

**Disability and Ageing: Exploring the synergy between the EU Green Paper
on Ageing and the EU Strategy for the Rights of Persons with Disabilities
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Introduction

Eighty-seven million persons in the EU have some form of disability.¹ Although this is not specific to the ageing life course per se, older persons with disabilities face great challenges to live in dignity and equality.² As a result, there are higher rates of discrimination, inequality, denial of autonomy and community marginalization among older persons with disabilities. Although the EU is highly committed to addressing such inequalities across the Member States, there are still gaps in practice to ensure the full realization of living independently and autonomously for people of all ages.

This report offers a unique insight into a rights-based perspective to ageing and disability as it applies to the right to independent living and personal autonomy within the European context. Specifically, it will explore the synergy between the EU Strategy for the Rights of Persons with Disabilities 2021-2030 and the EU Green Paper on ageing. The report acknowledges that the two documents do not have the same political weight, implementation force and level of priority at EU level. Whereas the EU Strategy for the Rights of Persons with Disabilities prescribes specific actions that the EU is committed to deliver and is accompanied by specific budget and internal mechanisms to achieve its objective, the Green Paper on Ageing merely stimulates discussion on some of the key issues facing Europe around demographic ageing today. The Green Paper invited stakeholders to participate in a consultation process and debate based on the proposals it put forward. The Green Paper may or not be followed by a White Paper detailing specific priorities or legislative developments for EU actions, but in the meantime, it cannot be operationalized without any follow-up. The report therefore critiques the two different narratives used in these documents and proposes that the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) can help bridge the implementation gap in practice, specifically by framing the rights of older persons with disabilities using Article 19 (Living independently and being included in the community) of the UNCRPD. This report is not exhaustive, merely created to highlight the synergies between all three documents.

¹ European Disability Forum, March 2021. <https://www.edf-feph.org/a-new-journey-for-disability-rights-the-european-disability-forum-welcomes-the-new-disability-rights-strategy-2021-2030/>

² AGE Platform Europe, <https://www.age-platform.eu/policy-work/news/ageing-disability-intersection-needs-urgent-exploring-conference-finds>

First, this report will define critical concepts such as independent living and personal autonomy, as they apply from a human rights perspective. Secondly, it will discuss how the right to independent living and personal autonomy manifests in the EU Strategy for the Rights of Persons with Disabilities 2021-2030 and the EU Green paper on ageing respectively. Thirdly, it will critically reflect whether these policies focus on a rights-based approach, as guaranteed by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

Independent Living – A Rights-Based Perspective

What is Independent Living?

“The Independent Living Movement grew out of the disability rights movement, which began in the 1960s in the United States of America. It is a movement to enable persons with disabilities to have choice over where, how and with whom they live, just like anybody else, and not to be separated from their community”.³

“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”.⁴

³ European Disability Forum, Independent Living and de-institutionalization Policy
<https://www.edf-feph.org/independent-living-and-de-institutionalisation-policy/>

⁴ European Network on Independent Living <https://enil.eu/independent-living/definitions/>

What is Autonomy?

Personal autonomy and self-determination are fundamental human rights that are guaranteed in several international human right treaties. Autonomy is the freedom and opportunity to choose and control one's lifestyle and daily activities. In essence, this can include but is not limited to access to transport, information, communication and personal assistance, place of residence, employment, personal relationships, clothing, nutrition, health care, religious activities, cultural activities, and sexual and reproductive rights. The opportunity to express this freedom is pivotal to the realization of independent living.

The UN Convention on the Rights of Persons with Disabilities – UNCRPD

What is the UNCRPD?

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was adopted on 13th December 2006.⁵

The UNCRPD gives voice, visibility, and legitimacy to all persons with disabilities – it frames existing human rights through a disability lens, which includes long-term physical, mental, intellectual, or sensory impairments. The important aspect to consider is that various barriers may hinder individuals' full and effective participation in society on an equal basis with non-disabled individuals.

” The UNCRPD follows decades of work by the United Nations to change attitudes and approaches to persons with disabilities. "It takes to a new height the movement from viewing persons with disabilities as “objects” of charity, medical treatment and social protection towards viewing persons with disabilities as “subjects” with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society.”⁶

⁵ UN General Assembly, Convention on the Rights of Persons with Disabilities: resolution/ adopted by the General Assembly 24 January 2007 A/RES/61/106)

⁶ United Nations Department of economic and social affairs /disability
<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

“The Convention is intended as a human rights instrument with an explicit social development dimension. It adopts a broad categorization of persons with disabilities and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. Under this broad definition of disability of the UNCRPD (article 1), all older persons who face some functional limitations or require some form of care and assistance can be considered as persons with disabilities for the purposes of the Convention. The UNCRPD clarifies and qualifies how all categories of rights apply to persons with disabilities and identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights and areas where their rights have been violated, and where protection of rights must be reinforced.”⁷

