# **Submission by the European Network on Independent Living on the rights of older persons with disabilities**

This submission brings together, for the most part, information compiled by the European Network on Independent Living for the 9th Session of the UN Open Ended Working Group on Ageing in 2018, and input into the ANED (Academic Network of European Disability Experts) Report on the European Pillar of Social Rights.[[1]](#footnote-1)

1. **Please provide information on the legislative and policy framework in place in your country to ensure the realization of the rights of older persons with disabilities, including both persons with disabilities who are ageing and older persons who acquire a disability.**

Article 25 of the European Union (EU) Charter of Fundamental Rights[[2]](#footnote-2) recognises “the rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life”. Furthermore, the EU and all 28 Member States have ratified the UN Convention on the Rights of Persons with Disabilities (CRPD), which sets out the equal right of *all* persons with disabilities to live in the community, with choices equal to others and requires that States Parties provide “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” (Article 19). The General Comment on Article 19 CRPD states that the right to independent living “refers to all persons with disabilities, irrespective of [...] age”.[[3]](#footnote-3)

The European Pillar of Social Rights sets out “the right to affordable long-term care services of good quality, in particular home-care and community-based services” and the right of older people “to resources that ensure living in dignity”.[[4]](#footnote-4)

The Commission Staff Working Document on Long-term care[[5]](#footnote-5), adopted as part of the Social Investment Package, is also of relevance. It notes that the need for long term care arises as a result of disability, mostly caused by health problems. Moreover, it calls for measures “to increase the ability of older men and women to continue independent living even as they become frail or develop disabilities”.

1. **Please provide information on discrimination against older persons with disabilities in law and practice.**

Although no research has been carried out in Europe to look into the effect of deinstitutionalisation measures for persons with disabilities over the age 65, anecdotal evidence shows that, despite deinstitutionalisation strategies and action plans covering persons with disabilities in general, older persons with disabilities are often left in institutions. This may be due to their needs being seen as too complex, the fact that they have spent many years in the institution, and the fact they are considered as ‘unable’ to live independently in the community (i.e., it is ‘too late for them’). In practice, priority is generally given to younger residents, while older residents are left to die in the institution.

Even among those that consistently promote the right to independent living for persons with disabilities, such as the Council of Europe Commissioner for Human Rights, there is a different approach when it comes to older persons. Thus, in a recommendation to the Council of Ministers of the Council of Europe, concerning the human rights of older persons, the Commissioner states that: “Member States should provide for sufficient and adequate residential services for those older persons who are no longer able or do not wish to reside in their own homes.”[[6]](#footnote-6)

1. **Please provide information and statistical data (including surveys, censuses, administrative data, literature, reports, and studies) related to the realization of the rights of older persons with disabilities in general, as well as with particular focus in the following areas:**
* **Exercise of legal capacity;**
* **Admission procedures to social or healthcare services, including involuntary admissions;**
* **Older persons with disabilities living in institutions;**
* **Access to support to live independently in the community;**
* **Access to free or affordable healthcare:**
* **Access to free or affordable rehabilitation goods and services;**
* **Access to social protection schemes; and**
* **End of life and palliative care.**

The support for persons with disabilities to live independently, such as personal assistance, is often limited to those of working age[[7]](#footnote-7); older people who acquire a disability are barred from applying[[8]](#footnote-8) or may receive lower levels of support. In other cases, adults with disabilities lose some support upon reaching a certain age. For example, support and care for older persons with disabilities may be limited to aspects deemed essential – such as personal care and medical needs – rather than participation in community life.[[9]](#footnote-9)

Many older people are forced into residential institutions, because of the lack of community-based services (CBS).[[10]](#footnote-10) There, they are likely to be subjected to violence, abuse and exploitation.[[11]](#footnote-11) Cuts to social and health care budgets, implemented across Europe, have made it more likely for adults with disabilities to be institutionalised as they get older.[[12]](#footnote-12) Moreover, the response to the lack of quality CBS for older persons in the EU has been to focus on the need for residential care, rather than on expanding CBS that allow people to remain at home.[[13]](#footnote-13)

ENIL is concerned about the placement of older people under guardianship[[14]](#footnote-14) in violation of Article 12 CRPD, and the fact that there is a close link between guardianship and institutionalisation.[[15]](#footnote-15)

There is a lack of disaggregated data, including by age, which would show the extent to which older persons with disabilities have access to support services that facilitate independent living.[[16]](#footnote-16) In some countries, statistics do not differentiate between older persons and persons with disabilities.[[17]](#footnote-17)

1. **Please provide information on the existence of long-term care services in your country and describe to what extent they promote the autonomy and independence of older persons with disabilities.**

Due to the lack of quality CBS for adults with disabilities, there is a high reliance of informal, unpaid care.[[18]](#footnote-18) These are mainly family carers - supporting an elderly spouse or parent - and the majority of them are women.[[19]](#footnote-19) While it is important to reduce reliance on family carers, they must be provided with adequate support. Family carers can help facilitate the right to independent living of older persons, if adequately supported and informed about the right to independent living.

Research recently conducted by the EU Fundamental Rights Agency on the transition from institutional care to community living contains very limited references to services targeting older persons with disabilities. With regard to services of institutional type, the report states that:

“While the services identified in this research typically target adults with disabilities, in many cases similar services are also offered to children with disabilities and, less frequently, to older people with or without disabilities. Day centres and centres for vocational training in Bulgaria, for example, offer services to both children and adults with intellectual, psychosocial and sensory disabilities. Small group homes for people with mental health problems in Luxembourg cater to children, adults and older people, while residential institutions in Hungarycover a broad range of age categories.[[20]](#footnote-20)

1. **Please describe to what extent and how are older persons with disabilities involved in the design, planning, implementation and evaluation of policies related to ageing and/or disability.**

It is key to raise awareness among older persons themselves about the CRPD, in particular the right to independent living. Peer support is a useful tool in this respect and can empower older people gain control over their support.

