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

An External Evaluation of European Network on Independent Living project Choice4All for period 2022 - 2023

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1 Introduction

This report is an assessment of the activities and work of the European Network for Independent Living (ENIL) in the light of the planned activities of the Choice4All Work Programme 2022–2025 (2022). ENIL is a Europe-wide network of people with disabilities, founded in 1989 in the European Parliament in Strasbourg by over 80 people with disabilities and with members across Europe and beyond. It is a forum for all people with disabilities, independent living organisations and other allies on issues relating to independent living. ENIL represents the disability movement for human rights and social inclusion based on solidarity, mutual support, deinstitutionalisation, democracy, non-discrimination, self-determination, overcoming disability and self-determination (ENIL, 2022a).

The purpose of the evaluation is to take a closer look at ENIL's work and activities in 2022 and 2023. The evaluation was conducted by external experts from the Social Protection Institute of the Republic of Slovenia in the period from July to November 2023. During this period, we collected evidence from desk research, survey, interviews and focus groups via Zoom and in person in Brussels on 23 and 24 October 2023.

The first chapter contains information about ENIL and its Work Programme 2022–2025 (2022). The second chapter briefly describes how the evaluation was conducted and which methods were used. In Chapters 4 to 7, we analyse ENIL's work in more detail against each of the objectives of the Work Programme 2022–2025 (2022). The chapters are divided into the following themes: (4) Management, movement and networks; (5) Implementation of disability rights policies in the European Union (EU); (6) Visibility and awareness raising; (7) Capacity and knowledge building. Finally, the last chapter contains 'Conclusions and recommendations' in which we summarise key findings from the research and make suggestions for improvement.

2 About ENIL and the Work programme 2022- 2025

ENIL is a Europe-wide network of persons with disabilities with members throughout Europe and beyond. It is a forum for all persons with disabilities, independent living organisations and other allies focusing on independent living issues. ENIL represents the disability movement for human rights and social inclusion based on solidarity, mutual support, deinstitutionalisation, democracy, non-discrimination, self-representation, cross-disability and self-determination (ENIL, 2022a).

Their purpose is to develop and support the Independent Living movement in Europe, enhancing the European disability sector by providing an arena for the sharing of disabled people's experience and by providing expertise on independent living. They promote the right to independent living globally by acting as the representative for Europe within the World Independent Living Network (ENIL, 2022a).

ENIL is not only an EU-based organisation, but also a globally recognised organisation for people with disabilities. The policies of the EU (but also the United Nations (UN)) have a great influence on the work of ENIL and vice versa. ENIL tries to influence the policies, funding of projects etc. of the EU. ENIL also has consultative status with UN Economic and Social Council and is a member of the Conference of INGOs at the Council of Europe (ENIL, 2021). As a European NGO, it is an actor in building a structured civil dialogue between citizens and governments.

It is a pan disability organisation, which means that ENIL promotes independent living for all persons with disabilities, regardless of their impairment, as set out in Article 19 of the Convention on the Rights of Persons with Disabilities (CRPD) and General Comment 5 of the Committee on the Rights of Persons with Disabilities (ENIL, 2021; 2022a). However, the impression is that the members are predominantly organisations for people with physical disabilities, with less representation for people with intellectual and psychosocial disabilities.

The Choice4All Work Programme 2022–2025 (2022) sets out what is to be achieved over the four-year period and sets out a timetable and costs for implementing the Work Programme 2022–2025. The Work Programme 2022–2025 contains five general objectives:

1. General management and governance of the organisation.
2. Support to the implementation of the European Strategy for the Rights of Persons with Disabilities 2021–2030, the European Pillar of Social Rights, the UN Convention on the Rights of Persons with Disabilities, and other relevant laws and policies in the EU.
3. Raise awareness of the right to independent living among persons with disabilities, their families, policy and decision makers and other stakeholders
4. Improve the capacity of ENIL members to contribute to the implementation of the European Strategy for the Rights of Persons with Disabilities 2021–2030, the CRPD and other relevant laws and policies at the local and national level.
5. Build a stronger and unified movement of persons with disabilities on independent living at the European level.

The main target groups of the ENIL programme are: people with disabilities, young people with disabilities, organisations of people with disabilities, families of people with disabilities, policy makers at EU, local and national level, service providers, researchers and the general public (ENIL, 2022a).

3 Methodology

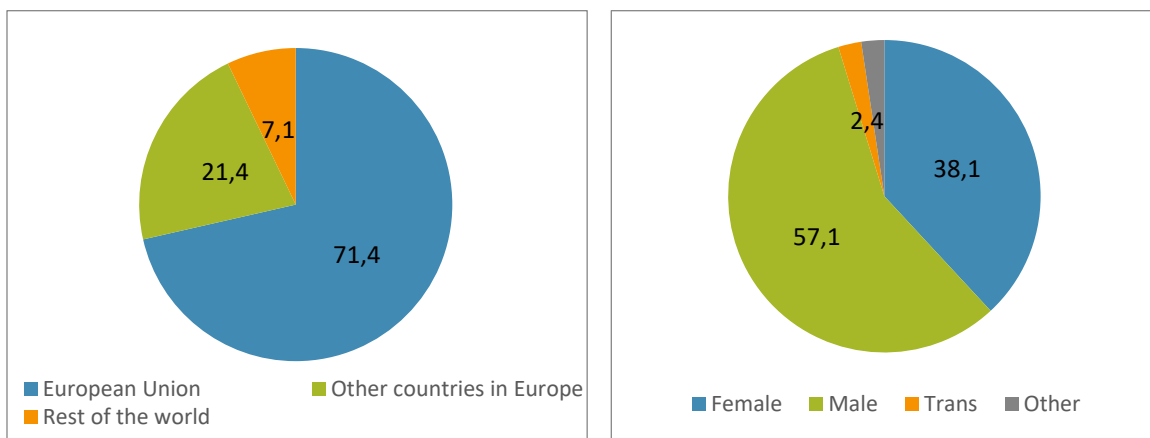
The evaluation was based on a detailed description of the work process, the objectives achieved and the experiences of key stakeholders and persons with disabilities on the strengths and weaknesses of ENIL’s processes and work in 2022 and 2023. This was done through a multi-level evaluation focusing on the work process (how objectives and results were achieved), the achievement of the objectives of ENIL’s Work Programme for 2022 and 2023 (2022) and the impact that ENIL’s work had on key stakeholders and the social environment.

The evaluation included a variety of qualitative and quantitative data gathered from a range of sources, including desk research, survey, interviews, workshops, focus groups and dialogues. Profile of the organisation was used as a reminder and as a basic tool for collecting qualitative and quantitative data. Some data was collected from existing sources (annual reports and other documentary sources, websites, etc.), while other data was collected through dialogue with ENIL staff, board members and other key stakeholders, as well as through observation¹ at the organisation.

Initially, available data was gathered through desk research. The collected data was used to identify information gaps that still needed to be filled for the evaluation, as well as which key informants should be contacted and which research methods were most appropriate. This was helpful when conducting interviews, focus groups, and workshops centred on the missing information.

The survey was launched in early September 2023 and remained open until November 2023. It collected both qualitative and quantitative data on ENIL’s work and processes. The survey was posted online and distributed through ENIL and our own networks. Reliability was ensured through triangulation, i.e., the cross-checking of multiple data sources. A total of 42 people took part in the survey, the majority of whom (71.4%) are based in EU countries, 21.4% in other European countries and 7.1% in other countries around the world. More than half are male (57.1%) and 85.7% identify as a person with disability.

