



**ENIL's contribution to the consultation on the draft
Council of Europe Disability Strategy 2017 – 2023**

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Introduction

The European Network on Independent Living (ENIL) is a Europe-wide network of disabled people¹, with members throughout Europe. ENIL's mission is to advocate and lobby for Independent Living values, principles and practices, namely for barrier-free environment, provision of personal assistance support and adequate technical aids, together making full citizenship of disabled people possible. ENIL's activities target European, national and local administrations, politicians, media, and the general society. ENIL works to strengthen the empowerment of disabled people, mainly through providing resources for peer counselling and peer training. ENIL enhances the European disability movement by providing the arena for the sharing of experience of services and in providing economical, logistics and technical expertise on Independent Living. ENIL also has a strong grassroots network and is actively engaged with the local Centers of Independent Living.

ENIL is a member of the European Disability Forum and the European Expert Group on the Transition from Institutional to Community-based Care (EEG), and has participatory status in the CoE conference of INGOs. In addition to preparing these comments, ENIL has also contributed to a joint EEG submission.

Importance of the Council of Europe Disability Strategy

The European Network on Independent Living (ENIL) welcomes the opportunity to contribute to the draft Council of Europe (CoE) Disability Strategy 2017 – 2023. We have used the 2006 – 2015 Action Plan extensively when promoting the rights of disabled people in the CoE Member States and believe it is important that the CoE continues providing guidance to its 47 Member States with the new strategy. This is of particular importance considering that, 10 years after the adoption of the UN Convention on the Rights of Persons with Disabilities (CRPD), there are still major barriers to disabled people's inclusion and participation in society across Europe.

Barriers to disabled people's inclusion and participation

ENIL is concerned about the fact that, across Europe, disabled people are still excluded from their communities because of the lack of support,

¹ ENIL prefers the term 'disabled people' over 'persons with disabilities' or 'people with disabilities', in order to reflect the fact that people are disabled by the environmental, systemic and attitudinal barriers in society, rather than by their impairment. This is in line with the social model of disability.

institutionalisation, lack of adequate housing, inaccessible environment, failure to access education and employment, stigma and other barriers. While there is recognition of the importance of promoting the **transition from institutional care to community-based services** across Europe, in many countries institutional care remains the predominant form of care. This is especially true for Central and Eastern Europe, the Baltic countries and the FSU (former Soviet Union) countries, with a strong legacy of institutional care and very few community-based services in place. For example, in Romania, the CoE Commissioner for Human Rights Nils Muižnieks noted in his country visit report of 2014 that “the number of residential social care institutions for adult persons with disabilities has more than doubled in the past eight years, from 141 at the end of 2005 to 335 at the end of December 2013”.²

Moreover, as has been highlighted by Thomas Hammarberg, the former CoE Commissioner for Human Rights in his Issue Paper on Article 19:

“Though governments increasingly recognise the inevitability of deinstitutionalisation, there is less clarity with regard to the mechanisms that replace institutionalisation and what would constitute a human rights-based response.”³

As a result, disabled people are often moved from large institutions into smaller settings, where the **institutional characteristics still prevail**. Such settings are often referred to as small group homes, family-type homes or living centres.

In recent years, **austerity measures** in Europe have also negatively affected disabled people’s access to vital support for independent living and the development of community-based alternatives to institutions.⁴ For example, disabled people have lost access to personal assistance, to social security benefits, to support which enables them to access

² ENIL-ECCL, 2014, *Shadow report on the implementation of Article 19 of the UN Convention on the Rights of Persons with Disabilities in the European Union*. Available at: <http://www.enil.eu/wp-content/uploads/2012/06/Shadow-Report-11-04-2014-final-WEB-1-1.pdf>

³ Council of Europe Commissioner for Human Rights, 2012, *The right of people with disabilities to live independently and be included in the community*, CommDH/IssuePaper(2012)3. Available at: <https://wcd.coe.int/ViewDoc.jsp?id=1917847>

⁴ European Foundation Centre, 2012, *Assessing the impact of European governments’ austerity plans on the rights of people with disabilities, European report*. Available at: http://www.enil.eu/wp-content/uploads/2012/12/Austerity-European-Report_FINAL.pdf

education and employment. Many disabled people have been forced into residential care as a result of losing support.

