The response of the European Network on Independent Living – ENIL to the European Commission's Call for Evidence in Relation to the "European Care Strategy"

29 March 2022

The European Network on Independent Living - ENIL welcomes the European Commission's proposal for the European Care Strategy, as means of ensuring improved access to community-based support and services for all persons with support needs, as well as improved early childhood education and care for children (ECEC). Our response to the Call for Evidence focuses on the long-term care component of the initiative, rather than ECEC. The structure of our response follows the structure of the Call for Evidence, dated 1 March 2022.

I. Political context

- **There is a need to clearly identify the target group(s) of the European Care Strategy.**

We welcome the reference to the European Disability Rights Strategy (ESRPD), which in turn aims to promote the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) in the European Union and globally. We wish to recall that both the European Union and all Member States are party to the CRPD. Therefore, for the European Care Strategy to ensure compliance with the ESRPD and the CRPD, it is important to clearly state who the target groups of the Care Strategy are.

We wish to note that older persons represent the majority of the overall population of persons with disabilities.[1] Yet, because of the fragmentation of policies for older persons and persons with disabilities, older persons who acquire impairments later in life often do not receive the support they need. Equally, persons with disabilities may lose essential supports, such as personal assistance, once they reach the old age threshold.[2] The European Care Strategy provides an opportunity to deal with the intersection between ageing and disability from a rights-based perspective.

[1] United Nations General Assembly (2019) Report of the Special Rapporteur on the rights of persons with disabilities, A/74/186, p. 4. Available at: https://documents-dds-ny.un.org/doc/UNDOC/GEN/N19/221/53/PDF/N1922153.pdf?OpenElement

[2] *Ibid*, p. 5.

- **It is important to recognise that all persons with support needs are protected by the CRPD.**

As highlighted by the UN Special Rapporteur on the Rights of Persons with Disabilities (further "Special Rapporteur"), it is not relevant whether a person identifies as a person with disabilities to benefit from the CRPD protection:

> "Older persons with disabilities who encounter barriers to the exercise of their rights owing to disability or age can seek protection under the Convention, regardless of whether they acquired a disability early or later in life. Furthermore, older persons who are perceived as having a disability are also protected by the Convention."[3]

As the only regional organisation to have ratified the CRPD, the European Union should use the development of the new Strategy to promote the implementation of the Convention. Of particular importance is Article 19 CRPD, on living independently and being included in the community, which requires States to ensure that persons with disabilities have access to "a range of in-home, residential and other community support services, including personal assistance, necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community".

Using a rights-based approach would allow the new Strategy to overcome the fragmentation of policies, ensuring that all individuals with care and support needs get the right community-based support and services at any stage in their lives, as set out in the CRPD. Referring to specific groups of stakeholders, who will benefit from the actions foreseen in the Strategy – such as persons with disabilities or older persons with disabilities - is preferable to referring to "people in need of long-term care". In addition, they should be treated differently from "care providers", who despite facing barriers of their own, should not be at the centre of the Strategy.

Importantly, the development of a rights-based Strategy requires full involvement of persons with disabilities and older persons with disabilities and their representative organisations in all stages of developing the Strategy.

- **The Strategy must recognise that people need support, not just care, and set out definitions of key terms.**

References to care in the Call, and indeed in the name "European Care Strategy" are indicative of the medical definitions and approaches, where persons with disabilities and older persons are seen merely as beneficiaries of care. The Special Rapporteur highlights the problem of using the term "care" in light of the CRPD:

> "While standards for older persons continue to extensively use the concept of "long-term care", the Convention has moved away from the notion of care to develop a paradigm of support (see A/HRC/34/58). This terminological difference reflects the criticism of service models of care by the disability

[3] *Ibid*, p. 7.

community for being paternalistic, reflecting the medical model and promoting the segregation, restraint and disempowerment of persons with disabilities."[4]

To ensure compliance with the CRPD, it is important for the new strategy to refer to both care (as in health care) and support. Furthermore, the strategy should clearly define the key terms, including "care", "community-based care", "community-based support", "residential care", "institutional care", "deinstitutionalisation" and other terms, in order to avoid ambiguity and the misuse of terminology. The General Comment 5, which provides authoritative guidance on the implementation of Article 19 CRPD, and itself contains definitions on the key terms should guide this process, to ensure full compliance with the CRPD.

II. Problems the initiative aims to tackle

In addition to the problems listed in the Call, ENIL calls for the new Strategy to address the following human rights violations:

- **Harm of institutionalisation, and the importance of deinstitutionalisation as means of facilitating access to independent living.**

The Call places all services on the same footing, by stating that "Many people in need of long-term care cannot access care services, whether they are provided as home care, or in community-based or residential settings." This implies that there is the same need for all types of services, including residential. Aside from the strong legal basis (see below) for moving away from residential care to living independently and being included in the community, including the EU and Member States' commitments under the CRPD, there is considerable research to show that the majority of older people prefer to remain in their own homes, instead of moving to a nursing home of other types of residential settings.[5] At the same time, very little progress has been made in the EU in the last decade and residential care provision remains prevalent in many Member States.[6] Furthermore, due to relying on informal care provided by family members, many may end up isolated in their homes and exposed to abuse or neglect.

