

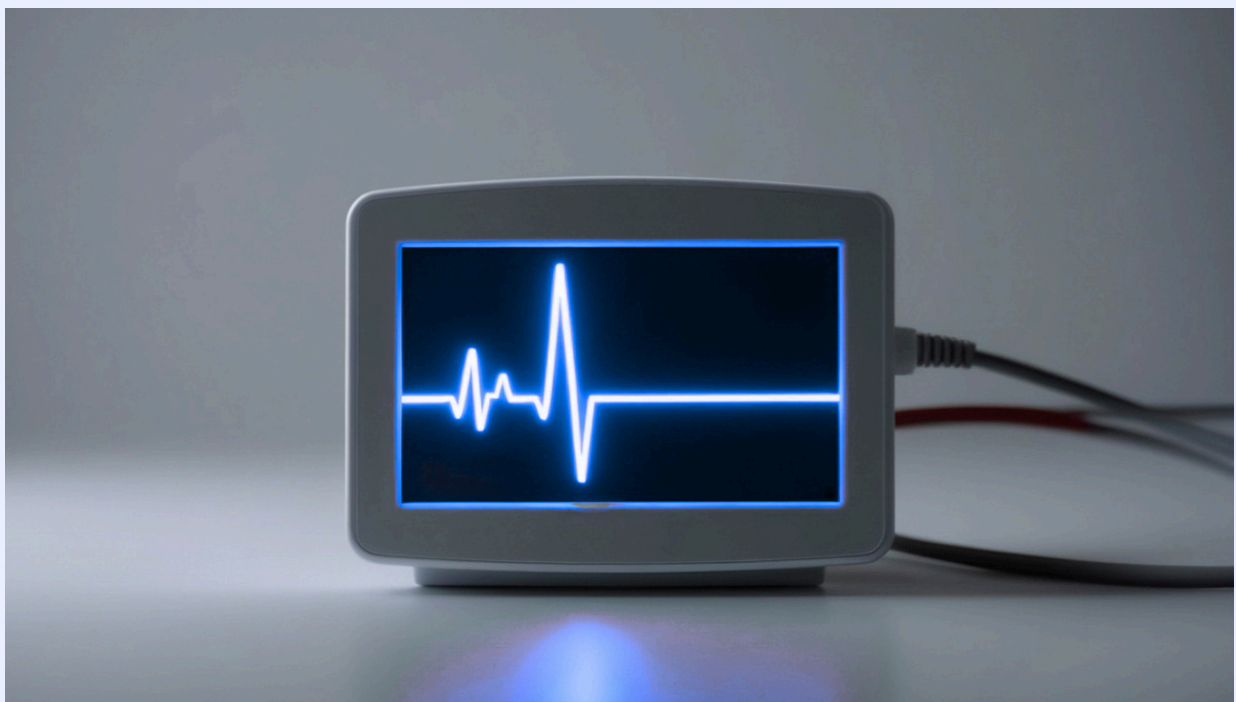


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Position Paper on Assisted Dying

European Network on
Independent Living



This document was written by Antonella Candiago, Policy Officer at the European Network on Independent Living. We are thankful to all ENIL members who provided input on the topic. Should you have additional suggestions, please write to antonella.candiago@enil.eu or secretariat@enil.eu.

Table of Contents

I. Introduction	4
II. Definition	5
III. Purpose and Methodology	6
IV. Context: Independent Living and Structural Barriers.....	7
V. ENIL Position: Reflections and Concerns	8
VI. Summary of Findings	15
VII. ENIL's Recommendations	16
VIII. Conclusion	18

I. Introduction

As debates on end-of-life choices evolve across Europe and globally, there is an increasing need for organisations representing disabled people to reflect thoughtfully and critically on the issue of **assisted dying**. The topic raises complex ethical, legal, medical, religious (for some), familial, and social questions that directly intersect with the rights, dignity, and lived experiences of disabled people. In response, the **European Network on Independent Living (ENIL)** recognised the importance of developing a well-informed position that reflects the diversity of its members and upholds the core principles of Independent Living: self-determination, self-representation, deinstitutionalisation, and choice and control. To do so, ENIL initiated a consultation process to open space for inclusive dialogues within the Independent Living movement in Europe.