The UNCRPD emphasizes that persons with disabilities are subject of rights and are rights holders. The general principles of the UNCRPD respect an individual’s inherent dignity, autonomy, and independence. Effective participation and inclusion in society are the foundations of the right to live.⁸

The UNCRPD recognizes the equal right of all persons with disabilities to live independently and be included in the community, with the freedom to choose and control their lives. The foundation of this right is the core human rights principle that all human beings are born equal in dignity and rights and all life is of equal worth⁹

The Core Elements of Article 19 of the UNCRPD

Article 19 is one of the key articles of the UNCRPD, capturing the essence of choice and control. As the UN CRPD Committee’s General Comment No. 5 stresses, the article covers two related concepts: the right to independent living and the right to be included in the community.¹⁰ Independent living and inclusive life in the community stem from persons living with disabilities asserting control over the way they want to live by creating empowering forms of support such as personal assistance and requesting that community facilities be in line with universal design principles¹¹

⁷ Ibid. fn 5

⁸ UNCRPD General Comment No. 5 on Article 19: Living independently and being included in the community, UN DocCRPD/C/GC/5, 2017 PARA 3

⁹ UNCRPD General Comment No. 5 on Article 19: Living independently and being included in the community, UN DocCRPD/C/GC/5 2017 para 2

¹⁰ UNCRPD General Comment No. 5 on Article 19: Living independently and being included in the community, UN Doc CRPD/C/18/1 (29 August 2017), para 19

¹¹ CRPD/C/GC/5, 2017 PARA 4

Independent living does not involve living arrangements only. It requires full and effective inclusion and participation in society¹² in all spheres of social life.¹³

Article 19 of the UNCRPD promotes the following concepts:¹⁴

1. Having choice and control over where and with whom one lives based on the availability of various types of accommodation - residential, community, support to avail of private rentals or to purchase on an equal basis with others.
2. Availability of supports and what that looks like, technology, personal assistance etc and the need for upgrades/adaptations as needs change over time.
3. Equal participation in community and what that entails - anti-discrimination/ anti-hate laws in civil and criminal codes, equality promotion policies, universal and accessible design of spaces and services.

¹² CRPD General Comment No. 5 on Article 19: Living independently and being included in the community, UN Doc CRPD/C/18/1 (29 August 2017), para 16 (b)

¹³ CRPD Committee, Concluding Observations: Cuba, UN Doc CRPD/C/CUB/CO/1 (10 May 2019) para 36 (b)

¹⁴ UNCRPD General Comment No. 5 on Article 19: Living independently and being included in the community, UN Doc CRPD/C/18/1 (29 August 2017), paras 19 and 16 (b)

The EU Green Paper on Ageing

What is the Green Paper on Ageing?

The purpose of the Green Paper is to 'launch a broad policy debate on ageing to discuss options on how to anticipate and respond to the challenges and opportunities it brings, notably considering the UN 2030 Agenda for Sustainable Development and UN Decade for Healthy Ageing'.¹⁵

The scope of the Green Paper can help the EU Member States develop their own, tailor-made policy responses to ageing. The Green Paper takes a life-cycle approach that reflects the 'universal impact of ageing and focuses on both the personal and broader societal implications of ageing'.¹⁶ According to the Green Paper, there are two policy concepts that can enable a thriving ageing society; these include healthy and active ageing and lifelong learning. Although there is a transparent fiscal element to the policy actions included in the Green Paper, widely derived from these two concepts can be the foundations of independent and autonomous living.

Is There a Rights-based Approach to the Green Paper?

There is a noticeably absent gap in the Green Paper on ageing, a consistent human rights-based approach to fundamental concepts of ageing and disability. Although certain human rights principles are mentioned briefly, only superficial coverage of autonomy and independent living are included. For example, the Green Paper mentions that "healthy and active ageing is a personal choice and responsibility".¹⁷ But this reference to choice, is not coupled with a rights-based approach, which involves the active involvement of older persons in all decision-making processes affecting their lives, but also the availability of support and services to exercise choice and control and fully participate in society.

¹⁵Green Paper on Ageing, 2021 https://ec.europa.eu/info/files/green-paper-ageing-fostering-solidarity-and-responsibility-between-generations_en p 2.

¹⁶ Green Paper on Ageing, 2021 https://ec.europa.eu/info/files/green-paper-ageing-fostering-solidarity-and-responsibility-between-generations_en p 2.