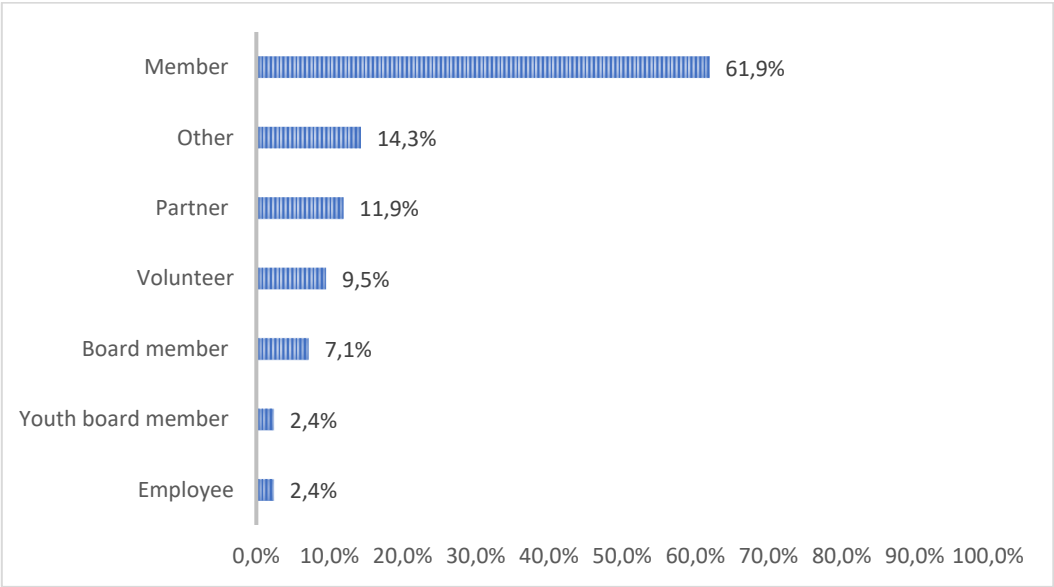
Figure 1: Region in which the participants are based (left); gender of the participants (right)



¹ In-person meeting in Brussels.

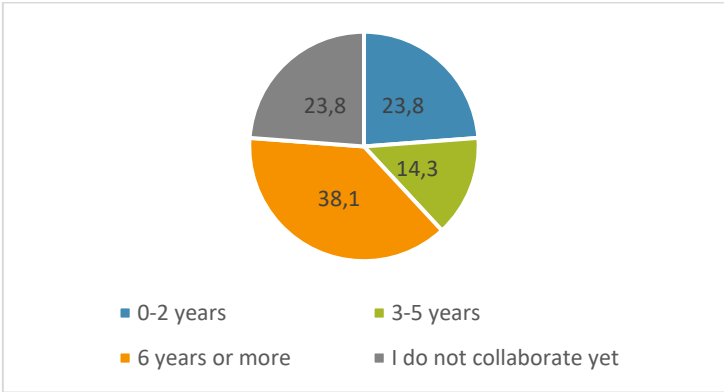
Almost two thirds of respondents were ENIL members (61.9%), among those who chose 'other' were supporters, advisory board members, newsletter recipients, people participating via online networks, and those who use resources to support advocacy.

Figure 2: Relationship to ENIL



Almost half of the participants have been working with ENIL for up to five years and almost 15% are not yet working with ENIL.

Figure 3: The duration of collaboration with ENIL



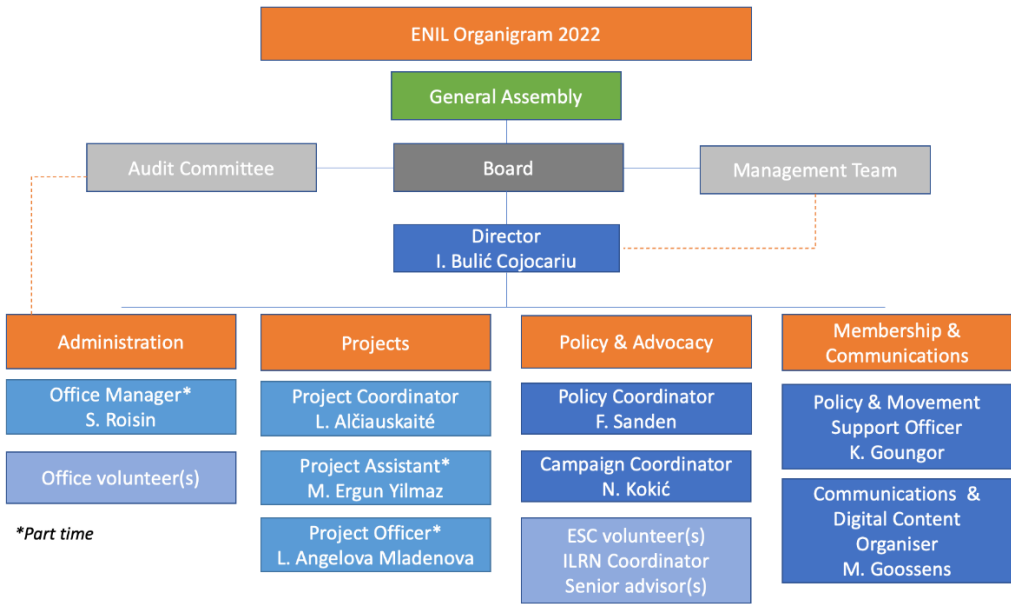
A total of five interviews were conducted using a standard set of questions to further explore the different perspectives of several key representatives and stakeholders, including members of other similar organizations (European Disability Forum -EDF, European Association of Service Providers for Persons with Disabilities -EASPD). Two focus groups were conducted with ENIL board members, members of the youth network, and the member organization (Društvo za teorijo in kulturo hendikepa -YHD). Additionally, a two-part workshop was organized—first live in Brussels and later online with ENIL’s secretariat. The workshop utilized NOISE analysis, which stands for Needs, Opportunities, Improvements, Strengths, and Exceptions. NOISE analysis is a strategic planning tool that offers a useful

alternative to SWOT² analysis, allowing decision-makers, managers, and business leaders to analyse the current state of the business and create a strategic improvement plan (Cardus, n.d.). This approach helped to focus the assessment not only on what has been achieved but also on how ENIL’s work and processes can be improved in the future.

4 Management, movement and networks

To assess how ENIL creates a movement and networks with other organisations, this section first describes how ENIL is organised and then examines how it networks with others. In this section, we describe ENIL's main structures, how ENIL works and how it is organised.

Figure 4: Organigram ENIL-a



The General Assembly consists of the members of ENIL, who are accountable to each other. The purpose of the General Assembly is to hold the organisation to account, elect the Board and adopt amendments to the Constitution (ENIL, 2022c). The General Assembly is the main decision-making body of the organisation and decides mainly on the following issues: amendments to the Statute; approval of the Board report and annual accounts, election of the Board, membership fees, as well as election of the Nominating Committee for the Board (ENIL, 2022c; 2023a).

ENIL offers different types of membership – for *organisations* (Full Members and Associate Members) and for *individuals* (Full Members and Associate Members). Full membership is open to all organisations from the Council of Europe area that are led by persons with disabilities and whose activities are in line with the ENIL Constitution. Associate membership is open to organisations that are not led by persons with disabilities but whose activities are also in line with the ENIL Constitution and

² SWOT stand for Strengths, Weaknesses, Opportunities, and Threats.

support the philosophy of independent living. Associate membership is also open to organisations and individuals from outside Europe (ENIL, 2019; 2022c).

The Nominating Committee and Advisory Group are accountable to and appointed by the General Assembly. The Nominating Committee ensures Board candidates are suitable. It also oversees Board elections at General Assembly. Advisory Group offers the Board advice on strategic and controversial issues as required (ENIL, 2019; 2022c).

The Board involves six to nine people. The final number of Board members is confirmed by the ENIL members at the General Assembly (ENIL, 2022). In 2022, the Board consisted of a total of 10 members, three of whom only joined the Board in October 2022. All Board members must be people with disabilities and more than 50% of Board members should be dependent on personal assistance as defined by ENIL. The aim is to have different countries, regions, cultures and disabilities represented on the ENIL Board. The Board is accountable to the General Assembly and its funders. The Board decides on the categories of membership and approves and dismisses members (ENIL, 2019; 2023a).

The Membership Committee, the Management Team and the Audit Committee are all accountable to the Board. The Membership Committee discusses membership applications in advance of Board meetings and makes a recommendation to the Board as to who should be granted full or associate membership (ENIL, 2022). The Audit Committee is an independent body established by ENIL to review the activities of the Board of Directors. The Audit Committee evaluates and reports on the effectiveness of internal, financial and other controls to help safeguard and efficiently utilise ENIL's resources. The Management Team supports the Director in making important decisions about the day-to-day running of the organisation and in long-term planning; it acts as a link between the staff members and the Board, and is coordinated by the Director (ENIL, 2019; 2021; 2023a).

ENIL also consists of various sub-groups, such as **the ENIL Youth Network**. The ENIL Youth Network was established to bring together younger people with disabilities. The Youth Network has its own constitution and youth board and has autonomy in decision-making as set out in the MoU. The ENIL Youth Network has a guaranteed place on the ENIL Board (ENIL, 2019; 2022d).