The new Strategy should commit to significantly extending the range and availability of community-based supports and services for all individuals with care and support needs, in line with the CRPD and the General Comment 5 on living independently and being included in the community. It should also include a clear commitment to deinstitutionalisation, to prohibiting investments in new institutions and to removing financial incentives for the renovation or building of new institutions – of all sizes – for persons with disabilities and/or older persons.

- **Impact of the COVID-19 pandemic on those in segregated settings.**

[4] *Ibid*, p. 13.
[5] European Centre for Social Welfare Policy and Research (2021) *Conceptual framework: developing a tool to collect and assess good practices in the context of non-residential community-based services for older people,* p. 4. Available at: https://www.euro.centre.org/publications/detail/3094
[6] Šiška, J., & Beadle-Brown, J. (2020). Report on the Transition from Institutional Care to Community-Based Services in 27 EU Member States. European Expert Group on Transition from Institutional to Community-Based Care.

There are a number of problems highlighted in the Call, which prevent persons with disabilities and older persons from obtaining the support they need. Among these are inequalities in access to support due to poverty, the inaccessibility of digital solutions and innovations, and the importance of human support, as well as the problems brought on by the COVID-19 pandemic.[7]

However, while noting that COVID-19 has "brought to the fore the structural weaknesses of care systems", there is no mention of the devastating impact on those living in nursing homes and other types of residential care settings. In fact, inadequate measures to protect the lives, health and safety of persons confined to institutions have been reflected in the disproportionate number of COVID-19 related deaths[8][9]. For example, deaths in nursing homes accounted for 51% of the total COVID-19 deaths in the Netherlands[10] and 68% of COVID related deaths in Spain[11].

The lessons learnt during the COVID-19 pandemic should be at the forefront of the new Strategy, which should have as its main objective to ensure access to community-based supports and services for those in need, and deinstitutionalisation.

- **Increased risk of violence, neglect and abuse by older women with disabilities.**

We welcome the reference to the gender dimension of the future Strategy, both in terms of those receiving care and support and those providing it. However, the Call fails to include a reference to the increased risk of violence, neglect and abuse by older women with disabilities, as well as increased risk of institutionalisation.[12] There is also no reference to violence against persons with disabilities and older people in residential care settings, despite a large body of evidence.[13] Recognition of these factors is key to ensuring that specific actions, aimed at prevention of violence and institutionalisation, are included in the future Strategy.

III. Basis of EU action – legal basis

There is a strong legal basis for ensuring access to supports and services in the community for all those in need of care and support in the European Union. The Strategy should clearly set out all the relevant laws and policies, including:

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[7] See, for example, Brennan, Ciara (2020) *Disability rights during the pandemic: A global report on findings of the COVID-19 Disability Rights Monitor*, at: https://covid-drm.org/assets/documents/Disability-Rights-During-the-Pandemic-report-web.pdf

[8] Danis, K., Fonteneau, L., Georges, S., Daniau, C., Bernard-Stoecklin, S., Domegan, L., ... & Schneider, E. (2020). High impact of COVID-19 in long-term care facilities, suggestion for monitoring in the EU/EEA, May 2020. Eurosurveillance, 25(22), 2000956.

[9] Comas-Herrera, A., Zalakaín, J., Lemmon, E., Henderson, D., Litwin, C., Hsu, A. T., ... & Fernández, J. L. (2020). Mortality associated with COVID-19 in care homes: international evidence. *Article in LTCcovid. org, international long-term care policy network, CPEC-LSE*, *14*.

[10] Comas-Herrera, A. et al (2021). Mortality associated with COVID-19 in care homes: international evidence. International Long-Term Care International.

[11] Comas-Herrera, A. et al. (2020). Mortality associated with COVID-19 in care homes: international evidence. Article in LTCcovid. org, international long-term care policy network, CPEC-LSE, 14.

[12] Ibid, p. 6.

[13] See, for example, ENIL (2022) *Shadow report on the implementation of the UN CRPD in the European Union*, February 2022. Available at: https://enil.eu/news/enil-submits-shadow-report-on-the-implementation-of-the-crpd-in-the-european-union/

UN Convention on the Rights of Persons with Disabilities, as well as its General Comments – key provisions which highlight the intersectionality of ageing and disability include Article 5 (equality and non-discrimination), Article 9 (accessibility), Article 19 (living independently and being included in the community) and Article 25 (health).

EU Charter for Fundamental Rights – the Charter recognises in Article 25 the right of older people to "lead a life of dignity and independence and to participate in social and cultural life" and in Article 26 the right of persons with disabilities to "benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community". Article 21, on non-discrimination, prohibits discrimination based on, among other, disability and age.

