

Annual Report 2020

European Network on Independent Living - ENIL



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Annual Report 2020

This report covers activities of the European Network on Independent Living - ENIL between 1 January and 31 December 2020. It was adopted by the ENIL Board on 24 May 2021. It is aimed at anyone who would like to find out more about ENIL and its work. This includes our members, allies, disabled people, funders, supporters and the general public. The Annual Report is divided into five sections:

1. Highlights - This includes a description of ENIL's main achievements during the year.

2. Overview of activities - ENIL's main activities are presented under six categories: Awareness raising, Policy, Capacity Building, Campaigning, Research, Projects and Strategic partnerships.

3. About ENIL – This section includes information about how we work, starting with our team, our members, fundraising and other areas.

4. Members – This section includes a list of ENIL's full and associated organisational members, as of 1 May 2021.

5. Financial report – A presentation of ENIL's income and expenditure in 2020.

Cover page: the photo was submitted for the 5th May by Suela Lala, from Albania, with a caption: "Liberty is ... rolling around with my niece in accessible spaces". It shows a woman in a wheelchair and a child on a bicycle with their backs turned, and a busy square with people on it.

Page 5, clockwise: Logo of a bird for the European Independent Living Day, created by our ESC volunteer Hatiye Garip; Hatiye Garip at the ESC office, with the publications she illustrated while at ENIL; a collage shared by the Independent Living Institute for the 5th May, with a message: "Liberty of disabled people even from home"; the cover of the Covid-19 DRM report.

Page 21, clock-wise: Some of the ENIL team during the staff meeting in Brussels; Marijeta Mojašević and Marianne Knudsen at the Zero Project conference in Vienna; a still from ENIL's animation on EU funds and Independent Living.

1. The Year's Highlights

DISABILITY INCLUSIVE COVID-19 RESPONSE

From the start of the COVID-19 pandemic in Europe, in March 2020, we started hearing stories of disabled and older people dying in institutions, people being locked away in their homes or residential settings, disabled people struggling to access personal assistance, personal protective equipment (PPE), food and medical supplies. It was vital to react, and we made an important decision to join other organisations in bringing attention to what was happening and calling for a disability-inclusive response. The *COVID-19 Disability Rights Monitor*, which came together with no additional funding and thanks to a major commitment from the seven organisations involved, provided a powerful platform to expose rights violations and channel voices of disabled people from around the world. It is a great example of how working together, without much prior planning or extra funding, can be a powerful tool in bringing to light serious human rights violations, through personal testimonies, and proposing solutions.

SAFETY THROUGH INCLUSION

As an organisation that has always campaigned for the closure of all institutions and independent living for everyone, ENIL was appalled at the fact so many people were dying in institutions all over Europe. We knew that this tragedy had to be used to convince Governments once and for all that institutions should not exist. Together with two of our close allies, the Validity Foundation and Disability Rights International, we decided to make a case for “emergency deinstitutionalisation”. This refers to the need to move as many people as possible out of institutions, and provide them with support in the community as a matter of urgency. We have been successful in putting this issue on the international agenda, and welcomed the establishment on the working group on deinstitutionalisation by the Committee on the Rights of Persons with Disabilities.

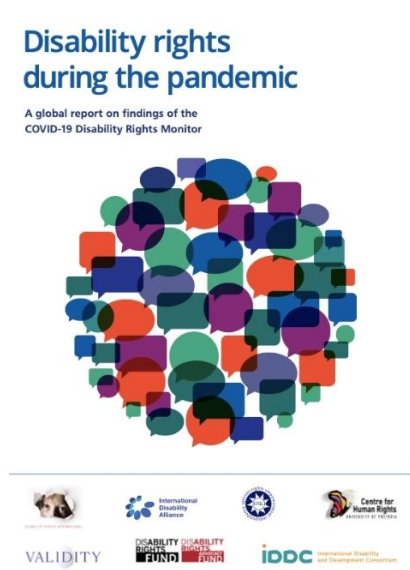
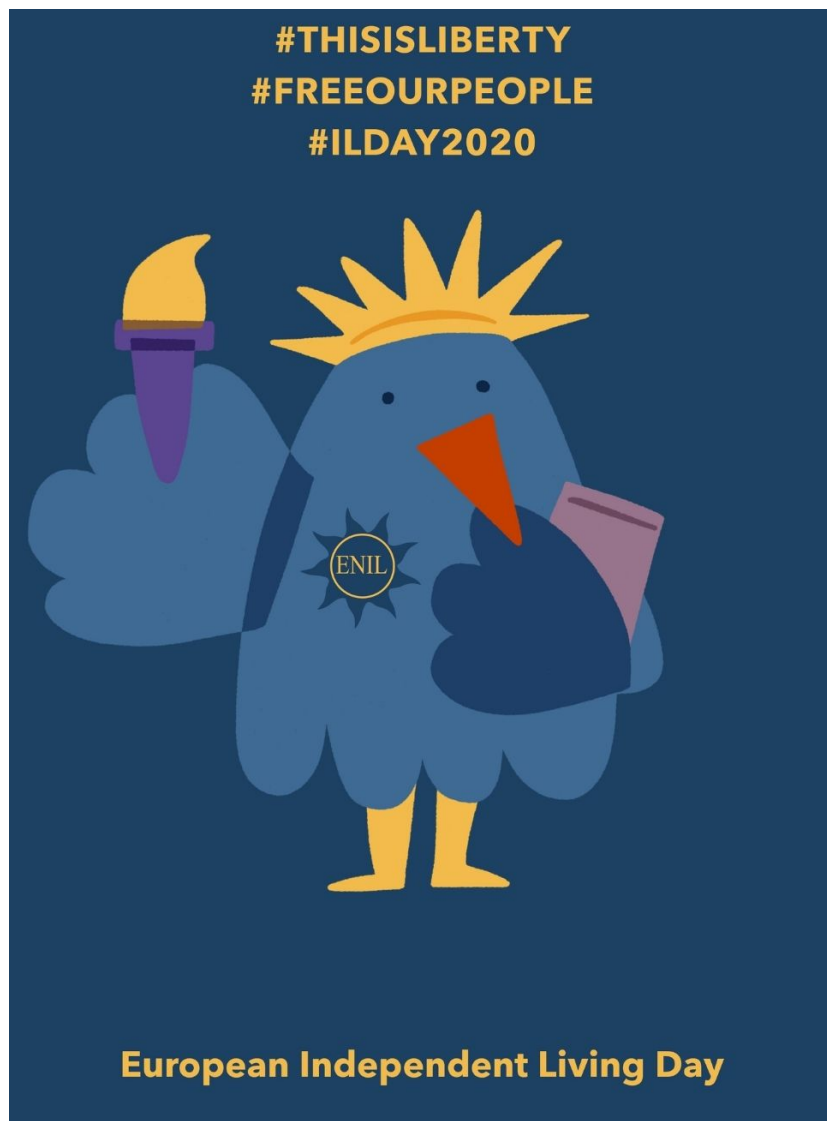
FIRST INDEPENDENT LIVING SURVEY

