ENIL's Proposal for the European Commission Framework for Social Services of Excellence for Persons with Disabilities

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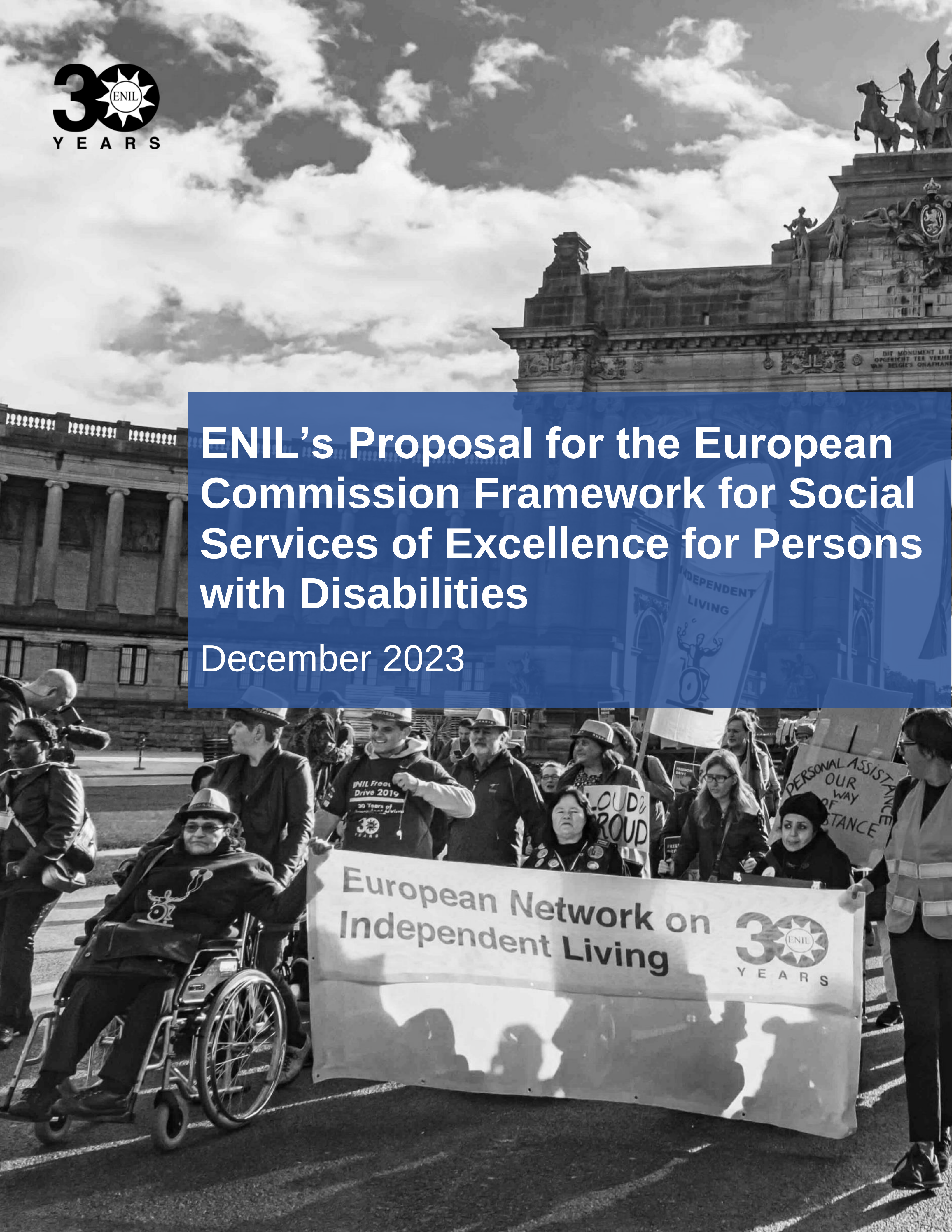

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About the European Network on Independent Living

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

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Executive Summary

According to the Social Model of Disability, disability is produced through barriers imposed by society and is distinct from impairment, with its physical, psycho-social, intellectual and sensory variations. Disabled people are thus a socially oppressed group. The United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) laid the foundations for the Human Rights Model of Disability, which turned the new conceptualisation of disability, brought about by the Social Model of Disability, into an agenda for policy change. According to the Universal Declaration on Human Rights and the UN CRPD, disabled people must enjoy all rights and freedoms on an equal basis with others. State parties need to proactively create conditions for inclusive equality through the provision of services for independent living of disabled people.

Community-based social services for disabled people must be organised according to the following principles:

- Peer support
- Co-production
- Intersectionality
- Availability, Accessibility, Acceptability, Affordability, and Adaptability

So that disabled people can access services, disability assessment procedures and eligibility criteria must also be addressed, and the coordination between public authorities across sectors and regions must be insured. Choice and control of disabled people over the services, including through supported decision making where needed, must remain present across all principles and are the precondition for ensuring that they are in compliance with the UN CRPD.

Monitoring of service quality is also key and should be based on the UN CRPD. A monitoring mechanism should be developed and implemented with the full involvement of those who use the services (i.e. disabled people).

1. Peer support

ENIL defines peer support as **“**the help and support that people with lived experiences are able to give to another individual in a similar situation.” The *Guidelines on Deinstitutionalisation, including in Emergencies* establish peer support as a vital principle of organising support services for disabled people.

Personal assistance user cooperatives, which work according to the peer support principle, are an example of good practice. Personal assistance services provided in this way have a superior quality than services provided by for profit companies. Centres for Independent Living (CILs), publicly funded peer counselling services, as well as self-help groups, are additional examples of good practice.

When it comes to personal assistance, user cooperatives and peer counselling services, quality should be ensured by training the staff in human rights. Nevertheless, according to information shared with the European Network on Independent Living - ENIL, the conditions for personal assistance user cooperatives and CILs, which work according to the peer support principle, have deteriorated in recent years. Because of their importance, the European Union and its Member States must therefore improve the legal and financial conditions for peer support services and facilitate access of these organisations to state aid grants and tax exemptions.

2. Co-production

Co-production is “a relationship where professionals and citizens share power to design, plan and deliver support together, recognising that both partners have vital contributions to make in order to improve quality of life for people and communities”. The UN CRPD requires active participation and consultation with disabled people through their representative organisations in the shaping of decisions that concern them. In practice, attempts at co-production are often tokenistic, because no redistribution of power is involved.

3. Intersectionality

Intersectionality is defined as “a powerful tool that helps us to understand how various forms of oppression and discrimination, based to various identifies, including race, gender, age and disability, immigration status, and many others are interconnected” (ENIL 2023). The UN CRPD and the *Guidelines on Deinstitutionalisation, including in Emergencies* call on state parties to take into account the discrimination against disabled people with intersectional identities. Disabled women become victims of violence and discrimination more often than disabled men. Intersectionality also refers to age and disability. Older disabled people and disabled children are frequently affected by institutionalisation and segregation. The European Union and Member States need to make sure that services are designed in such way to support disabled people of all identities.

4. Availability, accessibility, acceptability, affordability and adaptability

According to the *Guidelines on Deinstitutionalisation, including in Emergencies*, “support services for living independently should be available, accessible, acceptable, affordable, and adaptable”. Too often, services exist in theory, but disabled people cannot access them. This can be due to procedures which are inaccessible, unfair and not transparent. Authorities often act as gatekeepers, blocking access to services, rather than ensure that everybody obtains the support they need (Personal Communication). For example, when it comes to homeless people with psychosocial impairments, administrative requirements for housing services can be designed in a way that makes it impossible to apply in the first place. There are cases in which authorities abstain from providing services or benefits which have been approved or withdraw approvals in arbitrary grounds. The European Union should work with Member States to change procedures, in order to ensure a high take-up of services in the community.

5. Disability assessments

When it comes to disability assessments, procedures are often inaccessible, unfair and untransparent. They are largely based on medical criteria solely, rather than using a human rights approach to disability, without leadership or even consultation of disabled people and DPOs in the development of the assessment. Many disabled people have difficulties passing assessment procedures because authorities act as gate keepers. Other barriers that persist include long waiting times and undignified processes, poor diagnosis of hidden disabilities, late or no assessment of women with disabilities, and insufficient levels of support (European Disability Forum, 2021).

Plain Language Summary

The European Commission wants to improve the lives of people with disabilities in Europe.

To do this the Commission created the European Strategy on the Rights of Persons with Disabilities 2021-2030.

One part of the Strategy is to create a framework to improve social services for people with disabilities.

This will be called the Framework for Social Services of Excellence for persons with disabilities.

This document is a proposal by the European Network on Independent Living (ENIL).

A proposal is a way to tell the Commission what to think about when they create the Framework for Social Services of Excellence for persons with disabilities.

This proposal gives definitions of different topics. They are:

- Peer Support
- Co-production
- Intersectionality
- Availability and affordability
- Disability assessment procedures

This proposal gives examples of good practices for each topic and then gives policy recommendations.

Policy recommendations are the advice ENIL gives to the Commission.

ENIL had a meeting for people with disabilities to come and talk about the changes they need in social services. The opinions the people with disabilities gave were used for this document.

This means that the voices of people with disabilities were heard and will be brought to the European Commission.

Topic 1: Peer Support

Peer Support means the help and support that people with lived experiences are able to give to another person in a similar situation.

Lived experience means that person has had a similar experience in the past to someone else who is going through it now.