This position paper is the result of a consultation involving ENIL members, including stakeholders, experts, organisations, and disabled individuals – each offering unique perspectives shaped by their personal experiences and national contexts. The purpose of the consultation was to gather insights, concerns, and recommendations on assisted dying legislation. ENIL aimed to understand the ethical, legal, medical, and social implications of assisted dying, including its impact on disabled people and its relation to the principles of Independent Living.

By engaging with this sensitive and often polarising topic, we seek to ensure that any future policies and frameworks reflect a balanced and human rights-based approach, one that recognises self-determination while addressing structural inequalities and safeguarding against potential harms for the disabled community.

Hence, ENIL recognises the complexity and diversity of opinions among disabled people on this issue. Some emphasise self-determination and the right to choose in situations of extreme suffering. Others stress the grave risks that assisted dying poses in a context marked by ableism¹, structural discrimination, and chronic underinvestment in support services and the realisation of the Independent Living

¹ Definition of ableism available at:

https://dictionary.cambridge.org/dictionary/english/ableism#google_vignette and <https://www.tailalewis.com/blog/working-definition-of-ableism-january-2022-update>.

pillars.² This paper reflects a broad consultation of ENIL members and presents a position that:

- Respects the deeply personal nature of end-of-life decisions;
- Acknowledges diverse opinions among disabled people;
- Expresses concerns from an Independent Living perspective; and
- Clarifies that under current conditions in Europe, assisted dying cannot be considered a viable or safe option.

ENIL's position is rooted in the protection of human rights and in preventing any form of direct or indirect pressure on disabled people to end their lives due to lack of support, discrimination, institutionalisation, poverty, or neglect.

II. Definition

Although there is no single internationally agreed-upon definition of **assisted dying**³, the **term generally refers to medical practices that help a person end their own life**, usually in the context of terminal illness or unbearable suffering.

It typically includes two main categories:

- **Assisted Suicide:** when a person intentionally ends their own life by self-administering a lethal substance that has been provided by a doctor or another individual, at the person's request.
- **Euthanasia:** when a doctor or another individual directly administers a lethal substance to a person, also at that person's request, to end their life.

While some present assisted dying as an extension of self-determination and independent choices, many disability rights advocates argue that self-determination cannot be understood in isolation from social conditions. A "choice" made in the

² To read more about the Independent Living Pillars: <https://enil.eu/independent-living/>.

³ To learn more about the meaning of assisted dying: <https://dictionary.cambridge.org/dictionary/english/assisted-dying> and <https://pmc.ncbi.nlm.nih.gov/articles/PMC6243437/>.

absence of adequate support services, accessible healthcare, personal assistance, housing, and protection from discrimination is not fully free.

III. Purpose and Methodology

To shape this position paper, ENIL conducted a consultation process through an **online survey** distributed to its members. The purpose of this survey was to gather a wide spectrum of perspectives on the issue of assisted dying, ensuring that the position ultimately taken would reflect the diversity of voices within the Independent Living movement.

The **consultation** invited participants to provide:

- a) an overview of their country's legal situation regarding assisted dying;
- b) reflections on the ethical, legal, medical, and personal dimensions of the issue; and
- c) optional contributions such as written statements, video, or audio testimonies to provide deeper insight into their individual experiences and viewpoints.

Respondents were also asked what position they believed ENIL should adopt on assisted dying. This was a key part of the consultation, as it allowed participants to not only share their experiences and beliefs, but also engage directly in shaping the network's approach.

Taking a position on assisted dying within such a large and diverse network means recognising and respecting a wide range of ethical, cultural, and political perspectives. Even within national organisations in a single country, views can differ significantly. In carrying out this process, ENIL made a conscious effort to go beyond established Disabled People's Organisations (DPOs), actively reaching out to individual disabled members as well. This was done to ensure that personal perspectives – often overlooked in institutional discourse – were fully represented and included. This approach reflects ENIL's commitment to amplifying lived experience and valuing individual voices alongside organisational ones.