As has been documented by ENIL, **access to personal assistance and peer support** – the two services key to full inclusion and participation in the community – remains patchy across Europe.⁵ Although the majority of European countries have ratified the CRPD, thus committing to ensuring disabled people's access to the right to independent living, many disabled people are forced to rely on informal support by family members or friends, or are pushed into residential care.

Accessibility of mainstream facilities and services, such as housing, health care, transport and information, also remains a key barrier. By and large, disabled children continue to be excluded from mainstream education and sent to special schools and only a small percentage of disabled people are able to access employment in the open labour market.⁶

While there are many other barriers, it is worth noting that the way support **services for disabled people are funded** still in many cases favours institutional care provision. For example, in Portugal, institutions can receive up to 950 EUR of state funding per person (in addition to receiving 90% of that person's income), but should a disabled person choose to stay at home they can receive only 88 EUR per month.⁷ The European Union funding had also in the previous financing period helped build or renovate institutions (rather than community-based services) – a fact condemned by the UN Committee on the Rights of Persons with Disabilities (CRPD Committee) in respect of the EU and several EU Member States.⁸

⁵ See ENIL's Personal Assistance Tables, available at:

<http://www.enil.eu/policy/personal-assistance-tables/>

⁶ European Disability Forum, 2015, *Alternative Report on the Implementation of the UN Convention on the Rights of Persons with Disabilities*. Available at:

<https://www.dropbox.com/s/88lg96uknfyg8ps/2015%2003%2004%20EDF%20Alternative%20report%20final%20ACCESSIBLE.pdf?dl=0>

⁷ ENIL, 2014, *Comparing the Cost of Independent Living and Residential Care – A Survey by the European Network on Independent Living*. Available at:

http://www.enil.eu/wp-content/uploads/2012/06/Cost-survey_FINAL1.pdf; and

Independent Living Movement in Portugal, available at:

<http://www.enil.eu/news/independent-living-movement-in-portugal/>

⁸ ENIL-ECCL, 2014, *Shadow report on the implementation of Article 19 of the UN Convention on the Rights of Persons with Disabilities in the European Union*.

Available at: <http://www.enil.eu/wp-content/uploads/2012/06/Shadow-Report-11-04-2014-final-WEB-1-1.pdf>

Independent Living as a key priority area

ENIL welcomes the intention of the drafters to focus on a limited number of priority areas in the next Disability Strategy, in order to raise the chances of these areas being covered more effectively by the CoE. However, given the situation of disabled people in Europe, the fact that more than a million people remain institutionalised⁹ and many more excluded from society due to the lack of community-based alternatives, ENIL feels that not having Independent Living as one of the priority areas is a major oversight.

Although Independent Living (for definition, see Annex) is linked to other priority areas in the draft Strategy – equality and non-discrimination, awareness raising, accessibility, equal recognition before the law and freedom from exploitation, violence and abuse – it also requires specific and targeted actions which would facilitate the closure of long-stay residential institutions in the CoE Member States and encourage the development of community-based services, such as personal assistance, to support the right to independent living. This is key if the CoE wishes to reach the overall goal of the Strategy, which is “to ensure equal opportunities and independence [...] and to guarantee their freedom of choice, full citizenship and active participation in society.”

The right to live independently and being included in the community

Article 19 of the CRPD sets out the right of all disabled people to ‘live in the community, with choices equal to others’, requiring States to enable disabled people to be fully included and participate in society.

Although Article 19 does not create a new right,¹⁰ it is the first time that the right to live independently and be included in society has been made explicit in a human rights treaty. This right, which applies to all persons with disabilities, regardless of the type or degree of the impairment or the level of support necessary, provides a clear vision for the future - that people with disabilities can live in the community as equal citizens. In addition, the themes of inclusion and participation are integral to the CRPD as whole. Thus, the CRPD requires that action is taken to ensure

⁹ Mansell, Jim et al. 2007, *Deinstitutionalisation and community living – outcomes and costs: report of a European Study*. Volume 2: Main Report. Available at: http://www.kent.ac.uk/tizard/research/DECL_network/documents/DECLOC_Volume_2_Report_for_Web.pdf

¹⁰ See, for example, Article 26 of the Charter of Fundamental Rights of the EU and Article 15 of the Revised European Social Charter.

that all people with disabilities can live and receive the support they need to participate in society as equal citizens.

