International Disability and Development Consortium (IDDC) starting with 2024. Even though ENIL is not a member of IDDC, we have been active for many years through our Co-Chair Nadia Hadad, an expert in disability inclusive development cooperation.

# Promoting the Guidelines on deinstitutionalisation, including in Emergencies

Our focus in 2023 remained on the promotion of the CRPD Committee's Guidelines on deinstitutionalisation, including in Emergencies (adopted at the end of 2022) – a key document which should guide deinstitutionalisation reforms in Europe and abroad.

This we did by working within the Global Coalition on Deinstitutionalisation (GC-DI), and additional activities undertaken by ENIL.



With GC-DI, we submitted a joint submission for the General Comment on Article 11, focusing on the Guidelines, and which was presented at a closed briefing with the CRPD Committee on 17 March in Geneva. Joint action was also taken by GC-DI to address a USAID call that aims to fund deinstitutionalisation in Ukraine. Members of GC-DI and partners, acting as individual organizations, co-signed a letter sent by Disability Rights International addressed to USAID on this matter.

## 16th Conference of States Parties in New York

ENIL took part in the 16th Conference of States Parties to the UNCRPD and the Civil Society Forum in New York, from 13 – 15 June.

Together with the Permanent Mission of Malta, Agenzija Support, and GC-DI, we organised an in-person **side event on 15 June**, on the Guidelines on deinstitutionalisation. The side event, which included a survivor of institutionalisation from India, was very well attended and we realised the objective of increasing awareness about the Guidelines and the right to independent living.

We were represented in New York by our Co-Chair Nadia Hadad and by a member of the ENIL Youth Network, Esma Gumberidze, from Georgia. Esma delivered **statements**, prepared with the support of the Secretariat, during the General Debate and the Civil Society Forum. Nadia delivered a statement on behalf of the International Disability and Development Cosortium (IDDC) during the general debate and spoke during a side event on forced sterilisation, on behalf of EDF.

On the sidelines of COSP 16, Nadia Hadad had a number of meetings, including with: Ms Alessandra Locatelli (Italian Minister responsible for disability and social issues), Gertrude Oforiwa Fefoame (CRPD Committee Chairperson), Rosemary Kayess (CRPD Committee Vice-Chair), Marcus Schefer (CRPD Committee member), the EU's and the Belgian Permanent representatives to the UN, Carlos Espinosa (Human Rights Watch and the Inter-American Coalition on Deinstitutionalisation), Marion Lieser (Light for the World) and with Charlotte McClain-Nhlapo (Global Disability Advisor at World Bank Group).

# 29th session of the CRPD Committee in Geneva

In August, during the 29th session of the CRPD Committee in Geneva, we helped to organise and participated in the 1st Anniversary **Thematic session** on the Guidelines on deinstitutionalisation, organised by the CRPD Committee Secretariat. Rita Crespo Fernandez represented ENIL.

Before the session, ENIL contributed to the shadow report on **Hungary**, following up on the CRPD Committee inquiry, and drafted a shadow report on the **United Kingdom**, in cooperation with our members from the UK.

Being in Geneva was also a good opportunity to hold bilateral meetings and discuss with decision-makers. Meetings were held with the World Health Organization, the International Labour Organization, ATScale, and the Office of the High Commissioner for Human Rights, with various members of the CRPD Committee and DPOs.



#### **YOUTH FOCUS**

#### **ENIL Youth Network**

Members of the ENIL Youth Network delivered a successful week-long study session for young people on 12 -16 June at the European Youth Center in Strasbourg, with support from the Council of Europe Youth Department. The programming team consisted of Peadar O'Dea, Lauri Heikkinen, Borbala Ivicsics, Thiandi Grooff and Clementine Doevendans. The topic of the session was "CRIP CAMP: Disability Rights in Times of Conflict and Calamity". The report from the session is available here.

The Board of the Youth Network held monthly online meetings, with the support of the ENIL Secretariat. On 2 December, the Youth Board had its face to face meeting in Brussels, which was joined also by our young member from ULOBA Martine Eliasson, our ESC volunteer Fionn Crombie Angus, and Jessica Nguyen from the European Youth Forum. The Youth Board meeting took place right after the European Day of Persons with Disabilities, to allow Board members to attend this event as well.

Three members of the Youth Board, and Kamil Goungor, spoke at Camp Freedom, organised by ULOBA on 10 August. Members of the Youth Board and the Youth Network also represented ENIL Youth at high level events during the year. For example, Nicolas Joncour, from France, and Esma Gumberidze, from Georgia, were speakers at the Centre for Disability Law at **NUI Galway Summer school** on the rights of children with disabilities, which took place in June.

#### **Youth Leadership Programme**

After a number of years, we were able to restart our Youth Leadership Programme (YLP), focused on getting young disabled people into human rights work.

Four of our member organisations supported YLP – the Threshold (Finland), Independent Living Movement Ireland (Ireland), Validity Foundation (Hungary) and Foundation "All Together Now" (Albania). They all agreed to host a young disabled person for one week and to include them in the work of the organisation, by shadowing staff members and providing mentorship opportunities.