It is important to note that this is both a relatively recent topic of debate and a complex one, far from being a black-and-white issue. Therefore, forming a position requires not only acknowledging majority opinions, but also taking into account the underlying objectives, motivations, and concerns that inform all views, including those held by minorities. Every opinion shared contributes to a more nuanced understanding of the topic and strengthens the legitimacy and inclusivity of the final stance.

Through this consultation, ENIL aims to ensure that its position on assisted dying is grounded in the **lived realities of disabled people**, shaped by honest dialogue, and attentive to the multiple, sometimes conflicting, values held across the Independent Living community.

IV. Context: Independent Living and Structural Barriers

Across Europe, disabled people continue to face widespread institutionalisation, absent or insufficient personal assistance schemes, lack of accessible and affordable housing, reduced or denied healthcare access, including to sexual and reproductive health services, poverty and benefit conditionality, and social isolation and discrimination.

Under such conditions, assisted dying risks becoming a response to systemic failure rather than individual medical necessity.

ENIL's Independent Living Survey (2024)⁴ provides important context for this discussion. The survey highlighted **persistent gaps in the implementation of Independent Living across Europe**, including insufficient personal assistance, continued reliance on institutional settings, and barriers to accessible healthcare and housing. These gaps directly impact the ability of disabled people to exercise genuine self-determination and choice and control over their lives. According to the survey's results, the right to Independent Living is far from fully realised across

⁴ ENIL, *Independent Living Survey: Disabled People's Perception of Independent Living in Europe*, 2024: https://enil.eu/wp-content/uploads/2025/05/Independent-Living-Survey-2024_WEB.pdf.

Europe: on a scale from 1 to 5, no country reached a score indicating that Independent Living is fully guaranteed. Even the highest-ranking countries scored relatively low:

- Iceland (3.2)
- Sweden (2.9)
- Malta (2.8)

The fact that even the top-performing countries remain below 3.5 shows that significant gaps persist, including in countries with comparatively strong welfare systems. At the other end of the scale, France (1.3), Spain (1.5), and Montenegro (1.7) scored particularly low, reflecting serious barriers related to institutionalisation, insufficient personal assistance, and weak implementation of disability rights.⁵

Overall, the findings confirm that no country in Europe can claim that Independent Living is fully guaranteed. Across regions, including Nordic countries often seen as frontrunners, disabled people continue to face systemic barriers to personal assistance, accessibility, deinstitutionalisation, and adequate community-based support.

V. ENIL Position: Reflections and Concerns

Overview of the Survey Results

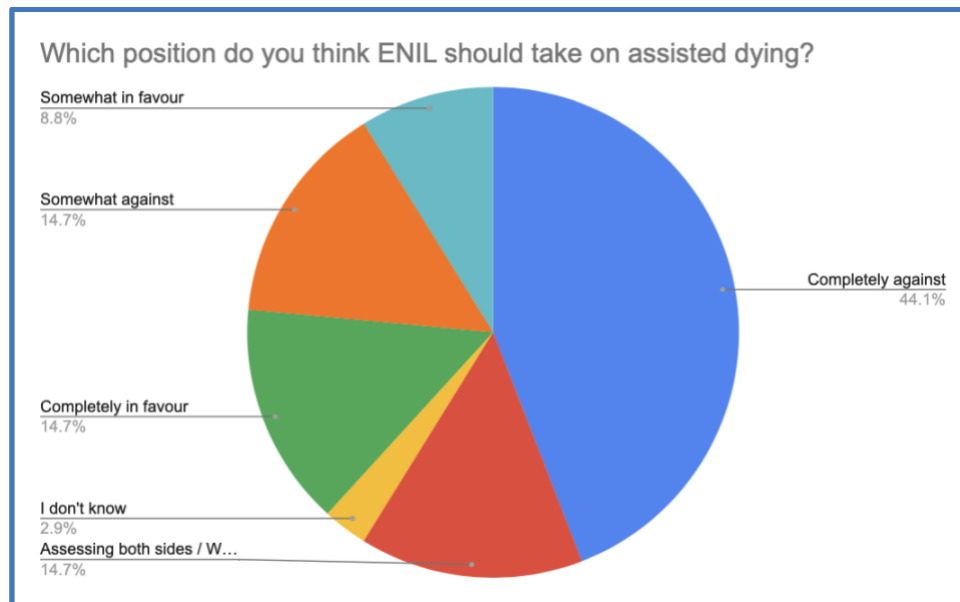
The results of the consultation conducted by ENIL demonstrate a clear majority (nearly 59%) expressing opposition to assisted dying (either complete or partial), with a key minority (23.5%) open to a supportive or a more nuanced approach. A notable portion of respondents also advocated for a balanced assessment, reflecting the sensitivity and complexity of the issue across the Independent Living movement.

