



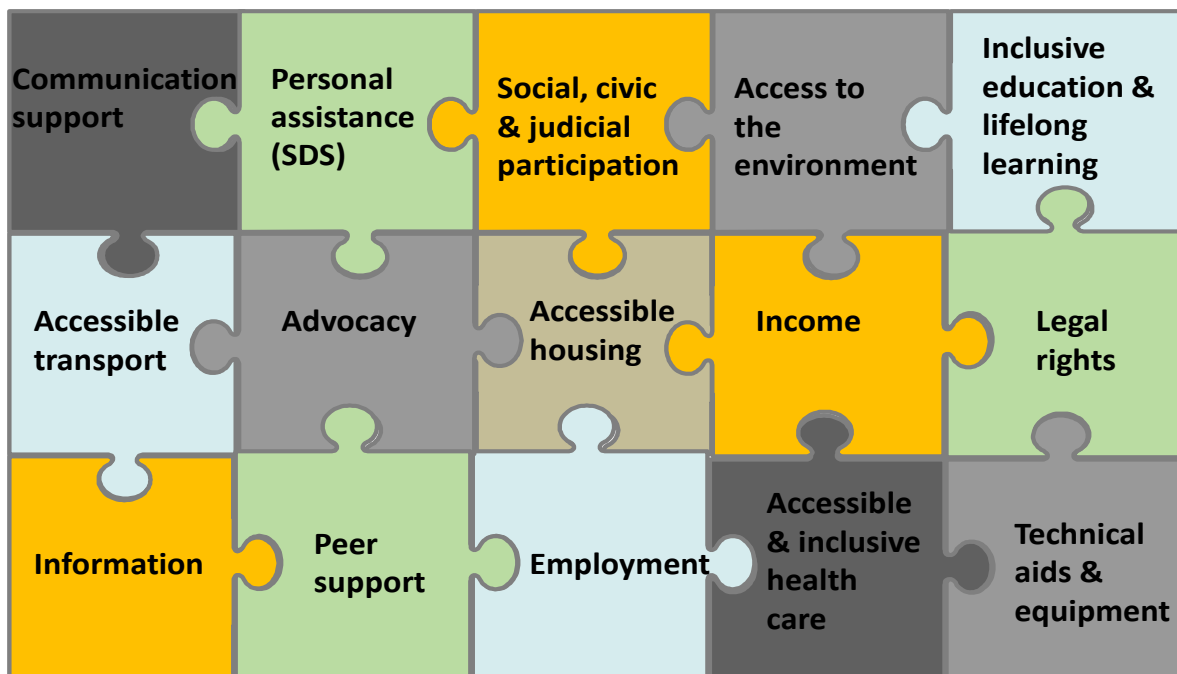
ENIL's Proposal for the EC Guidance on Independent Living and being included in the community

April 2023



Proposal of the European Network on Independent Living

for the European Commission Guidance on Independent Living and being included in the community



Independent Living Jigsaw – showing the inter-relationship of the various aspects of independent living as experienced by the individual; one of which is Personal Assistance (SDS) © GCIL Training 2000

Image description: a puzzle, with each puzzle containing the following word, from top left corner: communication support, personal assistance (SDS), social, civic and judicial participation, access to the environment, inclusive education and lifelong learning, accessible transport, advocacy, accessible housing, income, legal rights, information, peer support, employment, accessible and inclusive health care, technical aids and equipment.

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Executive Summary

Independent Living can mean different things to different people. As defined by the UN Convention on the Rights of Persons with Disabilities (UN CRPD), it means that disabled people can exercise choice and control over their lives, that they are able to take all decisions and exercise personal autonomy and self-determination. Independent Living means disabled people must have access to all areas of life.

This document brings together key recommendations by the European Network on Independent Living - ENIL on how to improve access to living in the European Union (EU). We believe that these recommendations should be included in the European Commission's guidance on Independent Living, because they are based on the lived experience of disabled people and the countries' obligations under the UN CRPD, the General Comments and the CRPD Committee's *Guidelines on deinstitutionalisation, including in Emergencies*.

This is the summary of our recommendations:

- Definitions of the terms 'independent living', 'institution', 'deinstitutionalisation' and other must be aligned with the UN CRPD and its General Comments, and included in all the relevant laws, policies and strategies.
- To make progress on deinstitutionalisation, EU Member States must repeal legislation which authorises the use of institutions, including involuntary detention and forced treatment based on disability, guardianship and institutionalised forms of "community care" (for example, 'community treatment orders'). They must also invest more financial resources into personal assistance and other community-based services, and stop funding institutions of any size.
- Personal assistance schemes need to be aligned with the General Comment 5 definition on personal assistance. For example, disabled people using personal assistance must be able to freely choose, hire, train, instruct and dismiss their assistants. Eligibility and needs assessment procedures need to be fair and transparent, and the personal assistance schemes adequately funded. Disabled people in residential settings need to receive active support in applying for personal assistance, so that they can move to the community.
- A broad range of community-based services must be available, including those aimed at people moving from institutions to the community, and to prevent institutionalisation. This includes better access to assistive devices and fairer and more transparent disability assessment procedures.
- To ensure disabled people can live in the community, Member States must ensure access to affordable and accessible housing options, including support with renting, social housing and challenging discrimination in access to housing.
- All disabled people must enjoy the right to inclusive education where they live. Member States must accelerate their efforts to implement the steps set out in

the General Comment 4 and ensure that their education systems are available, accessible, acceptable and adaptable.

- When it comes to employment, effective legislation is needed, banning direct and indirect discrimination, denial of reasonable accommodation, harassment and discrimination by association. Employers should launch affirmation action programs and receive training on including disabled people in the workplace.
- To improve access to healthcare, Member States should improve access to primary, secondary and other healthcare, including by making healthcare facilities and medical equipment accessible. Member States also need to take steps to improve timely access to mental health support of high quality, in the community, for people with psycho-social disabilities who wish to use it, while at the same time developing a range of other options. Any treatment must be strictly voluntary and focus on individual support needs.
- For independent living to become a reality for disabled people, there must be a change in how society views us. This includes raising awareness among everyone, including disabled people, about the social and/or the human rights model of disability. Disability assessment procedures must be reformed to ensure that all those who need support are able to access it. An intersectional and intersectoral approach is needed, to make sure that no one is excluded.
- Disabled people and their representative organisations must be involved in any processes that concern them, including in leadership positions and as equal partners, through co-production.

Plain language summary

Independent Living can mean different things to different people.

The United Nations Convention on the Rights of Persons with Disabilities says what independent living means.

Independent living means that disabled people have choice and control over their lives.

Independent living means that they are able to make decisions about their lives and be independent.

Independent Living means disabled people must have access to all areas of life.

The European Network on Independent Living has put together some **key points**.

The points are about how to make independent living better for people with disabilities in the European Union.

The points are based on the real lives of people with disabilities and the promises countries made when joining the United Nations Convention on the Rights of Persons with Disabilities.