Seven years after completing the last set of Personal Assistance tables, we launched our first Independent Living Survey. The aim of the survey is to assess, from disabled people's perspective, how much progress

countries are making in implementing Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) and to what extent the Personal Assistance schemes that are available facilitate living independently and participation in society, through choice and control. We obtained information about 44 countries, which was presented in country sheets and a summary report. The data that was collected will be used to inform policy making at the European level, in relation to independent living and deinstitutionalisation, and to compare the efficacy of deinstitutionalisation reforms and PA schemes in the Member States.

CHALLENGING THE USE OF EU FUNDS

The European Union is the best example that the availability of funding is no guarantee that countries will move forward with implementing the Convention, especially Article 19. In 2020, ENIL has continued with numerous activities to challenge the Member States and the European Commission for using EU funds to build, renovate and modernise institutions for disabled children, adults and older people. Although we have not achieved our aim – a total prohibition of building or renovating institutions of any size with EU funds – there is more pressure on the European Commission to set rules in line with international human rights standards, monitor what is happening and impose sanctions. Our advocacy will continue, especially given the unprecedented level of funding available to the Member States for the COVID-19 recovery.



2. Overview of activities

A. AWARENESS RAISING

European Independent Living Day - 5th of May

We marked the 7th European Independent Living Day in 2020, and organised a number of activities in the run up and on the 5th May itself. With most European countries in lockdown due to the COVID-19 pandemic, we chose the theme of LIBERTY and encouraged our members and allies to mark the day with online activities. In addition to collecting stories and photographs, which were shared on ENIL's social media, we organised two successful webinars. The first was on "Disabled Refugees & Liberty", organised jointly with the Independent Living Institute and the Disability Rights Defenders (DRD) Network, and the second was the European premiere of the "Wheelchair Road Movie", followed by a Q&A with the two film makers, Mari Sanders and Simona Constantin.

Media work and publications

The focus of our media work was on the impact of COVID-19 on disabled people, and we published a number of [statements](#) as part of the COVID-19 Disability Rights Monitor initiative (see *Policy*), as well as with [other organisations](#) (e.g. the European Disability Forum, Human Rights Watch and the European Expert Group on the Transition from Institutional to Community-based Care). One of these was on the use of police brutality against disabled protesters in Serbia.

Throughout the year, we were approached by journalists and organisations (such as the EU Fundamental Rights Agency), with requests to hear from disabled people living in institutions and in the community, on how they are being affected and what support they have received from the Government. Our members spoke to [Euronews](#) and to Al Jazeera, which released a two-part documentary "[Covid's Disabled Victims](#)" in February 2021.

On 22nd October, we published a [global report](#) on the impact of COVID-19 on disabled people (in English, with summaries in Easy-to-read and Bahasa), as part of the COVID-19 Disability Rights Monitor. The initial results of the report were presented at the opening session of the 23rd session of the Committee on the Rights of Persons with Disabilities (CRPD

Committee) in August, as well as in a closed meeting with the Committee, and the report received a lot of attention internationally. In December, we launched “[Lost in Interpretation](#)” - a report on the use of European Structural and Investment Funds in 2014 – 2020 and the impact on disabled people and the right to independent living. The drafting of the report was supported by the Left Group (GUE/NGL) in the European Parliament.

B. POLICY

Influencing EU policy

We took part in a number of consultations organised by the European Commission and the European Parliament, to ensure that the right to independent living and being included in the community is adequately addressed in the new EU policies, and is interpreted in line with Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) and the General Comment 5. We provided extensive written input and took part in structured dialogues in relation to: the European Disability Strategy 2021 – 2030, the Child Guarantee (jointly with Disability Rights International and the Validity Foundation), the Action Plan to Implement the European Pillar of Social Rights, the European Structural and Investment Funds Regulations 2021 - 2027 and the new Erasmus+ Programme.

On 29th January, we had a meeting with the Cabinet of the Commissioner for Equality Helena Dalli. The purpose of the meeting was to discuss the progress Member States have made on deinstitutionalisation, Independent Living, the use of EU funds and the freedom of movement.

We attended a number of meetings of the consultation group coordinated by MEP Katrin Langensiepen, and provided written input on the implementation of the principle of non-discrimination, set out in the EU Employment Directive. This work resulted in the [report](#) on “Establishing a general framework for equal treatment in employment and occupation, taking into account the UN CRPD”, adopted by the Committee on Employment and Social Affairs (EMPL) at the European Parliament.

On 15th December, we met with officials from DG Education, Youth, Sport and Culture at the European Commission, to discuss issues faced by Personal Assistance users during Erasmus+ exchanges. It was agreed

that steps must be taken to ensure disabled students do not face delays with getting assistance, once they arrive in the host country.

ENIL staff and Board attended many meetings and spoke at events related to the impact of COVID-19 on disabled people living in institutions and the community, personal assistance and direct payments, disability assessment, employment, accessibility (including of the European Parliament), transport, independent living of people with intellectual disabilities, and other.

COVID-19 Disability Rights Monitor

When it became clear that COVID-19 was having a major impact on disabled people, we decided to join forces with Validity Foundation and Disability Rights International (DRI), resulting in the launch of a rapid human rights monitoring initiative “COVID-19 Disability Rights Monitor” (DRM). After the initial discussions in March and the establishment of the Coordinating Group, additional organisations were invited to join: the Centre for Human Rights at the University of Pretoria, the International Disability Alliance, the International Disability and Development Consortium and Disability Rights Fund/Disability Rights Advocacy Fund. The initiative was endorsed by the then UN Special Rapporteurs on the Rights of Persons with Disabilities Catalina Devandas and the then Special Rapporteur on the Right to Health Dainius Puras.