¹⁷ Green Paper on Ageing, 2021 https://ec.europa.eu/info/files/green-paper-ageing-fostering-solidarity-and-responsibility-between-generations_en p 4.

Article 19 of the UNCRPD reaffirms ;Individualized support services are consonant with the right of people with disabilities to receive services at home in residential and other community support services, including personal assistance. They have to “support living and being included in the community,” and “to prevent isolation or segregation from the community.” The individualized support has to be chosen by the person and trimmed according to his or her needs and not necessarily to that offered by the provider. ¹⁸Among the most important services is personal assistance because it may boost choice and control over the support needed to live and be included in the community.

Article 19(c) of the UNCRPD requires states parties to ensure that community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs. The services have to allow them to enjoy all community rights, among them education, work, and transportation.

General Comment No. 5¹⁹ draws on Article 29 of the Universal Declaration of Human Rights understanding of ‘community’ as the structures which are essential for personal development in different economic, social, cultural and political contexts. The General Comment goes on to say that inclusion in the community is irrespective of age, race, gender, sexuality, ethnicity, family status, politics or any other identity²⁰. It further outlines that participation in the community involves participation in any political or cultural events that the individual chooses to be involved with²¹

While the Green Papers makes a concerted effort to address that ‘more people than ever remain active for longer’²²;it lacks specificity about how older people remain independent in old age through individualised and community supports. In contrast to the UNCRPD, the Green Paper does not propose policy action from a rights-based approach, rather it is driven

¹⁸ UNCRPD General Comment No. 5 on Article 19: Living independently and being included in the community, para 28

¹⁹ General Comment No. 5 (CRPD) is a treaty body's interpretation of human rights and treaty provisions. **General comments** often seek to clarify the reporting duties of State parties with respect to certain provisions and suggest approaches to implementing treaty provisions. General Comment No 5. Refers to Independent Living. (Adopted 31st August 2017).

²⁰UNCRPD General Comment No. 5 on Article 19: Living independently and being included in the community, UN Doc CRPD GC No. 5 (n1), para 8

²¹ UNCRPD General Comment No. 5 on Article 19: Living independently and being included in the community, UN Doc CRPD GC No. 5 (n1), para 16 (b)

²² Green Paper on Ageing, 2021 https://ec.europa.eu/info/files/green-paper-ageing-fostering-solidarity-and-responsibility-between-generations_en p 10

by fiscal concerns. Further, it assumes that older persons will not always make decisions about their lives and fails to guarantee these rights on an equal basis with others.

The EU Strategy for the Rights of Persons with Disabilities

What is the EU Disability Strategy?

“The EU Disability strategy aims to ensure that people with disabilities can experience full social and economic inclusion equally with others and live free from discrimination. It will focus on implementing the UN Convention on the Rights of Persons with Disabilities and consolidating the EU’s body of law in this field”.²³

It is the second strategy of this kind. It builds upon the work done on the 2010-2020 strategy, both through targeted action and by ensuring disability rights are considered across all EU policies, programmed and instruments.²⁴The strategy itself focuses on the three main themes:

1. EU rights.
2. Independent living and autonomy
3. Non-discrimination and equal opportunities

The scope of this report is to focus on independent living and autonomy, as it applies to the Green Paper on Ageing and the EU Disability Rights Strategy. Specifically, the Disability Rights Strategy gives “guidance to Member States to enable persons with disabilities to live in accessible, supported housing in the community, or to continue living at home (including personal assistance schemes), as well as other initiatives including a framework for Social Services of Excellence for persons with disabilities. ”²⁵

Considering the Ageing Life course in the Disability Strategy

The Disability Strategy is not an age-specific document. It does, however, include older persons with disabilities in its provisions on independent living and inclusion in the

²³ Strategy for the Rights of Persons with Disabilities 2021- 2030
A view from Equality Bodies <https://equineteurope.org/wp-content/uploads/2021/03/Disability-Strategy-Summary-1.pdf> <https://equineteurope.org/wp-content/uploads/2021/03/Disability-Strategy-Summary-1.pdf>

²⁴ Strategy for the Rights of Persons with Disabilities 2021- 2030
A view from Equality Bodies <https://equineteurope.org/wp-content/uploads/2021/03/Disability-Strategy-Summary-1.pdf> <https://equineteurope.org/wp-content/uploads/2021/03/Disability-Strategy-Summary-1.pdf>

²⁵ AGE platform Europe <https://age-platform.eu/policy-work/news/age-calls-specific-focus-older-people-disabilities-eu-upcoming-disability-rights>

community, stating that ‘[p]ersons with disabilities, **old and young**, have an equal right to live independently and be included in the community, with choices equal to those of others about their place of residence and with whom and how they live ‘.²⁶