In detail, out of all respondents:

- **44.1%** were **completely against** assisted dying,
- **14.7%** were **somewhat against**,

⁵ To read more about the individual countries: <https://enil.eu/il-map/>.

- **14.7%** supported **assessing both sides** neutrally,
- **14.7%** were **completely in favour**,
- **8.8%** were **somewhat in favour**, and
- **2.9%** responded with **“I don’t know.”**



Key Human Rights Concerns

Respondents who opposed assisted dying, whether completely or partially, raised a broad set of concerns grounded in ethics, human rights, lived experience, and socio-political realities. The key concerns and underlying motivations are outlined below.

Lack of support services and systemic failure

Many disabled people across Europe are denied adequate personal assistance, community-based services, assistive technologies, accessible housing, and inclusive healthcare. In such contexts, a request for assisted dying may reflect a lack of alternatives rather than a genuine, freely formed will to die. Respondents emphasised that institutionalisation, neglect, poverty, and service gaps create intolerable living conditions that are socially produced. Individuals may internalise societal messages that they are a burden on families or on public finances. In these

circumstances, assisted dying risks becoming a response to systemic failure. If all pillars of Independent Living were realised, assisted dying would far less frequently be framed as necessary.

Institutionalisation and personal assistance gaps

Where individuals are confined to institutions, denied sufficient personal assistance hours, or left without support for essential daily activities such as hygiene, mobility, or participation in community life, states are failing their obligations under the UN Convention on the Rights of Persons with Disabilities (CRPD). These obligations include Article 10⁶ of the CRPD, which reaffirms the inherent right to life of persons with disabilities on an equal basis with others, and Article 19,⁷ which recognises the right to live independently and be included in the community. Together, these provisions impose a positive duty on States to ensure that disabled people are not forced into institutionalisation, isolation, or degrading living conditions due to lack of support. A state that has not fully realised these rights cannot treat assisted dying as a parallel policy option without first addressing its structural failures.

Respondents stressed that people are often unable to leave institutions due to lack of funding for community-based alternatives, and families are pushed into crisis when respite and home support are unavailable. A state that has not exhausted all reasonable measures to guarantee Independent Living cannot ethically introduce assisted dying as a parallel policy option.

Ableism and societal devaluation of disabled lives

A recurring concern among respondents was the persistence of structural ableism, a set of stereotypes and practices that devalue and discriminate against disabled people, assuming that bodies and minds of non-disabled people are the “default,” and placing value on them based on societal perceptions of what is traditionally

⁶ UN, CRPD, *Article 10 – Right to life*:

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-10-right-to-life.html>.

⁷ UN, CRPD, *Article 19 - Living independently and being included in the community*:

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-19-living-independently-and-being-included-in-the-community.html>.

deemed to be “normal”.⁸ This results in lack of access to education, employment, and housing, and the severe isolation caused by institutionalisation.⁹ Many fear that assisted dying laws reinforce the notion that living with a disability is a fate worse than death. Disability is often culturally framed as loss of dignity, autonomy, or value. Research and lived experience show that medical professionals frequently underestimate the quality of life reported by disabled people themselves. In such an environment, decisions about assisted dying are shaped by biased assumptions. Respondents warned that normalising assisted dying risks reinforcing harmful narratives that equate disability with suffering and justify ending life on that basis.

