

Annual Report 2023

European Network on Independent Living

Easy to Read Version



Co-funded by the European Union

Chapter one: ENIL's Main Achievements in 2023

1.1. Proposal for Independent Living Guidance in Europe

The situation: Access to independent living is different across Europe.

Problem: Over 1 million disabled people live in institutions or group homes, funded by the EU.

ENIL's Action: ENIL created a plan to help countries improve independent living rights.

Key Event: The plan was shared with the European Commission on May 4, just before European Independent Living Day.

1.2. Opportunities for Young Disabled People

High costs and lack of support make it hard for young disabled people to work in Brussels.

ENIL offered 6-month volunteer roles for young disabled people.

In 2023, three volunteers from Ireland and Italy joined.

The first volunteer, Fionn Crombie Angus, started in October.





1.3. Investing in New Leaders

ENIL helps young disabled people learn to be leaders.

For that purpose we have ENIL's Youth Leadership Program.

Four young women from Ukraine, Montenegro, Norway, and Italy participated.

They spent a week with disability rights groups in Finland, Ireland, Hungary, and Albania to learn about advocacy.



1.4. Expanding to New Areas

ENIL wanted to address new issues that affect independent living.

ENIL's New Focus Areas:

- Climate change and its impact on disabled people.
- Collaborations in Ukraine and the Middle East on independent living.
- Partnership with the International Labour Organisation on personal assistants' working conditions.



• Exploring future work on artificial intelligence and energy poverty.

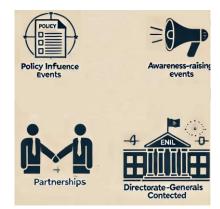
1.5. Work in Numbers

46 – Internal meetings with staff, volunteers, and board members.

- 23 Training and skill-building events.
- 90 Important meetings attended.
- 9 Policy influence events.
- 4 Awareness-raising events.
- 10 Partnerships formed.
- 5 Directorate-Generals regularly contacted.
- 15 Publications and position papers issued.
- 17 Consultations ENIL contributed to.

- 5 Surveys shared with the community.
- 17 Funding applications submitted.









Chapter two. Highlights by work area

2.1. Influencing Policy

ENIL worked on influencing policies to make Independent Living a reality for all disabled people in Europe.

2.1.1. Towards Strong Guidance on Independent Living

The European Commission is preparing new guidance for Member States on how to improve access to Independent Living.

ENIL published its proposal for this guidance after consulting with its Board and members.

On 4 May, ENIL presented this proposal in the

European Parliament during the European Independent Living Day.

At the event, we heard from:

- Members of the European Parliament (MEPs) like Stelios Kympouropoulos and Katrin Langensiepen.
- Officials like Katarina Ivanković-Knežević, the Director of DG Employment.

ENIL members from Spain and Belgium shared barriers to Independent Living in their countries.





ENIL met with officials, including the **Spanish Office for the Rights of Persons** with **Disabilities**, during Spain's EU Council Presidency.

We also gathered examples of good practices to include in the guidance, focusing on:

- Centres for Independent Living.
- Personal Assistance user cooperatives.

Articles about ENIL's proposal were published in:

• Social Europe.

- Scial Europe
 Centre for logendent Living
 Personal Assistance

 Scial Europe
 Centre for logendent Living
 Personal Assistance
- The Foundation for European Policy Studies.

2.1.2. Supporting EU Review by the CRPD Committee

ENIL submitted a **shadow report** to the CRPD Committee about the implementation of the UN CRPD in the EU.

In January 2023, ENIL participated in a consultation meeting with the European Commission to discuss their report to the CRPD Committee.

Unfortunately, the review of the EU's report was postponed until **2025** due to delays at the CRPD Committee.



ENIL plans to update its shadow report in **2024**, and submit it in February **2025**.

In December 2023, ENIL published a **thematic briefing** about how EU funds impact disabled people.



2.1.3. Helping to Shape the New Framework for Social Services of Excellence

ENIL is contributing to the **EU Framework for Social Services of Excellence**, part of the European Disability Rights Strategy.

We organised a webinar in July 2023 to gather input from:

- ENIL members.
- Academic experts.

The proposal focuses on key principles like:

- Peer support.
- Accessibility.
- The "Five As": availability,



accessibility, acceptability, affordability, and adaptability.

ENIL finalised the proposal in December 2023. It will be launched in **2024** in the European Parliament.

2.1.4. Exposing the Role of State Aid in Funding Institutions

ENIL investigated how **state aid** (public funding) supports institutions for disabled people.

We focused on **Germany** and **Portugal**, where state aid plays a major role.

A case study was published in December 2023, and will be presented to the European Commission in **2024**.

2.1.5. Proposing Changes to the European Disability Card

ENIL worked on improving the **European Disability Card** to increase freedom of movement in the EU.

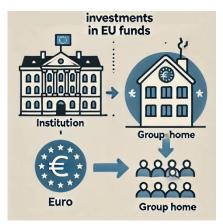
On **5 May**, ENIL submitted recommendations during a public consultation by the European Commission.

ENIL's response included:

- 1. Calls for a more ambitious approach.
- 2. Concrete amendments, shared with:
 - Members of the European Parliament, and
 - national governments.

Articles about this work were published in **Social Europe**.





2.1.6. Advocating for Disability Inclusive Youth Policies

In January, ENIL met with the Youth Department of the Flemish Government

to discuss accessible youth events.

In October, ENIL shared recommendations with the European Commission to make **youth programmes** more inclusive.

Our **Policy and Movement Support Officer**, Kamil Goungor, shared his experience as a volunteer and explained ENIL's work.



2.1.7. Resisting the Care Agenda

ENIL worked against the **Care Agenda**, which threatens Independent Living by promoting care instead of support.



2.1.8. Voting Rights for All

ENIL collaborated with the **Validity Foundation** and law firm **Covington & Burling** to identify cases of discrimination in voting rights.

In October, ENIL organised a webinar to raise awareness about voting barriers for disabled people.



We launched a **survey** on political participation, which informed a summary report published in December.