The points should be included in the European Commission's **Guidance on Independent Living**.

The Guidance will be a document for European Union Countries.

The Guidance will help countries improve independent living for disabled people.

Here are the 10 points by the European Network on Independent Living:

1. Countries should say clearly what they mean when they say independent living, or an institution.

We need to make sure that how these words are described is the same as in the UN Convention on the Rights of Persons with Disabilities.

2. European Union countries should give more money to help stop people with disabilities going to institutions.

Institutions are places where people with disabilities live with other people with intellectual disabilities.

They often live there apart from other people.

They often have little choice who they live with or who supports them.

No money should be spent on institutions.

The money should be spent on personal assistants and other things people with disabilities need to live independently.

3. Under **General Comment* 5** if you have a personal assistant you should get to choose, hire, train, direct and dismiss them.

Applying for a personal assistant should be fair and equal.

People in institutions should get support to apply.

Needs assessments should be transparent.

Personal assistance schemes should be properly funded.

General Comment* means a document written by the committee of the UN Convention on the Rights of Persons with Disabilities.

The document explains an article of the Convention.

It also gives countries details and directions on how to make sure the right is given to disabled people in their country.

4. There should be more community-based services.

Community-based services means support needs that are provided in the home and the community you live in.

To make sure no one is excluded, services should be provided with an intersectional and intersectoral approach.

Intersectional means all social identities of a person are considered.

For example, a person is disabled but is also an immigrant.

This person has overlapping needs from each social identity.

Intersectoral means all those involved work together to provide services.

For example, service providers, policy makers, disabled people and NGO's make rules together.

5. Countries should provide affordable housing for disabled people.

This includes rent support, social housing and no discrimination to access it.

Housing that is accessible and affordable makes community living possible.

6. There should be a right to inclusive education for all disabled people.

Countries should improve the availability, quality and accessibility of inclusive education.

This point is from **General Comment 4**.

7. New laws are needed for employment of disabled people.

To stop all discrimination and make sure disabled people are given reasonable accommodations.

Reasonable Accommodations means changes to the workplace based on a person's needs to make it fair for them.

For example, a person with sensory needs may need a special keyboard so they can do their job.

8. Countries should improve access to healthcare.

Healthcare facilities and equipment should be more accessible.

Community-based services for mental healthcare should be better and easier to access when needed.

This will help people with psycho-social disabilities to live independently.

Psycho-social disability means a mental health condition which creates barriers to taking part in society and may stop a person from getting all their rights.

These services must be a choice for the person.

These services should be focused on the person's individual needs at the time.

9. Countries should fight stereotypes against disabled people.

It is important for everyone to understand that disabled people have problems because of different barriers in society, and that we should all work together to get rid of these barriers.

A **stereotype** is when we think all people who have something in common, such as being disabled, behave in a certain way.

10. Whenever we speak about disabled people, they should be

asked for their opinion and should help make all the decisions. Disabled people should decide on the laws that talk about them, or on what types of support will be available.

I. Introduction

1.1. The political context

According to the [European Strategy on the Rights of Persons with Disabilities 2021-2030](#) (ESRPD), the European Commission will, by 2023, issue guidance recommending to Member states improvements on Independent Living and inclusion in the community (European Commission 2021).

The European Network on Independent Living - ENIL is a user-led Europe-wide network of 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 (ENIL 2022a). 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 what ENIL considers must be included in the forthcoming European Commission guidance on Independent Living and inclusion in the community. It was developed with the financial support of the European Union, ULOBA, STIL and GIL.

1.2. Methodology

This document is guided primarily by 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. Moreover, it takes into account the 12 Pillars of Independent Living. These twelve pillars have been identified by disabled people as conditions that are needed for everyone to live independently:

1. Appropriate and accessible **information**
2. An adequate **income**
3. Appropriate and accessible **health and social care provision**
4. A fully accessible **transport system**
5. Full access to the **environment**
6. Adequate provision of **technical aids and equipment**
7. Availability of accessible and adapted **housing**
8. Adequate provision of **personal assistance**
9. Availability of inclusive **education and training**
10. Equal opportunities for **employment**
11. Availability of **independent advocacy and self-advocacy**
12. Availability of **peer counselling**

Having identified the guiding documents, the ENIL Task Force on Independent Living was set up in May 2022 to give our members to opportunity to decide which of these principles they would like to see reflected in our recommendations. The members of the Task Force were disabled people and allies. In three meetings of two hours, 35 members discussed the barriers preventing disabled people from living independently,

as well as possible solutions through reforms of policies and legislation. The current recommendations are thus the outcome 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.

This document consists of four sections:

I. Definitions: sets out the definitions of key terms which should be included in the EC Guidance, in order to prevent misuse of terminology.

II. Key elements of EC Guidance on Independent Living: sets out the main thematic areas ENIL would like to see covered in the Guidance, with a discussion of the problems and recommendations to the EU Member States.

III. Horizontal issues: covers other key elements which are important for ensuring that any guidance has the outcome of improving the situation in the Member States, when it comes to independent living.

IV. References: includes the documents consulted during the drafting of this paper.

II. Definitions

Having a common understanding of the key terms, such as 'independent living', 'deinstitutionalisation' or 'community-based services' is key to ensuring full compliance with the UN CRPD. This also helps avoid misinterpretation of terminology; for example, 'independent living' can be misunderstood as referring to living without support, being self-sufficient, or even used to describe institutions (sometimes called 'independent living centres'). A common definition of an 'institution', in line with the UN CRPD and the related documents, is also crucial to ensure that all settings are included in deinstitutionalisation efforts.

For this reason, the European Commission guidance must include the key definitions and call on the Member States to include these in all the relevant laws, policies and strategies.

2.1. Independent Living

Independent Living is defined in Article 19 of the UNCRPD and in the [General Comment No. 5](#) of the Committee on the Rights of Persons with Disabilities (CRPD Committee) (CRPD 2017). The documents issued by the CRPD Committee serve as authoritative guidance for the interpretation of the UN CRPD. According to Article 19, disabled people have the right to live in the community, with choices equal to others. General Comment No. 5 specifies that Independent Living means that individuals with disabilities are provided with all necessary means to enable them to exercise choice and control over their lives.

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

In summary, disabled people need to be able to take all decisions concerning their lives and exercise personal autonomy and self-determination in choosing their place of residence, daily routine, habits, personal relationships, clothing, religious and cultural activities. Independent Living means that disabled people need to have access to all areas of life, such as education, transport, information, communication, personal assistance, decent employment, nutrition, hygiene, health care and sexual and reproductive rights on an equal level with non-disabled people. The right to Independent Living must, for example, include the ability to decide where and with whom to live, what to eat, whether one wants to sleep in or go to bed late at night, be inside or outdoors, have a tablecloth and candles on the table, have pets or listen to music.

2.1.1. Centres for Independent Living

A Centre for Independent Living (CIL) is a cross-disability organisation controlled by disabled people with a mission to promote social inclusion and mainstreaming of disabilities in all public policies. CILs should focus on personal assistance, peer support and building inclusive communities, information and training activities for both disabled and non-disabled people, policy research from the perspective of the UN CRPD and legal representation for disabled people who want to live independently but have no opportunities to do so.