By the end of June, we selected four young women to take part in the programme – Elisa Marino, from Italy, Ivana Janković, from Montenegro, Kateryna Shcherbyna, from Ukraine, and Miriam Tartusy, from Norway. The interest in the programme was high and we had to turn down many applicants due to only four spaces being available. We prioritised those who did not have many opportunities so far.

On the week of 23 October, the Youth Leadership Programme began with the first participant from Ukraine visiting Finland. This was followed by the Norwegian participant visiting Albania, the Italian participant visiting Ireland and the Montenegrin participant visiting Hungary. Whilst at their host organisations, the programme participants shadowed staff members and took part in different activities.

The YLP included a social media campaign, during which each of the disability rights activists was introduced and shared their experiences. It was wrapped up on the 12 December with a **webinar**, where all four participants presented about their week and drew comparisons between their home country and the host countries approach to disability policy and law.

#### **RESEARCH**

#### **Independent Living Research Network (ILRN)**

In April, the **Special Issue on Independent Living** of the International Journal on Disability and Social Justice, entitled "Independent Living in Europe and Beyond: Past, Present and Future", was published. This was the result of a collaboration between ENIL and the Centre for Disability Studies at the University of Leeds, led by Dr. Teodor Mladenov, the coordinator of our Independent Living Research Network – ILRN. The Special issue contains an editorial written by Dr. Mladenov, 5 full length articles, 3 current issue bulletins, accessible summaries of all the articles, as well as 12 interviews with Independent Living pioneers and leaders.

On 10 - 12 May, among 700 disability researchers, academics and activists, ENIL participated in the **Nordic Network on Disability Research conference**, held in Reykjavik, Iceland. Together with Dr Teodor Mladenov and our Icelandic members from NPA, we organised a session titled "Independent Living in Europe and beyond: past, present, and future", where we presented the work done on the International Journal of Disability and Social Justice (IJDSJ) and screened a summary video from the interviews with Independent Living activists.

On 14 – 15 February, several members of Independent Living Research Network (Radoš Keravica, Laura Alčiauskaite and Lazar Stefanović) presented at the conference on "Transition towards Independent Living within the Community for Persons with Disabilities", which took place in Lebanon. It was organised jointly by UN ESCWA in cooperation with the Government of Malta and the UN Special Rapporteur on the Rights of Persons with Disabilities. ENIL facilitated the participation of European Independent Living researchers in this meeting, in support of the UN ESCWA. **The conference proceedings are available here**.

Dr Teodor Maldenov and our Co-Chair Nadia Hadad represented ENIL in the Advisory Group of the UNIC Project on personal budgets, led by EASPD, and provided input into various project outputs, as well as the **final conference**.

#### **Independent Living Survey**

The Independent Living Map summary report, with the new chapter on access to personal assistance, was presented on 5 May at a **webinar** targeting policy makers and the disability community. Based on her contribution, Elena Pečarić wrote an **article on the functioning of personal assistance in Slovenia**. Hard copies of our summary report were distributed to policy and decision makers in the EU institutions.

To expand our Independent Living Map, a **survey on political participation** was launched in 2023. A **summary report**, focusing on participation in the European elections, was published in December.



#### **PROJECTS**

In 2023, ENIL implemented a number of projects, with numerous activities taking place in parallel throughout the year.

#### **New projects**

#### Promoting Choice, Control and Participation for All Persons with Disabilities in Europe and Beyond – Choice4All 2023

This was ENIL's main project, which provided the organisation with funding for the core expenses and the majority of activities set out in this report. The project was co-funded by the European Union (Citizens, Equality, Rights and Values Programme – CERV), and our members ULOBA (Norway), STIL and GIL (Sweden).

Project website: https://enil.eu/project/choice4all/

#### **European Solidarity Corps**

Having obtained a Quality Label for hosting ESC volunteers, we received a budget to host three new volunteers, in 2023 and 2024. After an open call, we recruited three young disabled people, each of whom will complete a 6-months volunteering programme at ENIL – Fionn Crombie Angus (Ireland), Michael Brennan (Ireland) and Francesca Spanghero (Italy). Fionn, a young man with intellectual disabilities, was the first to join us in October 2023. He became our first ESC volunteer with intellectual disabilities and the first post Covid volunteer. Fionn was supported by Aoife McGarry at the office and we received funding to employ a personal assistant for him part time for outside office hours.

#### LITI-GATE Project – Strategic Litigation as a Gateway to Address the Rights of Persons with Disabilities

LITI-GATE Project, led by Victim Support Europe, began in September 2023 and will run for two years. Among the first activities was the creation of an accessible project leaflet and the launch of research activities in five countries – Hungary, the Czech Republic, Romania, Slovakia and Bulgaria. Based on this research, project partners began developing a strategic litigation guidebook, as well as accessible information on how to access legal and support services.