2.2. Raising Awareness

2.2.1. European Independent Living Day

Every year, 5 May is European Independent Living Day.

In 2023, it was the **10th edition** of this important day.

Many events were held by:

- ENIL members.
- Disabled people's organisations (DPOs).
- Service providers.
- Governments across Europe.



ENIL organized two events:

- 4 May: We presented our proposal for the European Commission's Guidance on Independent Living at the European Parliament.
- 5 May: We hosted a webinar to share findings on personal assistance access with the policy and disability community.



This day is a key moment to raise awareness about the **right to Independent Living**, even though it should be respected every day.

2.2.2. Independent Living and Climate Change

In 2023, ENIL began working on the **impact of climate change** on Independent Living.

We wrote a **Position Paper** on this issue, which will guide our future activities.

We attended climate-related events, including:



- **Disability and Climate Action Caucus**, led by the International Disability Alliance.
- UN Disaster Risk Reduction meetings, to share how disabled people are affected by disasters.

- European Climate Stocktake, learning about global progress on the Paris Agreement.
- An event by the EU Agency for Fundamental Rights (FRA), where ENIL's Policy Officer spoke about the impact of climate change on disabled people.
- ENIL joined the European Alliance for a Just Transition, working for a fair and inclusive response to climate change.



2.2.3. Supporting Advocacy in Ukraine

ENIL increased its work in Ukraine, focusing on deinstitutionalisation.

Our Human Rights Officer, Rita Crespo Fernandez, led many of these activities.

We collaborated with organisations like:

- European Disability Forum.
- Save the Children.
- UN Human Rights Mission in Ukraine.



In April, we supported a **Study Visit** for the Ukrainian government to learn about deinstitutionalisation in the UK.

ENIL had regular meetings with partners like Fight for Right and Disability Rights International to discuss:

- Developments in Ukraine.
- Support needs.
- Strategies for recovery.



Together with partners, we released a **joint statement** calling for deinstitutionalisation to be included in Ukraine's recovery efforts.

2.2.4. Promoting Independent Living Everywhere

ENIL shared the message of Independent Living at events and meetings:

- January: We spoke at an exchange forum in Montenegro.
- **April:** ENIL gave a lecture to students at the Free University of Brussels about how we influence policy.
- June: ENIL participated in an event in North Macedonia, organized by the First Lady, to explain Independent Living.
- October: We met with the European
 Commission's Disability Unit to discuss the
 upcoming Guidance on Independent Living.



ENIL contributed to workshops, awards, and reports:

- We helped review good practices for the Zero Project and the European Social Services Award.
- ENIL members spoke at conferences in Zagreb and Brussels.
- We gave feedback on reports and surveys about disability rights, transport, and youth needs.

ENIL participated in the **Disability Platform**, which monitors the European Disability Rights Strategy.

We re-joined the **Facing the Facts network** to work on hate crime initiatives.





2.3. Capacity Building

2.3.1. Providing Technical Assistance on Deinstitutionalisation

ENIL helped the Government of Malta with technical support on personal

assistance and deinstitutionalisation.

This meant helping Malta close down institutions and move toward independent living.

In March, we had a visit from Julia Farrugia **Portelli**, the Minister for Inclusion, Voluntary Organisations, and Consumer Rights, and





They came to ENIL's office in Brussels to talk about setting up a good personal assistance system and finding alternatives to institutions.

In **September**, we met with the Minister and representatives from **Agenzija Sapport** (Malta's disability services) and the Maltese equality body.

- We discussed the deinstitutionalisation process in Malta.
- ENIL said no new funds should be used to create more institutional care.
- We stressed that institutions should be closed, not expanded, even if disabled people or their families ask for more beds.

In January, we learned that a project to create a deinstitutionalisation network in Lebanon and Palestine received funding from the UK Research Council.

ENIL is represented by our Co-chair **Nadia Hadad**, who attended several meetings about this project during the year.

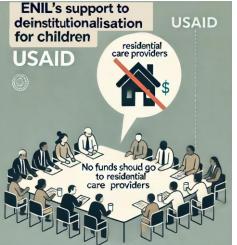
In July, we joined a meeting organised by USAID.

- The meeting discussed the language used in calls for deinstitutionalisation for children.
- We made sure that no funds should go to residential care providers, even if they promise to close their institutions.

In **July**, we also had a meeting with the **Spanish EU Council Presidency** to talk about independent living and deinstitutionalisation.







On 9 November, ENIL published an Open Letter about abuses in Slovenia's institutions for disabled people.

- We sent the letter to relevant Ministries, the European Commission, and the European Parliament.
- Only the European Commission replied.



In October, ENIL published and shared an **Explainer** about the **Guidelines on Deinstitutionalisation**, including in emergencies.

- This Explainer made the complex parts of the document easy to understand.
- We also helped translate the Guidelines into German, working with the German Human Rights Institute.
- This translation and others are available on the Committee's website.



2.3.2. Regional Members' Meeting in Portugal

ENIL organised the Regional Members' Meeting in Portugal on 14-15 September.

Our **Portuguese members** from **Centro de Vida Independente** helped us organise the meeting.

The meeting took place at **Matosinhos** city. Matosinhos is next to Porto.

Matosinhos is a good example of how to support **independent living** for disabled people.

We learned how the town helps disabled people **work**, **move freely**, and be part of the community.

11 countries joined the meeting:

Albania, Belgium, France, Germany,
 Greece, Italy, Malta, North Macedonia,
 Portugal, San Marino, Spain, and Norway.

Members from these countries shared updates from their countries and learned about ENIL's work.

They also gave suggestions for future activities.





Day 2 focused on Personal Assistance:

- We learned about personal assistance projects in **Portugal** and **Greece**.
- Nicolas Joncour, a Youth Board member, shared his experience of Personal
- Assistance as an autistic person.



Another meeting took place after the European Parliament of Persons with **Disabilities** on **23 May** at ENIL's office.

- ENIL staff and members exchanged information about their work.
- Elena Kochoska, from the ENIL Board, led the discussion.



