United Nations A/HRC/57/42

General Assembly

Distr.: General
18 July 2024

Original: English

Human Rights Council
Fifty-seventh session
9 September–9 October 2024
Agenda item 3
Promotion and protection of all human rights, civil, political, economic, social and cultural rights, including the right to development

Legal capacity and informed consent

Report of the Independent Expert on the enjoyment of all human rights by older persons, Claudia Mahler

Summary

In the present report, the Independent Expert on the enjoyment of all human rights by older persons, Claudia Mahler, provides an overview of her activities during the reporting period and undertakes a thematic analysis of the legal capacity and informed consent experienced by older persons.

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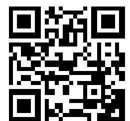

I. Introduction

1. The present report is submitted by the Independent Expert on the enjoyment of all human rights by older persons, Claudia Mahler, pursuant to Human Rights Council resolution 51/4. The report contains an overview of the activities of the Independent Expert during the reporting period and includes a thematic analysis of the autonomy, legal capacity and informed consent experienced by older persons. The analysis relies on previous work and extensive desk research, as well as 46 written submissions received from States, national human rights institutions, civil society organizations, academics and other stakeholders in response to the call for contributions issued in February 2024.[1] The Independent Expert is grateful to all those who contributed to the preparation of this thematic report.

II. Activities of the Independent Expert

A. Country visits

2. During the reporting period the Independent Expert visited Moldova, from 7 to 16 November 2023, and Peru, from 11 to 22 March 2024. She expresses her thanks and appreciation to the Governments of those countries for their invitations and for the cooperation extended to her before, during and after her visits and looks forward to continuing fruitful and constructive dialogues.

B. Other activities

3. During the reporting period, the Independent Expert addressed communications to Governments, both individually and jointly with other special procedure mandate holders, in relation to the human rights of older persons. She also issued press releases individually and with other mandate holders, including a statement on the need to translate the promise of the Universal Declaration on Human Rights into reality for older persons on the occasion of the International Day of Older Persons in 2023 and a statement on the situation of older persons in emergency and crisis situations marking World Elder Abuse Awareness Day in 2024.

4. In line with her mandate, the Independent Expert participated in the fourteenth session of the Open-ended Working Group on Ageing, providing remarks at the opening session and at an expert panel related to accessibility, infrastructure and habitat (transport, housing and access). She also spoke at a number of side events and held high-level meetings on the margins of the fourteenth session. During the session, she was a keynote speaker at a reception hosted by Member States to mark the tenth anniversary of the mandate. She welcomes the historic adoption of the decision submitted by the Chair of the Open-ended Working Group,[2] which identifies gaps in the protection of the human rights of older persons and makes recommendations to address them, including through an international legally binding instrument to promote, protect and ensure the recognition and realization, on an equal basis, of all human rights of older persons.

5. Between August 2023 and July 2024, the Independent Expert participated in several international, regional and national meetings, events and conferences to provide remarks on themes related to the human rights of older persons. To highlight some activities during the reporting period, the Independent Expert gave a keynote speech at the meeting of the International Longevity Centre Global Alliance in Tokyo, spoke at the Global Ageing Conference in Glasgow, United Kingdom of Great Britain and Northern Ireland, and delivered a keynote speech at the International Conference on the Human Rights of Older Persons in Vienna. She travelled to the Kyrgyz Republic and to Kazakhstan to support the launch of the Russian-language version of *Protecting Minority Rights: Practical Guide to the Development of Comprehensive Anti-Discrimination Legislation*, developed by the Office of the United Nations High Commissioner for Human Rights (OHCHR) and civil

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[1] All submissions are available at https://www.ohchr.org/en/special-procedures/ie-older-persons.

[2] A/AC.278/2024/2, chap. IV, decision 14/1.

society partners, and addressed the importance of combating age discrimination at the national level. The Independent Expert also provided opening remarks at an expert meeting convened by OHCHR on the human rights obligations of States regarding violence against and abuse and neglect of older persons in all settings, as mandated by the Human Rights Council in its resolution 54/13. She introduced current developments in the field of human rights of older persons and discussed possible next steps ahead of the fourteenth session of the Open-Ended Working Group on Ageing with delegates of the European Union at the meeting of the Working Party on Human Rights in Brussels in April 2024. As a member of the Coordination Committee of Special Procedures, she took part in regular in-person and online meetings of the Committee and attended a high-level event to mark the seventy-fifth anniversary of the Universal Declaration of Human Rights in Geneva.