From March until November, the DRM Coordinating Group met once a week. Among the first activities was the creation and translation of the survey (into 25 languages, thanks to volunteer translators), and the development of a [website](#). Once the survey was launched in April, the focus was on dissemination and reaching disabled people, their family members, DPOs, national human rights institutions (NHRIs) and Governments in all parts of the world. In the end, DRM collected 2,152 responses from 134 countries, mostly from disabled people.

Over 3,000 written testimonies, which came from every corner of the world, were analysed by Dr. Ciara Siobhan Brennan, an independent researcher, and used to write the report “[Disability rights during the pandemic – A global report on findings of the COVID-19 Disability Rights Monitor](#)”. The report was launched on 22 October, at an online event, with the participation of the newly appointed UN Special Rapporteurs on the

Rights of Persons with Disabilities and Health, Prof. Gerard Quinn and Dr. Tlaleng Mofokeng, as well as a number of the disabled activists who provided testimonies on their lives during the pandemic.

In addition to the survey, DRM launched several urgent actions/statements during the year. The first one, initiated by ENIL, was an [urgent appeal](#) on the denial of medical care to disabled people in Romanian institutions; we also provided additional information to Catalina Devandas, who sent an internal communication to the Romanian Government. Other statements were on the situation of disabled people in institutions, on police brutality during the pandemic and on access to food, medication and essential supplies.

The final event of the DRM was a side event during the 13th Conference of States Parties (COSP) to the CRPD in December, entitled “Mind the Gap: The need for a disability inclusive COVID-19 response”; it brought together panellists from disabled people’s organisations (DPOs), the World Health Organisation and the Association for the Prevention of Torture (APT).

The DRM initiative proved to be very effective in highlighting the impact of COVID-19 on disabled people globally, especially those in institutional settings. Having received no additional funding, apart from a grant to recruit a short-term consultant, the work of the DRM was possible thanks to the commitment and close cooperation by all members of the Coordinating Group.

Emergency deinstitutionalisation

One of the strands of the COVID-19 DRM was highlighting the impact of the pandemic on disabled people in institutions and making sure the voices of individuals inside such places were heard. ENIL, Validity Foundation and DRI led on this work, which aimed to encourage governments to create community-based alternatives and get people out of institutions as a matter of priority, as the only way of protecting them from infection and possible death. On 11th June, we organised a [high-level online event](#) with Catalina Devandas and the Chair of the CRPD Committee Danlami Basharu, calling for “emergency deinstitutionalisation” during the pandemic. As a result of our efforts, the CRPD Committee established a new working group on deinstitutionalisation during its 23rd

session in August 2020. (In December, ENIL was invited by the CRPD Committee to support a set of regional consultations, organised by the working group. The consultations were scheduled for the first half of 2021.)

In addition to the June event with COVID-19 DRM, we co-organised two additional side events during COSP on 2nd and 4th December: on the situation of children in institutions with the Validity Foundation and DRI, and with the Korean Disability Forum on the need for emergency deinstitutionalisation and what this would involve. The recordings of all the side events are available on the [UN Web Stream](#).

Another initiative related to deinstitutionalisation was the one led by Catalina Devandas, in cooperation with the Independent Expert on Older People Claudia Mahler. In this respect, ENIL was invited to a closed consultation in August, to contribute to research by the London School of Economics (LSE), commissioned by Ms. Devandas.

Complaint against Finland

With the Validity Foundation and Law Firm Kumpuvuori Ltd., we submitted a [complaint](#) to the European Social Rights Committee about the abuses of rights in housing units during COVID-19 in Finland. The complaint, submitted in November, challenges the legality of locking disabled people in residential care settings, preventing them from going out and receiving visitors.

Children's Rights

We have continued working with partners in the informal “Right to family for children strategy” group, consisting of Inclusion International, International Disability Alliance, Validity Foundation, Disability Rights International, Children's Rights International Network (CRIN) and the International Federation for Spina Bifida and Hydrocephalus (IFSBH). Unfortunately, a series of events that was due to take place at the United Nations in Geneva in March - a side event during the Human Rights Council meeting, a strategic planning meeting, and a closed meeting with the CRPD Committee – were all cancelled due to COVID-19.

The focus of the group was on the ongoing process between the CRPD Committee and the Children's Rights Committee (CRC Committee), the aim of which is to clarify states' obligations towards children with

disabilities. A response was sent to the Lancet, following the publication of papers on deinstitutionalisation of children by the Lancet Group Commission.

ENIL also joined the Coordinating Group for the Day of General Discussion in Children in Alternative Care, which was planned by the CRC Committee for September 2020, but was postponed until 2021. As part of this process, we nominated Marianne Knudsen (ENIL Youth, Norway) to be part of the Youth Advisory Group for the DGD.

Having received the “White Paper on the role of small group homes” from UNICEF (published in August), where ENIL was part of the reference group, we raised questions about the process of consultation and the fact that the White Paper was published without the involvement of the CRPD and the CRC Committees. A disclaimer was included in the paper as a result of this intervention.

Exclusion of disabled students from PISA

After receiving information from our membership about the exclusion of disabled students from the Programme for International Student Assessment (PISA), by OECD, we decided to undertake additional research and we sent an Open Letter to OECD in September. On 9th October, we met with the officials from OECD to discuss our concerns, the right of all children to inclusive education and what this entails. ENIL was supported at the meeting by the Alliance for Inclusive Education (ALLFIE) and the Centre for Disability Studies at University of Leeds. In addition, we discussed this issue with several MEPs, who agreed to send a written question to the European Commission.

The advocacy to ensure that all students are able to sit PISA tests, with the necessary accommodations, will continue in 2021.

C. CAPACITY BUILDING

During the year, we undertook a number of activities to help our members at the local and national level to better advocate for the right to independent living.

The regional members’ meeting, which was planned to take place in Belfast, in cooperation with the Centre for Independent Living Northern

Ireland (CILNI), was cancelled and moved online due to COVID-19 restrictions. Two events were held - an online members' meeting on 14th September, with a focus on Personal Assistance legislation, and an open webinar on 15th September, on Independent Living for ALL. Speakers with diverse impairments discussed what independent living means from their personal perspective.