The Strategy highlights the importance of accessibility and supported housing in the community as well as other initiatives including a 'framework for Social Services of Excellence for persons with disabilities.'²⁷ Further, the commission calls on the Member States to implement good practices of deinstitutionalization and secure financing for accessible and disability-inclusive social housing, including for older persons with disabilities. In essence, this Strategy aims to ‘improve the lives of persons with disabilities in the coming decade, in the EU and beyond. The objectives of this Strategy can only be reached through coordinated action at both national and EU level, with a strong commitment from Member States and regional and local authorities to deliver on the actions proposed by the Commission’.²⁸

The UN Special Rapporteur on the rights of persons with disabilities noted that ‘[o]lder persons with disabilities encounter significant barriers to the exercise of their rights owing to the intersection between ableism and ageism. Such barriers include stigma and stereotypes; discriminatory laws and practices; denial of autonomy and legal capacity; institutionalization and lack of community support; violence and abuse; and lack of adequate social protection’²⁹. For the UN Special Rapporteur, ‘[m]any of these human rights violations are frequently regarded as normal and rendered invisible to Governments, deepening the circle of discrimination and exclusion of older persons with disabilities’. Yet, the Disability Rights Strategy does not include specific action to increase visibility of and tackle these intersectional challenges. It also fails to ensure the mainstreaming of disability and ageing-related policies and programmes with the intent to ensure that the concerns and needs of older persons with disabilities are adequately addressed.³⁰

²⁶ [EU funding and deinstitutionalisation](https://eur-lex.europa.eu/legal-content/en/TXT/?uri=CELEX:52021DC0101) ; long-stay residential institutions were excluded from EU funding. Cited in <https://eur-lex.europa.eu/legal-content/en/TXT/?uri=CELEX:52021DC0101> Accessed 30th June 2021

²⁷ Strategy for the Rights of Persons with Disabilities 2021- 2030
A view from Equality Bodies <https://equineteurope.org/wp-content/uploads/2021/03/Disability-Strategy-Summary-1.pdf>

²⁸ <https://eur-lex.europa.eu/legal-content/en/TXT/?uri=CELEX:52021DC0101>

²⁹ Report of the UN Special Rapporteur on the rights of persons with disabilities (A/74/186) : <https://undocs.org/en/A/74/186>

³⁰ AGE platform Europe, <https://age-platform.eu/policy-work/news/age-calls-specific-focus-older-people-disabilities-eu-upcoming-disability-rights>

Conclusion

Over the past decade, there has been greater visibility towards the protection and promotion of older persons with disabilities. However, the intersection between old age and disability still needs to be reflected in several EU policies. Currently, the Green paper on ageing and the Disability Rights Strategy operate in silos. The Green Paper calls for the fostering of solidarity and responsibility between the generations. It recognizes that the Member States are facing significant challenges in ensuring affordable community alternatives towards independent living. Nonetheless, the Green Paper on ageing is not perceived as a rights-based document. Although there is a brief mention of meeting the health and long-term care needs of an ageing population, the paper does not explicitly expand on these notions beyond a short recognition of dignity, choice as general well-being principles. It is, therefore, recommended that the Green Paper cannot stand alone. It needs to be read in conjunction with the UNCRPD to fully realize Article 19 of the UNCRPD.

Further, while the EU Disability Rights Strategy is rights-based, it still lacks specificity to older persons especially when it comes to autonomy, independence, individual support and community support. Therefore, there is a need that the implementation of the disability rights strategy is more specific to the challenges faced by older persons with disabilities, such as those identified by the UN Special Rapporteur.³¹

Persons with disabilities need to be guaranteed the full enjoyment of their rights without discrimination.³² The effective application of a rights-based approach the intersection between older age and disability needs to be accompanied by a paradigm shift with respect to society's perception of ageing and older persons'³³. The rights-based approach has high normative value and can drive policy change on the ground. The implementation of the UNCRPD has led to wide-ranging legal and policy reforms across EU countries, including – among others – extending the scope of protection of people with disabilities from discrimination to cover access to goods and services and/or to provide reasonable accommodation beyond the area of employment; amending provisions on deprivation of legal capacity and providing more community-based options. Hence, this report makes the case for

³¹ <https://www.ohchr.org/en/issues/disability/srdisabilities/pages/srdisabilitiesindex.aspx>

³² <https://www.ohchr.org/en/issues/disability/srdisabilities/pages/srdisabilitiesindex.aspx>

³³ report of the UN Special Rapporteur on the rights of persons with disabilities (A/74/186) : <https://undocs.org/en/A/74/186>

the Green Paper and the Disability Rights Strategy to be embedded with an increased understanding of ageing and disability based on the human rights principles of the UNCRPD.

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