Project website: https://enil.eu/project/liti-gate/

#### **Projects ending in 2023**

#### **Global Coalition on Deinstitutionalisation Project**

ENIL was the Coordinator of the project funded by Disability Rights Fund/Disability Rights Advocacy Fund, which supported the activities of the Global Coalition on Deinstitutionalisation starting from June 2022 until April 2023. The project was implemented in partnership with the International Disability Alliance, Inclusion International, Transforming Communities for Inclusion, Validity Foundation, Disability Rights International and the Centre for Human Rights at the University of Pretoria. As a result of the project, the Guidelines on deinstitutionalisation, including in Emergencies were translated into many languages, including Easy to Read.

Project website: www.gc-di.org

#### **TRIPS Project – Transport Innovation for Disabled People**

TRIPS project came to an end in March 2023, after three years. Among the main results of the project was the Lecco Declaration for Accessible and Inclusive Public Transport, signed by cities, transport providers, DPOs and other stakeholders. Other key deliverables include: the TRIPS Co-design For All course, the TRIPS Co-design for All toolkit and the Mobility Divide Index website.

Project website: https://trips-project.eu/deliverables/

#### **Entrepreneurship for All - EntreAll Project**

EntreAll Project was completed at the beginning of 2023, resulting in a number of resources to help young disabled people who would like to start their own business. Project website: https://enil.eu/project/entreall/

#### Partnership ENIL - Centre for Disability Studies at the University of Leeds

The secondment of Kamil Goungor by ENIL to the University of Leeds came to an end in October 2023. Kamil supported CDS in developing an **online Masters programme** in Disability Studies Rights and Inclusion, which was launched in 2023.

# STRATEGIC PARTNERSHIPS

#### **European Disability Forum (EDF)**

ENIL played an active role in the European Disability Forum, through our Co-Chair Nadia Hadad, who is a member of the EDF Board and Executive Committee. ENIL Youth Board member Nina Portolan took part in the work of the EDF Youth Committee, and our individual member Elena Ratoi in the Women's Committee. They attended Committee meetings during the year and provided input into various documents, occasionally with support of the ENIL Secretariat.

Through Nadia Hadad as a speaker, ENIL was represented in many events at the European and international level. These include:

- January SOC Section meeting debate Community-based services for independent living and a successful implementation of the European Care Strategy
- March CEPLIS-Eurocadres conference on gender equality
- March Humanitarian Disability Talk

- March Meeting with the Italian Minister for Disabilities Ms. Alessandra Locatelli
- June Expert meeting of the European Disability Expertise Network
- June COSP 16 side event: Ending forced sterilisation of persons with disabilities and promoting sexual and reproductive rights
- October Fringe event Council ALDE EUROPA on disability in the European Year of Skills – Inclusion through skills creation and labour market integration
- November GLAD Network Engaging donor offices and delegations for the inclusion of persons with disabilities in budgets, programmes and policies worldwide
- November European Day of Persons with Disabilities EU Strategy on the Rights of Persons with Disabilities

On 23 May, the ENIL delegation took part in the 5th European Parliament for Persons with Disabilities in Brussels, organised by EDF. Our Policy Coordinator Florian Sanden delivered a statement, which focused on the barriers disabled people face in accessing support services. ENIL also contributed to the EDF Manifesto on the European Elections, which was adopted during the 5th Parliament.



# Global Coalition on Deinstitutionalisation (GC-DI)

We continued working closely with the International Disability Alliance, Inclusion International, Transforming Communities for Inclusion, Validity Foundation, Disability Rights International and the Centre for Human Rights at the University of Pretoria, as part of the Global Coalition on Deinstitutionalisation (GC-DI). In 2023, GC-DI adopted a Memorandum of Understanding, agreeing on a mandate for the group, with a focus on the Guidelines on deinstitutionalisation, including in Emergencies. A co-chairing system was also put in place, with Disability Rights International taking the helm at the end of 2023.

#### **World Independent Living Network (WIN)**

We continued meeting regularly with WIN members from the North America, Latin America and Asia-Pacific, to discuss barriers to independent living worldwide and opportunities for collaboration. The work of WIN is coordinated by the Japanese Independent Living Centre (JIL) and ENIL is represented by our Co-chair Nadia Hadad.

# **European Expert Group on the Transition from Institutional to Community-based Care (EEG)**

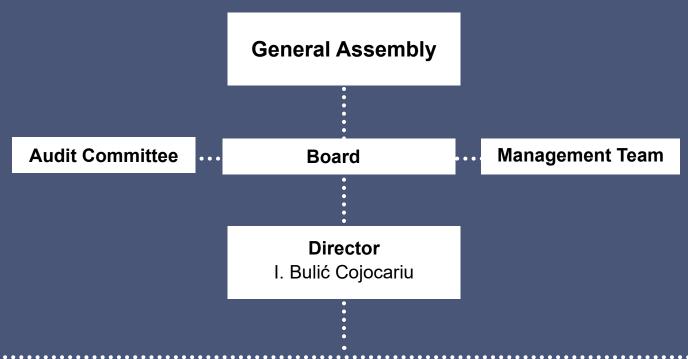
We met regularly with other EEG members and contributed financially to the part time EEG Coordinator, who helped ensure the group stays active. In addition to ENIL, the EEG consists of UNICEF, Lumos, Inclusion Europe, Mental Health Europe, the European Social Network, EDF, FEANTSA, Autism Europe, Eurochild, COFACE Families Europe and EASPD.