In Brussels, a small but dedicated teams works at **the Secretariat**. The team currently consists of nine employees and volunteers. They prepare reports about ENIL's work and updates for the Board (ENIL, 2022b). In the NOISE workshop, the Secretariat confirmed that they *»work very well and cohesively as a team and that there is a good atmosphere in the team«* (F2). The secretariat staff mentioned that *»ENIL has many members, but not all of them are active«* (F2). Members of the Board and Youth Network pointed out that the latter can be a problem, as it makes the active members *»more overburdened than they would otherwise be. Active members attend events and meetings, represent ENIL in public, carry out training, etc.«*(F2). Both Secretariat and Board members mentioned that *»it would be necessary to activate members who are not active and attract new members, especially members with disabilities«* (F1, F2).

Some secretariat staff pointed out that *»additional reinforcements would be welcome«* (F2) as they felt that they *»could not go into as much detail as they would otherwise«* (F2). One interviewee praised ENIL's work at EU level: *»They have a lot of technical expertise. Quite often European organisations, can't go in depth about a topic and everything remains quite theoretical and stuff not running. You can't go really in depth on very deep issues«* (N3).

The Secretariat and Board members highlighted the important role of **volunteers**. They consider that volunteers are an important part of ENIL, which also has an impact on relieving the pressure on staff and other active ENIL members (F1, F2).

4.1 ENIL funding

The finances are managed by **the office manager**, who works under the supervision of the director and the Management Team and the Audit Committee. ENIL works with an external accounting firm for its bookkeeping. ENIL has set up an Audit Committee to obtain advice and support from external financial experts (ENIL, 2022b). ENIL finances itself from an operating grant and various smaller projects (ENIL, 2022e). In 2022, ENIL received core funding from the EU (Choice4All project), with the Norwegian member, a cooperative for consumer-controlled personal assistance (ULOBA – Independent Living Norway), providing the majority of co-financing through the ENIL Foundation (ENIL, 2023a).

Additional co-financing was provided by its members in Sweden - STIL and GIL (ENIL, 2023a). The financial report for 2022 states that the total expenditure for the year 2022 was 643,347.35 € and the total income for the year 2022 was 684,943.76 €. (ENIL, 2023a). The report shows that ENIL's funding is stable, which was also confirmed by one of the members of the Auditee Committee (N2).

ENIL's strategy remains to continue diversifying funding sources, and in this way, increasing ENIL's capacity (ENIL, 2021). Some interviewees pointed out that *“the latter is fine to maintain the organisation's headcount, but it would be wise to consider how ENIL could obtain more stable funding”* (N2). In relation to several smaller projects, some interviewees mentioned that, in terms of the content of ENIL's work and vision, they do *“not necessarily contribute to improving the bigger picture, i.e. the independent lives of individuals and their involvement in the community”* (N2). This lack of focus and the fragmentation of ENIL projects also reduces the visibility of the organisation and the focus of its work (N2, N3).

Interviewees also highlighted that ENIL funding is not enough to ensure participation in activities of people with disabilities, as the unit costs established by the European Commission do not cover the additional costs that people with disabilities need to support their in person participation (e.g. more expensive hotel rooms for wheelchair users) (F1, F2). One interviewee suggested that ENIL should include additional costs for personal assistance or personalised packages for participants already in the phase of applying for funding, as they have seen with some other projects in the past (N2).

4.2 Collaboration with others

In addition to its participation within the ENIL membership, ENIL is also represented in various networks at EU and international level, as well as in various ad hoc advisory groups, and maintains links with the related networks of organisations at EU level and with European institutions.

ENIL is a member of the following networks (ENIL, 2021):

- European Disability Forum,
- European Expert Group on the Transition from Institutional to Community-based Care,
- Global Coalition on Deinstitutionalisation and the informal coalition on the rights of the child,
- World Independent Living Network,
- Disability Rights Defenders,
- Disability Platform,
- Common Provisions Regulation Group of Experts,
- Facing the Facts Network (on hate crime),

- UN ECOSOC and the Council of Europe Conference of INGOs.

In addition to membership of these networks, members of ENIL, Board members or employees of the Secretariat take part in various working groups or steering groups of different projects of their peer organisations. For example, they are members of the EDF Executive Committee, Women's Committee and Youth Committee, members of the steering group for the EASPD project on personal budgets (ENIL, 2023a). ENIL always seems to play a key role when it comes to putting the issue of deinstitutionalisation on the agenda, no matter where they are involved: *»So for us, what ENIL has been able to do in the last two years, to make sure that in all of the internal discussions inside our organisation, the deinstitutionalization remains high on the agenda. And whether it's to do with COVID or Ukraine or any other big things that we're working on, they have been impactful on the disability movement in that sense«* (N5).

The organisations report that they are always very satisfied when ENIL works with them, as they are always very committed and give positive, good feedback. *»I really appreciate the amount of time and effort that's put by ENIL representatives in different committees and the executive of our organisation. I think this is like I'm sure that for every organization they have to think carefully about where they put their time. So I really appreciate that they put their time into us because that makes our work more comprehensive«* (N3, N5).

Both organisations we spoke to expressed their interest in working with ENIL in the future. They would also like ENIL to invite them to their events and involve them more frequently in their work. They consider it important that ENIL maintains dialogue, even if they disagree with them and criticise them (N3, N5). It also seems important to them that ENIL does not withdraw from dialogue and participation in activities with which they disagree, as was the case with the care strategy, for example. They advise ENIL to refuse to continue to point out irregularities, even if they do not agree with some things. Otherwise, they give the impression that they (for example) do not care about the needs of older people with disabilities (N3).

4.3 Creating unified movement

ENIL has set itself the task of building a movement defending the philosophy of independent living at the level of the EU. Several interviewees expressed that they could not imagine ENIL not existing, as they recognise the important role of ENIL in drawing attention to the lack of respect for the rights of persons with disabilities and the lack of independent living practises (N1, N2, N3). At the NOISE workshop, the Secretariat felt that ENIL could do better in creating and sustaining a movement, as they feel that the current movement is not strong enough. This was confirmed by several members who pointed out that many people with disabilities are not even aware of ENIL, let alone the general public, politicians or other stakeholders (F1, N4).

The Secretariat suggested that methods for involving new members (including outside the EU) and methods for working with new allies could be developed for this purpose. It was also suggested that as an organisation, ENIL could attend more events as speakers to promote the work of the organisation while advocating for the philosophy of independent living and the rights of people with disabilities.

4.4 Key points

In essence, ENIL's continued commitment to its mission is critical in advocating for the rights and independent living of people with disabilities in the EU.

ENIL's significance in the field of disability associations is demonstrated by its strong organizational structure, relative financial stability, and collaborative efforts to promote a unified movement for independent living. The emphasis on deinstitutionalisation, personal assistance, and the promotion of independence, as expressed by participants in interviews, focus groups, and surveys, highlights ENIL's critical role.

While financial stability is recognized as important, concerns have been raised about the impact of smaller projects on implementing the ENIL's mission. It is recommended that ENIL's funding strategies be discussed, as well as that the community's awareness and engagement be increased. The organization's commitment to open dialogue, even in the face of opposing viewpoints, is critical to the network remaining dynamic and resilient.

5 Implementation of disability rights policies in the EU

ENIL's main objective is to support independent living, primarily through personal assistance services and legislation. ENIL defines independent living as *»The daily demonstration of human rights-based disability policies. Independent living is possible through the combination of various environmental and individual factors that allow disabled people to have control over their own lives. This includes the opportunity to make real choices and decisions regarding where to live, with whom to live and how to live. Services must be available, accessible to all and provided on the basis of equal opportunity, free and informed consent and allowing disabled people flexibility in our daily life. Independent living requires that the built environment, transport and information are accessible, that there is availability of technical aids, access to personal assistance and/or community-based services. It is necessary to point out that independent living is for all disabled persons, regardless of the gender, age and the level of their support needs»* (ENIL, 2021).