The work done by the CILs at the grassroots level is of fundamental importance to the continued emancipation of disabled people. For many disabled people in Europe, CILs are often the first point of contact with the Independent Living movement and philosophy. Historically, they have played a vital role in supporting disabled people to live in the community.

In addition to CILs, disabled people may be organised in **user co-operatives**. Typically, these are organisations that provide support for their members and that are owned, controlled and run by those members. Co-operatives may help disabled owners administer their direct payments, recruit and train personal assistants, as well as deal with other employment or financial issues linked to running a personal assistant scheme.

2.2. Institution

According to the General Comment 5 and the [CRPD Guidelines on Deinstitutionalisation, including in Emergencies](#), there are certain defining elements of an institution:

- Obligatory sharing of assistants with others
- No or limited influence as to who provides the assistance;
- Isolation and segregation from independent life in the community;
- Lack of control over day-to-day decisions;
- Lack of choice for the individuals concerned over with whom they live;
- Rigidity of routine irrespective of personal will and preferences;
- identical activities in the same place for a group of individuals under a certain authority;
- A paternalistic approach in service provision;
- Supervision of living arrangements;
- A disproportionate number of persons with disabilities in the same environment.
- Provision of housing and support in one package by the same service provider (CRPD 2022, para 16).
- By its very definition, Independent Living is impossible in residential settings (CRPD 2017, para 16c).

When it comes to children, anything other than a family (including married and unmarried parents, single parents, same-sex parents, adoptive families, kinship care, kafalah, sibling care, extended family, and substitute families or foster care), must be considered an institution. “Family-like” institutions are still institutions and are no substitute for care by a family (CRPD 2017, para 16c).

Importantly, the removal of one or more of these elements does not make a setting community-based (CRPD 2022, para 16).

Institutionalisation typically occurs in facilities such as: social care institutions, psychiatric institutions, long-stay hospitals, nursing homes, secure dementia wards, special boarding schools, rehabilitation centres other than community-based, half-way homes, group homes, family-type homes for children, sheltered or protected living homes, forensic psychiatric settings, transit homes, albinism hostels, leprosy colonies and other congregate settings. Mental health settings where a person can be deprived of their liberty for purposes such as observation, “care” or “treatment” and/or preventive detention are by definition a form of institutionalization (CRPD 2022, para 15).

According to the General Comment 5 and the Guidelines, institutionalisation should be considered as discrimination on the basis of disability. From the criteria listed, it follows that an institution is not necessarily where you live or with whom you live, but also under what conditions. Moreover, if someone is “forced” to live under specific conditions which are limiting their personal choices and they lack control over their life, they can be institutionalized in their own home. If a family does not consider the needs and wishes of the disabled member, they can act as an institution.

2.3. Deinstitutionalisation

ENIL defines deinstitutionalisation as a political and a social process, which provides for the shift from institutional care and other isolating and segregating settings to independent living. It includes an end to substitute decision-making, including guardianship, and to forced treatment (including in the community). Effective deinstitutionalisation occurs when a person placed in an institution is given the opportunity to become, or to resume being a full citizen and to take control of his/her life (if necessary, with support). Essential to the process of deinstitutionalisation is the provision of affordable and accessible housing in the community, access to public services, personal assistance, and peer support. Deinstitutionalisation is also about preventing institutionalisation in the future; ensuring that children are able to grow up with their families and alongside neighbours and friends in the community, instead of being segregated in institutional care.

The abolishment of all forms of institutionalisation, the ending of new placements in institutions and the termination of investments in institutions must be among the key objectives of a deinstitutionalisation strategy. Deinstitutionalisation processes should result in an end to all forms of institutionalisation, isolation and segregation of disabled people (CRPD 2017). To achieve deinstitutionalisation, states should abolish all legislation, policy and practices which authorise and condone institutionalisation, including mental health law and mental capacity law which authorise the use of disability-based coercion.

All deinstitutionalisation processes should address multiple discrimination experienced by some disabled people, which makes them more likely to end up or stay in an institution. This will include taking account of race, ethnic origin, migrant or refugee status, religion, political belief, age, gender, sexual orientation, language (including alternatives to verbal language), and discrimination which results from a person’s contact with the criminal justice system.

2.4. Personal Assistance

ENIL defines Personal Assistance as a tool which allows for independent living. Personal assistance is purchased through earmarked cash allocations for disabled people, the purpose of which is to pay for any assistance needed. Personal assistance should be provided on the basis of an individual needs assessment and depending on the life situation of each individual. The rates allocated for personal assistance to disabled people need to be in line with the current salary rates in each country. As disabled people, we must have the right to recruit, train and manage our assistants with adequate support if we choose, and we should be the ones that choose the employment model which is most suitable for our needs. Personal assistance allocations must cover the salaries of personal assistants and other performance costs, such as all contributions due by the employer, administration costs and peer support for the person who needs assistance.

Personal assistance is also defined in the General Comment 5. Paragraph 16(d) of the General Comment lists elements which distinguish personal assistance from other services:

i) Funding for personal assistance must be provided on the basis of personalized criteria and take into account human rights standards for decent employment. The funding is to be controlled by and allocated to the person with disability with the purpose of paying for any assistance required. It is based on an individual needs assessment and upon the individual life circumstances. Individualized services must not result in a reduced budget and/or higher personal payment;

(ii) The service must be controlled by the person with disability, meaning that he or she can either contract the service from a variety of providers or act as an employer. Persons with disabilities have the option to custom design their own service, i.e., design the service and decide by whom, how, when, where and in what way the service is delivered and to instruct and direct service providers;

(iii) Personal assistance is a one-to-one relationship. Personal assistants must be recruited, trained and supervised by the person granted personal assistance. Personal assistants should not be “shared” without the full and free consent of the person granted personal assistance. Sharing of personal assistants will potentially limit and hinder the self-determined and spontaneous participation in the community;

(iv) Self-management of service delivery. Persons with disabilities who require personal assistance can freely choose their degree of personal control over service delivery according to their life circumstances and preferences. Even if the responsibilities of “the employer” are contracted out, the person with disability always remains at the centre of the decisions concerning the assistance, the one to whom any inquiries must be directed and whose individual preferences must be respected. The control of personal assistance can be exercised through supported decision-making (CRPD 2017).

2.5. Community-based services

The development of community-based services requires both a political and a social approach, and consists of policy measures for making all public services, such as housing, education, transportation, healthcare and other services and support, available and accessible to disabled people in mainstream settings. Disabled people must be able to access mainstream services and opportunities and live as equal citizens. Community-based services should be in place to eliminate the need for special and segregated services, such as residential institutions, special schools, long-term hospitals for health care, or the need for special transport because mainstream transport is inaccessible, and so on.

