



9th Session of the Open-ended Working Group on Aging Topic: Autonomy and Independence

Submission by the European Network on Independent Living

Introduction

The aim of this submission is to ensure that the voice of older persons with disabilities is taken into account when considering the measures needed to ensure their 'autonomy and independence'. ENIL has gathered information for this submission from its members through a survey and a number of in-depth interviews. ENIL's past research into access to independent living¹ was also consulted, as well as various reports.

Question 1: In your country/region, how is the right to autonomy and independence of older persons defined in legal and policy frameworks?

Article 25 of the European Union (EU) Charter of Fundamental Rights² 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

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 Furthermore, the Commission Staff Working Document on Long-term care⁵ calls for measures "to

¹ See ENIL's Personal Assistance Tables, see: <http://enil.eu/independent-living/personal-assistance/>.

² Charter of Fundamental Rights of the European Union, see: http://www.europarl.europa.eu/charter/pdf/text_en.pdf

³ General comment on article 19: 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

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

⁵ Commission Staff Working Document Long-term care in ageing societies – Challenges and policy options, SWD(2013) 41 final, see: <http://ec.europa.eu/social/main.jsp?catId=792&langId=en>

increase the ability of older men and women to continue independent living even as they become frail or develop disabilities”.

Question 2: What other rights are essential for the enjoyment of the right to autonomy and independence by older persons, or affected by the non-enjoyment of this right?

The right to independent living is “one of the widest ranging and most intersectional articles” and “has to be considered as integral” for the implementation of the CRPD across all articles.⁶ Older people in residential institutions, or those living at home without adequate support, may not have access to a range of other rights: privacy and family life; freedom from torture, inhuman and degrading treatment; access to health care, or access to justice, among other.

Question 3: What are the key issues and challenges facing older persons in your country/region regarding autonomy and independence? What studies and data are available?

1. The support for persons with disabilities to live independently, such as personal assistance, is often limited to those of working age⁷; older people who acquire a disability are barred from applying⁸ 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

2. Many older people are forced into residential institutions, because of the lack of community-based services (CBS).¹⁰ There, they are likely to be subjected to violence, abuse and exploitation.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 Moreover, the response to the lack of quality

⁶ General comment on article 19: Living independently and being included in the community, para 6

⁷ This is the case in Belgium (Wallonia), Denmark, Italy, Norway, Slovenia, Sweden, Switzerland; see ENIL’s Personal Assistance Tables.

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.

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)

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> .

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

¹² See, for example: <https://www.theguardian.com/society/2018/mar/27/disabled-people-independent-living-care-homes>

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

3. ENIL is concerned about the placement of older people under guardianship¹⁴ in violation of Article 12 CRPD, and the fact that there is a close link between guardianship and institutionalisation.¹⁵

4. 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

Question 4: What steps have been taken to ensure older persons' enjoyment of their right to autonomy and independence?

The Common European Guidelines on the Transition from Institutional to Community-based Care¹⁷ (i.e. deinstitutionalisation), endorsed by the EU, set out the steps needed to develop a range of CBS for different groups with support needs, including older persons. Across Europe, many countries have started the process of deinstitutionalisation, or have closed down large residential institutions. However, there are major concerns about the lack of quality CBS for adults with disabilities and the fact that large institutions are being replaced by smaller facilities (i.e. group homes) that continue to segregate and exclude people from the society.¹⁸

With regard to preserving persons' autonomy, advance directives can be used to ensure that older persons are able to exercise autonomy and independence, in anticipation of declining cognitive or communicative ability. Statistics show a relatively low uptake of advance directives, where they exist.¹⁹

Question 5: What mechanisms are necessary, or already in place, for older persons to seek redress for the denial of autonomy and independence?

The Common European Guidelines highlight the measures needed to put in place an effective monitoring and evaluation system for services, as well as inspection systems for residential institutions in the process of transition and closure.²⁰ ENIL has been calling for a better monitoring and complaints system at the EU level, for

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>

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

¹⁵ See: <https://criticalgerontology.com/infantilized-elder/>

¹⁶ Concluding observations on the initial report of the European Union, CRPD/C/EU/CO/1, paras 72-73

¹⁷ European Expert Group on the Transition from Institutional to Community-based Care, *Common European Guidelines on the Transition from Institutional to Community-based Care*, 2012, see: <http://www.deinstitutionalisationguide.eu/wp-content/uploads/2016/04/GUIDELINES-Final-English.pdf>

¹⁸ European Parliament, *European Structural and Investment Funds and People with Disabilities in the European Union*, 2016, p. 26 – 28, see: http://enil.eu/wp-content/uploads/2016/06/COMMITTEES_PETI_2016_11-09_Study-EUFunds-Disabilities.pdf

¹⁹ <http://blogs.bmj.com/bmj/2017/09/12/kate-a-levin-low-uptake-of-advance-directives-and-the-cost-to-public-health/>

²⁰ European Expert Group on the Transition from Institutional to Community-based Care, *Common European Guidelines on the Transition from Institutional to Community-based Care*, 2012, Chapter 9, p. 136.

the transition from institutional care to community-based services for adults with disabilities.²¹ A good monitoring and complaints system plays a key role in preventing EU funds from being used for the building or renovation of institutions, and for ensuring that quality CBS are supported instead.

Question 6: What are the responsibilities of other, non-State, actors in respecting and protecting the right to autonomy and independence of older persons?

Due to the lack of quality CBS for adults with disabilities, there is a high reliance of informal, unpaid care.²² These are mainly family carers - supporting an elderly spouse or parent - and the majority of them are women.²³ 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.

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 an important role in facilitating access of older persons to independent living. It is therefore imperative that service providers work in 'co-production'²⁴ with the service users and help ensure that CBS meet the needs and requirements of older persons to live independently.

Conclusion

The cause of autonomy and independence for older persons has much in common with the disabled people's struggle for independent living. Rather than focusing on the 'deficiencies' of older persons, it is important to focus on removing barriers in society – environmental, systemic and attitudinal. A future Convention on the Rights of Older People must therefore include parallel articles to the Article 12 CRPD – Equal recognition before the law and Article 19 CRPD - Living independently and being included in the community.

²¹ ENIL, *European Union Structural and Investment Funds and the Transition from Institutional to Community-based Care, Towards a More Effective Monitoring and Complaints System*, 2017, see: http://enil.eu/wp-content/uploads/2017/07/OurRightsCampaign-Briefing_FINAL.pdf

²² 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

²³ ENNHRI, *Report on The Human Rights of Older Persons in Long-term Care in Europe*, 2017, p. 15

²⁴ ENIL Fact sheet on Co-production, see: http://enil.eu/wp-content/uploads/2016/06/FAQ_Co-production-1.pdf

About the submitting organisation

The European Network on Independent Living (ENIL) is a Europe-wide network of people with disabilities. It represents a forum intended for all disabled people, Independent Living organisations and their non-disabled allies on the issues of independent living. ENIL's mission is to advocate and lobby for Independent Living values, principles and practices, namely for a barrier-free environment, deinstitutionalisation, provision of personal assistance support and adequate technical aids, together making full citizenship of disabled people possible.

ENIL is a founding member of the European Coalition for Community Living (ECCL) and the European Expert Group on the Transition from Institutional to Community-based Care (EEG). ENIL has participatory status with the Council of Europe, consultative status with ECOSOC (granted in 2017) and is represented on the Advisory Panel to the EU Fundamental Rights Agency's Fundamental Rights Platform.

For more information, please visit www.enil.eu or contact secretariat@enil.eu