2.3.3. DI Guidelines Training for the CRPD Monitoring Body

ENIL worked together with the Center for Independent Living Innsbruck (CIL Innsbruck) to provide training for the Tyrolean CRPD Monitoring Committee.

The training was based on the **UN Guidelines on Deinstitutionalisation**, including in emergencies.

The training took place from **14–16 June** in **Innsbruck**.

ENIL Director Ines Bulić Cojocariu gave a presentation and led a workshop during a one-day open event for the **CRPD Monitoring Committee** members.

The meeting had many people:

- Members of the Committee.
- Disabled people.
- Survivors of institutionalisation.
- Service providers.

The event was **fully accessible**, with translations in **English**, **German**, and **Easy to Read**.



We also visited **CIL Innsbruck** and some of the **renovated institutions** funded by the EU around Innsbruck.

We could only see the buildings from the outside because we didn't have permission to enter.

2.3.4. Mutual Exchange Webinars on Deinstitutionalisation

ENIL organised **three webinars** to help governments, service providers, and disabled people learn how to make deinstitutionalisation reforms that follow the **CRPD**.

29 March. The first webinar was with ENIL and ECCL.

We talked about how to promote deinstitutionalisation.

We heard from:

- **Cool Crips** from **Greece**, who organise successful social media campaigns.
- A journalist from Slovenia, who provides information in accessible formats.

28 October. The second webinar focused on:

- The "Stay Up Late Campaign" from our
 ESC volunteer Fionn Crombie Angus.
- Kristin Torske from ULOBA presented a project on supported decision-making in Norway.
- YHD from Slovenia shared the Personal
 Assistance Handbook.





The third webinar was called "Getting People Out" and focused on:

- Japan's action plan on deinstitutionalisation.
- Experiences of closing institutions in Slovenia.
- A presentation from Starfire Council on creating alternatives to day care centres in the US.



End-of-Year Webinar Recording

At the end of the year, we also shared a webinar recording from 2021.

This was organised with **MDRI-Serbia** and focused on **personal assistance for adults with intellectual disabilities**.

The recording includes practical examples from **Sweden**, **Netherlands**, **Belgium**, and the **UK**.



2.3.5. Peer Support for Personal Assistance Users

Monthly meetings of the Personal Assistance Users Club (PAUC) were held online throughout the year.

The meetings were led by **Alessandra Grotta** and attended by about **ten disabled people** who use Personal Assistance from different countries in **Europe**.



The meetings discussed different topics related to being a **Personal Assistance employer**, like:

- Recruitment
- Conflict resolution
- Advertising

Meeting Topics:

In **September**, the group talked about:

"Do we have/need standards of peer counselling for PA users?"

In **October**, the group watched and discussed movies from the **Superfest Disability Film Festival**.



We also wrote an article about **PAUC** and ENIL's work on **peer support**.

This article was shared in the **Disability Rights Defenders newsletter**.

The newsletter featured many articles written by **Independent Living activists** from across Europe.



2.3.6. Capacity Building on Personal Assistance

ENIL is a leading organisation on **personal assistance** and the **right to independent living**.

We continue to receive requests, queries, and study visits.

Visits and Meetings:

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



21 March: We met with a delegation from the
 Eudajmnia Foundation in Poland, House
 Under the Nuts, and Fonix from Norway.

The meeting focused on **ENIL** and the **Freedom Drive**.

Italy.

28 March: Kamil Goungor spoke at a meeting called "**Inclusive** Education for an Inclusive Europe" in Monza,

Kamil talked about **inclusive higher education** and **mobility**, covering both **formal** and **non-formal** education.

 26 April: Kamil Goungor gave a guest lecture at Maynooth University in Ireland.

He talked about **independent living**, ENIL, **i-living Greece**, and our advocacy work.

 27 April: Nadia Hadad and Kamil Goungor shared their experiences at the launch of the EDF Human Rights Report on Employment.

They talked about the barriers and positive examples in **employment for disabled people**.









25 May: Flora Kalemi from the Albanian
 Disability Rights Foundation visited
 ENIL's office in Brussels.

The meeting was about their work and possible collaboration, especially on the **EU accession process**.



• **26 June**: ENIL supported **CHA**, our French member, in organising a conference on **Personal Assistance in France**.

The conference was held in **English and French**.

Ines Bulić Cojocariu presented on the implementation of Article 19 and the situation in Europe.

 1 October: Kamil Goungor represented ENIL at the EAMDA International Conference in Bucharest, Romania.

He gave a workshop on **personal assistance** and its importance for people with **neuromuscular disorders**.





5 October: ENIL held an online workshop on "Advocacy for Disability-Led Independent Living Policy" in Armenia.

We introduced models of **personal assistance** and **pilot projects** from Europe.

We also presented ENIL's Personal Assistance Checklist.

3 November: Jamie Bolling and Kamil Goungor spoke at a conference on personal assistance in Valencia, Spain. EU Laws and Policies

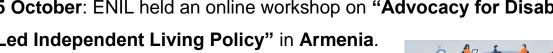
They presented the Swedish Personal Assistance model and EU laws and policies relevant to **Independent Living** and **Centres** for Independent Living in Europe.

20-26 November: Ines Bulić Cojocariu and Kamil Goungor visited

Yerevan, Armenia for an Independent Living/Personal Assistance Expert Visit and Training of Trainers.

They met with the **Armenian** government, UN bodies, and DPOs.

They also co-facilitated a **3-day** workshop on the basics of **Independent** Living and Personal Assistance.









29 November: Kamil Goungor spoke at an
 EDF event in Brussels for youth.

He talked about the **Freedom Drive** and how **technology** and **social media** help **youth disability activism**.

 11 December: ENIL organised a webinar on Erasmus+ opportunities for our members.

We heard from members who have implemented **Erasmus+ projects** and shared ideas on applying for funding.

Florian Sanden, ENIL's Policy Coordinator, supported our member,
 EUCAP, in setting up a policy working group.

This group aims to improve their **advocacy at the EU level**.

Florian also spoke with Kenneth Westberg from the Independent Living Institute about ENIL's work at the European level.