The year began with a **joint statement** in January, which brought to attention the continued support for institutionalisation of disabled people in Bulgaria. Later in the year, in October, we co-organised the EEG Study session on deinstitutionalization, aimed at the European Commission officials. During the session, we heard from DPOs and NGOs in Malta, the Czech Republic and Poland.

#### CHAPTER 3

# OUR STRUCTURE

### **ENIL Organisational Structure**



•				
	Administration	Policy & Advocacy	Membership & Communications	Projects
	Office and Events Coordinator A. McGarry Finance	Policy Coordinator F. Sanden  Human Rights Officer R. Crespo	Policy & Movement Support Officer K. Goungor Communications	Project Coordinator (part-time) LITI-GATE A. Santos Lavigne
	Manager (part-time) S Roisin	Fernandez  ESC volunteer(s) ILRN Coordinator Senior advisor(s)	& Digital Content Organiser M. Goossens	

#### **ENIL Secretariat**

In 2023, the ENIL Secretariat consisted of 6 full time staff members, 1 part time staff member, 1 project officer and 2 office volunteers.

Two of the staff members – Nataša Kokić, Campaign Coordinator and Melike Ergun Yilmaz, Office Assistant – left the organisation to pursue other work opportunities (in December 2022 and February 2023 respectively). Therefore, we published two vacancies at the beginning of February and recruited Rita Crespo Fernandez as the Human Rights Officer and Aoife McGarry as the Office and Events Coordinator. Both positions became full time, meaning we had an increase in capacity of 0,5 persons. Rita and Aoife started in their new positions on 1 April 2023, based at the Brussels Office.

Kamil Goungor finished his secondment at the University of Leeds (1 day per week) at the end of October and went back to working full time as part of the core team.

With the TRIPS and PAKT projects coming to an end, Laura Alčiauskaite and Lilia Angelova Mladenova also finished their work with ENIL (in March 2023 and December 2022 respectively).

A new consultant was recruited from September to work on the LITI GATE Project. Adela Santos Lavigne is a lawyer based in Spain and will work on the project remotely over 24 months.

In addition to the core and project staff, we were supported by two volunteers. Alexandrine Maas, from France, joined the team over the summer for 2 months, and Fionn Angus Crombie joined ENIL as a European Solidarity Corps volunteer at the beginning of October, for six months.

A face to face staff meeting was held in Brussels on 23 – 24 March, in order to plan activities for the year. A staff training day on Independent Living was organised on 27 July. The training covered key topics that ENIL is working on, and we had a chance to hear from one of ENIL's founders, John Evans OBE, about ENIL's history. Dr. Teodor Mladenov, who coordinates ENIL's Independent Living Research Network, spoke about the history of the global Independent Living movement. The purpose of the training was for the staff to learn about ENIL's positions and to be able to defend them.

#### Governance

The ENIL Board met four times during the year. Three meetings were held online, on 6 March, 12 June and 11 December. One meeting was held face to face in Porto, on 13 September. ENIL Director acted as Secretary during the Board meetings, and during each meeting there was a report from ENIL Youth and a report about ENIL's work in EDF.

There was one change in the Board membership, with Michael Holden stepping down before the September meeting, due to competing commitments. The Board coopted Mirko Tomassoni from San Marino, who took part in the December meeting.

During the September meeting, the Board decided to update its Terms of Reference and asked the Director to develop a document on how to increase Board engagement in ENIL's work.

During the June and December meetings, the Board held the General Assembly of ENIL Brussels Office and adopted key documents – reports for the previous years, and the work plan and budget for the forthcoming year.

The Board oversaw the work of the ENIL Secretariat through the Management Team, consisting of the two Co-Chairs Jamie Bolling and Nadia Hadada, and the ENIL Director. The Management Team met on a monthly basis and made decisions regarding human resources, funding, partnerships and ENIL's activities.

# Organisational and financial management

The Audit Committee met three times during the year: on 21 February, 5 June and 10 October. The Finance Officer has been acting as the Secretary for the Audit Committee and disseminated the cash flow and financial report prior to each meeting.

Michael Holden, who stepped down from the Board, also stepped down from the Audit Committee. He was replaced by another Board member, Elena Kochoska, who joined the existing Audit Committee members –Jamie Bolling, Patrick Wauters and Dimitris Karanastasis.

We have been working with the external auditor and the bookkeeping company from February until April, in order to complete the audit. The audit was successfully completed at the beginning of May. After the audit, we moved to a new bookkeeping company - GV&A – with more experience working on EU funded projects.

