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## Regional member's meeting – North European Network on Independent Living – ENIL

Stockholm, Sweden  
22 November 2024

### MEETING REPORT



#### 1. Welcome and introduction

The meeting was opened by Jamie Bolling, Co-chair of ENIL and the Director of the Independent Living Institute (Independent Living Institute), who welcomed all participants.

Asa Emtelin spoke on behalf of JAG, one of the 3 co-hosts of the meeting (alongside ILI and STIL). She spoke about the importance of personal assistance (PA) for disabled people in Sweden. She introduced her sister Anna Soderberg, a Board member at JAG, sitting next to her. Anna used to live in a group home and now lives

with her personal assistant, which allows her to live her life the way she wants and makes her much happier.

Kamil Goungor, ENIL's Policy and Movement Support Officer and the moderator for the day, welcomed participants on behalf of ENIL and invited participants to say their name, organisation and country. We had 46 participants (including personal assistants) from Sweden, Norway, Iceland, Denmark, United Kingdom, Belgium, as well as Bosnia and Herzegovina and San Marino.

Kamil then presented the agenda for the day.

## **2. Overview of key ENIL activities in 2024 and plans for 2025**

Ines Bulic Cojocariu, the Director of ENIL, presented the upcoming activities for this year, and plans for the next year (**Action point** – share Power Point presentation). She explained that Florian Sanden, the Policy Coordinator, would focus on activities related to EU advocacy.

Ines encouraged participants to join the strategic consultation for the North, planned for 9 December at 15:00 – 17:00 CET, and to complete the survey. (**Action point** – send registration link and the survey to meeting participants)

Florian presented key developments at EU level – the new Guidance on Independent Living, the European Disability Card and the work that ENIL is doing to influence the draft regulation on the protection of vulnerable adults in cross-border situations. (**Action point** – share Guidance on Independent Living). Florian also explained options of using anti-discrimination legislation to challenge institutionalisation. He noted the importance of the horizontal equality directive, which is still stuck in the European Council.

There were several questions from the participants –

- A clarification on using anti-discrimination legislation to challenge institutionalisation
- The number of people in institutions in Europe (**Action point** – share new Eurofound report)
- How to encourage countries to collect better data on disabled people in institutions

## **3. Key initiatives in the North**

### **a) Disability Rights Defenders Network (DRD)**

**Jamie Bolling, from the Independent Living Institute**, presented the Disability Rights Defenders Network. DRD has been working as an informal network since 2018 and is in the process of creating a 6-year impact report, which will be shared later. (**Action point** – share DRD impact report)

Jamie explained the two main ideas of DRD – to know your rights and use them, as well as to spread information and promote Independent Living.

Susanne Berg introduced DRD – Sweden – formed as ‘law as a tool association’. There were several cases with pro bono lawyers supporting clients through courts. She explained that one person won the case; it was about reasonable accommodation in the labour market. They also have a case at the moment at the UN CRPD Committee about discrimination in schools – it is about pupils with dyslexia. This is a slow process, because the Committee is overloaded with cases.

There was a suggestion from the audience:

- Suvad Zahirovic suggested to have DRD branches in different regions that are part of the network; this way local lawyers could be involved and connected

## **b) Nordic Competence Centre on Personal Assistance**

**Martine Eliasson from Uloba – Independent Living Norway** presented the Nordic Competence Centre (NCC) on Personal Assistance (PA), started during the Freedom Drive in 2019.

The aim is to ensure that PA systems – Norway, Sweden, Denmark and Iceland all have similar systems – are provided according to the CRPD.

When it comes to PA, the political debate is often focused on cutting the costs and there is Government propaganda against personal assistance, showing how much taxpayer funding is being spent on disabled people.

Martine shared the case of a young disabled woman moved from her family across the country into residential care – it is done under the claim of providing best service. They said she had to be put under guardianship, because she could not communicate her wishes, but her dad filmed her saying she was scared with the moving boxes going into the car.

The NCC is about working together in the 5 Nordic countries. The mission is to improve PA systems in all the countries by sharing experience and doing research, looking at the best practices. It provides a platform where Independent Living organisations can work together.