III. Key elements of EC Guidance on Independent Living

3.1. Deinstitutionalisation

3.1.1. Problem outline

According to estimates, within the EU, [1,4 million disabled people](#) under the age of 65 live in institutions (Siska & Beadle-Brown 2020). In 2007, 1,2 million disabled people were estimated to be confined to institutions (Mansel & all 2007, p. 25). In addition, more than [3 million](#) people over the age of 65 live in institutions (ENIL 2022b).

Currently, there is no information at the EU and the national level on how many disabled people live in all types of institutions – this includes nursing homes, psychiatric hospitals, group homes, shelters of supported or semi-autonomous living, social care facilities and children´s institutions. Without this information, there is a risk that not all institutions will be closed.

Disabled people confined to institutions are subject to many human rights violations. In large institutions or small group homes, disabled people are frequently restricted in their ability to leave the premises on their own accord, the staff have the right to enter rooms at any time, and contact with the outside world is strictly regulated. Moreover, following predetermined group or individual activity plans is mandatory and normal life choices such as forming relationship or having a pet are subject to rules or are banned altogether (Comp. Hubert & Hollins 2006; Glab 2021; Sanden 2023). Such conditions represent severe restrictions of liberty, personal privacy and self-determination.

Those detained in psychiatric hospitals have no choice about being there, frequently experience degrading environments, are forcibly treated and are subjected to restraint, seclusion and other coercive practices. Measure of this sort are justified on the basis of ill-founded concepts about risks that they might pose to themselves, or others and continue to be in force despite the lack of any adequate research evidence that they are even effective (Gooding 2017).

Disabled people in institutions are also exposed to an alarming rate of physical or psychological violence, health and safety hazards, forced and arbitrary medical interventions (Comp. ENIL. 2022a; Priestley & Hemingway. 2008, 2014; Brennan & Ciara. 2020; Herrera et all. 2020; Fox et all. 2007; Special Rapporteur, 2017; Hubert & Hollins 2006; Glab 2021; Sanden 2023. pp. 101)

Article 19 of the UN CRPD obliges state parties to ensure that, among other, persons with disabilities have the opportunity to choose their place of residence and where and with whom they live, and that persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance (United Nations 2006).

The CRPD *Guidelines on deinstitutionalisation, including in Emergencies* specify the meaning of Article 19: “State parties should abolish all forms of institutionalisation, end new placements in institutions and refrain from investing in institutions. Institutionalisation must never be considered a form of protection of persons with disabilities or a choice.” (CRPD 2022, para 8). The UN CRPD, the General Comment 5 and the *Guidelines on deinstitutionalisation* oblige state parties to dismantle institutional settings without exception. Disabled people with support needs must receive support services in the community, especially personal assistance. The EU and all Member States have ratified the UN CRPD and are thus obliged to implement it.

While parts of Article 19 (which contain economic, social and cultural rights) are subject to progressive realisation, countries are under an immediate obligation to: design and adopt concrete strategies, plans of actions and resources to develop support services, as well as make existing services inclusive of disabled people. Furthermore, they are under an immediate obligation to replace any institutionalised settings with independent living services (CRPD 2017, paras 41 and 42).

In its resolution “Towards equal rights for persons with disabilities” the European Parliament “calls on the Commission and the Member States to phase out institutional care settings for persons with disabilities as soon as possible, as set out in General Comment No. 5 by the CRPD Committee and bring about a shift from institutional and other segregated settings to a system enabling social participation where services are provided in an accessible community, taking full account of the individual needs, will and preferences of persons with disabilities, including community-based care” (European Parliament 2022).

To end institutionalisation of all disabled people the European Union, all Member States should adopt strategies and plans of actions for deinstitutionalization. Currently, [13 out of 27 EU-countries adopted deinstitutionalisation strategies](#) (ENIL 2020). In all 13 EU countries, disabled people think that their deinstitutionalisation strategy is ineffective. Strategies adopted by governments are often too broad and lack concrete actions or objectives —the strategies adopted by [Lithuania](#) and [Poland](#) are a good example of this (Lithuania 2014; Poland 2021). Similarly, there are no EU countries which comply with the UN CRPD in terms of ending substitute decision-making, involuntary detention in psychiatric hospitals and forced treatment on the basis of disability.

3.1.2. Actions to be included in the Commission Guidance

The European Commission must call on the Member States to:

- Adopt clear and targeted strategies and plans of action on deinstitutionalisation. Such strategies and action plans should be legally binding, and in line with the UN

CRPD, the General Comment 5 and the *Guidelines on deinstitutionalisation, including in Emergencies*. They should include, among other, specific time frames and adequate budgets, and should be written together with disabled people and their organisations. Deinstitutionalisation strategies and action plans should make it clear which of the countries' housing or living arrangements constitute an institution. Furthermore, deinstitutionalisation strategies must produce changes to legal systems, removing restrictions of legal capacity and expanding supported decision making.

- Ensure that deinstitutionalisation projects are not led by those managing institutions, whereby they are limited to “transformation”, rather than complete closure. Deinstitutionalisation should be led by disabled people, including those affected by institutionalisation, and their representative organisations.
- Abolish mental health and mental capacity legislation that authorizes depriving people of their liberty on the basis of their impairment. Instead, supported decision making should be introduced, supported with EU funding, together with a wide range of holistic, community-based resources.
- Collect information on the number of disabled people living in institutions – including in nursing homes, psychiatric hospitals, shelters of supported or semi-autonomous living, group homes, social care facilities and children’s institutions. This should be collected at both the Member State and the EU level.
- Cease all spending on institutions and redirect investments into a quantitative and qualitative expansion of personal assistance, and other community-based services.

3.2. Adequate provision of personal assistance

3.2.1. Problem outline

To be able to live independently, exercising self-determination on a level equal to others, disabled people must be provided with the support they need. Inadequate access to personal assistance (PA) and other forms of individualised support are one of the leading causes of institutionalisation (CRPD 2017, para 15). In parallel with ending placements in institutions, including involuntary detention in psychiatric hospitals and forced treatment (including in the community), Member States must expand access to personal assistance, making sure it is available to all disabled people who need it.

According to ENIL’s Independent Living Survey, 33 out of 43 countries in the Council of Europe area have personal assistance schemes in place (ENIL 2020). Within the EU, Luxembourg and Hungary do not have PA schemes, while Greece is about to run a pilot PA project for a limited number of disabled people.

According to ENIL’s members, the provision of personal assistance in the Council of Europe area and in the European Union currently does not meet the standard to enable disabled people to live independently. In 33 out of 35 countries included in the survey, access to PA schemes is rated inadequate or insufficient, meaning that many disabled

people who need personal assistance remain excluded or that the quality of provision does not enable self-determination and independent living (ENIL 2023).