The right to live independently and being included in the community has been described as “the key portal to living a fuller life”. It is “much celebrated since it is the one that delivers on ‘choice’ where it matters most to people – where to live and with whom”.¹¹ The vision, encapsulated by Article 19, is in stark contrast to the situation of people with disabilities who, in parts of Europe, are placed in large, often remote institutions, and have very little contact with the outside world. Thus, segregation of individuals solely on the basis of their disability is in itself a violation of their rights under Article 19, as they are prevented from engaging with family or friends or being involved in community life.

In his Issue Paper on Article 19, the former CoE Commissioner for Human Rights, Thomas Hammarberg, noted that Article 19 is closely linked to other rights such as equality and non-discrimination, as well as to “how health, education, social support systems and the labour market are shaped”. It also “embodies a positive philosophy, which is about enabling people to live their lives to their fullest within society”. The Commissioner emphasises the crucial importance of this right in addressing the social exclusion of people with disabilities:

“The core of the right, which is not covered by the sum of the other rights, is about neutralising the devastating isolation and loss of control over one’s life, wrought on people with disabilities because of their need for support against the background of an inaccessible society. ‘Neutralising’ is understood as both removing the barriers to community access in housing and other domains, and providing access to individualised disability-related supports on which enjoyment of this right depends for many individuals.”¹²

¹¹ Quinn, G. & Doyle, S. (2012a). *Taking the UN Convention on the Rights of Persons with Disabilities Seriously: The Past and Future of the EU Structural Funds as a Tool to Achieve Community Living*. *The Equal Rights Review*, Vol. 9, page 69 - 94. See: http://www.equalrightstrust.org/ertdocumentbank/err9_quinn_doyle.pdf

¹² Council of Europe Commissioner for Human Rights, *The right of people with disabilities to live independently and be included in the community*, CommDH/IssuePaper(2012)3, 2012, page 11.

Actions to promote Independent Living

The CoE Strategy should set out the following actions for the CoE bodies, Member States and other relevant actors:

- ❖ **Encourage** the development and implementation of comprehensive deinstitutionalisation strategies in the CoE Member States and the closure of long-stay residential institutions for disabled people.
- ❖ **Promote** a moratorium on the building of new long-stay residential institutions and ensure that funding by the CoE Development Bank (CEB) is not used for the building or renovation of long-stay residential institutions for disabled people; instead these funds should be used to support the development of community-based services for disabled people.
- ❖ **Promote** personal assistance and peer support, as key tools to ensure that disabled people are able to live independently in the community.
- ❖ **Collect** disaggregated data on the number and characteristics of disabled people in residential institutions in Europe (in cooperation with the EU) and report on progress in the transition from institutional care to alternatives in the community in the CoE Member States.
- ❖ **Identify**, collect and promote good practices in supporting disabled people to live independently in the community, in cooperation with organisations of disabled people.
- ❖ **Raise awareness** among the CoE bodies, partners and in the Member States about the right of disabled people to live independently in the community (through trainings, information materials and other awareness-raising actions), in cooperation with organisations of disabled people.
- ❖ **Monitor** access of disabled people to independent living in the Member States through the work of the CoE monitoring mechanisms, such as the Commissioner for Human Rights, the Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT), the European Commission against Racism and Intolerance (CRI) and the European Committee of Social Rights.