For example, a person with a disability who has lived in an institution can help and support a person with a disability who still lives in an institution.

Peer support can be paid or not paid work.

Helping in this way means more people with disabilities can learn about their rights and gain the skills and information they need to live independently.

The policy recommendations include the following things.

The Commission and countries should recognize the importance of peer support services.

The commission should tell countries to provide money for these services.

The commission and countries should use the money that goes to institutions on peer support services instead.

Topic 2: Co-production

Co-production is a relationship where professionals and citizens share power to design, plan and deliver support together.

Both partners have vital contributions to make to improve quality of life.

The policy recommendations include the following things.

The Commission and countries should use co-production between disabled people and decision makers to create community-based services.

Community-based services are social services that help people live independently in the community.

Disabled children's voices should be heard as well.

The Commission and countries should provide money so disabled people and disabled people's organizations can be paid for the advice they give.

The Commission and countries should use co-production for getting disabled people out of Institutions.

Topic 3: Intersectionality

Intersectionality means understanding that everyone has their own experience of discrimination.

We have to consider all the things that can cause a person to be discriminated against by society.

This can include their gender, race, disability or sexuality.

For example, a disabled person who is a woman is at risk of discrimination for being disabled and being a woman.

The policy recommendations include the following things.

The Commission and countries should ban forced sterilisation of disabled women.

The Commission and countries should make laws to protect all types of disabled people from violence.

The Commission and countries should make laws to stop discrimination of all types of disabled people in the workplace.

Topic 4: Availability and affordability of Services

The United Nations Convention on the Rights of Persons with Disabilities says that Countries need to recognize disabled people's right to an adequate standard of living and social protection.

This includes proper food, clothing and housing for disabled people.

Disabled people should get help with the cost of their disability.

The social services needed to live independently should be:

- Available
- Accessible
- Acceptable
- Affordable
- Adaptable

The policy recommendations include the following things.

The Commission and countries should make sure services are affordable for all disabled people.

Make information about services accessible with Easy to Read.

Train service workers to be able to help disabled people.

Topic 5: Assessment of Disability

Disability assessment is how a person is diagnosed with a disability by a professional.

The professional doing the assessment should put the disabled person first by listening to what they have to say.

The assessment should make it possible for disabled people to have the housing and support they need to live independently.

The policy recommendations include the following things.

The Commission and countries should make sure assessments use the social model of disability.

The Commission and countries should make sure assessments are fair, quick and open.

The professionals doing the assessment should be helpful. They should explain the assessment clearly and support the person during the assessment.

These are the topics and recommendations ENIL wants the Commission to think about when they are writing the Framework for Social Services of Excellence.

Peer support	**Co-production**	**Intersectionality**	**Access to services**
Principles which guide the provision of disability services			A legal right which is enforced in practice
Follows the UN CRPD, General Comment 5 and the Guidelines on DI, including in Emergencies	Ensure measures are in place which prevent professionals from exercising both hard and soft forms of power	Disabled people of all identities have access to personal assistance and are included in DI processes	Assessment and eligibility procedures follow the social and the human rights models of disability
The state promotes and funds PA User Cooperatives and Centres for Independent Living	Disabled people with various impairments, intersectional identities and qualifications are invited to participate	Families with disabled children are provided with tailored and needs-based support	Assessment and eligibility procedures are swift, fair and transparent
The state supports peer counselling services	DPOs are fully involved	Prosecute violence against disabled people of all identities	Effective and easy to use complaints mechanisms are in place
The state supports self-help groups	DPOs are provided with the resources they need to engage	Forced sterilisations are banned	Staff undertaking assessments are trained in the social and the human right model of disability
The state creates the legal and financial conditions, allowing peer support to flourish	Install permanent disabled people's advisory bodies	Non-discrimination is at the heart of service provision	Staff actively supports applicants in getting their support needs met
		Access to mainstream services is ensured	Services are adequately financed
			Accessible information about how to access services is easily available
			Authorities are accessible to people of all impairments
			Staff is trained in providing accommodations

1. Introduction

1.1. The Social and the Human Rights Model of Disability

In 1975, the Union of Physically Impaired Against Segregation (UPIAS) adopted a landmark document and a completely new definition of disability:

“In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society” (The Union of the Physically Impaired Against Segregation 1975)

In 1981, Disabled People’s International (DPI) stated that a sharp distinction needed to be drawn between impairment and disability. Impairment was defined as “the functional limitation within the individual caused by physical, mental or sensory impairment” and disability as the “loss or limitation of opportunities to take part in the normal life of the community due to physical and social barriers” (DPI 1981).

Building on the new definitions of disability, the disabled British sociologist Michael Oliver proposed the Social Model of Disability in 1981. According to the new concept, disability was to be viewed as a socially produced injustice which can be challenged and eliminated through radical social change. When introducing the Social Model of Disability, Oliver distinguished the new understanding from traditional approaches which he referred to as the ”individual model of disability”. This old view on disability “located the problem of disability within the individual and … seeing the causes of this problem as stemming from the functional limitations or psychological losses which are assumed to arise from disability” (Oliver 1981).

There are many, including some Disabled People’s Organisations (DPOs), who claim that the social model of disability was designed to overcome the medical model of disability, which reduces disability to a medical problem. However, Michael Oliver had a different conceptualisation in mind. For him, the individual model of disability encompassed “a whole range of issues and was underpinned by what I call the personal tragedy theory of disability. But it also included psychological and medical aspects of disability … In short, for me, there is no such thing as a medical model of disability”.

According to disability scholars Anna Lawson and Angharad E. Beckett, the Social Model of Disability signified a radical change in the self-conceptualisation of disabled people, allowing the development of political consciousness as an oppressed social group. It allowed for the development of the disability rights movement and was key in the drafting of the UN Convention on the Rights of Persons with Disabilities and the Human Rights Model of Disability (Lawson and Becket 2021).

The preamble of the UN CRPD recognises “that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others” (United Nations 2006).

Thus, according to the human rights model of disability, disability is a social construct (CRPD 2018, p. 2).

Letter (h) of the preamble, article 2, article 3 and article 5 define equality and non-discrimination as key principles of the Convention. Discrimination is seen as a violation of an individuals' inherent dignity. Disabled people have the right to enjoy all human rights and fundamental freedoms "on an equal basis with others". "The respect … for the freedom to make one's own choices and being independent" is placed at the heart of the principles of equality and non-discrimination." The UN CRPD calls on State Parties to recognise that all persons are equal before the law and to prohibit all discrimination based on disability. In addition, State Parties have to actively promote equality and eliminate discrimination".

On the basis of the UN CRPD, General Comment No. 6 of the Committee on the Rights of Persons with Disabilities (CRPD Committee) outlines the human rights model of disability. It explains that the wording "on an equal basis with others", repeated throughout the Convention, "signals the key roles of equality and non-discrimination" and why articles 3 and 5 are "interpretative tools for all other principles and rights enshrined in the Convention".

Section A of the General Comment No. 6 states that the recognition that disabled people are equal under the law "means that there should be no laws that allow for specific denial, restriction or limitation of the rights of persons with disabilities". Equal protection and equal benefit of the law means that legislatures "refrain from maintaining or establishing discrimination against persons with disabilities, when enacting laws and policies". Articles 1, 3, 4 and 5 in conjunction make it clear that State Parties must facilitate equal enjoyment of all rights by taking positive action, for example by making environments accessible, providing reasonable accommodation and individual supports.

Disabled people who live in institutions are prevented from enjoying all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field on an equal basis with non-disabled people. Therefore, institutionalisation constitutes discrimination on the basis of disability, as defined in article 2 of the Convention. Since State Parties have the duty to actively eliminate disability related discrimination, it follows that institutions have to be abolished. Article 19 of the UN CRPD and General Comment No 5 call for complete deinstitutionalisation. All disability support services need to be delivered outside institutions in the community. Personal assistance is one of the most important services to achieve the right to independent living.

To ensure equality and full and effective inclusion and participation in society, disabled people have to be able to live in self-determination on an equal level with others. The Convention defines this as the right to living independently. Freedom from institutions is insufficient to ensure equality in self-determination. Support needs stemming from a persons' impairment, including being able to make decisions about one's life, must not prevent them from living independently. Not adopting measures to compensate for this barrier constitutes discrimination under the UN CRPD. Thus, State Parties need to introduce community-based services providing support for independent living**;** this includes personal assistance, but also supported decision making, thus allowing for choice and control.

1.2. The political context

According to the European Strategy on the Rights of Persons with Disabilities 2021-2030 (ESRPD), the European Commission will, by 2024, present “a specific framework for Social Services of Excellence for persons with disabilities, to improve service delivery for persons with disabilities and to enhance the attractiveness of jobs in this area including through upskilling and reskilling of service providers” (European Commission 2021). The new framework will be based on an existing voluntary European Quality Framework for Social Services.

The European Network on Independent Living - ENIL is a European-wide network led by disabled people. It is our purpose to advocate for services and legislation that support Independent Living and strengthen the application of human rights for disabled people. We promote and monitor the implementation of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), in particular Article 19 on the right to live independently and being included in the community (United Nations 2006). We also support the European Union in implementing the ESRPD and monitor the extent to which disabled people in Europe are able to live independently in the community.

This document sets out ENIL’s proposals for the forthcoming European Commission Framework for Social Services of Excellence for Persons with Disabilities.