ENIL also advocates for opportunities for full participation in society and promotes and monitors the implementation of the CRPD and its General Comments. ENIL wishes for people with disabilities to gain empowerment and self-determination and advocates for respect of human rights for people with disabilities through laws and policies compliant with the CRPD and its General Comments. Therefore, ENIL's first objective is to support the implementation of the European Strategy for the Rights of Persons with Disabilities 2021 - 2030, the European Pillar of Social Rights, the UN Convention on the Rights of Persons with Disabilities, and other relevant laws and policies in the EU (CERV, 2022).³

5.1 Monitoring the rights of people with disabilities

ENIL has been very active in influencing EU policy over the past two years. ENIL's activities were (ENIL, 2023a):

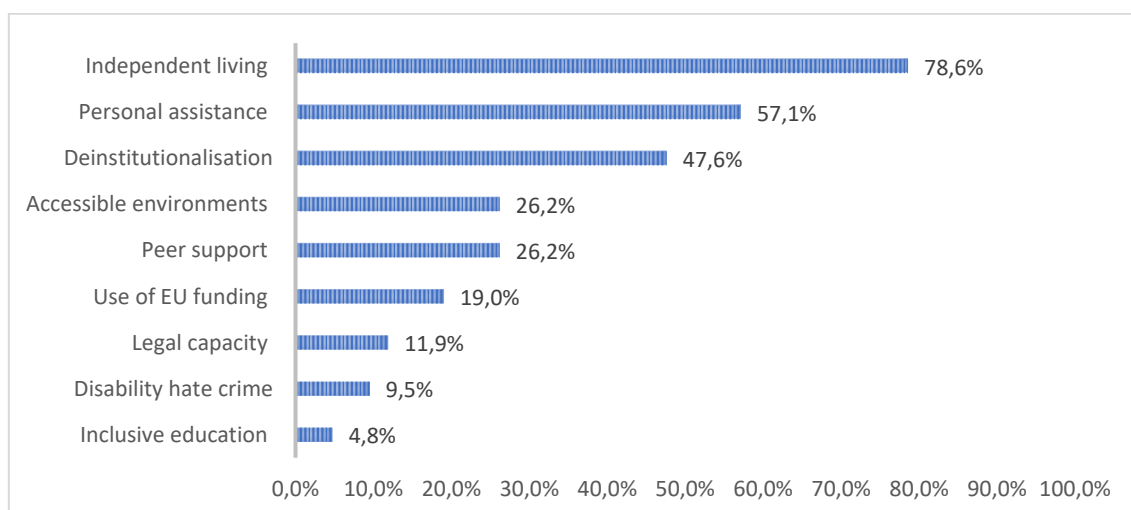
- a shadow report on the implementation of the CRPD in the EU with short videos on the individual articles of the CRPD, which ENIL has shared on youtube.com;

³ European Disability Strategy 2021 – 2030 ; European Pillar of Social Rights & the Action Plan; EU Strategy on the Rights of the Child and the European Child Guarantee; Cohesion Policy 2021 – 2027 (European Social Fund+, European Regional Development Fund, European Agricultural Fund for Rural Development) & Next Generation EU (Recovery and Resilience Facility); European Semester; Erasmus+; EU Charter on Fundamental Rights & EU Strategy to strengthen the application of the Charter of Fundamental Rights; EU Youth Strategy; Green paper on Ageing; Long Term Vision for Rural Areas; European Green Deal; Horizon Europe; UN Convention on the Rights of the Child and the related guidelines; Sustainable Development Goals etc. (ENIL, 2021).

- an update on the Independent Living Map;
- a contribution to the development of the EU Guidance on independent living and inclusion in the community;
- an open letter to the European Commission in which ENIL expressed its concern about the placement of children from Ukraine in institutions in the EU;
- monitoring the use of European Structural and Investment Funds (ESI) to ensure that they are used to promote the right to independent living;
- organising a campaign against the inappropriate use of ESI funds (institution building);
- presenting the EU Guidance on independent living and inclusion in the community, including in emergencies, together with the Validity Foundation and Bridge EU;
- pointing out that the EU care strategy is not in line with the CRPD;
- active participation in other bodies and structures such as the World Independent Living Network, the Global Coalition on Deinstitutionalisation; the European Expert Group on the Transition from Institutional to Community-based Care etc.;
- organisation of or participation in meetings with members of the European Commission, the European Community of Practise for Partnership, etc;
- organisation of various events as part of awareness-raising campaigns on the inappropriate use of resources and non-compliance with the CRPD.

Over the last two years, ENIL has carried out many activities to monitor and alert the EU institutions on the implementation of the CRPD at EU or national level. Most respondents believe that ENIL is very good at monitoring the implementation of the rights of people with disabilities and in particular advocating for the concept of independent living through deinstitutionalisation and personal assistance. In the interviews, in the survey or in the focus group, the majority respondents most frequently mentioned the main three topics that they themselves consider to be very important and are the centre of ENIL’s work. These are: independent living, personal assistance and deinstitutionalisation (survey, N1-5, F1, F2).

Figure 5: The percentage of respondents who deem the topic as important



Respondents consider ENIL to be moderately successful in its activities to influence EU policy with regard to the implementation of the CRPD (the average of responses on a scale of 1 to 5 was 3.3).

According to the respondents, ENIL also has a moderate impact on the implementation of various EU policies in line with Article 19 of the CRPD (the average of responses on a scale of 1 to 5 was 3.3).

ENIL has also included in its Work Programme 2022-2025 activities to monitor the use of EU funds for the purpose of achieving independent living. In the survey, respondents rated ENIL's performance in this area over the last two years as average (the average of responses on a scale of 1 to 5 was 3.2). The members of the Management Board believe that the implementation of the CRPD itself is difficult from ENIL's perspective, as they cannot force individual countries to take into account the rights of people with disabilities. They believe that this can be much more successfully implemented at EU level: *“But when it's about European legislation or European money - all the governments and all the regions are obliged to follow those (European) rules. And so that's the value of ENIL. You can outsource some topics where there is competence of European Union to ENIL to fix them or to realize them and you can then implement them at national and regional level”* F1).

Some interviewees pointed out that it is difficult to expect quick results, especially in the areas that ENIL deals with. These are areas where we always need to be active and raise awareness of the rights of marginalised or minority groups (F1, N1, N3, N4). ENIL pursues and implements its vision regardless of constant external pressures or circumstances (e.g. cuts in public spending on services for people with disabilities). It is one of the few organisations that draws attention loudly and clearly to the violation of the rights of people with disabilities (N3).

ENIL is not only an important partner in the development of the EU, but also an important actor in the development of EU disability policy. ENIL's role as an organisation that continuously draws attention to the only correct definition of independent living in the community is extremely important for ENIL members or for organisations working with ENIL. Some organisations said that together with ENIL they are more able to spread the message, while other organisations are satisfied with ENIL's activist stance, as it is more difficult to advocate such a position alone (N1, N3).

Nowadays, the terms "independent living" and "deinstitutionalisation" are often misused and interpreted differently (F1). However, in one of the focus groups with ENIL members, focus group participants also expressed concerns about the appropriateness of the communication style and activist stance: *“We (ENIL) are considered to always be: against, against, against. That's how sometimes people perceive us because we are against segregation, we are against the community living, at least people think that sometimes”* (F1). The main concern was that this could make it more difficult for ENIL to win new allies. This is because they often find themselves in situations where ENIL is the only one clearly advocating for the CRPD, while other related organisations prefer to remain silent for fear of losing a source of funding. Board members also feel that they would influence more people if their communication style was more positive (e.g. looking for good practises and only presenting these instead of criticising existing bad practises)⁴.

5.2 Advocacy and research

One of ENIL's activities in the area of monitoring various practises in the implementation of the rights of persons with disabilities is advocacy. ENIL is a very good advocate and promoter not only of the

⁴ In this context, one Board member points out that it is often difficult to find good practises that could be promoted.

concept of independent living, but also of the social model of disability in general (N1). In the field of advocacy, ENIL mainly addresses EU institutions, UN human rights bodies or other institutions. ENIL advocates for the principles of independent living through: position papers, briefings, submissions, letters, complaints, meetings, hearings, other events and expert groups.

At the NOISE workshop, the Secretariat expressed the view that ENIL is very good at advocacy but needs more allies. Both the Secretariat and other participants felt that ENIL should strengthen its movement and widen its circle of allies. Some also felt that ENIL should be more politically engaged (N1) or have more knowledge in the political field (F2), although the organisation has quite a strong influence at EU level as ENIL has contacts with Members of the European Parliament (MEP) and services in the EU Parliament (N1).

ENIL is additionally very active in research. This is important for other organisations as they can build on ENIL's research and support ENIL in promoting the concept of independent living and the rights of people with disabilities (N3).

Some ENIL members suggested that ENIL could consider additional topics as they feel that there is already a need for advocacy in other areas (e.g. climate change) due to the various changes in the world (F1, F2).