The shortcomings identified in ENIL's Independent Living survey include:

- In many countries, the quality of PA provision varies considerably between administrative areas;
- 25 countries currently do not allow disabled people living in institutions to apply for personal assistance;
- Many countries prioritize disabled people with certain types of impairment and discriminate against others. Disabled people with all types of impairments, who need personal assistance, must have access to it.
- 26 countries in Europe restrict the usage of PA. Restrictions defeat the purpose of PA to give disabled people full self-determination;
- 13 countries do not provide funding in the way of direct payments or personal budgets. Direct payments/personal budgets are key in giving the disabled person full autonomy and make it clear for the PA who their employer is;
- 15 countries do not provide PA based on the real needs;
- In 22 countries, disabled people using PA can select and hire their assistants, while in 11 they cannot;
- Many countries place eligibility and needs assessments exclusively in the hands of medical professionals who are likely to favour a medicalized view on disability rather than an approach based on the human rights model;
- 29 out of 33 countries do not provide training on Independent Living or the social model to those assessing needs of disabled people for PA;
- In 28 out of 33 countries, assessment procedures are not straightforward and transparent. Disabled people need to be able to trust the assessments. At the moment, trust is very low;
- In the Czech Republic, personal assistance is currently only available for 4-5 hours per day. The limit in Slovenia is 30 hours, while in the Greek pilot project there is no limit, but the available payment cannot cover more than approximately 50 hours per week. Disabled people with support needs which exceed this limit might have no choice but to rely on family members or to move to an institution;
- 21 out of 33 countries do not allow PA users to keep their assistance when moving to another region or local authority within the country. Between EU countries, there is no portability of personal assistance at all. Assessments have to be repeated from start. Non-disabled people who have, for example, reached pension age can take their pension entitlements with them when moving within and between countries. This inequality and discrimination puts disabled people at a significant disadvantage and is a significant barrier to their freedom of movement within the EU;
- In 22 out of 33 countries, there is no quality control mechanism. It should be self-explanatory that the quality of service needs to be monitored. The planning and implementation of the provision should be co-produced with organisations of disabled people;
- In 18 countries, peer support is not available, while in 16 it is. Access to peer support is crucial for the complete duration of the working relationship between assistant and the disabled person (Stainton & Boyce 2004).

Some countries are unable to respond to the increasing demand for personal assistance among disabled people. For example, the number of disabled people using PA in Slovenia increased by 44% between 2020 and 2021. In Belgium, there is a waiting list of up to 23 years to receive the personal budget needed to hire personal assistants. More financial resources should be invested into personal assistance schemes and monitoring is needed of how these resources are allocated.

3.2.2. Actions to be included in the Commission Guidance

The European Commission must call on the Member States to:

- Ensure that funding for personal assistance (PA) allows disabled people to cover all their needs in practice. If they have to pay a share of the costs of their personal assistance out of pocket, this will inevitably lead to financial constraints, inequality and poverty, and thus reduces self-determination. Furthermore, resources to pay for PA must be dispersed directly to the disabled person in the form of direct payments, such as personal budgets. State parties need to ensure low administrative threshold and should finance Centers for Independent Living (CILs) or PA user cooperatives which support PA recipients in working with their personal budget. Redirecting disabled people towards residential care, explained by the lack of funding for PA, must be categorically forbidden.
- Provide equal access to PA to disabled persons with all types of impairments, including physical, cognitive, sensory, psycho-social and neurodivergent, In addition, personal assistance must be available to persons under 18 and over 65. Supported decision making must be provided to those people that need it for managing their PA.
- Support disabled people in institutions, psychiatric hospitals and other residential care settings in applying for personal assistance, to allow them to leave the institution and to exercise their right to live independently in the community.
- Ensure that disabled people applying for personal assistance have access to adequate information and/or peer support. Furthermore, disabled people using PA need to have the option to receive training by their peers and their representative organisations, on how to manage their assistance. While disabled people using PA need to have the right to train their assistants by themselves, some might want support with this task.
- Ensure that disabled people can choose who provides the PA services, including that they are able to select and hire their assistants. The ability to choose one's personal assistant is rated as the number one feature of good personal assistance, since it enables choice and control (Comp. Mladenov 2019; Ratzka 2004).
- Ensure that eligibility and needs assessments are led by disabled people and aided by peers and professionals. They should be straightforward and transparent. Committees in charge of assessment should be properly trained, including in independent living and the social model of disability. Without training, a medical perspective is likely to dominate assessments. Moreover, disabled people applying for personal assistance need to have access to fair and transparent appeal procedures and access to legal representation.

- To enable a life of self-determination, ensure that personal assistance is recognised as a right and provided according to uniformly high standards. Such standards should ensure, among other that:
 - There are no restrictions on what PA can be used for. For example, assistants must be permitted to perform tasks related to health care equipment, after appropriate training.
 - There are no costs ceilings per disabled person using PA. Cost ceilings lead to disabled people not having enough PA hours and to reliance on family members for support, or to disabled people having restricted lives.
 - The number of assistant hours per disabled person depends solely on individual needs. Disabled people should not be forced to live together with other disabled people, in order to share personal assistance, and due to inadequate hours.
 - Disabled people are able to determine the times when assistance will be provided without any restrictions. This is key in creating choice and control for the disabled person, including the freedom to, for example, accept a job where one has to leave the house at 5:00 in the morning or to go to meet people at the pub at 21:00 in the evening. In other words, any spontaneous activity, such as a walk in the forest, must be possible.
- Make being a personal assistant a more attractive career choice. Personal assistants need to receive wages competitive with other professions, social security entitlements and career development options. Moreover, there should be no specific qualification requirements and level of education to work as PA, but assistants should have access to training, which should be performed by disabled people themselves.
- Fund awareness raising campaigns to promote the job of a personal assistant. Such campaigns should aim to address myths around supporting disabled people, focusing on independent living, the contribution disabled people make to their communities and the society, and the role of a PA in this. Any campaigns should move away from a medical or a charity approach and embrace a rights based approach.
- Take concrete steps to ensure portability of personal assistance within the EU, as a precondition for disabled people to exercise their right to the freedom of movement. Ensure that disabled people are able to keep their assistance when moving within or between EU countries, and that their disability status is recognised for the purpose of accessing services and benefits for disabled people.
- Put in place a quality monitoring system which allows the quality of PA provision to be monitored by disabled people and their representative organisations, including Centres for Independent Living, and by an independent body/agency.

3.3. Availability of accessible and adapted housing

3.3.1. Problem outline

In the European Strategy for the Rights of Persons with Disabilities insufficient provision of housing is named as one of the main barriers preventing inclusion. The

academic literature (Sperrin 2022), as well information from ENIL's members, showed that disabled people are affected by a lack of accessible and affordable housing. Many European cities, but also rural areas, consist of large stocks of old houses with steep steps and narrow doors and hallways. Disabled people report that in new buildings, accessibility standards are also often ignored. As a result, the stock of accessible housing is small and thus more expensive. In addition, disabled people report prejudices of landlords who refuse to rent a property to a disabled person, or make life difficult for them as tenants.