Service providers also play in important role in facilitating access of older persons to independent living. It is therefore imperative that service providers work in ‘co-production’[[21]](#footnote-21) with the service users and help ensure that CBS meet the needs and requirements of older persons to live independently.

1. **Please provide information on any innovative initiatives that have been taken at the local, regional or national level to promote and ensure the rights of older persons with disabilities and identify lessons learned from these.**

ENIL ran a webinar focusing on older people in December 2018, with speakers focusing on the work done in Europe and internationally to advance the rights of older people, ‘Dementia Friendly Communities’ in Italy and Community Catalysts in the UK (who work to develop small scale support providers in remote/rural local communities). The recording can be accessed [here](https://youtu.be/G7ebjg_PTQI).

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1. ANED, *Mainstreaming disability rights in the European Pillar of Social Rights – a compendium*, 2018, p. 85 (Long-term care). [↑](#footnote-ref-1)
2. Charter of Fundamental Rights of the European Union, see: <http://www.europarl.europa.eu/charter/pdf/text_en.pdf> [↑](#footnote-ref-2)
3. General comment on article19: Living independently and being included in the community, para 8, see: <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en> [↑](#footnote-ref-3)
4. European Pillar of Social Rights, Principle 18, on Long-term care and 15, on Old age income and pensions, see: <https://ec.europa.eu/commission/priorities/deeper-and-fairer-economic-and-monetary-union/european-pillar-social-rights/european-pillar-social-rights-20-principles_en> [↑](#footnote-ref-4)
5. Commission Staff Working Document Long-term care in ageing societies – Challenges and policy options, SWD(2013) 41 final. [↑](#footnote-ref-5)
6. Recommendation [CM/Rec(2014) 2](https://search.coe.int/cm/Pages/result_details.aspx?Reference=CM/Rec(2014)2) of the Committee of Ministers to member States on the promotion of human rights of older persons, <https://search.coe.int/cm/Pages/result_details.aspx?ObjectID=09000016805c649f> [↑](#footnote-ref-6)
7. This is the case in Belgium (Wallonia), Denmark, Italy, Norway, Slovenia, Sweden, Switzerland; see ENIL’s Personal Assistance Tables. [↑](#footnote-ref-7)
8. For example, in Bulgaria, a points based application system includes criteria such as being a student and being employed; in France, individuals retain previously approved support beyond 65 years, but new assessments beyond this age are carried out by a different agency and yield lower levels of support; see ENIL’s Personal Assistance Tables. [↑](#footnote-ref-8)
9. In Sweden, responsibility for supporting disabled people transfers from one department (disability) to another (elderly persons) and reductions in support, especially for ‘non-essential’ aspects have been noted (Personal communication from Riita-Leena Karlsson, 12th March 2018) [↑](#footnote-ref-9)
10. This is the case in Belgium, Croatia, Germany, Hungary, Lithuania, Romania; See ENNHRI’s ‘Report on The Human Rights of Older Persons in Long-term Care in Europe’, 2017, p. 11 – 13. Available at: <http://www.ennhri.org/Report-on-The-Human-Rights-of-Older-Persons-in-Long-term-Care-in-Europe> . [↑](#footnote-ref-10)
11. Concluding observations on the initial report of the European Union, CRPD/C/EU/CO/1, para 43-33, see: <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fEU%2fCO%2f1> [↑](#footnote-ref-11)
12. See, for example: <https://www.theguardian.com/society/2018/mar/27/disabled-people-independent-living-care-homes> [↑](#footnote-ref-12)
13. Eurofound, *Care Homes for older Europeans: Public, private and not-for-profit providers,* 2017, see: <https://www.eurofound.europa.eu/publications/report/2017/care-homes-for-older-europeans-public-private-and-not-for-profit-providers> [↑](#footnote-ref-13)
14. Teaster et al., *Wards of the State: A National Study on Public Guardianship,* 2005, see: <https://www.americanbar.org/content/dam/aba/administrative/law_aging/wardofstatefinal.authcheckdam.pdf>,p.93 [↑](#footnote-ref-14)
15. See: <https://criticalgerontology.com/infantilized-elder/> [↑](#footnote-ref-15)
16. Concluding observations on the initial report of the European Union, CRPD/C/EU/CO/1, paras 72-73 [↑](#footnote-ref-16)
17. See, for example, ENIL and FEVI submission on the implementation of Article 19 CRPD in Spain, February 2019, available at: <https://enil.eu/news/enil-and-fevi-point-to-increasing-institutionalisation-in-spain/> [↑](#footnote-ref-17)
18. COFACE Families Europe, *Who Cares? Study on the Challenges and Needs of Family Carers in Europe*, 2017, see: <http://www.coface-eu.org/wp-content/uploads/2017/11/COFACE-Families-Europe_Study-Family-Carers.pdf> [↑](#footnote-ref-18)
19. ENNHRI, *Report on The Human Rights of Older Persons in Long-term Care in Europe*, 2017, p. 15 [↑](#footnote-ref-19)
20. EU Fundamental Rights Agency, *From institutions to community living for persons with disabilities: perspectives from the ground*, 2018, p. 11; see: <https://fra.europa.eu/sites/default/files/fra_uploads/fra-2018-from-institutions-to-community-living-ground-perspectives_en.pdf> [↑](#footnote-ref-20)
21. ENIL Fact sheet on Co-production, see: <http://enil.eu/wp-content/uploads/2016/06/FAQ_Co-production-1.pdf> [↑](#footnote-ref-21)