5.3 Key points

ENIL is currently doing an excellent job of fulfilling its vision and explaining and defending the concept and principles of independent living, regardless of location, time, or circumstance. ENIL acts as an advocate and activist on behalf of those whose voices are not heard.

ENIL has actively influenced EU policy through a number of initiatives, such as shadow reports, updates to the Independent Living Map, contributions to EU Guidance, open letters, and campaigns. The organization monitors the use of EU funds to promote self-determination and participates in international bodies, demonstrating a commitment to human rights advocacy.

According to respondents, ENIL has been moderately successful in influencing EU policy and influencing the implementation of CRPD-related policies.

The organization's role in defining and preserving the true meaning of independent living is crucial, although some concerns exist about its communication style potentially hindering broader support.

ENIL promotes independent living through position papers, briefings, submissions, letters, and meetings. However, there are calls for ENIL to strengthen its movement, expand its allies, and potentially broaden its advocacy topics. The organization is active in research, providing a foundation for other entities to support the principles of independent living.

6 Visibility and awareness raising

In this chapter, we assess the steps ENIL has taken to increase the impact of its activities, as well as its activities in the area of raising awareness of the right to independent living among persons with disabilities, their families and decision-makers.

In its Work Programme 2022–2025 (2022), ENIL has set the goal of raising awareness of the right to independent living among people with disabilities, their families, policy makers and other stakeholders. The purpose of ENIL's awareness raising is to:

- advance the cause of independent living at local, national, European and international levels;
- to promote better recognition of hate crimes against people with disabilities and the prevention of hate crimes against people with disabilities;
- to promote the right to equal recognition before the law (Article 12 CRPD and General Comment 1).

6.1 Visibility

In the area of raising visibility, ENIL plans to produce annual reports for members, collaborate with traditional media and social media, organize storytelling events, campaigns, publish podcasts, produce newsletters and regularly publish on ENIL's website. ENIL's image and visibility at EU level are very important as they make it easier for ENIL to realise its vision (ENIL, 2021; 2022b). ENIL indeed has a high production of resources that enable the transfer of knowledge to its members and to the general public. Some of their more important outputs are various reports, position papers, tools, Independent Living Map (with reports and country sheets), newsletter, podcast and many other resources that are also accessible through the website. The members of ENIL particularly highlighted the newsletter as a source of important information and a way in which members feel connected to the international disability community. In an interview, the representative of a user-led organization also emphasized the importance of the newsletter for them, but that it has an even greater potential as now and it could be better used for recognition and activation of members.

ENIL summarized its activities in the field of visibility in its Annual report for 2022. The Annual Report is aimed at persons with disabilities and their representative organisations, ENIL partner organisations, policy and decision makers at EU level, funders, donors and the general public. The annual report is available online from ENIL's website and disseminated through social media and other communication channels, and by email (ENIL, 2023a).

ENIL employees and board members expressed their desire to expand the range of topics that ENIL deals with (care agenda, climate change, etc.) since "*the trends are coming up, world is changing, there are new topics coming up.*" The need or necessity for ENIL to deal with other topics was not expressed by the members.

In addition to the annual report, ENIL is present in the media and prepares a media pack for journalists before each big event. ENIL has established contacts with journalists and arranges interviews to increase the visibility of the organisation. ENIL also publishes press releases and opinion pieces on key global holidays – the International Women's Day, the European Independent Living Day, the International Youth Day, the International Day on the Rights of Persons with Disabilities and the Human Rights Day - to raise awareness of the importance of respecting human rights and to publicise important work or respond to rights violations at European level. The press releases and opinion pieces are also shared with relevant journalists working for European media (ENIL, 2023a).

ENIL publishes a monthly Members' Mailing, with information about the work of the ENIL Secretariat, Board and ENIL Youth in the previous month, as well as announcements of Calls for Action and upcoming activities. ENIL also publishes a monthly online newsletter with articles from members, independent living researchers and ENIL staff reporting on the organisation's activities (ENIL, 2023a).

“The monthly newsletter is very useful and educational. They present some role models and what is going on in each country”(N1).

The publication *The Myth Buster* was also mentioned several times as an important achievement, about which a member said in the interview: *“Mythbuster is very important. It is the document where they explain independent living... and have a good definition of what is a personal assistant, what is independent living and everything. I think it is very important to have a document that we can translate and share and everybody in Europe has the same”* (N4). ENIL members touched on the issue of language several times. One of the suggestions from the surveys was that ENIL should use more of native languages. In the interviews, the members also mentioned ENIL's support in translating texts as very positive.

ENIL also ran two social media campaigns on deinstitutionalisation, at the beginning and the end of the year 2022 (ENIL, 2023a). In its Activity plan for 2023 based on Work Programme 2022–2025 (2022), ENIL stated that in the beginning of the year 2023 a communications survey shall be carried out to find out how satisfied their members, and others, are with social media (ENIL, 2023).

During the evaluation, we found that ENIL's social media activities before the 2022-2025 work programme were rather uncoordinated. Since the Strategic Plan for the 2022-2025 (2021) and their Work Programme 2022–2025 (2022), they have focused on raising awareness of the importance of ENIL's work by using social media such as Facebook, X⁵, Instagram, YouTube and Tiktok (ENIL, 2023a). Some board members noted that social media has given ENIL more visibility, as ENIL and its content are now more present virtually. It was also mentioned that ENIL has come a long way when it comes to social media. As of 2022, ENIL has increased its presence on social media. ENIL has 6100 likes and 6500 followers on Facebook, 3269 followers on X, 370 followers on YouTube and 1009 followers on Instagram. In 2022, they launched the podcast *On our terms*, which currently has 6 episodes (ENIL, 2023a).

In the past, using simple social media such as Facebook was a challenge for ENIL members. Now ENIL has a communications officer who takes care of ENIL's image on social media. The positive influence of the younger generation on ENIL's digital transformation was emphasised. A Youth Board member pointed out that a similar problem – lack of digital skills – also exists in her home country and emphasised the importance of solidarity and support between generations, i.e. the need for the younger generation to help the older generation in the transition to greater digitalisation of the organisation's workflows (this can also be done by setting up e-mail addresses for the older generation) (F1).

We therefore assume that ENIL's Work Programme 2022-2025 has enabled ENIL to develop and improve its expertise in the field of informing about its work, to renew the way it provides information and raising public awareness. At the same time, the Youth Board may have the potential to bring ENIL's activities closer to younger members and increase its outreach to the public.

6.2. Awareness raising

To raise awareness, ENIL has planned to carry out campaigns on independent living, to organise a Freedom Drive, to raise awareness on climate change and its impact on the lives of people with disabilities, to raise awareness on hate crime against people with disabilities, to promote the right to

⁵ Previously: Twitter.

equal recognition before the law, and to disseminate research results in the field of disability (ENIL, 2023a).

When asked about ENIL and its activities, members of ENIL and outside observers saw ENIL as a strong and vocal organisation that clearly represents its views. Some even said ENIL is radical, but also that it is the only unwavering defender of independent living *»ENIL is very insistent on ensuring that the transition from institutions to community based services is complete and really based on community based services«* (N5).

Our co-speakers see ENIL as a tenacious organisation which, in all its activities, does not allow others to forget the importance of deinstitutionalisation in all its activities. While other organisations sometimes have to adapt to their members or are afraid to become more vocal and lose funding, ENIL continues to speak up. Compared to other organisations like ENIL, it is strong in promoting the social model of disability (N1).

The majority of our interviewees, as well as respondents to the survey, highlighted the Freedom Drive as the most iconic event organised by ENIL to promote independent living. It is not only an important event that allows people with disabilities from all over Europe to gather in Brussels and protest against exclusion and institutionalisation, but also an event that is recognised among other actors and related European organisations. *»And the Freedom Drive is a really good moment in the year because there's nothing else like it. And so it gets us out of the meeting rooms into the streets. And that's good!«* (N3).

The Freedom Drive is one of ENIL's most important campaigns. The Freedom Drive is a unique opportunity for supporters of the Independent Living movement to meet MEPs, promote the right to independent living and the implementation of the UN Convention on the Rights of Persons with Disabilities, and exchange experiences and ideas with fellow activists from across Europe. The Freedom Drive protest is an opportunity to raise awareness of the right to independent living and the need to close down institutions (ENIL, 2023a).