1.3. Structure of the document

According to the ESRPD 2021-2030, the Framework for Social Services of Excellence for people with disabilities will be based on the “existing Voluntary European Quality Framework for Social Services” published in 2010 (European Commission 2010). The objectives of the Quality Framework were to “develop a common understanding of the quality of social services with the EU by identifying quality principles that these services should fulfil.” The Framework was written to be “flexible enough to be applied in the national, regional and local context on the EU Member States and to a variety of social services”. The document identified two main categories of Social Services. First, social security schemes covering the main risks of life such as health, ageing, occupational accidents, unemployment, retirement and disability. Second, other essential services such as assistance in case of debt, unemployment, drug addiction, family breakdown, social housing and services to integrate persons with long-term health, disability problems or any other service. Thus, the Quality Framework did not refer to specific services but covered the full spectrum. On the one hand “overarching quality principles” were presented. On the other hand, the document covered quality principles concerning the relationships between service providers and users, the relationships between service providers, public authorities and other stakeholders and human and physical capital.”

The Quality Framework stated that social services should be “available, accessible, affordable, person-centred, comprehensive, continuous, outcome-oriented”. Activities in the more specific areas were supposed to be guided by “respect for users’ rights”, “partnership”, “good governance”, “good working conditions and working environment/Investment in human capital”.

Therefore, it is expected that the planned Framework for Social Services of Excellence for people with disabilities will contain horizontal quality principles. In its Proposal for the European Commission’s Guidance on Independent Living, which was published in May 2023, ENIL identified factors that need to be present in all disability support services if they are to be effective: First, services need to function according to the human rights model of disability, based on the principles of choice and control. Second, we need fair and transparent disability assessment systems. Third, services need to apply intersectional and intersectoral approaches.

1.3.1. Horizontal issues

Through our long-term advocacy for better disability services and consultations with our members, we have identified additional horizontal issues. All disability services need to be based on the five key principles, which are elaborated in detail in the remainder of this document. These principles should be incorporated into the Framework for Social Services of Excellence for Persons with Disabilities and applied in measurement or evaluation of the performance of disability services:

1. The human rights model of disability;
2. The provision of peer support;
3. The design and implementation of services using the co-production method;
4. The provision of available, accessible, acceptable, affordable, and adaptable services;
5. The full respect and consideration for the intersectionality of identities.

1.3.2. Disability assessment procedures

To able to access any type of disability support service, a person with an impairment needs to pass a disability assessment process. Disability assessments are regulated by national, regional or local authorities. There is evidence that those assessments are not always conducted in a fair and transparent manner. For the disability service to be effective, all persons requiring it need to have access in practice. For that to happen, assessment procedures need to be fair. We will only know if they are fair if they are transparent. Thus, disability assessment procedures are also a topic of this document.

1.4. Methodology

To seek input to base our document on, we held a consultation with ENIL members and academic experts on the 26th of July. During the meeting, our expert speakers gave short presentations. During a long discussion, participants raised their voice and expressed opinions on what makes social services for disabled people excellent. The five horizontal principles we wish to advance were discussed in detail. Many participants had in depth expertise on the topics due to prior professional or voluntary work, including in advisory councils to governments. Our members consist of disabled people and two of the academics were disabled too. Thus, our Proposal reflects the voices of people with lived experience. Our recommendations are the result of a democratic process of participatory decision making. Co-production by disabled peers is a horizontal principle that needs to become a reality in the planning of all disability support services. **Nothing about us without us!**

In addition to the opinions of disabled people, our Proposal is based on the UN CRPD, its General Comments and the Guidelines on deinstitutionalisation, including in Emergencies, adopted by the Committee on the Rights of Persons with Disabilities.

Last but not least, academic publications, including reflective articles and studies published in journals, were used to inform our document.

2. Peer Support

2.1. Key principles

According to the ENIL peer support study, published in 2016, “the European Network on Independent Living (ENIL) advocates for better access to peer support for disabled people, as essential to the implementation of the right to independent living. Since its establishment in 1989, ENIL has been highlighting the importance of peer support for the self-determination of disabled people” (ENIL 2016).

The ENIL Factsheet on peer support defines peer support as “the help and support that people with lived experiences are able to give to another individual in a similar situation.” It goes on to explain that it can refer to “support provided by someone using personal assistance (PA user) to another person using a PA. Or to support provided by somebody who has lived in an institution in the past to other people still living institutions. This support may be social, emotional, practical” (ENIL 2022a). The 2016 survey on peer support defines peer support as follows:

> “peer support refers to people with a common experience supporting each other on an equal basis. This involves the provision of information and practical, emotional, social or physical support through listening, education, mentoring, mediation, (self-) advocacy and other. Peer support can be provided one-to-one or in groups and can take place in different settings (for examples, people’s own home, peer-run organisations, such as Centres for Independent Living or self-advocacy groups, schools workplaces and social or health services) as well as by phone or online (e.g. social media, website, forums, email, etc.). It can be paid or unpaid and can be provided by people with or without training.”

The survey notes that for organisations promoting independent living “peer support [is] the foremost educational tool for sharing information, experiences and insights. Peer support can have the objective of making people with disabilities conscious of the audio, visual and cultural, psychological, social, economic and political oppression and discrimination that they are exposed to. It can also make persons with disabilities aware of their possibilities to reach full equality and participation. To empower persons with disabilities by assisting them to acquire the skills to manage their social and physical environment with the goal of full equality and participation in their families and society”.

2.2. Peer support and the UN CRPD

The UN CRPD mentions peer support in two separate articles. Article 24, paragraph 3 on education states that “State Parties shall take appropriate measures, including: a. Facilitating the learning of Braille, … and facilitating peer support and mentoring”. Article 26 on habilitation and rehabilitation states that “State Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence” (UNCRPD 2006).

The Guidelines on Deinstitutionalisation, including in Emergencies, establish peer support as a vital principle of organising services for disabled people (CRPD 2022).

- According to section III, paragraph B, 26, peer support is a disability support service: “support services include…peer support”.
- Section IV, paragraph C, 45 on Children and adolescents with disabilities, states that “Peer support for children and adolescents is essential for full community inclusion”. Paragraph 50 adds that “State parties should develop and ensure access to support services in the community, including personal assistance and peer support”.
- According to paragraph 70, “states parties should invest in peer support, self-advocacy, circles of support and other support networks – including organisations of persons with disabilities, particularly those of survivors of institutionalisation – and centres for independent living. States parties should encourage the creation of such support networks, provide financial support and fund access to and the design of training in human rights, advocacy and crisis support”.
- Paragraph 73 states that peer support should be self- directed, independent of institutions and medical professionals and autonomously organised by persons with disabilities.
- According to paragraph 86, “administrative support and empowerment, through peer support and self-advocacy, should be available to encourage the take-up of user-led funding options”. In this context user-led funding options refer to “individualised and direct funding that provides for basic incomes security and coverage of healthcare and disability-related costs”.
- According to paragraph 94, “peer support for institutionalised persons and survivors of institutionalisation should be facilitated as part of planning and transition to promote full inclusion”.

2.3. Key principles of peer support

Based on what is stated above, we can draw several conclusions about the nature of peer support:

- Peer support refers to disabled people lending support to each other;
- Peer support is an integral part of the provision of services to disabled adults and children. These can be very different services, such as personal assistance, emotional support, education, mediation, mentoring;
- The CRPD requires that governments invest in peer support;
- Peer support can take many organisational forms. For example, self-advocacy, circles of support**,** disabled people’s organisations, centres for independent living;
- Peer support is a tool for empowerment and deinstitutionalisation.

2.4. Examples of Good Practice

This chapter covers a range of good practices: PA user cooperatives and Centres for Independent Living (CILs), state funded peer counselling services and self-help groups.

As mentioned before, personal assistance services must involve choice and control for the disabled person, including the right to independently recruit, train and supervise the assistant(s). Because doing all these things alone, especially payroll work, can be overwhelming, having the support of a PA user cooperatives and Centres for Independent Living (CILs) can be helpful. Often, they manage funding coming from the public purse on behalf of authorities.

Other services should be provided as well: for example, support in finding employment, peer counselling services (which focus on providing advice) and self-help groups. Self-help groups are among the most non-professional and grassroots forms of peer support. They are a very flexible type of peer support, responding to the need for contact with peers outside any type of formalised environment. Self-help groups are particularly good at providing emotional and social support.

A variety of examples was selected, to reflect the variety of peer support services and to demonstrate the potential to provide support in many different areas of need

A. Personal Assistance user cooperatives and Centres for Independent Living

Good practice 1: STIL - Stiftarna av Independent Living (Sweden)

The Stiftarna av Independent Living i Sverige[1] (STIL, Sweden) is a non-governmental, disabled person's organisation from Sweden, providing personal assistance services. It also advocates for the rights of disabled people in Swedish politics. STIL is a user cooperative, meaning that it is owned and run by disabled people, many of whom are personal assistance users themselves. Since people are providing services to one another, the organisation's activities are based on peer support. For STIL, peer support is central to the provision of personal assistance (STIL 2023a, b; ENIL 2023).

A key objective of STIL is the development of support in the community, facilitating access to independent living. The work of STIL is embedded in a national policy framework, the legislation on support and services for people with impairments and the Social Insurance Code.