PA isn't about health care. It is about living independently and about achieving your human rights.

NCC had their first meeting in May 2024 in Drammen, at ULOBA's office. They decided what they want to do in the coming year. The next meeting will be connected to the Nordic Network on Disability Research Conference in Finland (May 2025). They applied to have a session on how PA works in different countries. This will also be connected to 5 May – the European Independent Living Day.

NCC are carrying out their research report now and can share it with everyone later, when it is ready. (**Action point** – Uloba to share NCC report when it is ready.)

Kamil explained that ENIL is coordinating the Independent Living stream during the NNDR Conference in Finland and we have received a number of good abstracts. We should see how to coordinate with NCC. (**Action point** – ENIL and NCC to coordinate activities during the NNDR in Finland, in May.)

There were a number of questions from the participants:

- There is a huge lack of self-determination when leading your own PA – what is the best practice?
- There was a discussion of how we as disabled people perceive PA – there is a need for capacity building, empowerment, peer support and training among disabled people
- There were a lot of fraud cases in Sweden – there was no debate, we just turned our backs to the subject; we didn't believe that someone among us could do such a thing
- It is very dangerous when things are too untouchable for us to discuss
- Martine wondered if the IL movement/organisations explain PA well enough. What IS the best practice?
- She suggested we need not only talk about (young) people needing services - they want to contribute to society
- We need a broader discussion on how to educate people, esp. educate young people, otherwise we will be going backwards
- Kamil gave the example of Greece, where there is legislation on PA since 2021 and a pilot project since 2023; however, many disabled people don't understand what PA is and there is a lot of discussion about what PA is
- Susanne Berg cautioned against getting into the narrative the media are pushing around fraud – fraud in social care is very small compared for example to tax fraud; the narrative is also closely linked to austerity measures
- Susanne suggested research articles in English about fraud/austerity – by Niklas Altermark Lundt University (<https://www.lunduniversity.lu.se/lup/publication/1de9f2ec-37c3-41ff-a56d-0f7884922df0>), and Ida Norberg from the Glasgow University (<https://www.gla.ac.uk/schools/socialpolitical/staff/idanorberg/#publications,articles>) (**Action point** – Susanne Berg to share research articles)
- One interesting aspect – look into social norms about how services, including PA, should be provided; Mari would suggest for the competence centre to look into this – how to achieve self-determination

### C) CRPD as a law

**Jonas Franksson from STIL, Sweden**, introduced the campaign 'CRPD as a law', whereby the aim is to incorporate UN CRPD into domestic law, so that it can be litigated in courts.

In 2014, the Swedish Government decided to put the Children's Rights Convention into Swedish law. However, this was the only Convention that was incorporated, not the others. At the same time, there was the perception that everything was perfect in Scandinavia and that there was no need to do anything more after the ratification of the CRPD. Worryingly, this view was also voiced by human rights defenders. Jonas referred to this as the 'Nordic exceptionalism'.

However, the situation in Sweden when it comes to independent living has been getting progressively worse. The cuts have been going on for some time and there are now about 5,000 people who lost the PA from the state level. At the same time, neither the politicians nor the Swedish courts care about the UNCRPD.

The campaign to get CRPD into law has the support of almost every big organisation within the disability and the IL movement.

The discussion revolved around the following questions:

- What type of strategies are needed to make sure everyone can live independently? We discussed working with the media, but reached the conclusion that this can be only one of the strategies. We also discussed protesting and how common it is for disabled in different countries to take to the streets.
- Relationship of STIL (i.e. the Independent Living movement) with other DPOs. Jonas shared that many DPOs work based on the medical model; therefore, it is good to not be fully accepted by everyone. However, there was consensus that it is good to join forces around certain areas – there is agreement on whether PA should be on municipal or state level and here DPOs can come together
- The participant from Iceland shared that IL was not won through protests – they have never been out in the street - but through the newspapers.
- Some participants pointed out that there is a difference between the IL movement and the established organisations (DPOs). The IL movement starts from the individual and proposes specific solutions. Established organisations get membership for credibility and ask politicians to come up with solutions.