Together with the Independent Living Institute (Sweden), we organised a webinar on "Ageing with Disabilities in the Community" on 6th February, with Judy Heumann, Prof. Gerard Quinn, Adolf Ratzka, Eric Rosenthal and Eve Hill as panellists.

In cooperation with Disabled People Against the Cuts – DPAC (UK) and the National Federation of Organisations of People with a Physical Disability – MEOSZ (Hungary), we organised a successful [webinar](#) on the 25th August on using inquiries under the Optional Protocol to the CRPD to advocate for Independent Living. We discussed the Committee's inquiries into violations of Article 19 in the UK and Hungary.

In January, we met with representatives of Disabled Women's Institute from Turkey, during their study trip to Brussels. We also responded to requests for support by our members and allies from Greece, Hungary, Poland, Slovakia, Portugal and Montenegro, among other, in relation to their ongoing deinstitutionalisation strategies and reforms affecting the right to independent living. In July, we wrote a [submission](#) for the Office of the High Commissioner for Human Rights, regarding the implementation of Article 30 CRPD, on access to sports and leisure.

A [guide](#) for ENIL members on how to advocate for independent living in the European Parliament was published. The guide explains how to approach MEPs, Parliamentary Committees and the Disability Intergroup, and what role they can play in relation to the CRPD implementation.

D. CAMPAIGNING

EU Funds for Our Rights Campaign

The “EU Funds for Our Rights Campaign” continued in 2020 with numerous activities, thanks to a grant from the Open Society Foundations – Public Health Programme.

Study for the European Parliament

After discussing with the Portuguese MEPs Marisa Matias and José Gusmao the feasibility of a study for the European Parliament, ENIL was commissioned to review the use of EU funds during the 2014 – 2020 and their impact on the right to independent living by the GUE/NGL group. In addition to drafting the study, we worked with a video artist to create a short animation illustrating the main issues and messages.

The study, entitled “[Lost in Interpretation](#)” and the videos with [English](#) and [Portuguese](#) subtitles and sign language were launched on 3rd December, the International Day of Persons with Disabilities. On 9th December, we organised a joint event with MEPs Marisa Matias and José Gusmao to discuss the findings and recommendations. The animated video has since been translated into [Hungarian](#) by TASZ (Hungary).

Case at the General Court in Luxembourg

At the end of 2019, with the Centre for Independent Living Sofia (CIL Sofia) and the Validity Foundation, we initiated Court proceedings against the European Commission for failing to prevent EU funding from being used by Bulgaria to build institutions for disabled people. In response to our complaint, the European Commission submitted a plea of inadmissibility, to which our legal team responded in March. Experts on the CRPD and EU law, Prof. Gerard Quinn (current UN Special Rapporteur on the Rights of Persons with Disabilities) and Prof. Grainne de Burca (NYU School of Law) provided supporting statements.

Unfortunately, at the beginning of September, the General Court in Luxembourg found our complaint inadmissible on procedural grounds, without looking into substance of the case. We decided not to join the appeal, which was subsequently submitted by the Validity Foundation and CIL Sofia.

The work on the case, which started in 2018, was led by a committed team of lawyers at Covington & Burling LLP, in Brussels, on a pro bono basis.

Complaints to the European Ombudsman

On the 30th July, we received a [decision](#) from the European Ombudsman in relation to our complaint on Hungary, Portugal and the Legal Service opinion of June 2018 (Case 1233/2019/MMO). The Ombudsman did not find maladministration by the European Commission; however, she found that the Commission “has not acted in a sufficiently timely manner” in Hungary and should have prevented investments in institutions from going forward.

Complaints against the national authorities

In cooperation with the Independent Living Austria and the Validity Foundation, respectively, we submitted official complaints against the Managing Authorities in Austria and Poland, for using ESI funds to build institutions for disabled adults and children.

On 20th November, one year after the submission, we received a decision in relation to our complaint against the Managing Authorities in Romania. Our complaint challenged the construction of at least 57 residential facilities (with complexes for up to 30 residents) and day care centres, affecting over 500 individuals. The European Commission failed to find a breach of the CRPD, the Fundamental Rights Charter or other EU law. With support of lawyers at Covington & Burling LLP, we submitted additional information and asked the Commission to keep the complaint open.

Webinar on the use of EU funds

On 21st September, we organised a successful [webinar](#) “Why is the EU still investing in institutions for disabled people?”, hosted by MEP Katrin Langensiepen. Panellists included disability activists from Bulgaria, Austria, Hungary and Portugal, Prof. Gerard Quinn, the UN Special Rapporteur, Jonas Ruskus, the Vice-Chair of the CRPD Committee, Normunds Popens, Director General at DG Regio, Maria Moustakali from the Office of the European Ombudsman, and the Secretariat of the CRPD Committee. The webinar was attended by over 100 participants and raise

important questions about the Commission's interpretation of their obligations under the CRPD.

Inquiry on Hungary under the Optional Protocol

The [result of the inquiry](#) on Hungary under the Optional Protocol to the CRPD was published on 16th April by the CRPD Committee, finding grave and systematic violations of Article 19 and Article 12 CRPD. On this occasion, ENIL, Validity Foundation and the Hungarian Civil Liberties Union (TASZ) published a [joint Press Release](#) and organised a virtual Press Conference in the morning of the 17th April.

Petition on Bulgaria

In 2018, together with the CIL Sofia, the Validity Foundation and the Bulgarian Helsinki Committee (BHC), we submitted a petition to the Petitions Committee (PETI Committee) at the European Parliament. The petition concerns the use of EU funds for the building of group homes for disabled and older people, as part of Bulgaria's process of "deinstitutionalisation". Having lobbied MEPs throughout 2019 to ensure that our petition gets a hearing in the PETI Committee, it finally took place on 20th February. Following an hour-long discussion, with the involvement of several MEPs, it was decided that our petition would remain open.

Campaign meetings

The annual campaign meeting, which was due to take place in Brussels, was replaced with an online meeting in July, with 14 Member States represented. The second meeting was organised on 16th November, with the focus on the evaluation of the Campaign and plans for the future.

Other initiatives

We met with the UN Special Rapporteurs Catalina Devandas and Dainius Puras to discuss the misuse of the European Structural and Investment (ESI) Funds for institutional care. Thanks to our efforts, and with our support, Ms. Devandas sent an internal communication to the European Commission, highlighting systemic problems in the European Union, in relation to ESI Funds use.