Threats to Independent Living and social supports

Respondents stressed that assisted dying is incompatible with the core philosophy of Independent Living if introduced in a context where support systems remain underdeveloped. There is a strong concern that legalising assisted dying may weaken political commitment to investing in personal assistance, accessible housing, inclusive healthcare, and community-based services. Some expressed fear that, implicitly or explicitly, the “right to die” could overshadow or replace efforts to secure the right to live independently. Without robust safeguards and strong welfare commitments, assisted dying risks shifting focus away from structural reform.

Eugenic risks and historical precedents

Several respondents raised concerns about historical and contemporary patterns of eugenics and social exclusion.¹⁰ They warned that disabled people, particularly those perceived as “costly,” “unproductive,” or highly dependent, may be subtly encouraged to see their lives as expendable. In societies facing economic pressures and ageing populations, there is a risk that cost-saving considerations may indirectly influence end-of-life frameworks. Such concerns are heightened by the history of

⁸ Disability & Philanthropy Forum, *What is Ableism*, available at: <https://disabilityphilanthropy.org/resource/what-is-ableism/>.

⁹ To learn more about ableism, watch: <https://www.youtube.com/watch?v=lelmZUxBIq0> and <https://www.youtube.com/watch?v=7r0MiGWQY2g>.

¹⁰ Independent Living Institute, *Eugenics and Disability Discrimination*, 1994: <https://www.independentliving.org/docs1/pfeiffe1.html>.

medical and institutional abuse experienced by disabled communities across Europe.

Safeguard failures and medical gatekeeping

There was widespread mistrust in the ability of legal safeguards to fully prevent abuse or misapplication. Determinations of “unbearable suffering” or “rational choice” are inherently subjective and may be influenced by ableist assumptions. International disability advocacy organisations, including Not Dead Yet,¹¹ have long highlighted concerns about physician gatekeeping, unreliable terminal prognoses, insufficient psychological assessments, and weak enforcement of safeguards. Evidence from jurisdictions where assisted suicide is legal shows that reasons cited often relate to loss of autonomy, feeling like a burden, or diminished participation, issues closely linked to disability and social exclusion rather than unmanaged physical pain. These concerns underline the structural vulnerability of disabled people within healthcare systems.

Precedents from other countries

Respondents referenced examples from countries where assisted dying is legal and where individuals reportedly accessed it not solely due to terminal illness, but also in contexts of inadequate housing, lack of social support, or insufficient care. While national systems differ, such precedents highlight the risk of assisted dying becoming a default option for people failed by social structures. These cases raise fundamental questions about whether genuine alternatives were available and whether states had fulfilled their obligations to provide support.¹²

Structural inequality and lack of alternatives

It was strongly emphasised that choice cannot be considered free in the absence of viable alternatives. Poverty, inadequate healthcare, inaccessible environments, and lack of services constrain autonomy and self-determination. Economic pressure, family fatigue, underfunded healthcare systems, and internalised ableism may all

¹¹ Not Ded Yet - The Resistance: <https://notdeadyet.org>.

¹² Examples and court cases available at: <https://notdeadyet.org/category/blog-archive/>.

contribute to subtle or indirect coercion. Until Independent Living is universally supported and the right to live in dignity is fully realised, assisted dying laws cannot be considered safe or just. The risk remains that individuals will feel pressured to choose death not because they desire it, but because they lack the means to live with dignity and full participation in society.

Common Ground Across All Perspectives

While opinions of disabled people around the issue of assisted dying vary significantly, with a majority of respondents being against it, there are shared concerns and several core principles that emerged as common ground:

Respect for self-determination and dignity

Whether respondents supported, opposed, or held a cautious view of assisted dying, there was a strong consensus that self-determination, self-representation, and dignity are fundamental rights. For some, this meant the right to make informed end-of-life decisions, including the option to pursue assisted dying under strict conditions. For others, dignity was framed not as the right to die, but as the right to live a life free from suffering, marginalisation, or neglect.

The crucial need for adequate support systems

Respondents from all sides of the debate stressed that Independent Living must be a guaranteed right, supported by personal assistance, supported decision-making, accessible healthcare, mental health services, housing, and social protections. Without these, the real concept of choice becomes meaningless, and any legalisation of assisted dying risks being built on unstable ground. No one should ever feel that death is their only option because they are denied the support needed to live well.