Risk analysis for Independent Living as a priority area

Risk analysis		
<p>Living independently in the community</p> <p>Persons with disabilities have access to a range of services in the community, including personal assistance, which facilitate their full inclusion and participation in the community and prevent exclusion and segregation</p>		
Risks	Mitigating actions	Outcome
<ul style="list-style-type: none"> - New institutions continue to be built, including with the EU and CoE funding 	<ul style="list-style-type: none"> - Adopt guidelines on deinstitutionalisation (DI), in consultation with disabled people, and disseminate to all CoE bodies, Member States and partners 	<ul style="list-style-type: none"> - There is progress towards independent living in the Member States
<ul style="list-style-type: none"> - DI strategies exclude certain groups of disabled people, such as people with intellectual disabilities or people with mental health problems 	<ul style="list-style-type: none"> - Support Member States in developing comprehensive DI strategies, consulting closely with organisations of disabled people - Promote the Common European Guidelines on the Transition from Institutional to Community-based Care¹³ 	<ul style="list-style-type: none"> - CoE Member States have comprehensive DI strategies in place, resulting in progress towards independent living

¹³ European Expert Group on the Transition from Institutional to Community-based Care, 2012, *Common European Guidelines on the Transition from Institutional to Community-based Care*. Available at: <http://www.deinstitutionalisationguide.eu>

<ul style="list-style-type: none"> - The closure of institutions is not accompanied by the development of community-based services - Community-based services do not support the right to live independently in the community (i.e. resulting in reinstitutionalisation of disabled people) 	<ul style="list-style-type: none"> - Facilitate exchange of good practice among Member States in relation to developing services that promote the right to independent living - Raise awareness about the right to independent living among the CoE bodies, Member States and partners 	<ul style="list-style-type: none"> - Long-stay residential institutions are replaced with community-based services which facilitate the full inclusion and participation of disabled people in society - CoE bodies promote the right to independent living in their work
<ul style="list-style-type: none"> - Further austerity measures result in the increased exclusion, isolation and segregation of disabled people 	<ul style="list-style-type: none"> - Call on the Member States to stop cuts to services and benefits for disabled people, in order to protect the right to live independently and be included in the community 	<ul style="list-style-type: none"> - Disabled people (in particular independent living services and benefits) are not affected by austerity measures

Links to other priority areas

Equality and non-discrimination: The draft Strategy should acknowledge the effect of cuts to services and benefits for disabled people, including access to legal aid, on access to equality and prevention of discrimination. The suggested actions should, therefore, include collecting information about the effect of austerity measures on disabled people by the CoE monitoring bodies and raising awareness among the Member States, as well as encouraging them to stop the cuts to services and benefits which facilitate citizenship, equal participation and non-discrimination of disabled people.

Awareness raising: Raising awareness about the right of people with disabilities to live independently and be included in the community is a key component of the process of deinstitutionalisation. Therefore, the CoE awareness raising initiatives and information campaigns should

also seek to raise awareness about institutionalisation of disabled people and the right to independent living, as set out in Article 19 of the CPRD. This should be done in close consultation with disabled people, in particular children and adults who have themselves lived in institutions. Any awareness raising activities should be based on the social model of disability, which highlights that people are disabled by the attitudinal, environmental and systemic barriers, rather than by their impairment.

Awareness raising activities should also encompass training for all CoE decision-making, standard setting, advisory and monitoring bodies on the CRPD, which should be delivered by organisations of disabled people.

Accessibility: As stated in the draft Strategy, accessibility is a precondition for disabled people to exercise their rights, participate in society, be independent and make choices about their lives. However, although the Strategy promotes accessibility as a concept wider than accessibility to the built environment, the suggested actions are limited mainly to accessibility of information and communication. If the CoE Strategy is to support the right to independent living, the priority on accessibility must include access to ‘community services and facilities for the general population’, as set out in Article 19, Paragraph C of the CRPD. This includes promoting access to education, employment, housing, health services, transport and other, among the Member States.

Finally, the CoE sure ensure that all of its decision-making, standard setting, advisory and monitoring bodies are accessible to disabled people, by having information available in accessible formats and ensuring that the buildings, meetings and events are accessible to disabled people and involve disabled people in their work.

Equal recognition before the law: Legal capacity is relevant to the implementation of Article 19 of the CPRD, in particular the right of disabled people to exercise their right to choose where and with whom to live. Concerns about the system of guardianship, particularly plenary guardianship, whereby a person is held to lack capacity and require another person (“the guardian”) to make all decisions on behalf of that person, have been raised by the CRPD Committee and the CoE Commissioner for Human Rights in respect of a number of European

countries.¹⁴ Therefore, the Strategy should make a clear link between promoting supported decision making and preventing institutionalisation.