With the European Union making significant funding available to the Member States to deal with the impact of COVID-19, our advocacy turned to calling for adequate monitoring and ensuring that the recovery funding

is not directed into institutional care. Among other, we took an active part in two online meetings of the Structured Dialogue Expert Group on ESI funds.

E. PROJECTS

TRIPS Project

On 10th February, we hosted the kick off meeting of the TRIPS project in Brussels. TRIPS is a 3-year European project, funded by the European Commission through Horizon 2020. Its main aim is to make the transport in seven European cities – Bologna, Brussels, Cagliari, Lisbon, Sofia, Stockholm, and Zagreb – more accessible for disabled people, older people, and the population in general.

During the first year of the project, ENIL has led on the qualitative report and the stakeholders engagement manual; we have helped develop co-production methodology and a survey on the future mobility trends, contributed to creating the Mobility Divide Index (MDI) and provided input into other [deliverables](#). We have also worked closely with local organisations and helped launch co-production groups in the participating cities. One of the activities undertaken locally by our partners were workshops about co-designing accessible future transport.

Many of the project activities could not take place as originally planned because of COVID-19 restrictions, and had to be moved online.

European Solidarity Corps

Significant efforts were invested into the European Solidarity Corps (ESC) projects, which enable young disabled people from Europe to gain work and life experience in Brussels. Thanks to good cooperation with our national agency JINT vzw, we have been able to secure a significant budget to cover the cost of accessible accommodation and personal assistance for our volunteers in 2019 - 2020.

In May, Nina Portal from Serbia joined the team for eight months, while in July, Hatiye Garip from Turkey finished her ESC programme. Due to the travel ban imposed by Belgium for non-EU countries, Nina was asked to complete her ESC remotely, from her home in Belgrade.

Following an open call, we also selected two volunteers for May 2021 - Àinne Kelly-Costello from Ireland (living in Norway) and Peadar O'Dea, also from Ireland.

Access of Disabled Women to Family Planning Services

ENIL was invited by the UN Population Fund (UNFPA) to join a project on access of disabled women, women with HIV/AIDS and women survivors of intimate partner violence (IPV) to family planning services in Eastern Europe and Central Asia (EECA) region. ENIL identified DPOs and independent researchers in 10 countries, who will be responsible for data collection among disabled women, and has taken part in developing the survey. The project is coordinated by the East European Institute for Reproductive Health (EEIRH) and will be finalised by the end of 2021. Data collected through quantitative and qualitative research will be used to draft a report on access of women from the three marginalised groups to family planning services in the EECA region.

F. RESEARCH

Independent Living Survey

On 30th June, we launched ENIL's first Independent Living Survey, in English, German and French. The survey followed Personal Assistance tables, published by ENIL in 2013 and 2015, and drew heavily on the "PA Checklist – A Tool for Assessing Personal Assistance Schemes", published in 2019. The questions were divided in two sections – the general section on Independent Living and deinstitutionalisation, and a section on the Personal Assistance scheme/policy.

The survey was aimed at Independent Living organisations and Personal Assistance users in Europe, and we collected over 130 responses from 44 countries. The responses were analysed and used to draft individual [country sheets](#), as well as the [summary report](#).

The first findings of the survey were presented during the Human Rights Day, 10th December, at a successful [online event](#). Panellists included MEP Katrin Langesiepen, Director-General at DG Employment Katarina Ivanković-Knežević, and survey respondents from Portugal, Croatia, Georgia and Finland.

Due to the complexity of Personal Assistance provision in many countries, especially with regard to regional differences, the remainder of the country sheets and the second part of the summary report, on Personal Assistance, will be published in 2021.

Independent Living Research Network (ILRN)

We invited several members of the [Independent Living Research Network](#) (ILRN) to present their research in the ENIL Newsletter. Articles were contributed throughout the year by Emma O'Neill (UK), Ciara Brennan (Ireland), Gabor Petri (Hungary), Eglė Šumskienė (Lithuania), Miro Griffiths (UK) and Radoš Keravica (Serbia/UK).

G. STRATEGIC PARTNERSHIPS

European Disability Forum (EDF): As a full member of EDF, ENIL provided input into EDF's position papers and internal working documents. Nadia Hadad was active on EDF's Board and the Executive Committee; she has participated in many meetings and spoken at different events during the year on behalf of EDF. Kamil Goungor also continued his mandate as the Chair of EDF's Youth Committee, where he represents the ENIL Youth Network. Zara Todd, our Senior Advisor, continues to sit on the Women's Committee. We have taken part in EDF's Annual General Assembly (with Suela Lala nominated to represent ENIL), Board meetings and regular coordination meetings for EU-level networks in Brussels. After March, all the meetings and events were moved online.

World Independent Living Network (WIN): Nadia Hadad, our Co-Chair, has been representing ENIL on the Board of WIN. Meetings were held approximately every two months, with representatives from North America, Latin America and Asia-Pacific.

European Expert Group on the Transition from Institutional to Community-based Care (EEG): On 16th January, ENIL Secretariat and members from Bulgaria, Spain, Hungary, Austria and Sweden took part in the launch of the "[Report on the Transition from Institutional Care to Community-based Services in 27 EU Member States](#)"; the drafting of the report was supported by the EEG. The conference took place in Brussels, and was co-organised by the EEG and the European Commission.

We took part in EEG internal meetings and in the open meeting with the European Commission on 28th October, where we were asked to present our findings on the misuse of EU funds. ENIL was active in the EEG Task force on the European Semester.

Inclusive Mobility Alliance and Erasmus+ Coalition: We continued our participation in the meetings of the [Inclusive Mobility Alliance](#) (a network of organisations coordinated by Erasmus Student Network) and the [Erasmus+ Coalition](#) (set up by the Lifelong Learning Platform and the European Youth Forum). Among other, we signed a [joint statement](#) calling for a more inclusive Erasmus+ programme.

We also took up a case of a Spanish Erasmus student in Prague, who was not provided with Personal Assistance and as a result, was stranded in her room, in pain, and forced to rely on the help of friends and volunteers. We contacted the relevant institutions, in the Czech Republic, Belgium and Spain, on her behalf, and have managed to help her secure a Personal Assistant.

EU Agency for Fundamental Rights: Zara Todd, our Senior Advisor, finished her two-year term as a member of the Fundamental Rights Platform [Advisory Panel](#). Our Co-chair Nadia Hadad represented EDF on the same panel and also finished her term. FRA decided not to hold new elections for the Panel in 2020.