Deep distrust of ableism in society and the healthcare system

Participants expressed concern about the role of ableist assumptions, particularly within the healthcare system, in shaping perceptions of disability and suffering. Many feared that stereotypes, including the idea that disabled lives are inherently less

valuable or a burden for society and carers, could lead to subtle pressure to consider assisted dying. This concern was shared even by those who supported the option in principle, reinforcing the need for systemic change.

Demand for strong safeguards and transparency

Respondents widely agreed that any legal framework surrounding assisted dying must be accompanied by strong safeguards. These should ensure that decisions are voluntary, well-informed, and not influenced by poverty, social exclusion, or medical neglect. Many called for independent oversight bodies, transparent monitoring, and meaningful involvement of disabled people and their organisations in shaping and evaluating any proposed legislation. Monitoring should be carried out in collaboration with disabled people's organisations and human rights experts.

In short, the consultation revealed that while there are arguments on all sides of the assisted dying debate, there is also a shared commitment to ensuring that no one is forced to choose death because society failed to support their right to live independently. This common ground can serve as a foundation for further dialogue and advocacy that centres both human rights and disability justice.

Translating Findings Into Policy: ENIL Final Position

In light of these findings, ENIL reaffirms that the realisation of the right to Independent Living, as enshrined in the CRPD, must remain the primary obligation of States. ENIL calls on States, as well as on European Union institutions including the European Commission, the European Parliament, and the Council of the European Union, to prioritise investment in community-based services, personal assistance, accessible healthcare, adequate housing, and social protection systems.

Before any consideration of assisted dying frameworks, governments must ensure that disabled people have alternatives and can exercise free and informed choice in conditions of dignity and equality. ENIL therefore claims that **safeguarding the right to live independently and be included in the community must be prioritised**, and that any legislative developments in this field must be grounded in human rights,

robust safeguards, transparency, and the meaningful participation of disabled people and their representative organisations.

VI. Summary of Findings

The consultation on assisted dying revealed a wide range of perspectives among ENIL members, reflecting the complexity and sensitivity of the issue. Participants acknowledged that end-of-life decisions are deeply personal and often shaped by individual circumstances. ENIL recognises both the diversity of views within the disability community and the fact that some individuals may, in extreme situations, perceive assisted dying as a meaningful choice.

At the same time, the overall findings of the consultation point to significant structural concerns. Respondents consistently emphasised the lack of comprehensive support services, the persistence of institutionalisation, ongoing barriers to personal assistance, poverty, discrimination, and the influence of ableist assumptions within healthcare systems. These factors raise serious questions about whether decisions regarding assisted dying can be considered fully voluntary in the current European context.

The discussion also highlighted the importance of grounding any position in human rights obligations, particularly the duty of states under the UN Convention on the Rights of Persons with Disabilities (CRPD) to ensure Independent Living, equal recognition before the law, non-discrimination, and access to adequate support. Across differing viewpoints, there was broad agreement that no person should ever feel compelled to seek death because society failed to provide the **conditions necessary to live with dignity**.

Taken together, the responses indicate that the present social, economic, and policy environment across Europe remains marked by **substantial gaps in the realisation of Independent Living**. These gaps must remain central to any continued debate or advocacy concerning assisted dying.

VII. ENIL's Recommendations

In light of the findings of this consultation, which highlight persistent structural gaps in the realisation of Independent Living and the risk of human rights violations under current conditions, ENIL calls on European states, European Union institutions, and relevant regional bodies to take the following actions:

- **Fully implement Independent Living**

European states must prioritise the full implementation of Independent Living as a binding human rights obligation under the CRPD. This includes guaranteeing access to personal assistance as an enforceable subjective right, ending institutionalisation, and ensuring the development of adequate community-based alternatives. Accessible housing, transport, and inclusive infrastructure must be strengthened, alongside comprehensive community-based healthcare and mental health services. EU institutions should support and monitor these efforts through funding instruments, policy guidance, and enforcement of disability rights standards. Without these foundations, discussions about assisted dying take place in a context where autonomy remains structurally constrained. Any future discussion on assisted dying must ensure the meaningful and continuous participation of disabled people and their representative organisations, in line with the principle of 'nothing without us'.