#### **4. Youth initiatives**

After lunch, we moved on to the topic of youth involvement in the Independent Living movement and how to increase it.

**Emma Astrand, from STIL**, explained how they work with young disabled people in Sweden. She shared that the disability movement is very diagnosis based – therefore, young people are separated based on type of impairments.

STIL offers another approach, based on intersecting identities that goes beyond impairment and offers peer support. Emma explained it is difficult to reach people and for people to find each other, but once they do, they stay involved. Young people have to find each other online and we need to talk about identity.

**Martine Eliasson, from Uloba – Independent Living Norway**, presented Camp Freedom. This is Uloba's initiative to find disabled youth and build the next generation of young activists.

Camp Freedom is a summer camp for young people aged 18 – 35 and two camps were organised, in 2022 and 2023. This year, the municipalities cut the hourly rate for PA, so there weren't enough resources to have the camp.

According to Martine, it is important to gather young activists, so they know they have to stand up for their rights. Camp Freedom is on pause, but we have to keep the momentum going. We have to look at other youth initiatives and see where the young people are – perhaps do more online initiatives and find young people that way.

In Sweden, they also had an online Crip Camp – identity is very important for GenZs.

The discussion revolved around the following questions:

- How to make sure young people stay engaged. Martine responded that we need to give to them responsibility.
- How to make sure young people stay and do not quickly move on to the next initiative. Emma responded that it was hard to get young people involved, but once they are involved, they stay – they have found their safe space.

## 5. Future strategy for ENIL North

Kamil Goungor opened the final session with the following questions:

- Should we have a coordinator for ENIL North and what would their role be?
- What could be some of the activities for next year?
- What is the value of ENIL to the North?

There was a good discussion on these points, with the **conclusions** as follows:

- Before deciding on the question of the coordinator, it would be important to decide what their role is and how they will be funded. There was an informal coordinator in the past, but without a clear understanding of their role.
- There is already a lot of cooperation between ENIL members in the North - through the Nordic Competence Center, the CRPD as a law campaign, participation in Uloba's Stolthetsparaden. It would, however, be important to disseminate this work better through ENIL, such as in the Newsletter or through webinars. Also, additional ENIL members could join these projects.
- The next meeting of ENIL North could take place during the NNDR conference in Finland next year, where ENIL is coordinating an Independent Living Stream.
- An additional role for the coordinator could be to coordinate funding proposals for the regional, for example through Erasmus+. One such project could be the cost-benefit analysis in different areas.
- The countries included in the North are the Nordic and Baltic countries, but at the moment we are missing someone from Latvia and Estonia, as there are no IL organisations in those countries.
- The focus of the North could also be empowerment of young people. For example, we could organise webinars or other activities aimed at young people.

- Bente Fund opens additional possibilities for the North (the deadline is on 9 February). For example, people could apply to attend the Stolthetsparaden in Norway.
- ENIL should focus on bringing news from the EU level and how these are relevant for them (could be good or bad), facilitating events where people from different countries can meet and informing members who is in the European Parliament, so that each country could lobby their MEPs.
- There are many funding opportunities for the region, including the Norway Grants, which allow for cooperation between the North and the Central Eastern Europe.

## 6. Updates from different countries

**United Kingdom** (Kamran Mallick) – the problems are very similar to those described in other countries. During Covid, 60% of people who died were disabled people. The decision of the UK to leave the EU had a very negative impact on disabled people, especially in terms of making access to PA much more difficult. There was also a reduction in social care funding, as a result of which people are being coerced into institutional care. They are getting so few hours that it's not feasible to stay at home.

There are many DPOs that still exist – DPO Forum England. They came up with Disabled people's manifesto – there is a website that we should share: <https://www.disabledpeoplesmanifesto.com/manifesto>

There has been an attempt at unifying requests from the Government. So far, the signals from the new Labour Government are worrying, but they are hoping it will get better.

**Lithuania** (Kristina Dudonyte) – they have had a regulation on PA for 3 years now. The problem is that funding for PA is small. It is difficult to understand what PA is doing and what is done by other services. A PA can do very little – there is a regulation that a PA can help only with very limited things (using the medical model).