Council of Europe: Marijeta Mojašević (Montenegro), from the ENIL Youth Board, was an active member of the Advisory Council on Youth. We submitted our regular 4-yearly report to the Council of Europe, in order to retain our participatory status (i.e. membership of the Conference of INGOs).

Disability Rights Defenders (DRD) Network: Together with the DRD Network and the Independent Living Institute, we organised three successful webinars – “Legal remedies through strategic litigation for the rights of disabled people” (17th November), “Legal Clinics, as a tool to promote disability rights” (26th May) and “Ageing with Disabilities in the Community” (6th February).



3. About ENIL

Secretariat

There were several changes at the Secretariat in 2020. In February, we recruited Laura Alčiauskaitė, from Lithuania to the position of the TRIPS Coordinator, for 3 years. Laura had planned to move to Brussels, but because of the COVID-19 pandemic, has been working remotely from Lithuania. Laura Partridge and Kyriaki Efthymiou joined the Brussels office as volunteers, and Dionysis Antanasiotis continued to support us with administrative tasks. Nina Portolan started as the ESC volunteer in May, working remotely from Serbia and leading on the work on the Independent Living Survey, and Hatiye Garip's ESC ended in July. We employed a Personal Assistant for Hatiye during her stay in Brussels.

After five years, we said good-bye to our first Brussels staff - Marco Carnesecchi, the Office Manager, and Frank Sioen, the Policy and Advocacy Coordinator. Marco left in November to join another Brussels-based organisation, and Frank left at the end of December to join the civil service in Flanders. We are thankful to Marco and Frank for their commitment and contribution to ENIL's work, and for helping to set up the Brussels office.

Marlene Nuhaan was hired in November to replace Marco, but resigned after a short time. She was replaced by Stanislas Roisin, who started in his position as a part time Office Manager in January 2021.

With many staff working remotely over the years, ENIL adapted well to the situation caused by the COVID-19 pandemic. All the working tools, such as a Zoom subscription, Microsoft Teams and a remote filing system had been in place before and there was, therefore, no disruption to ENIL's work. Luckily, a face to face staff meeting took place on the 28th February in Brussels, just before the travel restrictions were introduced. The meeting was used to plan activities in 2020.

Governance

The ENIL Board met four times in 2020 – on 2nd March, 2nd June, 7th September and 30th November. During the June meeting, the Financial

and Annual reports for 2019 were approved, and during the November meeting, the Board adopted the Work plan and a budget for 2020.

The Management Team, composed of the two Co-chairs and the Deputy Director, met on a monthly basis. A decision was made not to recruit a replacement for the Policy and Advocacy Coordinator in 2020, but to wait until it is clear what funding would be available in 2021.

The Audit Committee, composed of the Office Manager, Jamie Bolling, Nadia Hadad, Patrick Wauters and Dimitrios Karanastasis met in February, April and September 2020. Michael Holden replaced Nadia Hadad on the Audit Committee in the second half of the year.

ENIL Youth Network

ENIL Secretariat provided support to the new Board of ENIL Youth, by scheduling meetings, preparing documents and facilitating communication between the Board members. Two webinars were organised by the Youth Network – on “Peer Support in Times of Crisis” and on access of disabled people to health care.

In April, the Youth Board submitted a new application to the Council of Europe Youth Department for a study session in 2021, titled “Combating Ableism Through Law”, which was approved. Sadly, the study session that was due to take place in June 2020, co-organised with AEGEE, was cancelled due to COVID-19 and replaced by a shorter online event.

Two members of ENIL Youth – Marijeta Mojašević and Marianne Knudsen – spoke at the Zero Project conference in Vienna (19th – 21st February), on education. They were part of a group of young disabled people whose task was to help facilitate sessions during the conference.

Membership

Considering that a number of changes were introduced in ENIL’s Constitution at the General Assembly in October 2019, the Board decided to carry out a membership review in 2020. Prior to the review, the Board revised membership criteria, to ensure they were in line with the new Constitution. The membership review was launched in March and encompassed all organisational members. Because many reminders had to be sent and a number of responses had to be clarified and checked, the review was not finalised by the end of the year.

As a result of the review (based on the preliminary results), the number of organisational members changed – it decreased from 107 to 104 members. Our members come from 44 countries (39 European and 5 rest of the world). We gained a new member in Azerbaijan, and no longer have organisational members in Latvia, Cameroon and Palestine. With regard to individual members, their number increased from 717 to 764, with 378 of these also part of the ENIL Youth Network.

At the beginning of the year, we launched a communications survey, to check if our members were happy with ENIL's communication tools and to learn what improvements should be made. The results of the survey were discussed during the staff meeting in February.

On the 27th February, we published the [2019 Freedom Drive](#) report.

Funding

In 2020, we received core funding from our members in Norway and Sweden - ULOBA, STIL and GIL, with ULOBA funding the majority of ENIL's core costs. We received the final grant from the Open Society Foundations – Public Health Programme for the EU Funds for Our Rights Campaign due to changes in OSF's strategic priorities. Other funders included the European Commission (Horizon 2020), JINT (Erasmus+ European Solidarity Corps), East European Institute for Reproductive Health (family planning project) and the Council of Europe Youth Department (study session). A grant from the GUE/NGL Group in the European Parliament funded the work on the EU funds study and a video, and small grants from the Flemish Region and Brussels City (requested in 2019) were used to cover some of the 2019 Freedom Drive costs.

At the end of the year, we were informed that our proposal with the Association of Women with Disabilities in Turkey, funded by the European Union under the Civil Society Support Programme (CSSP – III) was approved. The PAKT Project, on personal assistance, will be implemented over 15 months, starting in April 2021.

To secure extra income, ENIL provided a small number of consultancy services: we successfully organised two webinars on inclusive online spaces for 350.org (the international climate justice movement), and two webinars were organised on the same topic for JEF Europe – Young European Federalists.

Communication

We have continued sending monthly Members' Mailings, with updates about ENIL's work, information about events and calls to action. A total of 12 mailings were sent to all organisational and individual members via Mailchimp.

A total of 12 online Newsletters have been published in 2020. These have been sent to 1,861 subscribers each month.