Freedom from exploitation, violence and abuse: ENIL welcomes the focus on preventing exploitation, violence and abuse in the draft Strategy. However, considering that disabled people in institutional care settings are most vulnerable to abuse, the suggested actions must include promoting deinstitutionalisation and the development of community-based alternatives in the community. Independent monitoring of institutions and services in the community is also key, and should be supported by the relevant CoE bodies (such as the CoE Commissioner for Human Rights and the Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment). Importantly, the CoE should be encouraging Member States to bring those responsible for human rights violations against disabled people to justice, rather than simply raising awareness. In this respect, the CoE should develop guidelines for the Member States and hold trainings for the relevant authorities and legal professionals, in close cooperation with organisations of disabled people.

Hate crime on the grounds of disability, and not only on internet, should be recognised as a significant problem, increasingly affecting disabled people in Europe and impeding their right to live independently in the community. The CoE should raise awareness about disability hate crime, promote the collection of data (in cooperation with the EU and OSCE) and provide training to the relevant authorities in the Member States, in close cooperation with organisations of disabled people.

General comments on the draft Strategy

Involvement of disabled people

A stronger focus on the involvement of disabled people is required throughout the strategy, in line with Article 4 of the CRPD (General obligations). Therefore, all the priority areas should be implemented in close consultation with and actively involve disabled people, including children with disabilities, through their representative organisations.

Moreover, the Ad Hoc Committee of Experts on the Rights of Persons with Disabilities at the CoE should involve a sufficient number of disabled persons in its work, in order to cover the diversity of

¹⁴ ENIL-ECCL, 2014, *Shadow report on the implementation of Article 19 of the UN Convention on the Rights of Persons with Disabilities in the European Union*.

experiences among disabled people. This will be of special importance when it comes to defining the actions and activities to be implemented by the CoE (i.e. the bi-annual work plan).

Terminology

The strategy should include definitions of the key terms, such as independent living, institution, deinstitutionalisation, community-based services, in order to ensure that they are understood correctly by the CoE bodies, Member States and other organisations and institutions targeted by the strategy. ENIL has highlighted the misuse of independent living terminology for actions and services that segregate disabled people (for example, 'independent living centres' referring to institutional care) and has therefore developed key definitions on independent living (see Annex 1). These (more precisely, the definition of Independent Living) have been endorsed by the European Disability Forum, and should be included in the policies and documents relevant to disabled people. ENIL's Myth Buster, translated into 10 languages, can also be used to raise awareness about the right to independent living.¹⁵

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¹⁵ ENIL's *Myth Buster on Independent Living*, 2014, is available at: <http://www.enil.eu/wp-content/uploads/2014/12/Myths-Buster-final-spread-A3-WEB.pdf>

Annex 1: ENIL's Key definitions on Independent Living

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

Personal assistance is 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.

Deinstitutionalisation is a political and a social process, which provides for the shift from institutional care and other isolating and segregating settings to Independent Living. Effective deinstitutionalisation occurs when a person placed in an institution is given the opportunity to become 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 institutionalization 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.

Other useful definitions:

An institution is any place in which people who have been labelled as having a disability are isolated, segregated and/or compelled to live together. An institution is also any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size.

Institutional care refers to the 'support' residents receive by staff working in the institution.

A residential care setting is terminology used by service providers to denote settings specifically designed for disabled people (such as group homes, service apartments¹⁶, protected/sheltered homes and living centres), where people are grouped together depending on their labelled type/severity of disability. Such settings can cater for children and adults, and can be smaller (for example, for 6 people) or bigger (for example, for 30 people). It is a model of service which links the supports a person requires with a particular type of housing, thereby restricting people's choices about where and with whom they will live. Residential care settings, despite being physically placed in a city neighbourhood or a suburb, are often based on a 'one size fits all' model and can be as isolating as an old-style institution. Residential care and institutional care are often used interchangeably by independent living activists.

¹⁶ A cluster of apartments in one building primarily offered to disabled people where 'support' is provided on a group basis.