Articles about this work were published on the **ILI's website**.





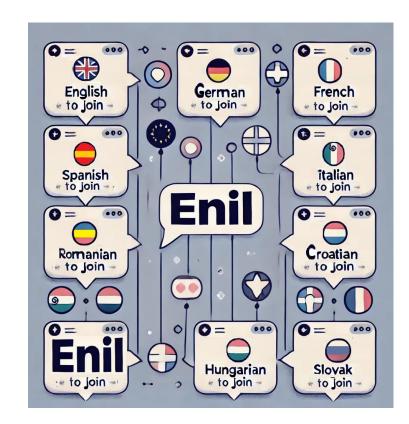


2.4. COMMUNICATION AND DISSEMINATION

2.4.1. Membership Campaign

ENIL wanted more people to learn about ENIL and the benefits of joining. We shared posts on **social media** in **nine languages**:

- English
- German
- French
- Spanish
- Italian
- Romanian
- Hungarian
- Slovak
- Croatian



Each post had a link so people could join easily.

2.4.2. Storytelling

We made short videos to raise awareness about **Independent Living** through the stories of disabled people.

These videos were made by **Michael Goossens**, our **Communications Officer** and **Digital Organiser**.

Here are the videos we created:

- Empowering Independence: A Day in the Life of a Personal Assistance User
- Interview with Rhoda Garland, the Maltese Commissioner for the Rights of Persons with Disabilities
- Disabled People Protest in Belgium for Personal Assistance
- Pleading for Independent Living
- MEP Katrin Langensiepen:
 I Want More People in the European Parliament



2.4.3. Podcasts

We recorded **three podcasts** about the **EU elections** happening in **June 2024**.

The podcasts include interviews with:

 Stelios Kympouropolous, a Member of the European Parliament



• Niamh Ni Hoireabhaird and Antonella Candiago, two disability activists

The podcasts were made by **Michael Goossens** and **Florian Sanden**, ENIL's **Policy Coordinator**.

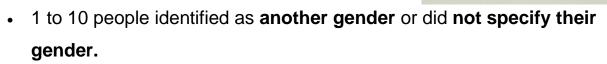
They were launched in **December**.

2.4.4. Members' Mailing

We sent out **twelve issues** of the **Members' mailing** each year, in the middle of the month.

The mailing was sent to **872 email addresses** each month.

- Almost 5 to 10 of the recipients were female
- A 4 to 10 people were male





The most common age group was **35-44** years, followed by **25-34** years. The opening rate of the mailing was **39%**.

This means almost 4 to 10 people opened the emails.

The top locations were **the Netherlands**, **Bulgaria**, and **Greece**.

2.4.5. ENIL Newsletter

We published **twelve issues** of the **ENIL Newsletter** at the end of each month. The newsletters were edited by **Michael Goossens**, and articles were written by:

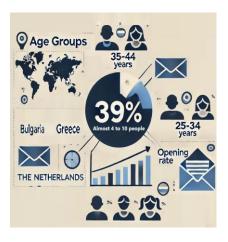
- ENIL staff
- Board members
- ENIL members
- Outside contributors

The newsletters were sent to **1,088 email** addresses each month.

- Almost 5 to 10 of the people were female
- Almost 4 to 10 were male
- More than 1 to 10 identified as another gender or did not specify their gender.







The most common age group was 45-54 years, followed by 35-44 years.

The opening rate of the newsletter was 40%.

This means 4 to 10 people opened the emails.

The top locations were **the Netherlands**, **Ireland**, and **Bulgaria**.

2.4.6. Social Media

ENIL was active on **social media**:

- Facebook:
 - 62,490 people reached
 - **8,222** profile visits
 - 235 new likes
- Instagram:
 - o 20,492 people reached
 - 2,024 profile visits
 - 216 new followers







- X (formerly Twitter):
 - 92,112 people reached
 - 124 new followers
- LinkedIn:
 - 717 reactions
 - 591 page views
 - o 328 new followers





2.5. TOP CAMPAIGN: EU FUNDS FOR OUR RIGHTS

2.5.1. Cooperation with other groups

EU Funds for Our Rights Campaign

The EU Funds for Our Rights campaign continued in 2023. Rita Crespo Fernandez, our new Human Rights Officer, leads the campaign.

She took over from Nataša Kokić.

During the year, we collected information from our members. We learned how EU funds are used. Some funds are used to build institutions.

Other funds are used to help more people get personal assistance.



Concerns about EU Funds

We found out that EU funds are being used to finance institutions in Spain and Poland.

We have started working on complaints about this.

We also worked with other organisations to find solutions and fight against the misuse of EU funds.

Working with the European Commission

ENIL is part of the CPR Expert Group. In June, we attended a dialogue with the European Commission.

We shared our concerns about EU funds being used to finance institutions for disabled people.

Webinars on EU Funds

In September, ENIL co-organised a webinar called "Stop Discrimination in EU Funds" with Bridge EU and other groups. In November, we co-organised a second webinar: "Stop Discrimination in EU Funds: The Role of Fundamental Rights Bodies." We shared our work on misusing EU funds and their role in deinstitutionalisation.







Feedback to the EU Fundamental Rights Agency (EU FRA)

ENIL gave feedback to the EU FRA. In December, the agency published a report on EU funds and human rights.

On 13 December, we spoke about the problems that Disabled People's Organisations (DPOs) have when accessing EU funds.

Working with Other Organisations

We also worked with the European Community of Practice. Our members from Portugal and Croatia shared their experiences of Personal Assistance schemes funded by the European Social Fund.

EU Funds Helpdesk Project

ENIL is part of the EU Funds Helpdesk Project. We joined three workshops.

We also gave suggestions on how to make sure EU funds support independent living.







2.5.2. Complaints and requests for information

In March, we received a decision on our complaint about EU funds for institutions for children in Austria. The decision said no violation was found, but we kept asking for more information. This means the European Commission said there was no violation of the EU Fundamental Rights Charter.

In April, we sent more information to the European Commission.

This included reports about human rights and points that we disagreed with in their decision.