We successfully passed a monitoring visit by JINT (the National Agency for Erasmus+) on 16 June. The purpose of the visit was to look into ENIL's ESC projects in 2020 and 2021.

After an open call, the Social Protection Institute of the Republic of Slovenia was selected to complete an external evaluation of ENIL's Choice for All Project in 2022 – 2023. The **external evaluation report** was finalised in November and presented to the Board during the meeting on 11 December.

#### **Funding**

In 2023, we received core funding from the European Union (Choice4All Project), with our member in Norway, ULOBA, providing most of the co-funding through the ENIL Foundation. Additional co-funding was provided by our members in Sweden - STIL and GIL, as well as through the Maribel subsidy. The situation remained largely unchanged in comparison with 2022.

Other funders included the European Union - under Horizon 2020, Erasmus+ (through JINT as the National Agency) and CERV (through the European Education and Culture Executive Agency), the Disability Rights Fund and the Council of Europe Youth Department (study session). At the end of the year, we received a small grant from the European Disability Forum for a project on Artificial Intelligence.

We were contacted by many organisations interested in having ENIL as part of their funding application, and have also decided to apply for some projects alone. Thus, we were a co-applicant in an EU Citizens, Rights and Values (CERV) project named FURI (EU funds for fundamental rights), led by the Greek Council of Refugees and coordinated by Bridge EU. The FURI project was selected for funding, with a starting date in March 2024. We also joined a project on energy poverty in South-Eastern Europe – ASSERT – submitted by Aisfor, Italy, which was approved for funding, with a starting date in October 2024.

An application for a new study session in 2024, with CEJI – A Jewish Contribution to an Inclusive Europe – was submitted in March and approved by the Council of Europe Youth Department.

We were commissioned by the International Labour Organization (ILO) to write a report and a fact sheet on personal assistance in 2024. The focus of the report is on personal assistance schemes, benefits, working conditions, and training.

#### **CHAPTER 4**

### **MEMBERSHIP**

As of December 2023, ENIL had members in all 27 EU Member States and 45 other countries – 38 European and 7 rest of the world.

Full organisational members: 86 organisations

Associate organisational members: 30 organisations

Full individual members: 676 individuals (disabled people)

Associate individual members: 223 individuals

Members of the ENIL Youth Network: 385 individuals.

The list of organisational members (full and associate) is available at the end of the report.

	Full members	Associated members
Albania	Skarp Inclusive Health Center NGO - www.skarp.am	Albanian Disability Rights Foundation (ADRF) - www. adrf.org.al
Albania	Unison NGO for Support of People with Special Needs - www.unison.am	Together Foundation - https:// www.facebook.com/ sebashkufoundation/
Austria	BIZEPS-Zentrum für Selbstbestimmtes Leben (BIZEPS) - https://www. bizeps.or.at/	
	SLIÖ - Selbstbestimmt Leben Österreich (Independent Living Austria) - www.slioe.at	
Azerbaijan		Union of Disabled People Organisations of Azerbaijan - www.udpo.az
Belarus	Office for the Rights of People with Disabilities - www. disright.org*	
Belgium	AMT Concept asbl - www. handy.brussels	Fondation Shan - http:// fondationshan.be
	GRIP vzw - www.gripvzw.be	

	Full members	Associated members
	Bosnian Doctors for Disabled - https:// bosniandoctorsfordisabled. ngo/	SUMERO - Union of organisations for support of people with intellectual disabilities - https://www.adrf.al/index.php/en/*
Bosnia and Herzegovina	Information center for persons with disabilities "Lotos" Tuzla - www.ic-lotos.org.ba	Association "Dajte nam šansu" - http://www.dajtenamsansu. org/*
	Humanitarian Organization Partner - http://www. hopartner.org/*	
Bulgaria	Centre for Independent Living Sofia (CIL-Sofia) – www.cil.bg	
Croatia	Croatian Union of Associations of Persons with Disabilities (SOIH) - www.soih.hr	
Gioana	Spinalne ozljede Zagreb (Spinal Injuries Zagreb) - www. soz.hr	
Cyprus	Cyprus Paraplegics Association - http://opak.org. cy/	
	European Social Forum (ESFC)	
Czech Republic	European Council of Autistic People z.s https://eucap.eu	
Denmark	LOBPA – Landsorganisationen Borgerstyret Personlig Assistance - www.lobpa.dk*	
Finland	Kynnys Ry ( The threshold) - http://www.kynnys.fi/en/*	

	Full members	Associated members
	Association GRE A GRE - www.greagre.asso.fr	
	Alliance Autiste - http:// allianceautiste.org/	
France	CHA- Coordination Handicap et Autonomie – Vie Autonome France - http://coordination- handicap-autonomie.com	
	Observatoire des politiques du handicap - https://www.observatoirehandicapmonde.com/	
	Accessible Environment for Everyone - http://dpo.ge/en	
Georgia	Coalition for Independent Living - www.disability.ge	
	National Network of Women with Disabilities - www.wandr.	
	Interessenvertre tung Selbstbestimmt Leben in Deutschland e.V. (ISL E.V) - https://www.isl-ev.de/	
Germany	Netzwerk für Inklusion, Teilhabe, Selbstbestimmung und Assistenz – NITSA - http:// nitsa-ev.de/	
	Rhein-Main inclusiv e.v http://www.rhein-main- inklusiv.de/	