Sweden adopted the first law on personal assistance in 1994. Before that date, disabled people with support needs could only choose between home care services or a life in institutions. Home care services were so restrictive that people became institutionalised in their own homes. In the mid 1980s, STIL launched a project in which users spent the money that would have been paid to home care services for personal assistance. The

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[1] The Founders of Independent Living in Sweden

results were successful. In 1994, Sweden adopted a law on personal assistance. In Sweden, personal assistance can be provided by the national government and by municipalities. If the service is provided by the national government, the national government has to finance it. If it is provided by the municipality, the municipality has to provide the funding. Because municipalities often struggle with mobilising financial resources, there are plans to recentralise the provision on the national level, in order to have equal provision across the country.

STIL supports a broad target group in administering their personal assistance. Children with physical, intellectual, psychosocial or developmental impairments, as well as adults with intellectual, psychosocial or developmental impairments form part of the target group.

Before becoming a beneficiary of PA services, applicants need to be approved by the Swedish Social Insurance Agency or the municipality at the place of residence. In Sweden, persons with an intellectual impairment, autism, a condition resembling autism, brain damage in adulthood due to an external force or physical illness, physical or mental impairments are eligible for personal assistance. Once approved, disabled people have four different options to administer their personal assistance:

1) They can hire assistant(s) directly and become employers;
2) It is possible to delegate the service to the municipality;
3) It is possible to delegate the service to a private company;
4) Another option is to become part of a cooperative such as STIL.

In Sweden, in line with General Comment No 5 and the Guidelines on Deinstitutionalisation, including in Emergencies, the funding for personal assistance is dispersed directly to disabled people (PA users). Direct payments in the form of personal budgets are the gold standard in the provision of personal assistance, since they allow recipients maximum self-determination. When delegating the provision of PA to a user cooperative, disabled person forwards the personal budget to the organisation so it can hire and pay personal assistants on their behalf. It is STIL's policy, in line with the independent living principles, that the PA users recruit, train and supervise their assistants themselves. If requested, they can receive support from STIL with these tasks.

As a member of STIL, PA users retain full decision-making power concerning all aspects of their assistance. They decide who works for them, which tasks they perform and at which times, how the tasks are performed and where. Some people choose to let their family and friends help out in supervising.

To become a personal assistance provider, organisations need an authorisation by the Swedish Health and Social Care Inspectorate - Inspektionen för vard och omsorg (IVO). The Inspectorate conducts checks to see whether the applicant complies with certain criteria. These criteria can, for example, include economic and juridical knowledge. IVO also conducts unannounced inspections of the services provided.

According to STIL's experience, PA user cooperatives conduct their work in line with the UN CRPD and provide better access to independent living than municipalities or private companies. There is evidence that members of cooperatives are granted more personal assistance hours than people who use private providers (STIL 2023a, b; ENIL 2023). These facts underline the importance of peer support based personal assistance.

Good practice 2: Uloba (Norway)

Uloba - Independent Living Norway is a non-profit organisation owned and run by disabled people, which means that its services are provided for and by disabled people. Uloba is a non-profit cooperative for consumer controlled personal assistance, founded in 1991 by five Independent Living pioneers. Now in 2023, Uloba has 2,000 members, a staff of 135 and employs 7,0,00 personal assistants. The association is part of the Independent Living Movement **(**Uloba 2023a, b; ENIL 2023).

Uloba is the only cooperative for personal assistance in Norway. Its objective is to tear down socially constructed barriers, fight discrimination, myths, prejudice and disempowerment, to change attitudes and promote liberation for disabled people. Uloba works to promote the Independent Living philosophy, de-medicalisation and de-professionalisation of disability. Just like STIL, which was a role model for Uloba, it functions according to the principles of peer support and peer counselling.

Uloba's task is to facilitate the members' establishment, management and operation of personal assistance. Those who get support from **U**LOBA with administering their assistance, recruit, train, schedule and supervise their assistant(s) themselves. At the start, Uloba helps disabled people apply for personal assistance at the municipality and to assess what hours they will need. The disabled person then gets an adviser who is disabled her-/himself and has assistance, and who provides guidance. Disabled people participate in compulsory courses on being an employer, which are organised by Uloba .

The organisation is democratic and every member has one vote. Only disabled people can have full membership with voting rights. Anyone who wants to become a member of ULOBA must pay a share contribution of NOK 300 or EUR 26,04. The share deposit is refunded on termination of membership. Members do not have to pay a membership fee. At least 50% of the administrative staff at Uloba must be disabled. Disabled people with assistance needs are prioritised for leadership positions.

In 2000, consumer controlled personal assistance was introduced in Norway by law, thanks to Uloba 's advocacy efforts. Municipalities approve who should have personal assistants and administer the funding. Municipalities can decide between three employer models: 1. The disabled person employs the assistants directly; 2. The municipality employs the assistants, 3. A cooperative like ULOBA employs the assistants or a private company. The first option gives full consumer control but involves a lot of administrative work which might be overwhelming for some. If the municipality employs the PAs, there is less paperwork, but also less consumer control. If a cooperative is the employer, there is less administrative work for the beneficiary, but there is consumer control, as well as peer support and peer counselling.

Personal assistance in Norway suffers from various shortcomings. Despite PA being covered by law as an individual right since 2015, consumer control needs to be negotiated individually with local governments. Municipalities do not always provide information about the various ways one can benefit from personal assistance in Norway. The focus of municipalities is on taking care of the basic needs of old and sick people. The services are usually geared towards taking care of people in their homes. To enable independent living, the disabled person needs to have full control over the service. To have normal lives which is their right, disabled people need to be able to take their assistant(s) to work, meetings, concerts, cinemas, cafes, week-end trips, holidays etc.

Uloba organises an annual Independent Living Festival and publishes the podcast Selvsagt. The cooperative advocates for the UN CRPD to be incorporated into Norwegian law. Uloba is covered by the Norwegian Transparency Act, which entered into force in 2022. The Act grants the public the right to access documents and information held by public bodies. This way it is possible to find additional information about Uloba and the services it provides to disabled people.

Good practice 3: YHD (Slovenia)

YHD – Society for the Theory and Culture of the Handicap is a disabled people's organisation, founded in 1996. It has its origins in the experiences of young disabled students who were forced to live and study in an institution - the Institute for Training Disabled Youth in Kamnik (CIRIUS Kamnik). At the end of high school, Emil Bohnic, Elena Pecaric and Klaudja Poropat learned that life outside the institution was not possible for someone who needed constant physical assistance. At the time, no support for living independently was available. The debate on disability was dominated by disability associations in which disabled people had no representation. Those associations strongly opposed Independent Living of disabled people. YHD stands for equal opportunities and responsibilities for disabled people in all areas of social life, establishing the rights of the disabled as human rights, influencing legislation and policy, developing the theory of disability, striving for emancipation and self-determination (YHD 2023a, b; ENIL 2023).

YHD carries out the following activities:

1. The promotion of independent living and the development and expansion of the network at the national and international level.
2. Independent living education for personal assistants, users, professionals, parents and other interested public.
3. Counselling and information on the possibilities of independent living.
4. Collection and transmission of literature, audio and video production in the field of disability, and publishing.
5. Implementation of social welfare programs and all other activities that contribute to a more equal life.
6. Advocating for equal opportunities for the disabled, fighting against discrimination, prejudice and stereotypes in all areas of social life.
7. Informing and raising awareness of the public, cooperation in the formulation of measures at the local, national and international level.

A main objective of YHD was the adoption of a Personal Assistance Act in Slovenia. In 2012, the association gathered more than 7 000 signatures of Slovenia's voters. Based on this, a petition was submitted to the National Assembly for consideration. With the adoption of the personal assistance act, persons with high support needs received the legal right to personal assistance services and thus the possibility of living independently.

Personal assistance has become available to all disabled persons between the ages of 18 and 65 who need more than 30 hours of assistance per week. To offer personal assistance services, providers have to be registered with the Ministry of Labour, Family, Social Affairs and Equal Opportunities in the register of providers.

YHD offers disabled people a range of suitable candidates for personal assistants, according to their specific needs and wishes. It provides support and assistance to disabled people in the management and organisation of personal assistance and to personal assistants in the delivery of the service. Together with the disabled person, an agreement on the provision of assistance is created. YHD provides trainings for disabled people or legal representatives and personal assistants. The association takes care of administrative and accounting tasks and smooth financial operations.

YHD has numerous partnerships and forms of cooperation with non-governmental organisations outside Slovenia to share experience and good practices. For example, representatives from the Swedish municipality of Pitea visited YHD for a study visit in a project financed by the European Social Fund. The association also advised the Polish Center for the Rights of Persons with Disabilities on the preparation of the Act on Personal Assistance.

Good practice 4: Centro de Vida Independente (Portugal)

The Centro de Vida Independente (CIV) is a Disabled Person’s Organisation advocating for the rights of disabled people and providing the service of personal assistance. Through CIV, the Portuguese government is implementing a personal assistance scheme called Support Model to Independent Living or “Modelo de Aoio á Vida Independente” (MAVI). MAVI is not a permanent personal assistance scheme; it is a pilot project. While CIV is an example of good practice, it is important to mention that the Portuguese personal assistance scheme is not to be considered worth replicating (Centro de Vida Independente, 2023a, b).

CVI originated from a political movement of disabled people, fighting for the implementation of policies based on the Independent Living philosophy. The centre was founded in 2015, when the Lisbon City Council provided funding to finance personal assistance for 5 disabled people. In 2019, a pilot project of personal assistance, MAVI, started at the national level. The pilot project was extended several times and ended in 2023.

Internally, CVI functions according to the peer-to-peer principle, entailing that members have control over how the organisation works.