- **Exhaust all support before considering assisted dying**

States must ensure that all viable and reasonable support measures are fully exhausted before any assisted dying framework is considered. This includes ensuring access to personal assistance, community-based support services, adequate income, healthcare, services for habilitation and rehabilitation, high-quality palliative care, and genuine alternatives to institutionalisation. Peer support and peer counselling should be made available to ensure that individuals can explore their options free from undue pressure. EU bodies and monitoring mechanisms should reinforce the principle that assisted dying cannot be assessed independently from states' obligations to provide comprehensive social support. A decision cannot be regarded as fully voluntary where meaningful alternatives to live in dignity are absent.

- **Protect against human rights violations**

Robust safeguards must be put in place to prevent discrimination and human rights violations. States should establish independent oversight mechanisms with effective monitoring powers, ensure transparency and systematic data collection, and formally involve disabled people's organisations in policy design and evaluation. European institutions, including EU agencies and human rights bodies, should provide guidance and scrutiny to ensure that disability does not become a basis for differential or discriminatory treatment in healthcare systems. Protection against direct or indirect pressure must be central to any regulatory framework.

- **Mandatory training for medical professionals**

Comprehensive and mandatory training for healthcare professionals is essential. Doctors and practitioners must be trained on the right to life from an Independent Living perspective, on the obligations arising from the CRPD, and on supported decision-making principles. Training must address unconscious ableism, challenge assumptions about quality of life, and reinforce suicide prevention practices in disability contexts. EU institutions can play a role in promoting common standards and guidelines to ensure that medical decision-making across Europe is grounded in human rights and disability equality.

- **Adopt a cautious and rights-based approach**

Given the wide disparities in welfare systems, healthcare infrastructure, and societal attitudes across Europe, a uniform or accelerated expansion of assisted dying frameworks would create disproportionate risks, particularly in countries where Independent Living remains underdeveloped. ENIL therefore calls on both states and EU institutions to adopt a cautious, rights-based approach that centres disability equality and social investment. Public policy should first ensure the full realisation of the right to live independently and with dignity. Strengthening support systems must precede, and remain central to, any future debate on assisted dying within Europe.

VIII. Conclusion

Independent Living does not mean isolation. It recognises the interdependent nature of human life: everyone relies on support structures at different times. True self-determination requires access to community-based services and personal assistance, healthcare, mental health services, adequate income, and freedom from institutionalisation. Without these, the concept of “free choice” becomes compromised.

This consultation demonstrated the complexity of opinions among ENIL members. However, the dominant concern across discussions was clear: in a Europe where Independent Living remains under-implemented and structural ableism persists, assisted dying risks becoming a response to policy failure.

ENIL therefore takes a clear and consistent position: **under current social, economic, and policy conditions, assisted dying cannot be supported as a rights-based option.** Our stance is not rooted in ideology, but in the prevention of human rights violations and the protection of disabled people from pressure, discrimination, and structural neglect. The primary duty of states is not to facilitate death, but to ensure that every disabled person has the genuine opportunity to live independently, with dignity, support, and equality.

Only when the right to live independently is fully realised can discussions about end-of-life choice occur without the shadow of inequality.

ENIL remains committed to holding states and institutions accountable for fulfilling the right to Independent Living, without which no end-of-life policy can be considered just or ethical.

About the European Network on Independent Living

The European Network on Independent Living (ENIL) is a disabled-led, cross-disability network of disabled people and their representative organisations. ENIL promotes the right to independent living, as set out in Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD), its General Comments and the *Guidelines on deinstitutionalisation, including in emergencies*. ENIL's work is guided by the CRPD and the Independent Living principles, enshrined in the Independent Living Pillars. ENIL is active at the European level, and internationally, through cooperation with Centres for Independent Living from around the globe. ENIL's actions and activities are based on the social and the human rights models of disability, and on the principles of inclusive equality, self-determination, solidarity and intersectionality.

ENIL has participatory status with the Council of Europe (i.e. is a member of the Conference of INGOs) and consultative status with ECOSOC.

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