	Full members	Associated members
	Association of People with mobility problems 'PERPATO' - perpato.gr	
Greece	i-living - Independent Living Organization of Greece - https://www.facebook.com/ gr.iliving/	
	Paraplegicss' Association of Drama - http://spnd.gr/	
Hungary	The National Federation of Associations of Persons with Physical Disabilities ("MEOSZ") - www.meosz.hu	Validity Foundation - www. validity.ngo
Iceland	NPA miðstöðin - www.npa.is	
	Independent Living Movement Ireland (ILMI) - https://ilmi.ie/	Fionnathan Productions - www. fionnathan.com
Ireland	NCPD - The Natonal Council for (the status) of People with Disabilities Company Limited by Guarantee - Galway.NCPD. ie	Irish Wheelchair Association - www.iwa.ie*

	Full members	Associated members
	Agenzia per la Vita Independente Onlus (AVI ONLUS) - www. vitaindipendente.org	
Italy	Associazione Vita Indipendente - www.avitoscana.org	
Italy	Comitatio Lombardo per la Vita Independente delle Persone con Disablitá - https://vitaindipendentelombardia.wordpress.com/	
	ENIL Italia - www.enil.it	
Lithuania	Independent Living Association - https:// savarankiskasgyvenimas.lt/	
	Lithuanian Disability Forum - http://lnf.lt	
Luxembourg	Nëmme Mat Eis asbl - www. nemmemateis.lu	
	Commission for the Rights of Persons with Disability (CRPD) - www.crpd.org.mt	Inspire (The Eden and Razzett Foundation) - http://www.inspire.org.mt/*
Malta	Malta Federation of Organisations Persons with Disability (MFOPD) - www. mfopd.org	Malta Association of Supported Employment

	Full members	Associated members
	Association of Youth with Disabilities of Montenegro (UMHCG) - http://umhcg.com	
Montenegro	Initiative of Youth with Disabilities of Boka - https:// www.facebook.com/ Inicijativa-mladih-s- invaliditetom-Boke-I-MI- Boke-111829123575190/	
North Macedonia	Polio Plus – Movement against disability - www.polioplus.org.	
Namusi	Foreningen JAG - www.jagas- sistance.no	
Norway	Uloba – Independent Living Norway - www.uloba.no	
	Institute for Independent Living - www.niezaleznezycie.pl	
Poland	Disabled Human Rights Centre Poland - https:// www.facebook.com/pages/ Centrum-Praw-Os%C3%B3b- Niepe%C5%82nosprawnych/ 577383109057548?fref=nf	
	'Stowarzyszenie Kobiet Niepełnosprawnych 'ONE.pl' (The Association of Women with Disabilities 'ONE.pl') - http://onepl.org.pl/	

	Full members	Associated members
Portugal	Centro de Vida Independente - www.vidaindependente.org	Caregivers Portugal - Associação Portuguesa de Cuidadores - https://www. caregiversportugal.pt/
		Asociatia Magidream - www. dogtors.ro
Romania		AEPADO – European Association for the Defense of Human Rights - www.aepado. ro*
		Ceva de Spus - www. cevadespus.ro
Russia		Kaliningrad regional public organization of disabled "Kovcheg" - http://39kovcheg.ru/
San Marino		Attiva – Mente - www.attiva- mente.info
Serbia	Center for Independent Living Serbia (CIL Serbia) - www. cilserbia.org	
	Center Living Upright - https://www.czuns.org/en/	
Slovakia	Organization of Muscular Dystrophy in the Slovak Republic - www.omdvsr.sk, www.osobnaasistencia.sk, www.belasymotyl.sk*	
Slovenia	Društvo za teorijo in kulturo Hendikepa (YHD) - www.yhd- drustvo.si	

	Full members	Associated members
	Eginaren Eginez - www. eginez.org	
Spain	Independent Living Federation of Spain (FEVI) - www. federacionvi.org	
	Vigalicia (OVI Galicia) - www. vigalicia.org	
	GIL – Individual Independent Living - www.gil.se	
Sweden	Independent Living Institute (ILI) - www. independentliving.org	
	JAG Association - www.jag.se/	
	Stiffarna av Independent Living i Sverige (STIL) - www.stil.se	
Switzerland	Selbstbestimmung.ch - http:// selbstbestimmung.ch*	
	The Association of Women with Disabilities - http://engellikadin.org.tr/	Izmir City Council Disability Council
Turkey		Abled youth and sports club, Kocaeli
		Down Syndrome Association of Turkey - https://www.downturkiye.org/