The Independent Life Support Model - MAVI was created as a pilot project by the Portuguese Government and instituted by Decree Law no 129/2017. MAVI’s objective is “through the provision of a personal assistance service, to support people with disabilities or impairments to carry out activities that, due to the limitations resulting from their interaction with environmental conditions, they cannot carry out on their own." The entity responsible for implementing the MAVI is the National Institute of Rehabilitation – INR.

CVI is not an official implementing body like the INR, but an organization registered as managers of the personal assistance pilot project. When receiving their registration, organisations are being awarded the title "Centro de Apoio a Vida Independente" (CAVI). CVI applied for and obtained CAVI status in Porto, Leira, Lisbon, and Faro, in Algarve.

The personal assistance pilot project ended in July 2023 and the personal assistance service is now in a transition period, funded by the public social security scheme, until the definitive law is published. Personal Assistance is integrated in the National Strategy for the Rights of Persons with Disabilities for 2021-2025.

The pilot project was funded by the European Social Fund and the Portuguese government. The overall budget of the intervention was between EUR 1 million and EUR 5 million. The City of Matosinhos and the City of Lisbon provided offices for CVI.

Adults with physical, intellectual, psychosocial or developmental disabilities can benefit from the Portuguese personal assistance scheme. At the moment, CVI is working with 95 personal assistance users and 170 personal assistants. Disabled people using personal assistance services provided through CVI reported increased levels of quality of life.

Good Practice 5: The Glasgow Centre for Independent Living (UK)

The Glasgow Centre for Inclusive Living (GCIL) was established in 1995 by a group of disabled people, assisted by Jim Elder-Woodward, who at that time was working for Glasgow City Council, which funded the project. Jim, a disabled person himself, had been promoting the concept of CILs since 1985, when he joined the Council as a Community Development Worker with disabled people (Personal Communication 2023c).

In 1995, it was already possible to purchase personal assistance through direct payments from local authorities; and, for some, who were in danger of being institutionalised, additional money could be sought from a UK-wide Independent Living Fund, resourced by the UK Government.

GCIL was established to support disabled people using their direct payments to employ Personal Assistants. Today, in addition to its Glasgow Support Services, the Take Control Services offer support to disabled people in three additional local authority areas surrounding the City. Altogether, today, GCIL Support and Take Control have 1170 people in Glasgow and surrounding authorities that they are actively supporting.

Alongside the day-to-day support of people managing their own budgets to pay the wages of their Personal Assistants, or to access support from a care agency, GCIL also provides a number of other services:

1) Payroll service, which offers two levels of support: a) The Standard Service, which works out tax and insurance deductions for each Personal Assistant, but leaves

the payments of such to those who prefer to control their own support funding; b) An Enhanced Service, which takes responsibility for the person's bank account and pays their PA's wages directly. The Enhanced Service also helps disabled people navigate taxation, pension providers, student loans etc. With this option, GCIL holds the PA user's funds and makes all the relevant payments from their account.

2) Housing Support Service**,** which matches available and suitable houses to people seeking housing. GCIL also offers advice around reasonable adjustments to help people remain in their own homes.

3) Employment services for those who have been unemployed for several years. This Open Door Project works with those most removed from the employment market. GCIL seeks to support and train disabled people into jobs or education.

4) GCIL also has a Disabled Graduate Employment programme**,** which supports disabled graduates during employment placements, within the National Health Service. These posts tend to last, on average, two years. Until now, thanks to GCIL's two-year Graduate programme, approximately 87% of trainees secured employment and 5.5% returned to further their studies. By September 2023, GCIL's successful outcome rate was around 92.5%.

Here is some of the feedback from people attending GCIL Workshops or accessing GCIL services:

- "Friendly faces and the offer of help, very good if feeling vulnerable."
- "I had zero knowledge of Self-Directed Support (SDS) (direct payments) before the workshop. It was great to be walked through it all."
- "When your parents need care, it can be overwhelming, and you have explained how SDS works really clearly."
- "Without GCIL I don't think I'd be in a flat which is accessible for me, this is somewhere I can call home and know that no matter what lies ahead with surgery and health, I will be able to stay here and build my life. The staff at GCIL are incredibly helpful and have been a great support to me over the past few years. "
- "Without them (NHS Line manager and placement coordinator) I wouldn't even have known about this career, never mind developing the skills and knowledge to secure a permanent role and focus on climbing the content design career ladder. The programme has opened so many doors and helped me build an invaluable network of fantastic people."

B. State funded Peer counselling services in Germany

Peer counselling is a form of peer support. In 2017, Germany undertook a major reform of its disability legislation. The new federal law on inclusion triggered significant changes in the social code, book IX (SGB IX), on rehabilitation and inclusion of persons with disabilities. The reformed SGB IX introduced a new advisory service for disabled people, called supplementary, independent counselling on inclusion (EUTB 2023).

The offices offer advice on access to services in the area of rehabilitation and inclusion. EUTB counselling services can be visited before applying for concrete services. An important objective is the empowerment of disabled people and support in arriving at a self-determined decision. Empowerment is understood as a process of discovering one's strengths. EUTB offices help with questions such as:

- How can I get my disability recognised?
- Where can I apply for a disability card?
- Is the personal budget the right choice in organising the services provided to me?
- Which services in the context of employment will allow me to retain my job?
- How can I leave the sheltered workshop which is employing me to find work in the regular labour market?

The number of disability support services covered is broad.

EUTB was created in addition to the existing advisory services of service providers. It does not replace or take over the advisory work of service providers. EUTB offices are supposed to provide independent advice on the rights of disabled people when accessing services (Bundesministerium der Justiz 2023).

The objective of EUTB is to staff all advisory positions with disabled advisors. Disabled people seeking help will get an adviser who is disabled too. Disabled people counselling other disabled people make EUTB a form of peer support, or peer counselling. Counsellors who are disabled themselves know the lived reality of a disabled person and therefore possess greater ability to empathise. In addition, there is often more motivation to provide quality advice. In addition, disabled counsellors can share knowledge derived from personal experiences of navigating services.

The new counselling service on inclusion is financed by the Ministry on Labour and Social Affairs. Since 2017, 500 counselling offices have been created across the entire country. From 2023, EUTB has been receiving EUR 65 million per year from the federal budget. Costs for administration, networking, quality control and public relations work are covered.

The inclusion-counselling services are expected to strengthen the position of applicants when interacting with service providers.

C. Self-help groups

One could define self-help groups as meeting configurations organised by disabled people for disabled people. Often, self-help groups are organised on a volunteer basis without a connection to an association or organisation with professional staff. This form of peer support is probably the closest to the anti-professional stance of the Independent Living Movement.

Since 2022, one of ENIL's volunteers has been running the Personal Assistance User's Club (PAUC). PAUC brings together only PA users, who meet regularly to discuss matters related to living with personal assistance. PAUC provides a safe space, so members can share personal problems and experiences (ENIL 2022b).

There is data, according to which neurodivergent people benefit strongly from self-help groups (Crompton & all 2022; Zhao & all 2019; Shea & all 2022; Crompton & all 2023; Lyons & all 2021). Especially autistic people may find it difficult or even impossible to build lasting relationships with people who are neurotypical. Possible causes for this are neurologically conditioned differences in approaches to and styles in social interaction and communication. Being among each other, normal social interaction, including its benefits on well-being, can be experienced. Volunteer based associations, providing self-help groups are for example ADHD, ASC & LD Belgium which offer the neurodivergent adults group, the ADHD women and a newly established neurodivergent hiking group. Other examples are Voz do Autista from Portugal or Aspies e.V. from Germany, both members of the ENIL member EUCAP (ADHD, ASC & LD Belgium 2023; Associação Portuguesa Voz do Autista 2023; Aspies e.V. 2023).

2.5. Application in practice

When it comes to personal assistance, choice and control of beneficiaries are key. To ensure choice and control, funding should be provided to beneficiaries through direct payments in the form of personal budgets. Disabled people receiving personal assistance services must have the liberty of hiring their assistants directly, for example through job adds. They must have the right to recruit, train and supervise their assistants. Some disabled people might want support in completing these steps. Also being an employer and doing all the work involved can be overwhelming. In such cases, it can be helpful to have the support of a Personal Assistance User Cooperative or a Centre of Independent Living. Such organisations administrate direct payments on behalf of the beneficiary. In fact, there is evidence that personal assistance services work better if such organisations are involved (Stainton & Boyce 2004).

There is recent evidence that the conditions for providers of peer support for personal assistance users are deteriorating in some countries. Instead of expanding personal assistance, governments are restricting access. Many in need of personal assistance have lost the right to the service. PA user cooperatives face economic and organisational problems, due to altered legislation and financial drawbacks. In some countries, private companies offer and organise personal assistance on a large scale. Massive marketing has reduced the space and opportunity for cooperatives. PA users who sign up with these companies become economically committed to them and hence find it difficult to change the provider. Cooperatives provide services which are more in line with Independent Living. Users often receive more PA hours than with a private company (ENIL 2023).

In 2016, ENIL conducted a survey to obtain general information about disabled people's access to peer support in Europe and ways in which peer support is provided, as well as to map the differences between countries and to identify the main gaps in the provision of peer support.