ENIL's Facebook page, Twitter account and website have been updated on a daily basis, and we have seen an increase in the number of followers. The number of Facebook followers increased again, from 4,710 to 5,651 followers, while the number of Twitter followers also increased from 1,992 to 2,580. We published a total of 3,667 tweets, and our maximum daily reach on Facebook was 10,278, on 5th May – the European Independent Living Day. Our Freedom Drive Facebook page is followed by 1,185 people.

In 2020, we created an Instagram page, which now has 308 followers, 52 permanent posts and numerous stories.

4. Membership

	Full members	Associated members
Albania		Albanian Disability Rights Foundation (ADRF) - www.adrf.org.al
		Together Foundation - https://www.facebook.com/sebashkufoundation/
Armenia	Skarp Inclusive Health Center NGO - www.skarp.am	
	Unison NGO for Support of People with Special Needs - www.unison.am	
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	
Bosnia and Herzegovina	Bosnian Doctors for Disabled - https://www.facebook.com	SUMERO - Union of organisations for support of people with intellectual

	/bosniandoctorsfordisable d/	disabilities - http://sumero.ba/ *
	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)	
Denmark	LOBPA – Landsorganisationen Borgerstyret Personlig Assistance - www.lobpa.dk *	
Finland	Kynnys Ry (The threshold) - http://www.kynnys.fi/en/ *	
France	Association GRE A GRE - www.greagre.asso.fr	Coordination Handicap et Autonomie – Vie Autonome France - http://coordination- handicap-autonomie.com
	Alliance Autiste - http://allianceautiste.org/	

Georgia	Accessible Environment for Everyone - http://dpo.ge/en	
	Coalition for Independent Living - www.disability.ge	
Germany	Interessenvertretung 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 inklusiv e.v. - http://www.rhein-main-inklusive.de/	
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	
Ireland	Independent Living Movement Ireland (ILMI) - https://ilmi.ie/	Fionnathan Productions - www.fionnathan.com
	NCPD - The National Council for (the status) of People with Disabilities	Irish Wheelchair Association - www.iwa.ie *

	Company Limited by Guarantee - Galway.NCPD.ie	
Italy	Agenzia per la Vita Indipendente Onlus (AVI ONLUS) - www.vitaindipendente.org	
	Associazione Vita Indipendente - www.avitoscana.org	
	Comitatio Lombardo per la Vita Indipendente delle Persone con Disabilit� - https://vitaindipendentelombardia.wordpress.com/	
	ENIL Italia - www.enil.it	
Lithuania	Independent Living Association - https://savarankiskasgyvenimas.lt/	
	Lithuanian Disability Forum - http://Inf.lt	
Luxembourg	N�mme Mat Eis asbl - www.nemmemateis.lu	
Malta	Commission for the Rights of Persons with Disability (CRPD) - www.crpdpd.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
Montenegro	Association of Youth with Disabilities of Montenegro (UMHCG) - http://umhcg.com	
	Initiative of Youth with Disabilities of Boka -	

	https://www.facebook.com/Inicijativa-mladih-s-invaliditetom-Boke-l-MI-Boke-111829123575190/	
North Macedonia	Polio Plus – Movement against disability - www.polioplus.org.mk	
Norway	Foreningen JAG - www.jagassistance.no	
	Uloba – Independent Living Norway - www.uloba.no	
Poland	Institute for Independent Living - www.niezaleznezycie.pl	The Sowelo Foundation (Fundacja Sowelo) - https://sowelo.net.pl/
	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/	
Portugal	Centro de Vida Independente - www.vidaindependente.org	Caregivers Portugal - Associação Portuguesa de Cuidadores - https://www.caregiversportugal.pt/
Romania	Ceva de Spus - www.cevadespus.ro	Asociatia Magidream - www.dogtors.ro
		AEPADO – European Association for the Defense

		of Human Rights - www.aepado.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	
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	
Spain	Vigalicia (OVI Galicia) - www.vigalicia.org	
	Independent Living Federation of Spain (FEVI) - www.federacionvi.org	
Sweden	GIL – Individual Independent Living - www.gil.se	
	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
United Kingdom	Alliance for Inclusive Education - https://www.allfie.org.uk/	Euro Youth Mental Health - https://euroyouthmhblog.wordpress.com/
	CIL Northern Ireland - www.cilni.org	
	Disabled People Against Cuts (DPAC) - www.dpac.uk.net	
	Disability Rights UK (DRUK) - www.disabilityrightsuk.org	
	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	
	Inclusion Scotland - www.inclusionscotland.org	
	Independent Living Alternatives - www.ILAnet.co.uk	

	Linda Laurie Associates - http://www.llassociates.co.uk/	
	Leeds Disabled People's Organisation - https://www.facebook.com/LeedsDPO/	
	National Survivor User Network - https://www.nsun.org.uk	
	Reclaiming our Futures Alliance (ROFA) - www.rofa.org.uk	
	Scottish Personal Assistance Employers Network (SPAEN) - http://spaen.co.uk/	
	Self-Directed Support Scotland - http://www.sdsscotland.org.uk	
	SPECTRUM Centre for Independent Living - www.SpectrumCIL.co.uk	