Unfortunately, the appeal was unsuccessful, and the complaint was closed.

In November, we sent a Freedom of Information request. We asked for documents between the European Commission and the Managing Authority about this issue. We got the documents we requested.



In November, we sent another request for information. This time, we asked how the European Commission checks if the requirements for funding are being met. We still haven't received an answer by the end of 2023.

2.5.3. Giving feedback to the European Commission

We answered two consultations in **June**.

One was about the **Resilience and Recovery Fund**, and the other was about **funding outside the EU**.

In **October**, we gave feedback on the **Regional Development Fund**. We told the EU about the money being spent on **institutions** and suggested actions to stop it.



2.5.4. Promoting Independent Living worldwide

In July, Esma Gumberidze from the ENIL Youth Network spoke for ENIL at the High-Level Political Forum in New York. She shared the views of disabled youth.

ENIL sent a written statement to the High-Level Segment of the Economic and Social Council. In our statement, we talked about how COVID-19 affected

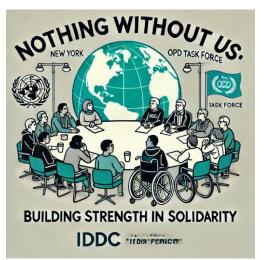
disabled people. We pointed out that recovery efforts after the pandemic used money for segregation instead of inclusion.

In the 75th Anniversary of the Universal Declaration of Human Rights, Nadia Hadad, our Co-chair, spoke at an event in Brussels, organised by the UN OHCHR.



In December, ENIL was invited to a meeting in New York called "Nothing Without Us: Building Strength Through Solidarity." Kamil Goungor represented ENIL.

ENIL was elected to lead the OPD Task Force in the International Disability and Development Consortium (IDDC) starting in 2024.



Although ENIL is not a member of IDDC, we have been active for many years. Nadia Hadad, our Co-chair, is an expert in disability inclusive development.

2.5.5. Promoting Deinstitutionalisation Guidelines

In 2023, ENIL continued to focus on promoting the CRPD Committee's Guidelines on Deinstitutionalisation, including in emergencies.

These guidelines were adopted at the end of 2022. They are very important for guiding the reform of institutions in Europe and other parts of the world.

ENIL worked within the Global Coalition on Deinstitutionalisation (GC-DI) and also carried out other activities.



Key Activities:

From 23-25 January, ENIL attended the first face-to-face meeting of GC-DI in

Mexico City. This meeting was funded by the Disability Rights Fund.

The first two days were about planning for the future. On the third day, ENIL met with the Inter-American Coalition on Deinstitutionalisation.

The Vice-Chair of the CRPD Committee, Amalia Gamio, also joined the meeting.

Together with **GC-DI**, ENIL **submitted a joint submission** about the **General Comment on Article 11** of the CRPD. This submission focused on the Guidelines and was presented to the CRPD Committee in a private meeting on **17 March** in **Geneva**.

GC-DI also worked together to respond to a call from **USAID**, which aims to support deinstitutionalisation in **Ukraine**. ENIL and other partners signed a letter sent by **Disability Rights International** to **USAID**, supporting deinstitutionalisation efforts in Ukraine.





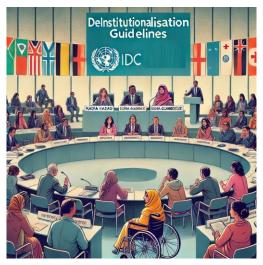


2.5.6. 16th Conference of States Parties in New York

In **June**, ENIL attended the **16th Conference of States Parties** in **New York**. ENIL was represented by our Co-Chair Nadia Hadad and Esma Gumberidze, from the ENIL Youth Network in Georgia.

Esma made statements during the General Debate and the Civil Society Forum.

Nadia Hadad spoke on behalf of the International Disability and Development Consortium (IDDC) during the General Debate. She also spoke at a side event on forced sterilisation on behalf of the European Disability Forum (EDF).



During the Conference, Nadia Hadad had meetings with important people:

- Ms Alessandra Locatelli, Italian Minister 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
- Marion Lieser from Light for the World
- Charlotte McClain-Nhlapo, Global Disability Advisor at World Bank Group
- Carlos Espinosa, from Human Rights Watch and the Inter-American Coalition on Deinstitutionalisation.

ENIL also organised a **side event** on **Deinstitutionalisation Guidelines** and had a meeting with representatives from **Malta** and the **CRPD Committee**.

A survivor of institutionalisation from India joined us to speak at the event.

It was a successful event with many people attending.

Our goal was to raise awareness about the Guidelines and the right to independent living.



2.5.7. 29th session of the CRPD Committee in Geneva

In August, ENIL went to the 29th meeting of the CRPD Committee in Geneva.

We helped to organise and took part in a special session for the 1st Anniversary of the Guidelines on Deinstitutionalisation. This session was organised by the CRPD Committee Secretariat. Rita Crespo Fernandez represented ENIL.



Before the session, ENIL worked on two reports:

- A shadow report on Hungary following up on the CRPD Committee's request.
- A shadow report on the United Kingdom with our members from the UK.

During the meeting in Geneva, we had many important discussions.

ENIL met with decision-makers from:

- the World Health Organization (WHO),
- the International Labour Organization (ILO),
- ATScale, and
- the Office of the High Commissioner for Human Rights (OHCHR).



ENIL also met with different members of the CRPD Committee and Disabled People's Organisations (DPOs).

2.6. YOUTH FOCUS

2.6.1. ENIL Youth Network

ENIL Youth Network had a study session for young people from 12 to 16 June at the European Youth Center in Strasbourg.

This was supported by the Council of Europe Youth Department.

The theme of the session was "CRIP CAMP: Disability Rights in Times of Conflict and Calamity".

The Youth Network Board met online every month.



On 2 December, the board had a meeting in Brussels.

This meeting was joined by:

- Martine Eliasson from ULOBA (Norway)
- Fionn Crombie Angus, ESC volunteer
- Jessica Nguyen, European Youth Forum

This meeting was held after European Day of Persons with Disabilities.



In August, Youth Board members spoke at Camp Freedom, organised by ULOBA.