III. Legal capacity and informed consent of older persons

A. Introduction

6. The current human rights framework does not include a clear and consistent definition of the concept of autonomy. Even though there is no comprehensive description under human rights law, it is commonly described as “the right to have control over one’s life, to make one’s own decisions and to have those decisions respected”, including “the right of older persons to take risks”.[3] The Independent Expert has previously noted that autonomy has a broader dimension involving “an individual aspect, which includes the capacity to make decisions; an economic and financial aspect, understood as self-sufficiency and the ability to generate and receive income; and a societal aspect”.[4] Autonomy is often coupled with independence, which has been described as the “ability of a person to perform functions related to daily living, to be able to carry out one’s decisions in practice and to be able to remain fully integrated in society and community life”.[5] To guarantee human rights in old age, individuals must overcome discrimination, prejudice and stereotypes of older persons as being less worthy and less capable of exercising autonomy and independence.[6]

7. Legal capacity enables adults to fully participate in society through the exercise of civil, political, economic, social and cultural rights. Legal capacity confers legal standing on adults, enabling them to participate in society, for example by entering contracts, making financial decisions and providing informed consent to medical treatment, services and supports, including their placement in residential settings. Older persons have the right to “enjoy legal capacity on an equal basis with others in all aspects of life” stated in the Convention on the Rights of Persons with Disabilities. Older persons can and will contribute “to the functioning of society if adequate guarantees are in place”.[7] Adequate guarantees include protection of the rights of older persons to make choices about how and where to live, what medical and social services to receive and how to use their resources and time.

8. While the health and functioning of older persons is more heterogenous than that of younger adults,[8] older persons as a group are often characterized as suffering from physical

[3] Open-ended Working Group on Ageing, substantive inputs – autonomy and long-term care, https://social.un.org/ageing-working-group/documents/tenth/A_AC.278_2019_CRP.4.pdf, para. 10 (English only).

[4] A/HRC/30/43, para. 44.

[5] Open-ended Working Group on Ageing, substantive inputs – autonomy and long-term care, https://social.un.org/ageing-working-group/documents/tenth/A_AC.278_2019_CRP.4.pdf, para. 10 (English only).

[6] Quinn, G. and Doron, I., *Against Ageism and Towards Active Social Citizenship for Older Persons: The Current Use and Future Potential of the European Social Charter*, Council of Europe (2021), available at https://rm.coe.int/against-ageism-and-towards-active-social-citizenship-for-older-persons/1680a3f5da.

[7] A/66/173, para. 4.

[8] Nguyen, Q. D., Moodie, E. M., Forget, M. F., Desmarais, P., Keezer, M. R. and Wolfson, C. (2021), “Health heterogeneity in older adults: exploration in the Canadian longitudinal study on ageing”, *Journal of the American Geriatrics Society*, vol. 69, No. 3, pp. 678–687.

and cognitive decline and heightened vulnerability to abuse and exploitation.[9] Limitations on the rights of older persons to exercise choice "have frequently been the result of stereotyped assumptions about the capacities, desires and needs of older persons, leading to the neglect of their wishes, assumptions about their preferences, disregard for their values and views and making decisions for them".[10]

9. Older persons may experience deprivation of their rights to exercise legal capacity and control their lives. In some cases, this is driven by cultural and family norms, where younger family members simply make decisions about older persons' lives.[11] In other cases, it results from a formal finding in a health-care or legal context, sometimes, but not always, based on a formal medical assessment of the person's decision-making capacity. Because of their age, older persons "are often denied their right to make their own decisions about their finances, employment, management and disposal of their property, who to vote for, where and with whom to live, access to health services, family life and participation in community, voluntary or social activities".[12]

10. Informed consent in health care is "a voluntary and sufficiently informed decision, protecting the right of the patient to be involved in medical decision-making, and assigning associated duties and obligations to health-care providers".[13] Its social and legal ramifications stem from the principles of non-discrimination, autonomy, privacy, self-determination, bodily integrity and well-being. Its interpretation under human rights law and clinical practice is mainly focused on health care, but its implications extend to all aspects of life. Consent must be given without coercion, undue influence or misrepresentation and on the basis of adequate and accessible information. Consent is an integral part of the enjoyment of the right to health and presupposes legal capacity. It also involves the right to refuse treatment.