Disabled people are at a high risk of homelessness. A large part of the homeless population consists of people with psycho-social disabilities and those who are neurodivergent. For many disabled people, bureaucratic barriers in accessing social housing can be insurmountable or there is simply no social housing available. Furthermore, prices to rent and buy housing are increasing rapidly, outpacing wage or welfare benefits increases. In large cities such as Brussels, housing that is wheelchair accessible can be unaffordable despite a decent income from work. As a result, disabled people continue to reside with their families long into their adulthood, because of lack of housing options. In most countries, disabled people depend on their family support to rent an apartment. Many disabled people state that they do not receive any public support in accessing housing.

The lack of social housing, rental support and other housing services, is also a key barrier to disabled people being able to leave institutions, as they have nowhere to move to.

3.3.2. Actions to be included in the Commission Guidance

The European Commission must call on the Member States to:

- Adopt a comprehensive housing strategy, setting out actionable steps on improving access to housing of all disabled people, with clear responsibilities, a timeline and resources allocated. Disabled people and their organisations should be involved in the drafting of such strategy, which should be preceded by the mapping of housing needs, including among those who currently live in institutions or are homeless.
- Develop a range of housing options, which should be physically accessible, financially affordable and should take into account particular issues for people with different impairments (for example, people with psycho-social disabilities). Support in access to housing includes, for example, assistance with adapting one's home, access to suitably adapted social housing, housing-cooperatives or self-managed co-housing (people who choose to live together and who manage their accommodation), free matching services and assistance in challenging housing discrimination (by landlords and local community members who do not want disabled people in their neighbourhood).
- Increase the stock of social housing that is accessible, and ensure that any new housing complies with the standards on accessibility in built environment. Financial

incentives for home owners, such as easily accessible grants to adapt housing for people with different impairments should be considered.

- Provide housing subsidies to disabled people, so they can rent a flat or a house in the open housing market, in their preferred location (where they have family, friends, support networks, work etc.).
- Increase the rates of home ownership among disabled people by promoting programmes providing preferential loan conditions, providing support in saving for home ownership, providing personalised and effective support to pass the bureaucratic threshold, where needed.
- Ensure there is no discrimination between disabled people with different impairments when it comes to accessing disability benefits, rental subsidies or social housing. To prevent homelessness among disabled people, there must be outreach programmes with a low bureaucratic threshold and personalised support in running and maintaining a household.

3.4. Access to community-based services and assistive devices

3.4.1. Problem outline

The CRPD *Guidelines on Deinstitutionalisation, including in Emergencies* require that state parties develop a range of quality, individualised support and inclusive mainstream services in the community. Having the support needed to carry out daily activities based on one's own choices is a core element of living independently. Support should be individualised, personalised and offered through a variety of options. Disabled people should be enabled to exercise their legal capacity in choosing, managing and terminating the provision of community-based support. Support in exercising legal capacity can be provided as a service.

Support services for living independently should be available, accessible, acceptable, affordable and adaptable. Such services include personal assistance, peer support, supportive caregivers for children in family settings, financial support, crisis support, support for communication, support for mobility, provision of assistive technology, support in securing housing and household help. Support should also be available for persons with disabilities to gain access to and use mainstream services, such as education, employment, the justice system and healthcare.

Disabled people might need additional support when moving from institutions to the community, especially if they spent years living in institutions. Having lived in an institution for a long period of time – with rigid routine and without having an opportunity to make decisions for themselves – many people do not have confidence that they can live independently, or may have to live with psychological and physical trauma of living in an institution. As part of the transition from an institution to the community, they should be provided with access to independent living information, advice and peer support, as well as other services to address their support needs.

Support should also be provided to disabled people in the criminal justice system. This includes the ability to access support through intermediaries, who are independent of the state, or related support, as well as an end to the practice of denying disabled people access to a trial on the basis of “incapacity” and an abolition of forensic units in psychiatric hospitals.

For many disabled people, the ability to live independently can depend on access to assistive devices, assistive animals or other aids, like wheelchairs, guide dogs or devices producing speech. In many countries, such assistive devices, like electric wheelchairs are expensive and providers are few. Guide or other working dogs can support blind people, but also autistic people, for example. Digital (including smart technology) can also support disabled people to live independently, in addition to personal assistants and other “human” support.

For disabled people unable to work, due to their impairments or persisting societal barriers, income replacement schemes (disability benefits) will be key. The amount of these payments should be high enough to guarantee an adequate standard of living.

3.4.2. Actions to be included in the Commission Guidance

The European Commission must call on the Member States to:

- Ensure that all persons with disabilities have access to a variety of accessible, affordable, and high-quality mainstream services in areas such as personal mobility, accessibility, communication, healthcare, family life, an adequate standard of living, inclusive education, employment, participation in political and public life, housing, social protection, and participation in cultural and community life, leisure, recreation and sport.
- Use any available funding, including funding from the European Union, to create a wide range of community-based services that support the right to live independently and being included in the community. This includes:
 - Self-advocacy, peer support, circles of support, in particular for those leaving institutions;
 - Personal assistance and home care services (including support with cleaning, gardening, or other household tasks);
 - Support for children with disabilities and their families, including personal assistance, services that support reintegration of children into their families of origin, support for foster carers;
 - Services that support access of disabled children and young people to mainstream education, such as assistants, training for teachers and educators, measures to make schools and other education settings accessible to all children, legal aid to challenge discrimination in access to mainstream education;
 - Employment support, such as work assistance and job coaching, mentoring and promotion of gender equality as well as work-life balance;
 - Provision of legal aid to people in institutions and in the community, to prevent institutionalisation;

- Services to prevent isolation, such as community clubs (incl. sports clubs, book-reading, gardening, chess, walking etc.), self-advocacy/peer support groups, and various other online and in person services run by Centres for Independent Living or other disabled people's organisations;
 - Psychological support for people with psycho-social disabilities, including community based centres with a wide range of options;
 - Information in accessible formats, including in easy read and plain language, captioning, audio description, sign language interpretation;
 - Centres for Independent Living, user-cooperatives and self-advocacy groups, to provide peer support and information about services and financial support that are available, among other;
 - Other community-based services, in line with the *Guidelines on deinstitutionalisation* and Deinstitutionalisation assessment criteria (Bridge EU 2023).
- Provide financial support to disabled people to cover all the additional costs of having an impairment, and ensure that unemployment, sickness and other benefits guarantee everyone an adequate standards of living, making sure that no disabled person is forced to live in poverty. Carry out awareness raising campaigns and fight against stereotypes whereby disabled people in receipt of benefits are seen as "scroungers".
 - Ensure access of disabled people to inclusive education at all levels, including preschool, primary, secondary and tertiary education, vocational training and lifelong learning, extracurricular and social activities, without discrimination and on an equal basis with others, in line with Article 24 of the UN CRPD and the General Comment 4.
 - Ensure non-discriminatory access to mainstream public and private general technical and vocational guidance, training and placement services. Provide disabled people with access to training, retraining, education and capacity building. Provide employers with training on the employment of persons with disabilities.
 - To support transition from institutions to the community, provide persons leaving institutions with support to prepare physically and emotionally. Put in place a robust social protection package, covering immediate, mid-term and long-term economic and social support to avoid homelessness and poverty. Provide disabled people leaving institutions with information about housing options, transport, work and employment. Ensure that persons leaving institutions enjoy the right to enter into legally binding rental or ownership agreements.
 - Provide peer support for institutionalised persons and survivors as part of planning the transition. Furthermore, family members of persons who have been institutionalised should be provided with information, guidance, economic and administrative support and dedicated services.
 - Provide access to remedies, redress and reparations to survivors of institutional care, in line with the *Guidelines on deinstitutionalisation, including in Emergencies*.