In June, Nicolas Joncour (France) and Esma Gumberidze (Georgia) spoke at the Centre for Disability Law at NUI Galway Summer School.

They talked about children's disability rights.



2.6.2. Youth Leadership Programme

ENIL restarted the Youth Leadership Programme.

This programme helps young disabled people join human rights work.

Four organisations helped with the programme:

- Threshold (Finland)
- Independent Living Movement Ireland (Ireland)
- Validity Foundation (Hungary)
- Foundation "All Together Now" (Albania)

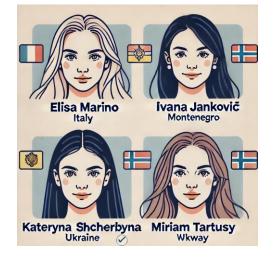
These organisations hosted one young disabled person for one week.

The young people could learn from staff by shadowing them.

In June, we selected four young women for the programme:

- Elisa Marino (Italy)
- Ivana Janković (Montenegro)
- Kateryna Shcherbyna (Ukraine)
- Miriam Tartusy (Norway)

Many young people wanted to join, but we could only accept four participants.



We selected those who had not had many chances before.



In October, the programme started.

The first participant from Ukraine visited Finland.

The Norwegian participant visited Albania, the Italian participant visited Ireland, and the Montenegrin participant visited Hungary.

While at their organisations, the participants learned about the work and joined in activities.

We ran a social media campaign during the programme.

Each young person shared their experience.

On 12 December, we had a webinar.

The participants spoke about their experiences.

They also compared disability policies in their home countries with those in the host countries.







2.7. RESEARCH

2.7.1. Independent Living Research Network (ILRN)

In April, the Special Issue on Independent Living was published in the International Journal on Disability and Social Justice.

This special issue is called "Independent Living in Europe and Beyond: Past, Present, and Future". It was made by ENIL and the Centre for Disability Studies at the University of Leeds. Dr. Teodor Mladenov led the project, and he is the coordinator of our Independent Living Research Network (ILRN).

The special issue includes:

- An editorial by Dr. Mladenov
- 5 full-length articles
- 3 current issue bulletins
- Easy-to-read summaries of all the articles
- 12 interviews with leaders of Independent Living



From 10-12 May, ENIL joined 700 disability researchers, academics, and activists at the Nordic Network on Disability Research conference in Reykjavik, Iceland. Together with Dr. Teodor Mladenov and our Icelandic members from NPA, ENIL organised a session titled "Independent Living in Europe and Beyond: Past, Present, and Future". We presented the work done in the International Journal of Disability and Social Justice and showed a video of interviews with Independent Living activists. From 14-15 February, several members of the Independent Living Research Network (Radoš Keravica, Laura Alčiauskaite, and Lazar Stefanović) presented at a conference in Lebanon called "Transition Towards Independent Living Within the Community for Persons with Disabilities."

This conference was organised by the UN ESCWA, the Government of Malta, and the UN Special Rapporteur on the Rights of Persons with Disabilities.

ENIL helped European researchers take part in this important event.

Finally, Dr. Teodor Mladenov and our Co-Chair Nadia Hadad represented ENIL in the Advisory Group of the UNIC Project on personal budgets.

This project was led by EASPD, and ENIL gave feedback on the project and at the final conference.

2.7.2. Independent Living Survey

On 5 May, we held a webinar about the **Independent Living Map**. This included a new chapter on **access to personal assistance**.

Elena Pečarić wrote an article about how **personal assistance** works in **Slovenia** based on her talk at the webinar.



REPOR

Personal Assistance





We sent copies of the **summary report** to policy makers in the **EU institutions**. In 2023, we started a **survey** on **political participation**.

This survey focused on how people with disabilities take part in the **European elections**.

A summary report was published in December.

2.8. PROJECTS

2.8.1. New Projects

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

This is ENIL's main project. It helped ENIL pay for the core expenses and many activities in this report.

The project received funding from the European Union (Citizens, Equality, Rights and Values Programme – CERV) and our members ULOBA (Norway), STIL and GIL (Sweden).

Website: https://enil.eu/project/choice4all





European Solidarity Corps

ENIL got a Quality Label for hosting ESC volunteers. This gave us money to host three new volunteers in 2023 and 2024. We recruited three young disabled people:

- Fionn Crombie Angus (Ireland)
- Michael Brennan (Ireland)
- Francesca Spanghero (Italy)

Fionn, a young man with intellectual disabilities, was the first volunteer to join us in October 2023. He is the first ESC volunteer with intellectual disabilities and the first post-Covid volunteer.



Fionn was supported by ENIL's office, and we received money to hire a part-time personal assistant for him outside office hours.

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

The LITI-GATE Project, led by Victim Support Europe, started in September 2023 and will run for two years. Some of the first activities included:

- Creating a project leaflet that is easy to read
- Starting research in Hungary, the Czech Republic, Romania, Slovakia, and Bulgaria

Based on the research, partners began developing a guidebook on strategic litigation and accessible information about legal and support services.

Website: https://enil.eu/project/liti-gate/



2.8.2. Projects ending in 2023

Global Coalition on Deinstitutionalisation Project

ENIL led the project funded by the Disability Rights Fund/Disability Rights Advocacy Fund. The project supported the work of the Global Coalition on Deinstitutionalisation from June 2022 to April 2023.

ENIL worked with other groups like the International Disability Alliance, Inclusion International, and Validity Foundation.



The project helped translate the Guidelines on Deinstitutionalisation, including in Emergencies, into many languages, including Easy to Read.

Website: http://www.gc-di.org/

TRIPS Project – Transport Innovation for Disabled People

The TRIPS project ended in March 2023 after three years.

The project created the Lecco Declaration for Accessible and Inclusive Public Transport, signed by cities, transport providers, and other groups.

The project also produced the TRIPS Co-design For All course and toolkit, and the Mobility Divide Index website. Website: https://trips-project.eu/deliverables/



Entrepreneurship for All – EntreAll Project

The EntreAll Project finished at the beginning of 2023.