	Full members	Associated members
	Alliance for Inclusive Education - https://www.allfie.org.uk/	Euro Youth Mental Health - https://euroyouthmhblog. wordpress.com/
	CIL Northern Ireland - www. cilni.org	musicALL - www. musicallscotland.uk
	Disabled People Against Cuts (DPAC) - www.dpac.uk.net	
	Disability Rights UK (DRUK) - www.disabilityrightsuk.org	
United Kingdom	Dudley CIL - http://www. dudleycil.uk/	
	Equal Lives - https:// equallives.org.uk/	
	Glasgow Centre for Inclusive Living - www.gcil.org.uk	
	Glasgow Disability Alliance - http://www.gda.scot/*	
	Inclusion London - www. inclusionlondon.org.uk	

Full members	Associated members
Inclusion Scotland - www. inclusionscotland.org	
Independent Living Alternatives - www.ILAnet.co.uk	
Leeds Disabled People's Organisation - https://www. facebook.com/LeedsDPO/	
National Survivor User Network - https://www.nsun.org.uk	
North Yorkshire Centre for Independent Living - www. nycil.org.uk	
Reclaiming our Futures Alliance (ROFA) - www.rofa. org.uk	
Self-Directed Support Scotland - http://www.sdsscotland. org.uk	
SPECTRUM Centre for Independent Living - www. SpectrumCIL.co.uk	

#### **Rest of the world**

Country	Associated members
Bangladesh	Community Development Centre*
India	Abled Fitness Foundation
Israel	AlManarah - www.almanarah.org
Japan	Independent Living Center Arc Spectrum - http://arcsp.sakura.ne.jp/
Lebanon	Forum Of The Handicapped In North Lebanon - www.theforum-lb.org*
Nepal	Center for Independent Living of Persons with Disabilities, CIL-Kathmandu - http://www.cil.org.np
	KOSHISH National Mental Health Self-Help Organization - www. koshishnepal.org

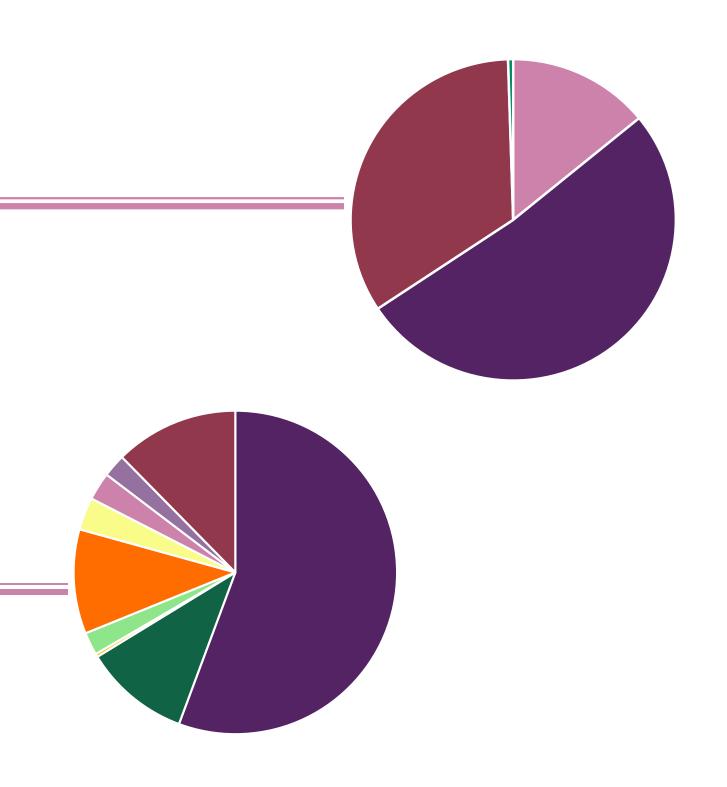
### **CHAPTER 5**

# FINANCIAL REPORT

EXPENDITURE 2023	2023
Services & other goods	87,247 €
Personnel	319,280 €
Projects & events	209,370 €
Financial costs	3,145€
TOTAL EXPENDITURE	619,043 €

INCOME	2023
European Union (Choice4All)	342,277 €
European Union (TRIPS)	65,151 €
European Union (LITI-GATE)	1,973 €
JINT (ESC)	13,996 €
Disability Rights Fund	64,200 €
Maribel Social Fund	20,000 €
University of Leeds	17,137 €
International Labour Organisation	14,091 €
Unrestricted funds (STIL Sweden, own funds, other donations)	76,051 €
TOTAL INCOME*	619,043 €

The income does not show the entire donation of 125,000 € from ULOBA, Norway in 2023, since this was paid into the account of ENIL Foundation. A total of 51,333 € from ENIL Foundation was used in 2023 to cover the cost of ENIL's work (included under unrestricted funds in the table above).