**Denmark** (Jesper Mathiesen) - in Denmark, they used to have very good PA. Now it is different, and people who had PA for many years suddenly have none. Jesper shared a story about a man who used to have PA 24 h/day for decades. The municipality took his assistance away and it took him 2 years to get back (the person was using a ventilator). More stories like this are coming out. Overall, there are not so many people with PA, from the total of people who would need it.

**Flanders, Belgium** (Nadia Hadad)– in the Flemish region, there is a stand still principle in the legislation. In relation to personal budgets, this means that once they are allocated, they cannot be taken back. However, there are some 17,000 people on the waiting list, some more than 20 years. Nadia shared about the court case brought by GRIP against Government's decision to reduce the personal budgets allocated, to reduce the waiting lists. This mean that some people would get a much smaller budget than they need. They won the case thanks to the stand still principle.

**Norway** (Martine Eliasson) – in Norway, PA is in Health and Care Services Act. Uloba is advocating for a dedicated PA act. They published a report and now they are trying to make an alliance with DPOs – to make them see the importance of the social model. Linked to this, Uloba is working to incorporate the Convention into the human rights act, but the organisations of municipalities are working against this. They do not think it is sustainable that people are allowed to choose where and with whom to live. They find it more sustainable for people to be sent to group homes

## 7. Concluding remarks

Ines summed up the key points discussed during the meeting and introduced the next steps – sharing of the report and the presentations. Kamil thanked all participants and our co-organisers of the regional meeting – STIL, ILI and JAG. The meeting was followed by dinner, sponsored by STIL, and a showing of the documentary “**The Struggle to Have a Life – Disability Politics in Sweden**”.



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## PLAIN LANGUAGE SUMMARY

Members of the European Network on Independent Living from Northern Europe met in Sweden on 22 November.

Kamil Goungor from ENIL moderated the meeting.

There were 46 people and their personal assistants.

They came from Sweden, Norway, Iceland, Denmark, United Kingdom, Belgium, Bosnia and Herzegovina and San Marino.

At the beginning of the meeting, ENIL explained what activities we will do this and the next year.

We asked everyone to be involved, especially when we have to decide about ENIL's future plans.

We spoke about a lot of important **laws and policies that the European Union has for disabled people**, such as the new document on Independent Living.

This document is called "Guidance on Independent Living".

Then we heard about interesting projects implemented by our members.

Jamie Bolling from Independent Living Institute in Sweden spoke about a group called **Disability Rights Defenders Network**.

This network wants to help disabled people who would like to go court.

They organise webinars where everyone can get involved.

Martine Eliasson from Uloba in Norway talked about the **Nordic Competence Centre on Personal Assistance**.

In this project, different organisations from Northern Europe work together on Personal Assistance.

For example, they collect information and will publish a report next year.

Jonas Franksson from STIL spoke about a **project on the UN Convention on the Rights of Persons with Disabilities**, called 'CRPD as a law'.

STIL is running a campaign for the UN Convention to be a law in Sweden.

If this happens, disabled people can use the UN Convention to defend their rights in court.

The next part of the meeting was about involving young disabled people in the independent living movement.

Again, we heard about what our members are doing to involve young people.

STIL, in Sweden, organises peer support **groups for young disabled people** where they can talk about the things important to them.

For young people, who they are and what they feel like is very important. They can talk about personal things in a safe space, online or in person.

Uloba, in Norway, is running **Camp Freedom**.

This is a summer school for young disabled people where they learn about their rights and about independent living.

The last part of the meeting was about **how ENIL members in the North of Europe can better work together**.

We also heard about the **right to independent living in different countries**.

Everyone agreed that we should have more projects together in the North. We should also make sure that other ENIL members know about these projects.

Everyone would like ENIL to explain the laws and policies that the European Union has and how they can contact the European Parliament.

We heard that most countries have the same problems.

For example, disabled people do not have enough personal assistance.

In some countries, like Denmark and the United Kingdom, things got worse in recent years. Especially during Covid, many disabled people died.

We also heard that organisations of disabled people are doing a lot to improve independent living.

Everyone agreed that we should work more together and share information, so that we can use different ideas to work better in our own countries.