It created resources to help young disabled people start their own businesses.

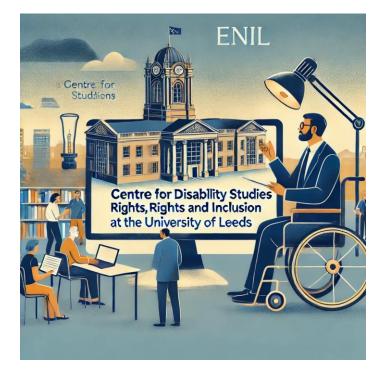
[Website: https://enil.eu/project/entreall/]



Partnership ENIL – Centre for Disability Studies at the University of Leeds

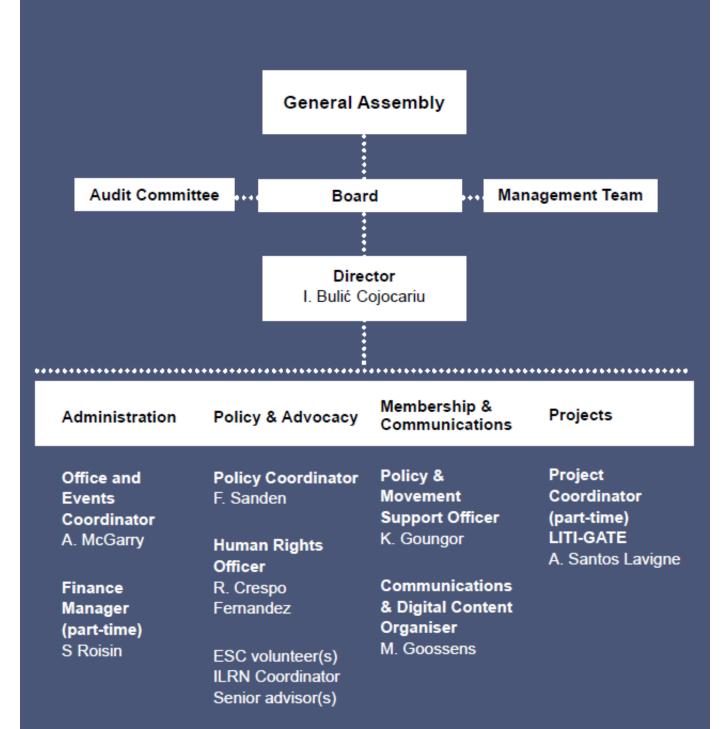
The partnership with the University of Leeds ended in October 2023.

Kamil Goungor helped develop an online Masters programme in Disability Studies, Rights, and Inclusion, which launched in 2023.



Chapter Three. Our structure

ENIL Organisational Structure



3.1. ENIL SECRETARIAT IN 2023

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

Two staff members left the organisation:

- Nataša Kokić (Campaign Coordinator) left in December 2022.
- Melike Ergun Yilmaz (Office Assistant) left in February 2023.

In February 2023, ENIL hired two people:



- Rita Crespo Fernandez became the Human Rights Officer.
- Aoife McGarry became the Office and Events Coordinator.

Both Rita and Aoife started on 1 April 2023. They work full-time at the Brussels office. Kamil Goungor finished working one day per week at the University of Leeds at the end of October. He returned to working full-time at ENIL.

Some staff finished their work with ENIL:

- Laura Alčiauskaite finished in March 2023.
- Lilia Angelova Mladenova finished in December 2022.

ENIL hired a new consultant in September for the LITI GATE Project:

• Adela Santos Lavigne, a lawyer from Spain, works remotely on this project for 24 months.

ENIL also had two volunteers:

- Alexandrine Maas from France joined in the summer for 2 months.
- Fionn Angus Crombie joined as an ESC volunteer in October for 6 months.



ENIL had a staff meeting in Brussels on 23-24 March to plan activities for the year.

In July, ENIL organised a staff training day about Independent Living.

During the training, staff learned about ENIL's work and positions.

They also heard from one of ENIL's founders, John Evans OBE, about ENIL's history.

Dr. Teodor Mladenov spoke about the global Independent Living movement.

The training helped staff defend ENIL's positions.



3.2. GOVERNANCE

The ENIL Board met four times in 2023.

- Three meetings were online: 6 March, 12 June, and 11 December
- One meeting was in person in Porto on 13 September.

During each meeting:

- ENIL Director acted as the Secretary.
- The ENIL Youth gave a report.
- There was a report on ENIL's work in EDF.

Changes in the Board:

- Michael Holden left the Board before the September meeting due to other commitments.
- Mirko Tomassoni from San Marino joined the Board in December.

In September:

- The Board decided to update its Terms of Reference.
- The Director was asked to create a document on how to increase Board engagement.





Meetings in June and December:

- The Board held the General Assembly in the Brussels Office.
- They approved important documents:
 - Reports for previous years.
 - Work plan and budget for the next year.



The Board also worked with the ENIL Secretariat:

- The Management Team included the two Co-Chairs, Jamie Bolling and Nadia Hadad, and the ENIL Director.
- The Management Team met every month to make decisions about:
 - Human resources
 - Funding
 - Partnerships
 - ENIL's activities



3.3. ORGANISATIONAL AND FINANCIAL MANAGEMENT

The Audit Committee met three times in 2023: 21 February, 5 June, and 10 October.

The Finance Officer acted as Secretary for the Audit Committee. Before each meeting, the Finance Officer shared the financial reports.

Michael Holden stepped down from both the Board and the Audit Committee.He was replaced by Elena Kochoska, who joined other members: Jamie Bolling, Patrick Wauters, and Dimitris Karanastasis.



ENIL worked with an external auditor and a bookkeeping company from February to April to complete the audit. The audit was completed successfully in May.

After the audit, ENIL switched to a new bookkeeping company, GV&A, which has more experience with EU-funded projects.

On 16 June, ENIL passed a monitoring visit by JINT (National Agency for Erasmus+). The visit focused on ENIL's ESC projects in 2020 and 2021.