- Ensure all disabled people can access assistive devices and digital technology necessary for living independently. For these to be more widely available, improve regulatory conditions for providers of assistive devices and digital technology, reducing unnecessary red tape, while at same time enforcing safety standards, as well as incentivise the production and provision of assistive devices and digital technology by providing financial support to providers.

3.5. Equal opportunities for employment

3.5.1 Problem outline

Access to decent employment is closely linked to the ability of disabled people to live independently. According to Article 27 of the UN CRPD, “States Parties recognize the right of persons with disabilities to work, on an equal basis with others [...] States Parties shall safeguard and promote the right to work”. The General Comment 5 adds that “Personal autonomy and self-determination are fundamental to independent living, including access to [...] decent employment” (CRPD 2017, para 16a).

According to the *Guidelines on Deinstitutionalisation, including in Emergencies*, poverty among persons with disabilities and their families is a leading driver of institutionalisation (CRPD 2022, para 89). According to the former UN Special Rapporteur on the Rights of Persons with Disabilities, in some OECD countries poverty rates among the disabled exceed 30% and are thus drastically higher than for the general population (Special Rapporteur 2015, p. 12). In the EU, 28,5% of disabled people are at risk of poverty, compared to 22,4% of the non-disabled population (Langensiepen 2021). Some disabled people living in institutions state that they could live independently if they had access to income from work.

There is a large disability employment gap in all EU countries. This means that disabled people are much less likely to be employed, compared to non-disabled people. In the EU as a whole, 50,6% of disabled people are employed, compared to 74,8% of non-disabled people. For people with certain impairments, the situation can be even worse. Among 30 million blind and partially sighted people, the unemployment rate is 75%. Among autistic people, only 10% are in employment (Langensiepen 2021). According to ENIL’s Independent Living Survey from 2020, 96% disabled people and their organisations think that labour market access is either inadequate or requires improvement (ENIL 2020). According to the General Comment 8, on the right of persons with disabilities to work and employment, disabled people “face high unemployment rates, lower wages, lower standards in hiring conditions, lack of accessibility of the work environment, and are also less likely than other persons to be appointed to managerial positions when they are formerly employed, all of which are exacerbated for women with disabilities. Persons with disabilities are more likely to earn lower wages than persons without disabilities and are more likely to be in vulnerable employment, including being employed in the informal sector, being self-employer or engaging in part-time work” (CRPD 2022b).

3.5.2. Actions to be included in the Commission Guidance

The European Commission must call on the Member States to:

- In line with the General Comment 8, prohibit discrimination on the grounds of disability in connection to work and employment. This should extend to four main forms of discrimination: direct discrimination, indirect discrimination, denial of reasonable accommodation, harassment and discrimination by association. Establish accessible and effective redress mechanisms and ensure access to justice, on an equal basis with others, for victims of discrimination based on disability.
- Adopt legislation, policies and programmes to ensure that complaints of discrimination are considered to determine both liability and remedies. The stricter employment protection legislation (and thus the less flexicurity), the more likely it is that people with disabilities are employed, compared to people without disabilities” (Zwan, van der & Beer, de 2021). Ensure the provision of reasonable accommodation via measures and programs that provide technical and financial assistance to public and private employers.
- Ensure equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions and the redress of grievances. Remunerations should never be below the minimum wage and disabled people should not lose their disability allowances when they start work. End restrictions of legal capacity and replace them with supported decision-making, so that every disabled person has the right to be hired or start a business.
- Develop and implement affirmative action measures both in the public and private sector. Such measures can include: quotas defined as a requirement to employ at least a specific percentage of employees with disabilities or targets; allocation of targeted funding to finance modifications of the working environment, apprentice wage support, payroll tax deductions and wage subsidies. Public procurement measures such as tendering processes giving advantage to enterprises owned by disabled people can also be supported.
- Promote reporting by State and non-State employers on the levels and conditions of employment of disabled people (CRPD 2022, b, p. 9, 19).

3.6. Appropriate and accessible health provision

3.6.1. Problem outline

According to Article 25a of the UN CRPD, “State parties shall...provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons....”. According to Article 25b “State parties shall...provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimise and prevent further disabilities”.

Disabled people face barriers in accessing mainstream healthcare services, as well as specialist health care services. According to the European Strategy on the Rights of Persons with Disabilities, disabled people report unmet needs for medical examination four times more often than persons without disabilities. Healthcare is often too expensive, too far to travel, not accessible and subject to long waiting lists. The

situation in rural areas is often particularly challenging. Persons with invisible disabilities such as chronic pain or intellectual disabilities, rare diseases or cancer do not always receive the tailored support needed.

In its recent report “Towards equal rights for persons with disabilities”, the European Parliament listed several barriers in access to healthcare: the lack of investment in facilities required to provide specific treatment by specialists; screening equipment can be inaccessible for certain impairments resulting in examinations which cannot be conducted adequately; public health campaigns and communication on disease prevention, screening and treatment are typically not disseminated in accessible formats.

The COVID-19 pandemic revealed weak spots in the healthcare systems, with disabled people having limited access to emergency medicine and intensive care. The COVID-19 pandemic also had a strong impact on the mental health of disabled people. According to Eurofund research, 71% of respondents to a survey were at risk of depression, while 25% indicated that they could not access mental health services, which is twice as high as for those without disabilities.

People on the autistic spectrum or with psycho-social disabilities report severe difficulties in accessing mental health support. In many countries, the costs of psychotherapy have to be paid exclusively by the individual and are not covered by the state. Applied behavioural analysis (ABA) is still practiced, despite numerous studies and individual accounts demonstrating its ineffectiveness in improving the well-being of autistic people and even having harmful impacts (Pukki et al 2022, p. 97; Anderson 2022; Mc Gill 2020; Wilkenfield et al 2020).

3.6.2. Actions to be included in the Commission Guidance

The European Commission must call on the Member States to:

- Improve timely access to effective healthcare for disabled people. This requires increased investment into primary and other healthcare services, to ensure an adequate coverage of well qualified professionals, including specialised services.
- Implement comprehensive plans to make healthcare facilities and screening equipment accessible for people with all types of impairments.
- Ensure that all healthcare is based on the free and voluntary participation of the individual seeking help, and prohibit any involuntary health interventions. At no point of the treatment process must any kind of pressure be exerted onto the individual. Termination of treatment must be possible at any point. Medical practice and research must be based on co-supervision and co-decision making by disabled people and their representative organisations.
- Improve access to mental health care, so that anyone wishing to use such services can benefit. All aspects of mental health care should be based on informed consent, co-decision making and peer support. Community-based mental health support must be as easily accessible as other types of healthcare. Disabled people should also be free to seek holistic and non-clinical alternatives.