The survey found that, in 2016, the most common types of peer support were self-advocacy groups, individual counselling services and job coaching. Self-advocacy groups were available in 16 countries, individual counselling services in 14 and job coaching in 12. In many countries, the types of peer support offered largely depended on regions and municipalities, for example in Italy. Peer support was provided in majority by non-governmental organisations (NGOs), disabled people's organisations (DPOs) or Centres for Independent Living (CILs). In 17 countries, there was no public funding for peer support, while only 7 countries had legislation or policies on peer support in place. More research is needed on this topic.

2.6. ENIL's Recommendations on Peer Support

ENIL calls on the European Commission and the Member States to:

1. Establish peer support as an important principle in the provision of services for disabled people, while also supporting direct payments and direct employment of personal assistant by beneficiaries. Community-based services for disabled people and the concept of peer support have to follow the principles established in the CRPD and further explained in the General Comment No. 5 and the Guidelines on Deinstitutionalisation, including in Emergencies.
2. Recognise the added value of the various types of services based on the principle of peer support in disability policies, legislation and strategies. Most importantly, support the expansion of Personal Assistance User Cooperatives and Centres for Independent Living, Peer Counselling Services and Self-Help Groups, by including them in the relevant laws, policies and strategies.
3. Promote and fund Personal Assistance User Cooperatives and Centres for Independent Living, which facilitate choice and control by disabled people over the services (specialised or mainstream) provided by the state or the local government; this includes personal assistance but also housing, employment, education and others.
4. Support the establishment of peer counselling services which provide guidance in accessing services and are independent from public authorities.
5. Recognise the significance of self-help groups in providing practical and emotional support. Provide financial support to such groups, so they can rent rooms for their gatherings, pay to have an official address or run activities.
6. Create the legal and financial conditions that allow services, organised according to the principle of peer support, to flourish. Such organisations should benefit from the same favourable conditions in state aid, taxation and public procurement as Social Economy organisations.
7. Stop funding segregating services such as institutions and sheltered workshops, and instead invest in peer support-based services.

3.Co-production

3.1 Key principles

Co-production brings together two different concepts: co-design and co-decision making. The term co-production emerged within US academia in the late 1970s. It has been introduced by the US political scientist Elinor Ostrom to explore the workings of public services. The term became more prominent in Europe, when it was introduced to the UK by the New Economic Foundation and the Social Care Institute for Excellence (Mladenov 2023; ENIL 2023).

The definition favoured by the Independent Living movement was developed by the New Economic Foundation. It highlights the need to redistribute power to achieve co-production:

> “Co-production is a relationship where professionals and citizens share power to design, plan and deliver support together, recognising that both partners have vital contributions to make in order to improve quality of life for people and communities”.

Co-production without redistribution of power is fake and harmful, because it lends legitimacy to the status quo. Co-production is often framed as a matter for the improvement of service quality, but it is also a matter of social justice and human rights. Genuine co-production helps to counteract professional power, to ensure the knowledge and voices of disabled people are taken into account and to shape outcomes and enhance the self-determination of people who use services.

The Social Care Institute for Excellence (SCIE) identifies the following components in co-production:

- Co-design, including planning of services
- Co-decision making in the allocation of resources
- Co-delivery of services, including the role of volunteers in providing the service
- Co-evaluation of the services

The earlier in the policy making process that co-production happens, the more genuine it is. Co-production is more likely to happen when citizens have some control over the funding of services. For example, direct payments provide citizens with a certain degree of control and make co-production more likely to happen (Mladenov 2023; ENIL 2023).

The UNCRPD refers to co-production in its preamble. Letter (o) states that “persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them”, Article 4 on general obligations states in paragraph 3 “In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, State Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their presentative organisations” (United Nations 2006).

The Guidelines on Deinstitutionalisation, including in Emergencies, state in paragraph 67 that “Persons with disabilities and their representative organisations, including those of children with disabilities and particularly those of survivors of institutionalisation, should be involved and consulted at all stages of deinstitutionalisation” (CRPD 2022).

3.2 Application in practice

When co-production is attempted but does not involve redistribution of power, disabled people involved cannot really decide anything; it becomes tokenistic. Fake co-production lends actors a justification for not making any changes (Mladenov 2023; ENIL 2023).

The group of people using disability services is not homogeneous. Sometimes, parents represent disabled people. However, even within disabled people’s movement, there are different ideological positions. There are hierarchies of impairments and views on subjects can differ between different impairment groups. Disability and factors such as class, gender, age, nationality and ethnicity can intersect. All these factors create lived experiences that might differ and translate into different views on subjects. Some groups might be under-represented within the larger disabled people’s movement. Excluded groups within the disability movement might experience continuing exclusion even in cases of genuine co-production.

Professionals may exercise soft forms of power to control co-production, for example non/provision of information, nudging, professional jargon, categorising/labelling or subtle silencing.

The lack of peer support for service users seriously limits genuine co-production. Peer support can be provided by user cooperatives, Centres for Independent Living, Peer counselling services or self-help groups. Lack of such services weakens co-production. People who use services need to be supported to work together and to learn from each other. Engaging in peer support can show disabled people how to cope with soft forms of professional power or how to speak with people in a position of authority. It can also help overcome internalised ableism.

Co-production is resource intensive, financially and time wise. Therefore, a real or perceived lack of resources often limits co-production.

3.3 Examples of good practice

Good practice 1: Hammersmith and Fulham Council in London, England

The co-production work of the Hammersmith & Fulham Council in London, England can be regarded as an example of good practice. Hammersmith & Fulham is a borough in West London with a population of 183.157 inhabitants. The Council applies the following definition to its work: “Co-production (working together) means that Disabled residents and decision makers are working together in an active way to plan, design and review policy and services that affect our lives and get rid of the barriers we face” (Hammersmith & Fulham Council 2023a).

On the occasion of the International Day of Disabled people 2015, the Hammersmith and Fulham Council agreed to improve how they work with disabled people. A Disabled people’s Commission was set up, consisting of ten disabled people. The Commission produced a definition of co-production which guides the work of the Council: “Co-production is working togethers [which] means local disabled people living in an area are working together with decision makers. Co-production means disabled residents and decision makers together planning, designing and reviewing policy and services that affect our lives to get rid of barriers”. The Commission also produced 8 recommendations to guide the future co-production work. Sessions of the focus groups were chaired by members of the Commission.

In 2021, the Council adopted a co-produced Disabled People’s Housing Strategy, which members of the Disabled People’s Commission helped shape. The Council also held focus groups with disabled residents to gather input. Some local civil society organisations were also consulted. (Hammersmith & Fulham Council 2021).

The housing strategy is divided into four objectives, containing commitments, action plans and an outline of possible measures.

> Objective 1 aims to introduce a culture of co-production with disabled residents. The first listed commitment states that the Council will “publicise resident engagement and co-production options to disabled residents and Disabled People’s Organisations”. The first item in the action plan indicates that the Council will “promote the work of the Resident Involvement Teams particularly the resident involvement groups”. This will be measured by the “number of residents engaged”.
>
> Objective 2 on improving access to housing information commits to working “with DPOs to develop tailored housing options and advice for disabled residents” and to take action on developing “new information in everyday language explaining the full range of housing options available to disabled residents. This should include housing options advice leaflet and Disabled Facilities Grant (DFG) and Adaptations information leaflet”.
>
> Objective 3 on improving housing services with disabled residents commits to improving “the system for allocation and matching all accessible and adapted homes to

> which the council can nominate" and to "recruit disabled residents to co-produce a review of the Disabled Facilities Grant and Adaptation Service". The Disabled Facilities Grant is a means tested scheme to provide grants for home adaptations to disabled people.
>
> Objective 4 pledges to identify ways to increase supply of accessible housing. It commits to "deliver genuinely affordable homes that meet the needs of disabled residents" and take action on promoting "the work of the Disability Forum Planning Group (DFPG)".

According to information provided by the Council, home building projects, involving the provision of affordable and accessible apartments are under way (Hammersmith & Fulham 2023b, 2022).

Good practice 2: National Model Agreement for Direct Payments in Scotland

The Scottish Government is working on a National Model Agreement for Self-Directed Support Services in co-production with disabled people. The National Model Agreement will be shaped to ensure consistency and better outcomes for supporting people who employ personal assistants. The Scottish Government Adult Social Care Workforce, Fair Work Division and Social Work Scotland Self-directed Support Team are the entities leading on the project (Social Work Scotland 2023a, b).

Evidence suggests that, depending on where in Scotland someone lives, direct payments to employ personal assistant(s) vary significantly in design. Some provide better framework conditions, enabling good working conditions for assistants. Ideally, the direct payments allow the payment of competitive wages, holidays, sick payment and other features.

The authorities hope that the co-produced agreement will help to address these problems and to provide conditions for strong mutual relationships between assistants and their employers.

An advisory body called the Personal Assistance Programme Board has formed a subgroup, the "National Model Agreement for Option 1 Direct Payment to Employ Personal Assistants workstream group" which is directing the work. This working group includes Disabled People's Organisations, Centres for Independent Living, independent support organisations and individual employers. To further inform this work, an employer of personal assistants' expert group will be set up, which is supposed to become the main driver of the wider subgroup.

3.4 ENIL's Recommendations on Co-Production

ENIL calls on the European Commission and Member States to:

1. Design and implement all community-based services for disabled people in co-production between disabled people and decision makers. This includes services

working according to the peer-support concept. Co-production must never be tokenistic but involve a real sharing of power, like it occurs in collective bargaining processes.