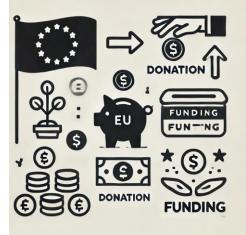


The Social Protection Institute of the Republic of Slovenia was chosen to do an evaluation of ENIL's "Choice for All" Project (2022-2023). The evaluation report was finished in November and shared with the Board on 11 December.

3.4. FUNDING

In 2023, ENIL received money to carry out its work:

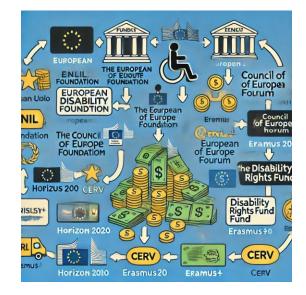
- The European Union funded the Choice4All Project.
- Our member ULOBA in Norway gave us most of the co-funding through the ENIL Foundation.
- We also received money from our members in Sweden – STIL and GIL, and from the Maribel subsidy.



In addition, we got support from:

- The European Union through Horizon 2020, Erasmus+, and CERV.
- The Disability Rights Fund.
- The Council of Europe Youth
 Department for a study session.

At the end of the year, we got a small grant from the **European Disability Forum** for a project on **Artificial Intelligence**.



Partnerships and Projects

- Many organisations asked ENIL to join their funding applications.
- ENIL decided to apply for some projects on its own.

We are part of these projects:

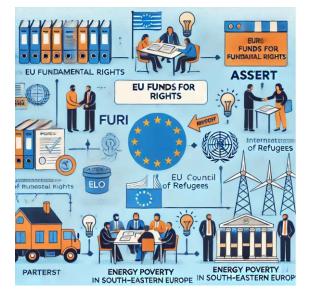
- FURI (EU funds for fundamental rights) This project is led by the Greek Council of Refugees and coordinated by Bridge EU. It was approved and will start in March 2024.
- ASSERT This project is about energy poverty in South-Eastern Europe. It was submitted by Aisfor in Italy and will start in October 2024.

We also applied for and received approval for a study session in 2024 with

CEJI – A Jewish Contribution to an Inclusive Europe, approved by the

Council of Europe Youth Department in March.

In 2024, ENIL was asked by the International Labour Organization (ILO) to write a report and fact sheet on personal assistance. This report will talk about personal assistance schemes, benefits, working conditions, and training.



Chapter four. Membership

ENIL Membership in December 2023

ENIL has members in all 27 EU countries and 45 other countries around the world.

ENIL has:

- 86 full organisational members
- 30 associate organisational members
- 676 full individual members (disabled people)
- 223 associate individual members
- 385 members in the ENIL Youth Network

You can find the full list of organisational members 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
	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
Bosnia and Herzegovina	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/*
	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	
	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
France	Association GRE A GRE - www.greagre.asso.fr	
	Alliance Autiste - http:// allianceautiste.org/	
	CHA- Coordination Handicap et Autonomie – Vie Autonome France - http://coordination- handicap-autonomie.com	
	Observatoire des politiques du handicap - https://www.obser- vatoirehandicapmonde.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. ge	
Germany	Interessenvertre tung Selbstbestimmt Leben in Deutschland e.V. (ISL E.V) - https://www.isl-ev.de/	
	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
Greece	Association of People with mobility problems 'PERPATO' - perpato.gr	
	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	
Ireland	Independent Living Movement Ireland (ILMI) - https://ilmi.ie/	Fionnathan Productions - www. fionnathan.com
	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	
14-1-1	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://Inf.It	
Luxembourg	Nëmme Mat Eis asbl - www. nemmemateis.lu	
Malta	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 Federation of Organisations Persons with Disability (MFOPD) - www. mfopd.org	Malta Association of Supported Employment

	Full members	Associated members
Portugal	Centro de Vida Independente - www.vidaindependente.org	Caregivers Portugal - Associação Portuguesa de Cuidadores - https://www. caregiversportugal.pt/
Romania		Asociatia Magidream - www. dogtors.ro
		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
Spain	Eginaren Eginez - www. eginez.org	
	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*	
Turkey	The Association of Women with Disabilities - http:// engellikadin.org.tr/	Izmir City Council Disability Council
		Abled youth and sports club, Kocaeli
		Down Syndrome Association of Turkey - https://www. downturkiye.org/

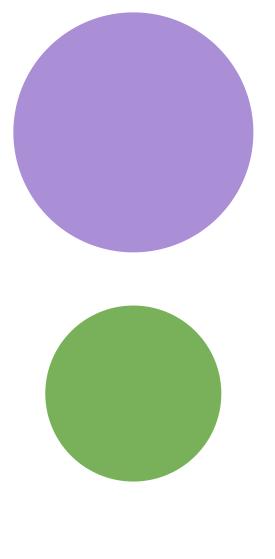
	Full members	Associated members
	Alliance for Inclusive Education - https://www.allfie.org.uk/	Euro Youth Mental Health - https://euroyouthmhblog. wordpress.com/
	CIL Northern Ireland - www. cilni.org	musicALL - www. musicallscotland.uk
	Disabled People Against Cuts (DPAC) - www.dpac.uk.net	
	Disability 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*
Nonal	Center for Independent Living of Persons with Disabilities, CIL- Kathmandu - http://www.cil.org.np
Nepal	KOSHISH National Mental Health Self-Help Organization - www. koshishnepal.org

Chapter five: Financial report Who gave ENIL money?



ENIL received most money from the European Union.

This money was for ENIL activities, events and projects.

ENIL also received money from our members, such as Uloba in Norway and STIL in Sweden.



We also received money from other organisations and people.

They were JINT, Disability Rights Fund, Maribel Social Fund, University of Leeds and International Labour Organisation.

What did ENIL spend money on?



ENIL spent most money to pay for salaries of people working for us.

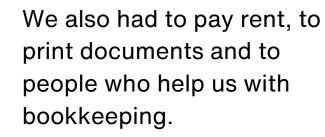
We also spent a lot of money

to organise meetings and



For example, we paid for plane tickets, hotels and food costs.

events.





We paid some money to the bank too.