The Freedom Drive also includes a number of workshops and conferences that allow Freedom Drive participants to participate even more directly. *“The Freedom Drive is something that always manages to make a mark on policymakers«* (N5). Participants also highlighted other events organized by ENIL which have left a positive impact over the past two years by bringing together individuals with slightly different perspectives, emphasizing inclusivity by not limiting participation to those who share the same views. Notably, events involved collaboration with service providers, even those critiqued by ENIL, showcasing an openness to diverse opinions and fostering constructive dialogue (N3).

The organisation of such events is very important, but it should not be the only one or the one on which most emphasis is placed. For the EU, its bodies and its MEPs, Freedom Drive can be just *part of the 'news of the day', which is forgotten within two weeks* (N1). It is therefore necessary to build a broader network of levers to realise the concept of Independent Living, and that is exactly what ENIL is doing.

ENIL members also consider it extremely important to work on the implementation of Article 19 of the CRPD and to draw a clear line between personal assistance and other support or care services. In addition to raising awareness in the field of deinstitutionalisation and personal assistance, their work also enables their members to exchange knowledge in this field and thus raise awareness in their own countries (N1).

Some members also consider strategic litigation to be an extremely important way for ENIL to raise awareness. ENIL encourages its members to use strategic litigation aimed at bringing about systemic change through legal means. ENIL has, jointly with its members, gone to court when the EU funds aimed at implementing deinstitutionalisation reforms were misused. In a sense, it is a kind of “public blame and shame”. Strategic litigation puts the issues of people with disabilities in the spotlight, which is already a success in the awareness-raising department “*The eyes are on it, the media is on it*” (F1).

“For example, you know, we had that strategic litigation where we supported our members to go to court when European funds were misused. You know there are special funds to realize the deinstitutionalization and then some member countries really built small group homes near a wood really at the end of the road. The fact that we supported them and that members dared to take the initiative to go to court against the government and telling them about the misuse of funds, that's already a big achievement. It's like a public kind of blame and shame. Sometimes it was not well received because they found that the evidence was not strong enough and sometimes we even received answers from the Commission like: ‘Some member states are still in the transition phase and they are in need of smaller entities for persons with disabilities to protect them’. So they allowed it. But the fact that we have already brought this in the spotlight is already a success. It has been mentioned. So the eyes were on it, the media was on it. So it's already that awareness, change of paradigm shift. That was good” (F1).

ENIL is therefore doing awareness raising work at the EU level that no other organisation is doing. It is constantly focused on implementing Article 19 of the CRPD, even though everyone else is willing to compromise and partially overlook what independent living truly means.

6.3 Key points

ENIL aims to increase awareness at local, national, European, and international levels. Key goals include promoting independent living, recognizing hate crimes against people with disabilities, preventing such crimes, and advocating for the right to equal recognition before the law. As we show above, ENIL employs various strategies to enhance its visibility, such as producing annual reports, collaborating with media, organizing events, campaigns, podcasts, and maintaining a strong online presence and producing diverse resources, including reports, position papers, tools, an Independent Living map, newsletters, podcasts, and more, accessible on its website. As of 2022, ENIL has increased its presence on social media. ENIL additionally plans campaigns on independent living, a Freedom Drive event, awareness on climate change's impact on people with disabilities, and initiatives against hate crimes.

7 Capacity and knowledge building

In this chapter, we first assess how capacity building takes place within ENIL and what the strengths, needs and opportunities are. In the second part, we look at ENIL's capacity building efforts and impact in the wider European area and in co-operation with its members. In the final part, we look at how ENIL's knowledge can be used to shape practises in European countries.

7.1 Capacity building within ENIL

Capacity and knowledge building is an important part of ENIL's activities, which is reflected in the work plans, activities carried out and results achieved. The activities in this area are related to the work of the ENIL organisation itself and the training for its demanding work, as well as the production of knowledge and training that is important for ENIL members and the realisation of human rights for

persons with disabilities. One of the goals of the ENIL is to improve the capacity of ENIL members to contribute to the implementation of the European Disability Strategy 2021 – 2030, the CRPD and other relevant laws and policies at the local and national level (ENIL, 2021; 2022b). Capacity and knowledge building is also specifically planned each year and includes various methods and approaches, such as: freedom drive, members' meetings, study visits, workshops, conferences, seminars and youth leadership program, some of which we have already described in previous chapters.

ENIL seeks to create opportunities for ENIL members to support each other with best practices in independent living and to encourage young people with disabilities to develop leadership skills and strengthen their ability to advocate for independent living, support each other and share knowledge and best practices.

ENIL's employees at NOISE workshop see their advantages and strengths in their broad knowledge and expertise, especially in human rights and CRPD. There is a lot of emphasis on issues persisting over time, particularly EU funding, deinstitutionalisation and personal assistance. They believe that they should devote more time and effort to working on just one or two related topics, allowing them to be more focused within one topic. In the future, new topics such as the care agenda, climate change, etc. should also be addressed. One area of knowledge that should be further developed and above all shared is methods and strategies for advocacy (F1).

ENIL's work is carried out by a small team that engages productively and critically with issues, but also involves board members and volunteers well and is connected to the grassroots. They have made improvements in the training of the team and ensure internal and external evaluation of their work. In recent years, improvements have also been made in knowledge sharing and online mentorship for external people. For further development, ENIL would need more staff, more training and more time. One of the challenges for ENIL is to find younger people who are interested in activism and to train them. There are often problems with training and mentoring, as employed or active members do not have enough time to mentor others. In addition, it often happens that young people who do training and acquire different skills soon find another job. One problem is therefore both finding young people, offering well-paid jobs that retain staff and other opportunities for involvement in ENIL. Many members of ENIL pointed out that they *"urgently need to find younger people in ENIL who are willing to continue ENIL's mission"* (F1, N1). One member of the Youth Board pointed out that *"lobbying among peers is difficult. Often young people are not interested or do not recognise the benefits of ENIL membership. A challenge for the future is to get more members or people with disabilities interested in working for ENIL, especially as the organisation is known to be run by people with disabilities"*. Volunteers are also an important part of ENIL. ENIL members believe that they have a good network of volunteers who support the staff in their work and in realising their vision (F1, F2, N2).

An important task for the future is a good mentoring programme for new employees and others to help them become experts. ENIL staff feel that there is potential and opportunity to develop experts by supporting a few determined organisations and people with disabilities working on the front line (in the policy field), new people recognising ENIL's expertise and giving them the opportunity to go to events and speak out, influence people and help with common goals.

In the discussion with the Board members, the idea came up that with the resources available that there should also be some form of helping other organizations, capacity building in other countries so ENIL is more present.

7.2 Building and exchange of knowledge

The survey among ENIL members shows that members see advocacy and awareness-raising as ENIL's most visible work. Nonetheless, many members emphasised the importance of knowledge creation and sharing through ENIL, both in the interview surveys and in a focus group.

The user-led organizational members emphasized the importance of connecting and exchanging knowledge (N1). One of the key achievements of ENIL is setting up a space where information, practices, knowledge and theoretical knowledge can be exchanged and compared among ENIL members. Internal dialogue on important substantive and conceptual issues is key in ENIL, because this is not possible in other disability organizations in such an open way. ENIL creates a space where it is possible to develop, defend and enforce the concept of independent living and related personal assistance. Collaboration with other like-minded organisations is particularly important for members who want to bring about changes in their own countries: *“We search for good practices or some example how it is done in other countries and ENIL always has a good contact. ... I think this is the strength of the network»* (N4).

In a survey⁶ one of the ENIL's member mentions the importance of information provided by ENIL: *»ENIL has a good and concrete strategy and tools for online communication with membership, offering us all to be immediately informed and enabling participation in almost all events online or listening to them and include during them or afterwards which is a great asset and resource both for its work and work of its members enabling the feeling of the full participation in each important moment or activities regarding the scope of ENIL's work. It should keep up this way.»*

7.3 The impact of use and misuse of ENIL's knowledge

In an interview, a question was raised about how to proceed in areas where no significant progress has been made. One of the central issues is the struggle for *“visibility and campaigning and keeping the issue that people are placed in institutions, and keeping this on the agenda and not letting people get distracted because this is something where there has not been progress”* (N1). In doing so, the question was raised on how to proceed: *“So that is something that we all need to collectively reflect on. So for example, often what policy makers ask for is examples of models of things that work. And so I think this is something that ENIL could contribute. Study a little bit more things that work. They're extremely effective at pointing out what doesn't work, but I think focusing maybe on things that work would be useful”* (N5).