2. Ensure measures are in place which prevent professionals from exercising both hard and soft forms of power. Introducing a neutral third party to act as moderator and referee could be such a measure. Such an arbiter could, for example, ensure that in meetings both sides have an equal amount of time to speak and review documents to make sure contents are balanced. With the help of such a moderator, rules of procedure could be established which might help avoiding arbitrariness.
3. Invite disabled people with various impairments, intersectional identities and qualifications to participate in co-production processes. Also, children with disabilities must be able to voice their views on matters concerning them.
4. Invite both organisations representing disabled people and disabled people working independently to participate.
5. Provide resources to DPOs to enable them to engage in co-production work, in consistence with UNCRPD General Comment No 7. Provide compensations to disabled people participating on an individual basis.
6. Install permanent bodies consisting of disabled people to advise decision makers on all governmental levels. Such bodies should be able to produce recommendations for the review and reform of existing or the design of new services which shall be treated with the utmost care by decision makers.
7. Establish a disabled people’s group in the European Economic and Social Committee.
8. Initiate co-production processes on the EU level to design a European Deinstitutionalisation Strategy, containing plans for the expansion of community-based services, a European strategy to facilitate employment of disabled people and a strategy to ensure all disabled people have access to mainstream housing and education, among other. Disabled people participating in an official co-production capacity should receive a monetary compensation, modelled after the compensations paid to the members of the European Economic and Social Committee.

4. Intersectionality

4.1. Key principles

Intersectionality is “a powerful tool that helps us to understand how various forms of oppression and discrimination, based on various identifiers, including race, gender, age and disability, immigration status, and many others are interconnected”. An intersectional perspective encourages a deeper understanding of the complexities of discrimination and the importance of recognising the full range of identities that shape everyone’s experiences. Nobody is one dimensional and we all have multiple identities. Some increase a persons’ privilege; others make us more vulnerable (Brennan 2023; ENIL 2023).

The UN CRPD also refers to aspects of intersectionality in its preamble. Letter (p) expresses concern “about the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status”. Letter (q) recognises “that women and girls with disabilities are often at greater risk, both within and outside the home, of violence, injury or abuse, neglect or negligent treatment maltreatment of exploitation.” Letter (r) highlights “that children with disabilities should have full enjoyment of all human rights and fundamental freedoms”. Letter (s) emphasises “the need to incorporate a gender perspective in all efforts”.

Article 6 “Women with Disabilities” states that “State Parties recognises that women and girls with disabilities are subject to multiple discrimination, and in this regard, shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms. State Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention”. For women and girls, there is an increased risk to fall victim to violence. Women are more likely to have their right to legal capacity taken away than men.

Article 7 on “Children with disabilities” oblige state parties to “take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children. … In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration. State Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them”.

General Comment No. 6 explains that discrimination against disabled people can be based on intersecting characteristics. “Intersectional discrimination occurs when a person with a disability or associated to disability suffers discrimination or any form on the basis of disability, combined with, colour, sex, language, religion, ethnic, gender or other status”. State Parties must provide gender-sensitive health services, including sexual and reproductive rights.” (CRPD 2018, p. 5, p. 15).

According to the Guidelines on Deinstitutionalisation, including in Emergencies, ”The personal identities of persons with disabilities are multifaceted and disability is only one characteristic. Other characteristics include race, sex and gender, gender identity and expression, sexual orientation, sexual characteristics, language, religion, ethnic, indigenous or social origin, migrant or refugee status, age, impairment group, political or other opinion, experience of imprisonment or other status…” (CRPD 2022). Therefore, “state parties should adopt an intersectional approach to tackling discrimination, segregation, isolation and other forms of ill-treatment of persons with disabilities…” (p. 39) and they “should ensure that intersectionality is considered throughout all aspects of deinstitutionalisation processes … in developing inclusive community support systems and inclusive mainstream services.” (p. 41)

The Guidelines on Deinstitutionalisation, including in emergencies, warn that multiple discrimination may occur in the community through lack of support services. State parties are asked to consider intersectionality throughout all aspects of the deinstitutionalisation process. The closure of institutions, the development of community support systems and inclusive mainstream services are named as key stages. State parties are advised to tackle structural racism, to prevent discrimination and institutionalisation on the basis of race and ethnic origin and conjunction with disability.

Community services which are based on single, isolated characteristics, fail to address the intersections of identities. On the other hand, community-based services which are tailor made can achieve the integration of intersectionality because they acknowledge the multifaceted identities. (Brennan, 2023)

Brennan suggests a three-step strategy to incorporate intersectionality into services for disabled people:

> Firstly, services need to be tailor-made. For this to happen, services need to be designed, implemented, and run through inclusive processes, involving stakeholders from diverse backgrounds, including disabled individuals from various intersecting identities. User-led services are inherently age and culturally sensitive and consider the specific needs and challenges faced by underrepresented communities. Services should give the user the power to choose their own staff, determine the type and timing of assistance and make decisions that align with their personal values and goals.
>
> Secondly, we need better data that captures the intersections of disability with other identities to identify disparities and areas of intervention.
>
> Thirdly, intersectional perspectives should be mainstreamed into all policies and programs. This entails examining the potential impact of policies on various intersecting identities and ensuring that interventions are designed to address multiple forms of discrimination.

4.2. Application in practice

4.2.1 Disabled women

There is evidence from the EU that women are more likely to become victims of violence due to their disability and their gender. One example of this is forced sterilisation of disabled women, which according to the European Disability Forum, is permitted by law in 13 Member States.[2] In Czechia, Hungary and Portugal forced sterilisation of minors is allowed (European Disability Forum 2022).

In Germany, for example, 17% of all women with disabilities had been sterilised in 2017, comparing to 2% of all women in the entire country. In 2016, out of 31 requests for approval of sterilisation of disabled persons submitted by a legal guardian, 23 were approved. In Spain, the sterilisation of 140 women with disabilities was reported in 2016. According to the General Council of the Judiciary, over a thousand disabled women were sterilised in the past decade.

NGOs from Belgium, Lithuania and Poland reported that forced sterilisation of disabled women are still occurring in their countries. In Belgium, it is alleged that such sterilisations are widespread in institutions and are held as an entry requirement in many of such settings. Similar claims have been made for France and Hungary. Forced sterilisation also affects young women and girls with disabilities. The best interest of the person, medical reasons, protection against sexual abuse, easing contraception and the belief that a disabled person may not be capable of caring for a child are commonly cited as justifications.

Disabled women are also strongly discriminated against in the labour market. Thus, only 20% of disabled women are in full time employment compared to 28,6% of disabled men (Langensiepen 2021).

4.2.2 Other groups

Because of their age, children are in a situation of special vulnerability due to their age. The Guidelines on deinstitutionalisation, including in Emergencies state that living in an institution is especially dangerous for children and that they have the right to grow up in a family. Children placed in an institution on the basis of their actual or perceived impairment, poverty, ethnicity or other social affiliation are likely to develop impairments, or existing impairments are likely to be exacerbated as a result of institutional placement.

The Guidelines state that children and adolescents must not be excluded from access to personal assistance, peer support and support services in the community. Children with disabilities are to be included in mainstream schools. They are to be provided with support in expressing their views.

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[2] Portugal, Denmark, Czechia, Slovakia, Hungary, Croatia, Malta, Finland, Estonia, Latvia, Lithuania, Bulgaria, Cyprus

The Guidelines detail, that deinstitutionalisation must include older persons with disabilities. Older people with disabilities must not be included from deinstitutionalisation and access to community-based services because of their age.

Nevertheless, there is evidence that the number of children in the EU which live in institutions has only marginally decreased since the adoption of the UN CRPD. The same research also indicates that while large institutions for disabled people have reduced in some countries, older disabled people have been excluded from this process (Siska & Beadle-Brown 2019, 2020)

According to the ENIL Independent Living Survey, persons over 65 have only access to personal assistance in 15 countries in the country of Europe area.[3] Persons under 18 have access to this service in 18 countries.[4] These figures indicate that young and older people are very often excluded from access to personal assistance.

Young disabled people are heavily discriminated against in the labour market: 24,9% are unemployed compared to 16,6% in the general population (Langensiepen 2021).

4.3. ENIL's Recommendations on Intersectionality

ENIL calls on the European Commission and the Member States to:

1. Ensure that community-based services for disabled people are tailor-made, designed in co-production with disabled people and contain measures which ensure that the needs of disabled people of all intersectional identities are being addressed.
2. Make sure disabled people of all intersectional identities have access to personal assistance and are included in deinstitutionalisation processes.
3. Provide tailored and needs-based support to families with disabled children, preventing institutionalisation and poverty. The existence of impairment or the lack of support for parenting disabled children should never be the ground for separation.
4. Guarantee that violence against disabled people of all intersectional identities is persecuted to the full extent of the law and develop services which provide rapid and needs-based aid to disabled victims of violence, including domestic violence.
5. Ban forced sterilisation of women and girls with disabilities and support their full enjoyment of reproductive rights.
6. Ensure that service providers do not discriminate against disabled people of intersectional identities when delivering their services. To that end, anti-discrimination measures should be adopted.

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[3] Albania, Azerbaijan, Bulgaria, Cyprus, Estonia, Finland, Germany, Greece, Italy, Malta, Montenegro.

[4] Albania, Azerbaijan, Belgium, Bulgaria, Czech Republic, France, Finland, Germany, Iceland, Latvia, Malta, Netherlands, Norway, Romania, Slovakia, Sweden, United Kingdom.