11. Under contemporary medical ethics, informed consent cannot be provided by a person found to lack the capacity to provide consent. This concept emerged within medical settings as a component of informed consent for treatment but has expanded to areas such as financial decision-making.[14] Despite tools and guidelines for assessing capacity, there is no objective, accurate or reliable definition of cognitive capacity and capacity assessment is therefore fundamentally flawed.[15] When older persons lack the necessary information, language, legal or digital skills required to understand and initiate a process of giving informed consent or drafting advance directives, they may be wrongly assessed as lacking capacity, deprived of the ability to give informed consent and subject to the decisions of a substitute decision maker.

12. Restrictions on legal capacity affect the autonomy of older persons in regard to nearly all types of personal decisions, including managing their finances, choosing employment, handling their property, deciding their vote, selecting their living arrangements and companions, accessing health services and participating in family and community activities. Government and local authorities, policymakers and also health-care professionals, as well as family and friends, often exclude older persons from making decisions about their own affairs, failing to support their involvement and empowerment.[16]

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[9] Vervaecke, D. and Meisner, B. A., "Caremongering and assumptions of need: The spread of compassionate ageism during COVID-19", *The Gerontologist*, vol. 6, No. 2 (February 2021), pp. 159–165.

[10] OHCHR working paper containing an update to the 2012 analytical outcome study on the normative standards in international human rights law in relation to older persons, available at https://social.un.org/ageing-working-group/documents/eleventh/OHCHR%20HROP%20working%20paper%2022%20Mar%202021.pdf, para. 116.

[11] See World Health Organization (WHO), *World Report on Ageing and Health*, Geneva, 2015.

[12] Submission by HelpAge International.

[13] A/HRC/34/32, para. 17.

[14] Moye, J. and Marson, D. C., "Assessment of decision-making capacity in older adults: an emerging area of practice and research", *The Journals of Gerontology Series B: Psychological Sciences & Social Sciences*, vol. 62, No. 1 (2007), pp. 3–11.

[15] Diller, R., "Legal capacity for all: Including older persons in the shift from adult guardianship to supported decision-making", *Fordham Urban Law Journal*, vol. 43, No. 3 (2016), p. 495.

[16] Submission by HelpAge International.

13. The loss of legal capacity by older persons can manifest in various ways. It can start with seemingly protective actions by others, such as performing tasks on their behalf, blocking access to potentially hazardous areas, or restricting certain foods owing to health conditions. This can escalate to patronizing behaviours, including the confiscation of personal identification, the inappropriate use of first names and the application of psychological pressure, intimidation or blackmail. In more severe cases it can lead to outright harassment that disregards the fundamental rights of older persons or to the deprivation of their liberty.[17]

14. Guardianship is a particularly stringent form of a legal mechanism for removing legal capacity because a person "lacks capacity" or is in need of protection. It has been described as "civil death" because it takes away some or all legal capacity rights.[18] When guardianship for older persons is normalized, as it has been in many countries, it can become the default for addressing the challenges some older persons face. For example, victims of financial exploitation may have their rights removed under guardianship, even though guardianship may not protect the person while, at the same time, imposing "financial and personal costs", rendering it "a cure worse than the disease".[19] Guardianships may be established because a person cannot competently manage their business.[20] Social service organizations may file for guardianship in situations when older persons are on the verge of eviction or when nobody is available to manage the person's care payments or entitlements.[21] Guardians may be family members, friends, attorneys, public guardians or professional guardians.[22] Hospitals and nursing homes may seek guardianship for various reasons, including to improve their financial status or to punish "challenging" patients or residents.[23] Guardianships have been associated with physical abuse, psychological or emotional abuse (including social isolation), financial abuse, sexual abuse, impairment-related abuse and other forms of violence.[24]

15. Forced institutionalization is another avenue that can be used to restrict the legal capacity of older persons. In many countries it is common practice for families or authorities to override the legal capacity of older persons in order to put them in institutions where they may experience restrictions on freedom of movement and the ability to provide informed consent for treatment.[25] The European Network of National Human Rights Institutions has described cases where the informed consent of the older individual is not a prerequisite for their admission into residential care.[26] The Network also reported examples of restricted autonomy, such as forcing care residents to sign their pensions over to the care home and lack of consultation regarding their care plan or daily routine. Other concerns that have been raised about persons with dementia in nursing homes include overmedication and the

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[17] Submission by Respect Seniors.