- Improve access to habilitation and rehabilitation services in the community, tailored to the needs of individuals and with the objective to improve their health and well-being and to facilitate inclusion in the community. Habilitation and rehabilitation must always be based on disabled person's free and informed consent.
- Reform and modernise study and further education programmes for all health professionals, including mental health professionals. Ableism, the drive for pathologisation, sanism and notions of medical superiority need to be eliminated. Health professionals, including mental health professionals, must respect the lived experience of disabled people as important sources of knowledge. People with lived experience taking over co-teaching roles at universities must become the norm.
- Phase-out applied behavioural analysis (ABA) in favour of more sustainable support instruments which are focused the well-being of autistic individuals.
- Introduce oversight mechanisms to supervise health professionals, including mental health professionals. Disabled people should have easy access to effective complaints procedures which generate action.

IV. Horizontal issues

There are a number of preconditions for independent living, which must be addressed horizontally, throughout the European Commission's guidance on Independent Living, with concrete recommendations to the Member States.

4.1. Paradigm shift

A decade after the entry into force of the UN CRPD in the European Union, societal views on disabled people have not changed. We as disabled people are still seen as sick people or passive receivers of care. Most impairments are still extremely stigmatised, for example intellectual, neurodivergent and psycho-social disabilities. The prevalence of the medical model among professionals, the media and the general public influences models of support that are being developed.

There is a concern that no country intends to fully implement the UN CRPD. Barriers to full UN CRPD implementation are linked to prevalent misconceptions among policy and decision makers and service providers, who often think that disabled people are receiving the best possible "care". The views that providing effective disability support is unnecessary or would be too costly is equally present. On paper, existing disability policies often seem effective. In reality, support is far from optimal. Despite notable exceptions, disabled people are rarely visible in the community in leadership positions.

The European Commission must call on the Member States to:

- Take action to change the way society views disabled people. This includes raising awareness among all parts of society, including among disabled people, about the social and/or the human rights models of disability. The social and/or the human rights models of disability must be established as the framework in which anything relevant to disabled people is discussed, including in the media.
- Adopt the definition of disability from the UN CRPD, to make sure no one is excluded from access to Convention rights: "Persons with disability include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".
- Encourage disabled people to be active and visible in the community by taking down barriers and creating opportunities for participation and providing adequate support. A greater visibility of disabled people in the community in itself promotes social inclusion and a paradigm shift.

4.2. Disability assessments systems

Without passing the disability assessment to have their impairment recognised, disabled people cannot access the support services available. In many countries, disabled people report recognition procedures as being untransparent and unfair. People with psychosocial and intellectual disabilities, those who use alternative communication and those who are neurodivergent might struggle to master the very bureaucratic processes. In some countries, disability assessors discriminate against

these groups of disabled people, finding that they are not “disabled enough”, due to a restrictive definition of disability. The high suicide rates as well as high levels of homelessness can be partially explained by the lack of support provided to people with psycho-social disabilities and those who are neurodivergent.

The European Commission must call on the Member States to:

- Implement reforms of disability assessment procedures. Instead of trying to keep the rates of disability low, assessors should focus on ensuring support where support is needed. Disability assessments should be conducted by disabled people themselves (peer assessments), trained in the social and/or human rights model of disability and in identifying support needs, based on the UN CRPD.
- Introduce effective accountability mechanisms, ensuring that assessments are independently monitored, for example by independent human rights bodies or organisations of disabled people. Disabled people undergoing assessment need to have access to timely and effective complaint procedures. Conflicts of interest, whereby the same person deals with the original assessment and the complaint, must be avoided.

4.3. Intersectional and intersectoral approaches

The right to independent living applies to all disabled people, regardless of their race, ethnic origin, migrant or refugee status, socio-economic status, religion, political belief, age, gender, sexual orientation, language and other characteristics. In practice, however, disabled people may be denied access to services because of their age (being too young or too old) or because of their residence status, for example. Girls and women with disabilities may be subject to multiple discrimination, face heightened risks of violence and abuse, or denied access to the necessary support. In many countries, children do not have access to personal assistance, while in others it is denied to those above 65.

Countries across Europe have a twin track (or ‘silo’) approach when it comes to disabled people and older people, with the latter most commonly addressed through “long-term care”. The UN CRPD is often completely missing from policies on long-term care, resulting in many disabled people falling through the gaps. One consequence is that many young disabled people end up being placed in nursing homes for older people, in countries where institutions for disabled people have been closed or have limited capacity. Others may lose disability supports, including those aimed at facilitating independent living, after the age of 65 and forced to go into residential care.

Similarly, the entrenched mind set which has been apparent in European countries around detaining and forcibly treating people under mental health and mental capacity law is having a still more negative effect on people who, for example, also belong to minority ethnic communities, including asylum seekers and refugees, experience particular socio-economic disadvantages, are deaf, or identify as lesbian, gay, bisexual or transgender.

Integrated social and health care services are also lacking, not to mention other sectors, such as education, transport or employment. This leads to people unable to

access the support they need and in many cases being directed to special services – residential institutions, psychiatric hospitals, special schools. The patchy, or missing services also act as a disincentive for disabled people and their families to choose a life in the community, with many finding it less “risky” to live in residential settings, where everything is provided in one place.

The European Commission must call on the Member States to:

- Apply an intersectional approach in any laws, policies, strategies or action plans relevant to disabled people. Pay particular attention to those groups that are at a higher risk of multiple discrimination or of being left behind.
- Improve coordination between different sectors, including social care, health care, education, housing, employment, transport and other, to ensure that there are no gaps or barriers to independent living. One of the ways of achieving this is by having CRPD focal points in all the relevant departments and making sure that deinstitutionalisation reforms have cross-sectoral support. Equally important is coordination between different levels – national, regional and local – again, to ensure that there is broad support for any processes aimed at facilitating access to independent living.
- Involve disabled people and their representative organisations in any processes that concerns them, including in leadership positions (for example, as leads/coordinators on Independent Living or deinstitutionalisation). Principles of co-production should be applied, whereby disabled people are involved in all decisions from the beginning of the process and are an equal partner among other stakeholders.
- Use co-production in the development and delivery of services to be used by disabled people, including mainstream services such as housing, transport, education and health care. Co-production is a “relationship where professionals and citizens share power to plan and deliver support together, recognising that both have vital contributions to make in order to improve quality of life for people and communities” (SCIE).
- Put in place quality assessment systems that monitor the effectiveness of services from the perspective of Independent Living, based on the UN CRPD, the General Comment 5 and the *Guidelines on deinstitutionalisation, including in Emergencies*. Involve disabled people and their representative organisations in monitoring and quality assessment, and in making sure that such systems are fit for purpose.

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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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