7. Ensure access to mainstream services, including in the area of personal mobility, accessibility, communication, health care, family life, an adequate standard of living, inclusive education, participation in political and public life, housing, social protection, and participation in cultural and community life, leisure, recreation and sport.
8. Set-up data collection and research projects, including through funding provided by the EU Horizon programme, to improve the knowledge base on the intersectional dimension of disability.

5. Access to services

5.1. Key principles

5.1.1 Availability, accessibility, acceptability, affordability, and adaptability

According to Article 19 of the UN CRPD on “Living independently and being included in the community”, disabled people must “have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community” (United Nations 2006).

Article 28 on “Adequate standard of living and social protection” obliges State Parties to “recognise the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing, and housing, and to the continuous improvement of living conditions”. For this right to become a reality, governments are required to develop social protection and poverty reduction programmes, and to ensure access by disabled people and their families living in poverty to support with “disability related expenses, including adequate training, counselling, financial assistance and respite care”, as well as to “public housing programmes.”

Support services for living independently must be available, accessible, acceptable, affordable, and adaptable (Guidelines on deinstitutionalisation, CRPD 2022).

Among other, “eligibility criteria and procedures for gaining access to support services must be defined in a non-discriminatory way and must focus on the requirements of the person rather than the impairments, following a human rights-based approach” (General Comment No. 6, CRPD 2018).

5.1.2 Disability assessments

A precondition for accessing disability support services is to have one’s disability recognised. To do so, it is necessary to undergo a disability assessment. In order to ensure access to services and benefits that will support an individual’s right to independent living, disability assessments must be based on the social model of disability.

A disability assessment entails a relationship between an applicant and an assessor. It is essential that the power between the applicant and the assessor is equally balanced. Thus, a key part of any assessment should be to understand what is going on in the applicant’s life and listening to what they have to say. Disability assessments need to build on the applicant’s strengths and redress unequal power relationships. The information gathered this way can be used to make a decision about eligibility and get the right amount of support in place (ENIL 2023).

The UNCRPD, the General Comments or the Guidelines on Deinstitutionalisation, including in Emergencies, contain no guidance on disability assessments. However, UN CRPD recital (e) and article 1 indicate that disabled people include those “who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers” for example attitudinal and environmental “may hinder their full and effective participation in society on an equal basis with others”.

The Committee on the Rights of Persons with Disabilities uses this conceptualisation to deduce criteria to evaluate and comment on state parties’ disability assessments in their Concluding Observations. The distinction of the UN CRPD between impairments and disabling barriers stems from the social model of disability. A statement from the International Labour Organisation and the International Disability Alliance argues that disability assessments should not only consider impairment and activity limitations, but also attitudinal and environmental barriers faced by persons with disabilities (Labour Organisation & International Disability Alliance 2019). Indeed, the Committee on the Rights of Persons with Disabilities has pointed out the need for a contextual understanding of disability and voiced concerns about assessments that focus on individual impairment but not interactions with the social environment (Waddington & Priestly 2021).

5.2. Application in practice

5.2.1 Availability, accessibility, acceptability, affordability, and adaptability of services

Access to services and benefits can be blocked by rules and regulations going against the rights and the best interest of disabled people seeking support. In many places, authorities impose unreasonable amounts of administrative requirements and barriers on applicants who require support. Such requirements may be arbitrary and in no way create a fair application procedure. Gate keeping functions, to limit the number of individuals accessing support, are the most likely reason.

One example is the application for the personal budget from an autistic person living in Berlin. In an interagency conference, support needs were assessed and officially confirmed. The social administration approved the personal budget. Because the disabled person was temporarily not in Berlin at the scheduled start date of receiving the personal budget, the authority cancelled the entire process. The regulation governing access to benefits and services and the conduct of the authority in question did not to take into account the specific situation of the person. In the concrete situation, the support need of the disabled person continued regardless of where in the country they were based.

In a similar case, a public authority admitted in front of court that a disabled person had the right to receive support to pay rent. The authority announced in front of a judge that payments would be executed. In practice, the benefits were never dispersed. No justification was given, and the authority is not reacting to e-mails or phone calls.

In a third a case, authorities dismissed a carefully designed support plan for a young autistic person who had survived two years of institutionalisation. The reason given was that autism is a condition of the soul not of the mind. Such as distinction has no evidence base in science. Even if it were correct, the disabled person still has support needs (Personal Communication 2023a).

In Belgium, the personal budget exists in Flanders but there are waiting lists for up to 20 years.

In all examples, benefits and services were available in theory. In practice, bureaucratic barriers prevent people with support needs from accessing benefits and services. General Comment no 5 and the Guidelines on Deinstitutionalisation, including in emergencies, clearly state that the support need should determine access to services. (CRPD 2022).

5.2.2 Disability assessments

In practice, many disability assessments function with the medical model of disability at their core. Disability assessments are designed to determine someone's eligibility and are based on the level of need. To do this, a professional will collect a set of information to make a professional judgement. Depending on this judgement, the applicant will receive access to support or not. This entails a relationship which is heavily balanced in favour of the professional. Assessment professionals apply this power to identify a persons' deficits, to make a judgement. In this process, the person is identified as the problem. This way of carrying out assessments does not take into account what the person has to say or what matters to them. Disabled people and DPOs are not involved in the design of disability assessments (ENIL 2023).

The Concluding Observations of the Committee on the Rights of Persons with Disabilities show that countries do not provide disability assessments which take into account environmental and attitudinal factors. Disability is mostly awarded based on medical diagnosis. The Committee criticised the disability assessments of Hungary, Lithuania, Czechia and Croatia for focusing only on the impairments of the applicants. Italy, Portugal, Latvia, Luxembourg and Serbia were criticised for basing their disability assessments on medical aspects. Assessments should not de-contextualise the person from their environment. Relying on medical diagnosis in isolation of disabling barriers is not compatible with the UN CRPD (Waddington & Priestly 2021).

Since its inception, the Independent Living Movement has been challenging the power of traditional healthcare professionals over disabled people. Doctors, therapists, social workers and nurses tend to focus on a persons' deficit through the narrow lens provided by their training. Often, solutions are identified and imposed without taking into account the person's voice.

Other barriers that persist include long waiting times and undignified processes, poor diagnosis of hidden disabilities, late or no assessment of women with disabilities, and insufficient levels of support (European Disability Forum, 2021).

5.3. Examples of good practice

Good practice 1: Peer support in applying for services

There are also cases of authorities which are responsive to the needs of disabled people and process applications for support not in the spirit of gatekeeping but in the interest of the disabled person. Anecdotal evidence suggests that in such cases, committed staff members play a key role. In an inclusion office in Kaiserslautern, Germany, a clerk not only helped a young autistic man with filling out the necessary application forms but volunteered to do the paperwork for him. The clerk worked according to instructions given over the phone by a volunteer who supports autistic survivors of institutionalisation and is himself autistic. Thanks to this successful cooperation between a public authority and a peer lending support, a survivor of an institutionalisation was able to access the support he needs to live a life with self-determination (Personal Communication 2023b).

Good practice 2: Disability identity card

There are some practices which show potential. In Malta, the Commission for the Rights of Persons with Disability issues a disability identity card (SID). Holders of an SID benefit from reductions in admission fees, but also get access to social services like social housing schemes. The Equal Opportunities Act defines disability as “long-term physical, mental, intellectual or sensory impairment which in interaction with various barriers may hinder one’s full and effective participation in society on an equal basis with others”. This definition is very close to the disability concept expressed in the UN CRPD. Unfortunately, the assessment process once again depends on medical diagnosis. At the same time, medical assessors are interviewed by the Executive Director of the Commission for the Rights of Persons with Disability to ensure that they are familiar with the principles underlying the UN CRPD (Waddington 2018).

5.4. ENIL’s Recommendations on Access to Services

ENIL calls on the European Commission and Member States to:

1. Guarantee that services for disabled people are not only available in theory but also in practice. Access to social services has to be recognised as a legal right for those in need and must be actively enforced.
2. Put in place disability assessment procedures compliant with the UN CRPD and in line with the social model of disability, and which are swift, fair and transparent.
3. Put in place effective and easy to use complaints mechanisms. Complaints procedures have to be carried out by independent antidiscrimination bodies. Authorities deciding about access to services must be obliged to cooperate with such bodies.
4. Train staff of service providers and disability assessors in the human rights and the social model of disability.

5. Instruct staff to actively help applicants by, for example, explaining procedures in an understandable way and providing support in filling out application forms. Train staff of the relevant authorities in the human rights and the social model of disability.
6. Provide adequate levels of financing to community-based services for disabled people and abolish waiting lists. Budgets have to ensure availability and affordability to all disabled people in need of support.
7. Ensure accessible information, including in easy to read, about services is available and actively distribute them within the disability community. Such information should explain which services are available and how to access them.
8. Ensure public authorities are accessible to people of all impairments and are adequately staffed. Accessibility refers to the built environment, but also to procedures and forms of communication which are possible. Applicants need to be allowed to communicate in Alternative or Augmented Communication for example.
9. Train staff to provide accommodations to people with various impairments, including people with intellectual and psychosocial impairments, or those who are neurodivergent. Disabled people should be treated with the same respect as non-disabled people.

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Contact us

European Network on Independent Living (ENIL)
6th Floor – Mundo J
Rue de l’Industrie 10
1000 Brussels
Belgium
E-mail: secretariat@enil.eu
www.enil.eu

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