The question of misuse of ENIL's knowledge was highlighted in survey and focus group, focusing i.e. on a much-debated question of how the terms "independent living" and "personal assistance" are used by the various stakeholders. The contrast between the knowledge developed by ENIL and the misuse of this knowledge in practice by stakeholders was mentioned in our research: *“ENIL has a body of knowledge that is often used by different decision-makers, but often selectively and not entirely in accordance with the concepts that ENIL advocates. Many organizations that provide personal assistance do so in the form of a care service”* (N1). ENIL's members expressed the view that it is necessary to track the knowledge developed by ENIL and the (mis)use of knowledge in the nation states and to establish control methods. ENIL has the knowledge and the network to strengthen its influence in the fight against bad practices: *“Developing, defending and enforcing the concept of independent*

⁶ The open question in survey was: *How could ENIL improve its support to members and further increase membership?*

living and personal assistance is crucial. ENIL must strengthen its defense of the social model and insist on the consistent implementation of Article 19 of the Convention on the Rights of Persons with Disabilities” (N1).

7.4 Key points

The chapter begins by assessing how capacity building takes place within ENIL, emphasizing strengths, needs, and opportunities. ENIL works to increase its members' capacity to contribute to the implementation of the European Disability Strategy and other relevant laws. The need for more staff, training, and finding younger activists are among the challenges. The significance of mentoring programs and the involvement of volunteers is emphasized. Furthermore, ENIL members see advocacy and awareness-raising as the organization's most visible work. However, knowledge creation and dissemination are also critical. ENIL is viewed as a platform for its members to exchange information, practices, and theoretical knowledge. Internal dialogue on substantive issues is cited as a major accomplishment. Collaboration with like-minded organizations is critical for sharing best practices and influencing positive change in different countries. However, the potential misuse of ENIL's knowledge by decision-makers who may selectively interpret terms like "independent living" and "personal assistance" is raised. ENIL members express the need to monitor and control the use of their knowledge to ensure consistency with their advocacy goals, especially in relation to the CRPD.

8 Conclusions and recommendations

ENIL's vision is that all people with disabilities are able to determine and control their own lives, on an equal basis with others, and that they are valued members of the community who enjoy all their human rights as set out in the CRPD. Their role is to advocate for the values, principles and practises of independent living, i.e. a barrier-free environment, the provision of personal assistance and appropriate technical aids to enable people with disabilities to participate fully in society (ENIL, 2022). Based on interviews with ENIL members and staff and the results of the survey (see appendix), we conclude that ENIL is pursuing and realising its vision and mission very effectively. ENIL is an expert in explaining the concept and principles of independent living and is very good at implementing them, regardless of place, time or situation. Below we present the most important results of the survey.

Management, movement and networks

The study also took a closer look at how ENIL itself works. ENIL is organised as a network of members from different countries across Europe. We found that this does not cause ENIL any major problems in organising and coordinating its activities and that the various bodies are well connected and interlinked. The organisation of the work itself is good and efficient, although most activities are carried out remotely. This suggests that, despite the organization's overall efficiency in organizing and coordinating activities, there might be constraints on the staff team's capacity or resources, potentially affecting their ability to thoroughly explore and address specific issues.

One aspect of the organisation's performance is its financial stability. In the past, ENIL's funding was based on several smaller projects, but in 2022 ENIL was awarded the larger Choice4All operating grant, which secures the organisation's financial stability in the longer term. While the approach of bidding for multiple projects to ensure financial stability has proven successful in securing jobs, it can pose a challenge to implementing the organisation's mission. This is because the project calls require the organisation's work to be aligned with the call and not the other way around. This in turn makes it difficult for the organisation to fulfil its mission consistently, especially if the organisation is funded by multiple projects on a range of different topics.

Recommendations for ENIL: Explore opportunities and resources for additional staff; develop a long-term fundraising strategy to achieve ENIL's vision.

Implementation of disability rights policies in the EU

ENIL is currently doing a good job of fulfilling its vision and explaining and defending the concept and principles of independent living, regardless of location, time, or circumstance. ENIL acts as an advocate and activist for those whose voices are not heard. ENIL should become more visible and gain more allies to have a greater impact. While it is critical for ENIL to adhere to the idea of a clear and uncompromising interpretation and implementation of Article 19, it is also prudent to maintain a positive communication approach, as suggested. This includes highlighting best practices, presenting good examples, and making constructive suggestions for replication of upscaling of such practices.

Given the current pressing issues, it should be considered whether ENIL should broaden the scope of its operations. This type of initiative was mentioned several times in the survey, and we recommend that the members of the General Assembly consult on it.

Recommendations for ENIL: develop lobbying and advocacy strategies; consider whether ENIL should begin working on new pressing topical issues (while remaining within the scope of independent living); maintain a consistent presence in defending the principles of self-determination, regardless of location or time.

Visibility and awareness raising

Significant progress has been made in improving the visibility and raising the profile of ENIL. Respondents generally recognise the importance of these activities and positive steps have been taken with the recruitment of a communications manager under the operating grant. ENIL has also been very successful in some of its campaigns, one of the most high-profile being the Freedom Drive.

ENIL also produces a lot of educational and research material. To increase the reach of key documents, we suggest that ENIL translates documents into several languages. The translation of main materials into national languages is also an important activity to standardize ideas, although we understand that this is highly dependent on the funding itself.

Some ENIL members also participate in various events. In our survey, we found that these are mostly more or less the same members who are otherwise very active in the areas in which ENIL is active. More outreach activities are needed for existing inactive members or new members who are also experts but have not yet shown themselves publicly. Possible improvements in terms of visibility and awareness include strengthening the activities of the Youth Board in order to reach young people and the public even better.

Recommendations for ENIL: Improve the management of social networks to reach more people; refine the social network strategy based on feedback from members and ensure that it is in line with the organisation's objectives; strengthen the activities of the Youth Board to further improve outreach; translate key documents into several languages.

Capacity and knowledge building

Over the years, ENIL as an EU-level organisation has made a name for itself in society as an expert and researcher in the field of independent living, deinstitutionalisation and personal assistance. ENIL has managed to maintain its expert status over the last two years as it continues to be recognised as an EU-level organisation with extensive and in-depth knowledge in the field of human rights, particularly in the defence of the CRPD. As a network, ENIL is the only organisation that deals intensively with the areas it covers. Some of the most successful outcomes of the last two years have been the following documents: Guidelines on deinstitutionalization, including in emergencies, action against the European Care Strategy, Mythbuster on personal assistance.

Members appreciate support with national legislative changes, study visits, information provided by ENIL, exchange of knowledge and building capacity of people around Europe to implement independent living. One of the things that was highlighted is the importance of exchanging knowledge and experience in different ways.

ENIL members have a wealth of knowledge that needs to be shared with younger generations in order to ensure that ENIL continues to fulfil its mission for generations to come. Recognizable members and faces of ENIL should cooperate well with the younger generation and ensure a good and quality succession with the aim that ENIL as an organization will continue to grow. In spite of the fact that ENIL established a Youth Network, members and employees still feel that they lack '(youth) activism'. ENIL

needs people who would fight for independent living agenda today and in the future, because it is not a given that the acquired rights will last forever.

It is also important that ENIL has many contacts of different stakeholders on EU or international level, because in practice this means the transfer of knowledge and practices between countries. Contacts and networking also enable comparisons between countries. Through regional meetings, the members have new opportunities to get in touch and exchange experiences and undertake joint advocacy beyond those meetings.

Recommendations for ENIL: establishing mentoring programmes or initiatives that facilitate knowledge sharing between different age groups can strengthen internal collaboration and efficiency.

ENIL holds a crucial advocacy and activist role and takes the side of people whose voices are not heard. Their work is very important in the field of human rights and implementation of the CRPD and has impact throughout Europe, although members often feel that change is slow or invisible. ENIL is concerned with the rights of people with disabilities in line with the philosophy of independent living. The fight for respect for rights is a constant struggle, with ups and downs, and the process is certainly not yet complete. The rights of people with disabilities cannot be taken for granted and must be actively fought for. In this context, ENIL has a special role to play, as it campaigns for the rights of people with disabilities. ENIL highlights the challenges and lack of respect for these rights and works tirelessly to realise an independent life for all, free from prejudice and restrictions.

Perhaps the most sincere appreciation and appeal for the future ENIL endeavours is the suggestion of a member from the survey:

Keep fighting!