	2021	2022	2023
EXPENDITURE	343,068.00 €	643,347.35 €	619,043 €
INCOME	343,071.00 €	684,943.76 €	619,043€

#### **CHAPTER 6**

# **OUR TEAM**

(January – December 2023)

#### **Board members**

Nadia Hadad (Co-Chair, Belgium)

Jamie Bolling (Co-Chair, Sweden)

Radoš Keravica (Serbia)

Suela Lala (Albania)

Vibeke Marøy Melstrøm (Norway)

Tess van Deynse (Belgium)

Elena Kocoska (North Macedonia)

Ingrid Thunem (Norway)

Michael Holden (United Kingdom, until September 2023)

Mirko Tomassoni (San Marino, from October 2023)

#### **Staff**

Ines Bulić Cojocariu, Director

Florian Sanden, Policy Coordinator

Kamil Goungor, Policy and Movement Support Officer

Michael Goossens, Communications Officer and Digital Organiser

Stanislas Roisin, Finance Manager (part time)

Rita Crespo Fernandez, Human Rights Officer (from April 2023)

Aoife McGarry, Office and Events Coordinator (from April 2023)

Nataša Kokić, Campaign Coordinator (until March 2023)

Laura Alčiauskaité, TRIPS Project Coordinator (until March 2023)

Adela Santos Lavigne, LITI-GATE Project Coordinator

(from September 2023)

Lilia Angelova Mladenova, Consultant

Senior advisor (voluntary position)

Zara Todd (United Kingdom)

#### **Volunteers**

Fionn Crombie Angus (ESC volunteer, from October 2023)

Alexandrine Mas (June – August 2023)

Dr. Teodor Mladenov (Independent Living Research Network)

Nic Crosby (European Coalition for Community Living)

Frank Sioen (Independent Living training)

We wish to thank our outgoing staff, all our volunteers and Board members for their contribution to our work. We are, as ever, grateful to our members – ULOBA, STIL and GIL – for their continued generous support of our work, as well as to all other funders.

#### About ENIL

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

ENIL's vision is of Europe where all disabled people are able to exercise choice and control over their lives, on an equal level with others; where they are valued members of the community and can enjoy all of their human rights, as set out in the UN Convention on the Rights of Persons with Disabilities (CRPD).

ENIL's mission is to advocate and lobby for Independent Living values, principles and practices, namely for a barrier-free environment, provision of personal assistance support and adequate technical aids, together making full citizenship of disabled people possible. ENIL's activities target European, national and local administrations, politicians, media, and the general society. ENIL works to strengthen the empowerment of disabled people, mainly through providing resources for peer support and peer-to-peer training. ENIL enhances the European disability sector by providing an arena for the sharing of disabled people's experience of services and by providing economical, logistics and technical expertise on independent living. ENIL prides itself on providing a strong platform for grassroots activists and organizations.

ENIL is a pan disability organization, which means that we promote Independent Living for all disabled people. We work directly with disabled individuals, organisations (such as Centers of Independent Living), politicians, media, the business world and any individual or organization interested in learning about Independent Living history, values, principles and its practical application. We also work with non-disabled people and mainstream human rights organizations, whom we consider to be important allies to disabled people's rights movement.

#### Our main objectives are:

- To connect lived experience of disabled people across Europe to policy making at the EU level;
- To build the capacity of disabled people and disabled people's organizations to gain skills and confidence needed to lead change and advocate for their rights;

- To campaign for independent living, the full implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) in Europe, against poor practices, and to ensure that disabled people and disabled people's organizations are heard; and
- To champion disabled people's rights to have choice and control over their lives and to be part of their communities, through research, publications and toolkits.

We work on a selected number of areas, namely: Independent Living, deinstitutionalization, personal assistance, peer support, accountability in the use of funding, youth, disability hate crime, inclusive education and development cooperation. We use an intersectional approach and promote real co-production.

We strive to reach our objectives by carrying out four main types of activities:

- AWARENESS RAISING ACTIVITIES: these include the Freedom Drive, the European Independent Living Day on the 5th May, and the EU Funds for Our Rights Campaign.
- ADVOCACY ACTIVITIES: we target EU institutions, the Council of Europe, the United Nations treaty bodies and agencies, the national Governments and funders, through position papers, briefings, submissions, letters and meetings.
- CAPACITY BUILDING ACTIVITIES: these include seminars, conferences, study sessions, trainings, study visits, training modules, webinars, the leadership programme for young disabled people and the European Coalition for Community Living.
- 4. ANALYTICAL ACTIVITIES AND DATA COLLECTION: these include surveys, studies, fact sheets, manuals and toolkits, as well and the Independent Living Research Network.

### The European Network on Independent Living

The European Network on Independent Living (ENIL) is a Europe-wide network of disabled people. It represents a forum intended for all disabled people, Independent Living organisations and their non-disabled allies on the issues of independent living. ENIL's mission is to advocate and lobby for Independent Living values, principles and practices, namely for a barrier-free environment, deinstitutionalisation, provision of personal assistance support and adequate technical aids, together making full citizenship of disabled people possible.

ENIL has participatory status with the Council of Europe (i.e. is a member of the Conference of INGOs) and consultative status with ECOSOC.



enil.eu