European Pillar of Social Rights – Principle 18 on Long-term Care recognises that "everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services".

IV. Practical need for EU action

We welcome the reference to reducing the risk of poverty and social exclusion as one of the objectives of the new Strategy, as well as to fundamental rights of persons in need of care and support, including independent living, non-discrimination and social inclusion. Providing better access to formal care services, including in remote and rural communities, as well as the ambition to reach Sustainable Development Goals (SDGs) are also welcome components of the new Strategy. In addition to these, ENIL would like to propose that the following rights violations and barriers to accessing rights are placed at the core of any strategy and future actions:

- **Continued investments in institutions, and the lack of support for community-based support and services.**

As highlighted above, in many Member States institutionalisation (including in nursing homes, psychiatric institutions, group homes etc.) remains a predominant form of care, especially for individuals with high support needs. The risk of institutionalisation increases over age for many persons with disabilities, as their families become less able to provide informal support, as their support needs increase and their support or funding is reduced. As summarised by the UN Special Rapporteur:

> "While younger persons with disabilities are increasingly encouraged and provided with support to live independently, in many countries older persons with disabilities are regularly coerced to reside in long-term care facilities, including nursing homes and care homes. Many of these facilities are in fact segregated institutions, where staff exercise control over the person's daily life and make decisions about the person's care, including their placement in segregated locked wards, the administration of chemical restraints such as psychotropic drugs and the use of other physical restraints. Of particular concern is the emergence of dementia villages in developed countries, which

> represent a systemic form of disability-based segregation and isolation[14] […] As service models targeting both older persons and persons with disabilities are often distinct, persons who acquire an impairment later in life have fewer options to exercise autonomy and are more likely to receive rudimentary support in the community.[15]"

Despite the lack of community-based supports and services, including mainstream housing, many Member States continue investing in new institutions. This includes investments from the European Structural and Investment Funds and through the European Investment Bank.[16] A number of Recovery and Resilience Plans also include investments in institutions, especially nursing homes.[17]

The new Strategy should make it clear that Member States must invest into community-based alternatives to institutional care, such as personal assistance, home care and other types of support, accessible housing in the community, "ageing in place" programmes, assistive technology and other. The Strategy should explicitly state that investing into institutional forms of care is not compliant with the EU's and the Member States' obligations under the CRPD and other EU laws and policies (including the ESRPD).

- **Denial of legal capacity.**

Many persons with disabilities and older persons with disabilities continue to be placed under guardianship and subjected to institutionalisation, home confinement and involuntary treatment.

The new Strategy should encourage Member States to revoke guardianship laws and provisions, to reinstate legal capacity of those under guardianship and to introduce supported decision making for those in need.

- **Discrimination in access to services.**

As stated earlier, due to the fragmentation of policies aimed at persons with disabilities and those aimed at older persons, many individuals who require support later in life are not eligible for disability supports and services. This includes rehabilitation services, which in many countries are not offered to persons with dementia.[18]

The Strategy should promote non-discrimination in access to services (including those provided by the health care and social care sectors), which should be person centred and user-led. The same applies to access to social protection (such as poverty reduction programmes, housing programmes, retirement benefits and disability-

[14] United Nations General Assembly (2019) Report of the Special Rapporteur on the rights of persons with disabilities, A/74/186, p. 12.
[15] Ibid, p. 13.
[16] ENIL (2022) *Shadow report on the implementation of the UN CRPD in the European Union*, February 2022.
[17] EEG (2021) EEG's main findings on the submitted Recovery & Resilience National Plans. Available at: https://deinstitutionalisationdotcom.files.wordpress.com/2021/09/summary-of-the-findings-final-rr-plans-1.pdf
[18] United Nations General Assembly (2019) Report of the Special Rapporteur on the rights of persons with disabilities, A/74/186, p. 11.

related benefits), which should be available to everyone, regardless of their age and support needs, and which should promote independent living and social inclusion. Access to palliative care in the community must also be available on an equal basis, including to persons with disabilities.

- **Stigma and stereotypes.**

It is due to stigma and stereotypes that many persons with disabilities and older persons with disabilities face social exclusion and segregation. Such views are prevalent among the general population, but also among service providers and health professionals.[19]

The new Strategy should address the impact of stigma and ableist and ageist stereotypes on persons with disabilities and older persons, and foresee actions to tackle this problem, aimed at all stakeholders. The Strategy must also make sure not to perpetuate stigma and stereotypes by basing its assumptions and actions on outdated models of care, including by promoting continued segregation of persons with support needs in residential care settings.

About the European Network on Independent Living - ENIL

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 organizations 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, please visit our website. Contact person: Ines Bulic Cojocariu, ines.bulic@enil.eu

[19] *Ibid*, p. 10.