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9 Appendix

Appendix A: Summary

The report evaluates ENIL's work in 2022 and 2023 as part of the Choice4All work programme 2022–2025. The performance of the Choice4All work programme is assessed against the achievement of the objectives in the areas of overall governance and management of the organisation, supporting the implementation of European social policy, raising awareness of the right to independent living, strengthening the capacity of ENIL members to contribute to the implementation of the European Disability Rights Strategy 2021-2030, the CRPD and other relevant laws and policies at local and national level, building a stronger and united disability movement for independent living at European level.

The evaluation was based on a detailed description of the work process, the objectives achieved and the experiences of key stakeholders and persons with disabilities on the strengths and weaknesses of ENIL's processes and work in 2022 and 2023. This was done through a multi-level evaluation focusing on the work process (how objectives and results were achieved), the achievement of the objectives of ENIL's work plan for 2022 and 2023 and the impact of ENIL's work on key stakeholders and the social environment.

Our key findings were that ENIL is successful in realising its vision. ENIL is very good at explaining the concept and principles of independent living and is very good at advocating for their implementation, regardless of place, time or situation. Members and other EU networks appreciate the breadth and depth of knowledge ENIL has in the field of human rights, especially in the defence of the CRPD.

Freedom Drive, awareness raising, guidelines on deinstitutionalisation, including in emergencies, actions against the European Care Strategy, Mythbuster are just some of the many ENIL projects in recent years that have perhaps been the most memorable.

ENIL members appreciate the support on national legislative changes, study visits, information provided by ENIL, knowledge sharing and capacity building across Europe to realise independent living. To have a greater impact, ENIL should become more visible and have more allies. ENIL would also need more staff and should persistently look for younger successors. Recognisable members and faces of ENIL should work well with the younger generation and ensure a good and high quality succession so that ENIL can continue to grow as an organisation. ENIL needs people who are committed to the independent living agenda now and in the future, as it is not necessary for the rights acquired to last forever.

More activism and the presentation of positive developments are needed in the area of awareness-raising. At first glance, the two proposals seem incompatible, but perhaps ENIL could maintain its activist tradition and critical perspective while showcasing examples of good or promising practises. The first attempts at such an operation are already online webinars organised within the European Coalition for Community Living - ECCL.

It is also necessary to raise awareness in the Member States and other European countries that are not part of the EU. The ideas and values of ENIL should be transferred to all European countries.

ENIL plays a crucial role as an advocate and activist, standing on the side of people whose voices are not heard. Their work is very important in the field of human rights and the implementation of the CRPD and has an impact across Europe. ENIL's work is respected by its members, especially given the major obstacles to the realisation of the human rights of people with disabilities.

Appendix B: Survey response summary

What region are you based in?

	Frequency	Percent	Valid Percent	Cumulative Percent
European Union	30	71,4	71,4	71,4
Other countries in Europe	9	21,4	21,4	92,9
Rest of the world	3	7,1	7,1	100,0
Total	42	100,0	100,0	

Which of the following best describes your gender?

	Frequency	Percent	Valid Percent	Cumulative Percent
Female	16	38,1	38,1	38,1
Male	24	57,1	57,1	95,2
Trans	1	2,4	2,4	97,6
Other	1	2,4	2,4	100,0
Total	42	100,0	100,0	

Do you identify as a person with disabilities?

	Frequency	Percent	Valid Percent	Cumulative Percent
Yes	36	85,7	85,7	85,7
No	6	14,3	14,3	100,0
Total	42	100,0	100,0	

What is your age?

	N	Minimum	Maximum	Mean	Std. Deviation
Age	42	28	73	47,48	13,112
Valid N	42				

What is your relationship to ENIL?

	selected	
	Count	Row Valid N %
Employee	1	2,4%
Board member	3	7,1%
Youth board member	1	2,4%
Member	26	61,9%
Volunteer	4	9,5%
Partner	5	11,9%
Other	6	14,3%

How long have you been collaborating with ENIL?

	Frequency	Percent	Valid Percent	Cumulative Percent
0-2 years	10	23,8	23,8	23,8
3-5 years	6	14,3	14,3	38,1
6 years or more	16	38,1	38,1	76,2
I do not collaborate yet	10	23,8	23,8	100,0
Total	42	100,0	100,0	

In which of the following ENIL activities do you participate:

	selected	
	Count	Row Valid N %
meetings or events	18	42,9%
creating ENIL's strategic plan	6	14,3%
preparing work programme	3	7,1%
preparing project applications	1	2,4%
preparing reports or position papers	3	7,1%
contributing to surveys	22	52,4%
contributing to consultations	16	38,1%
participating in the Freedom Drive	18	42,9%
following what ENIL does	32	76,2%
through carrying out common projects	5	11,9%
other	2	4,8%
I do not participate in any ENIL activities	5	11,9%

Which thematic areas do you find most important?

	selected	
	Count	Row Valid N %
Independent living	33	78,6%
Deinstitutionalisation	20	47,6%
Personal assistance	24	57,1%
Peer support	11	26,2%
Accessible environments	11	26,2%
Inclusive education	2	4,8%
Use of EU funding	8	19,0%
Disability hate crime	4	9,5%
Legal capacity	5	11,9%

ENIL is working very hard to build a stronger and unified movement of persons with disabilities on independent living in Europe. How would you rate their impact?

	Frequency	Percent	Valid Percent	Cumulative Percent
Very low	0	0	0	0
Low	4	9,5	9,5	9,5
Moderate	19	45,2	45,2	54,8
High	11	26,2	26,2	81,0
Very High	8	19,0	19,0	100,0
Total	42	100,0	100,0	

ENIL is supporting the implementation of different policies at the European level. How would you rate their impact on the implementation of the Article 19 of the CRPD in Europe?

	Frequency	Percent	Valid Percent	Cumulative Percent
Very low	0	0	0	0
Low	6	14,3	14,6	14,6
Moderate	20	47,6	48,8	63,4
High	11	26,2	26,8	90,2
Very High	4	9,5	9,8	100,0
Total	41	97,6	100,0	

How would you rate ENIL's impact on the use of the EU funds in compliance with the CRPD?

	Frequency	Percent	Valid Percent	Cumulative Percent
Very low	1	2,4	2,4	2,4
Low	6	14,3	14,6	17,1
Moderate	19	45,2	46,3	63,4
High	13	31,0	31,7	95,1
Very high	2	4,8	4,9	100,0
Total	41	97,6	100,0	

ENIL is working to raise awareness on the right to independent living among persons with disabilities, their families, policy and decision makers and other stakeholders. How would you rate their impact on raising awareness?

	Frequency	Percent	Valid Percent	Cumulative Percent
Very low	0	0	0	0
Low	3	7,1	7,3	7,3
Moderate	17	40,5	41,5	48,8
High	11	26,2	26,8	75,6
Very high	10	23,8	24,4	100,0
Total	41	97,6	100,0	

ENIL is working to improve the capacity of ENIL members to contribute to the implementation of the European Strategy for the Rights of Persons with Disabilities 2021-2030, the CRPD and other relevant laws and policies at the local and national level. How would you rate their impact?

	Frequency	Percent	Valid Percent	Cumulative Percent
Very low	0	0	0	0
Low	4	9,5	10,0	10,0
Moderate	16	38,1	40,0	50,0
High	15	35,7	37,5	87,5
Very high	5	11,9	12,5	100,0
Total	40	95,2	100,0	

Descriptive statistics:

	N	Minimum	Maximum	Mean	Std. Deviation
ENIL is working very hard to build a stronger and unified movement of persons with disabilities on independent living in Europe. How would you rate their impact?	42	2	5	3,55	0,916
ENIL is supporting the implementation of different policies at the European level. How would you rate their impact on the implementation of the Article 19 of the CRPD in Europe?	41	2	5	3,32	0,850
How would you rate ENIL`s impact on the use of the EU funds in compliance with the CRPD?	41	1	5	3,22	0,852
ENIL is working to raise awareness on the right to independent living among persons with disabilities, their families, policy and decision makers and other stakeholders. How would you rate their impact on raising awareness?	41	2	5	3,68	0,934
ENIL is working to improve the capacity of ENIL members to contribute to the implementation of the European Strategy for the Rights of Persons with Disabilities 2021-2030, the CRPD and other relevant laws and policies at the local and national level. How would you rate their impact?	40	2	5	3,53	0,847