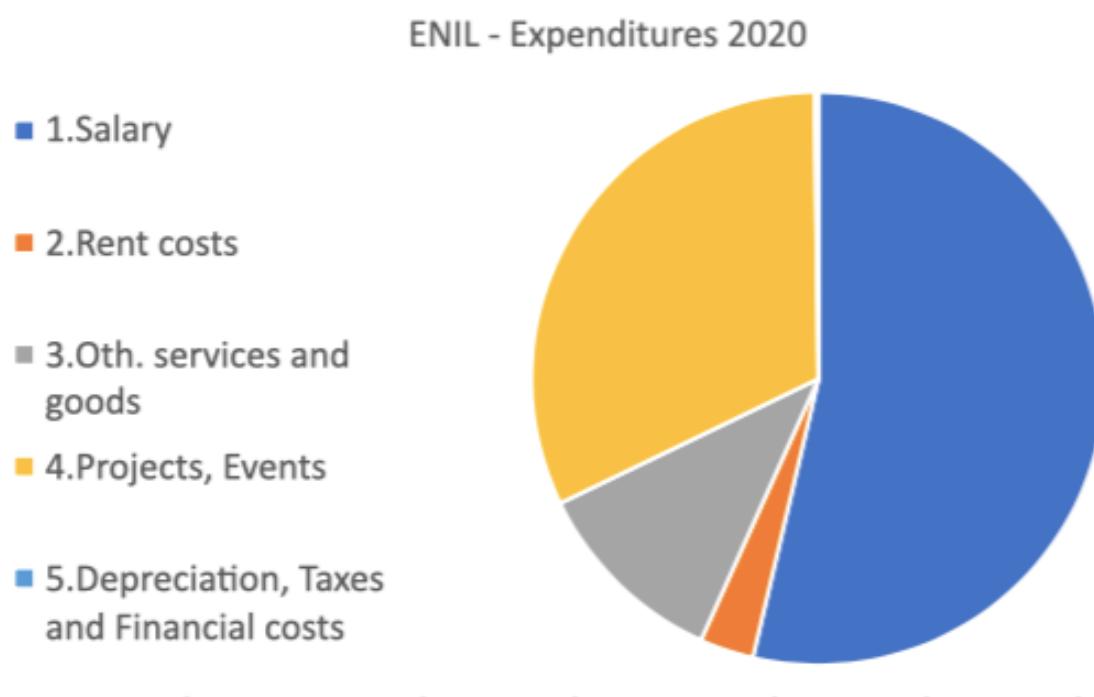
Rest of the world

Country	Associated members
Bangladesh	Community Development Centre*
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	CIL Kathmandu - http://www.cil.org.np

*As part of the membership review, additional information needs to be gathered from these organisations, in order to confirm their membership status.

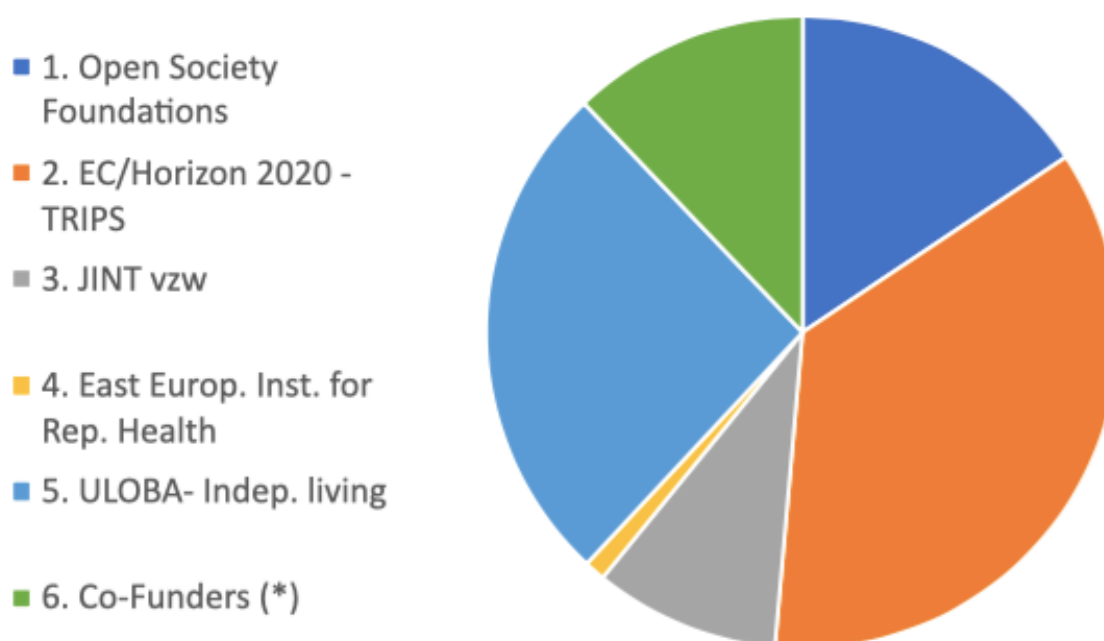
This list was updated on 1 May 2021. The list of individual members is not made public, in compliance with ENIL's Privacy Policy.

5. Financial report



EXPENDITURES	2020
Personnel costs	241,783.09 €
Rent costs	13,691.99 €
Other services and goods	50,115.28 €
Projects & events	143,729.71 €
Depreciation, taxes and financial costs	1,041.99 €
TOTAL EXPENDITURES	450,362.06 €

ENIL - Income 2020



INCOME	2020
EC/Horizon 2020 - TRIPS	172,321.67 €
ULOBA	125,000.00 €
Open Society Foundations	75,515.96 €
JINT vzw - ESC	45,777.44 €
East European Institute for Reproductive Health	5,114.00 €
Other funders (STIL, GIL, GUE/NGL European Parliament, Flemish Region, 350.org, Korean Disability Forum, personal donation)	58,478.47 €
TOTAL INCOME	482,207.54 €

	2019	2020
Expenditure	380,527.13 €	450,362.06 €
Income	390.225,79 €	482,207.54 €

6. Our team

Board members

Nadia Hadad (Co-Chair, Belgium)
Jamie Bolling (Co-Chair, Sweden)
Armen Alaverdyan (Armenia)
Michael Holden (United Kingdom)
Radoš Keravica (Serbia)
Jukka Kumpuvuori (Finland)
Suela Lala (Albania)
Vibeke Marøy Melstrøm (Norway)
Tess van Deynse (Belgium)

Senior advisor (voluntary position)

Zara Todd (United Kingdom)

Staff

Ines Bulić Cojocariu, Deputy Director
Frank Sioen, Policy and Advocacy Coordinator (until December 2020)
Nataša Kokić, Campaign Coordinator
Marco Carnesecchi, Office Manager (part time) (until November 2020)
Kamil Goungor, Development Officer (part time)
Lilia Angelova Mladenova, Project Officer (part time)
Laura Alčiauskaitė, TRIPS Project Coordinator (from February 2020)
Marlene Nuhaan, Office Manager (November – December 2020)
Stanislas Roisin, Office Manager (part time) (from January 2021)

Volunteers

Nina Portolan (European Solidarity Corps) (from May 2020)
Hatiye Garip (European Solidarity Corps) (until July 2020)
Kyriaki Efthymiou (July – October 2020)
Laura Partridge (part time) (until December 2020)
Dionysis Antanasiotis (part time)
Dr. Teodor Mladenov (Independent Living Research Network)

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 other all other funders.

About the European Network on Independent Living

The European Network on Independent Living (ENIL) is a Europe-wide network of people with disabilities. 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.

Contact us

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