[18] Dinerstein, R., "Implementing legal capacity under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The difficult road from guardianship to supported decision-making", *Human Rights Brief*, vol. 19, No. 2 (2012).

[19] Diller, R. and Salzman, L., "Stripped of funds, stripped of rights: a critique of guardianship as a remedy for elder financial harm", *University of Pennsylvania Journal of Law and Social Change*, vol. 24, No. 2 (2021). p. 149–151.

[20] Submission by Ecuador, p. 2.

[21] Diller, R., "Legal capacity for all: Including older persons in the shift from adult guardianship to supported decision-making", *Fordham Urban Law Journal*, vol. 43, No. 3 (2016), p. 495.

[22] Nwakasi, C. C. and Roberts, A. R., "Older adults under guardianship: Challenges and recommendations for improving practice", *Journal of Aging & Social Policy*, vol. 34, No. 3 (2022), pp. 401–417.

[23] Hirschel, A. and Smetanka, L., "The use and misuse of guardianship by hospitals and nursing homes", *Syracuse Law Review*, vol. 72, (2022), pp. 255–256.

[24] Bedson, L., Chesterman, J. and Woods, M., "The prevalence of elder abuse among adult guardianship clients", *Macquarie Law Journal*, vol. 18 (2018), pp. 15–33.

[25] Open-ended Working Group on Ageing, "Analysis and overview of guiding questions on long-term care and palliative care received from Member States, 'A' Status National Human Rights Institutions and accredited non-governmental organizations" (2018), available at https://social.un.org/ageing-working-group/documents/ninth/OEWGA9_Substantive_Report_LTC_Palliative-Care_DESA.pdf.

[26] European Network of National Human Rights Institutions, "*We have the same rights": The Human Rights of Older Persons in Long-Term Care in Europe* (2017), available at http://www.ennhri.org/IMG/pdf/ennhri_hr_op_web.pdf.

administration of antipsychotic drugs without free and informed consent to "manage" residents in care homes with inadequate staff and training.[27]

B. Legal and policy standards

International frameworks

16. The right to equal recognition before the law is recognized in article 6 of the Universal Declaration of Human Rights. Article 16 of the International Covenant on Civil and Political Rights provides everyone with "the right to recognition everywhere as a person before the law". It encompasses the ability to be the holder of rights (including legal standing) and the ability to exercise those rights (legal agency).[28] While it prohibits discrimination based on race, religion or property it does not explicitly prohibit discrimination based on age.

17. In principle, older persons' rights to legal capacity should be protected and age-based discrimination prohibited under the International Covenant on Civil and Political Rights; in practice, the Covenant does not adequately protect the legal capacity rights of all populations, in particular those facing intersecting forms of discrimination. This is illustrated by relevant articles of the Convention on the Elimination of All Forms of Discrimination against Women and the Convention on the Rights of Persons with Disabilities, which reaffirm the legal capacity rights of women and persons with disabilities, respectively.

18. Article 15 of the Convention on the Elimination of All Forms of Discrimination against Women establishes that States parties shall accord to women, in civil matters, a legal capacity identical to that of men and the same opportunities to exercise that capacity. The Committee on the Elimination of Discrimination against Women states that older women are particularly vulnerable to exploitation and abuse, including economic abuse, when their legal capacity is deferred to lawyers or family members, without their consent. The Committee recommends that States parties ensure that older women are not deprived of their legal capacity on arbitrary or discriminatory grounds.[29]

19. Roughly half of all older persons have a disability, and globally older persons comprise one in four persons living with a moderate to severe disability.[30] Article 12 of the Convention on the Rights of Persons with Disabilities recognizes that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. Furthermore, the Committee on the Rights of Persons with Disabilities has interpreted article 14 of the Convention (liberty and security) to mean that the involuntary detention of persons with disabilities is incompatible with the Convention.[31] Under article 25 (health), the provision of all services, including institutional care, should be based on the free and informed consent of the individual concerned and all laws that allow the involuntary treatment upon the authorization of third parties, such as family members should be repealed.[32] The Independent Expert emphasizes the need for regular evaluation of a person's wish to receive care and to allow exit from care, when desired.

20. Because full participation in society is one of the key principles and objectives of the Convention on the Rights of Persons with Disabilities, this right includes voting, participation in public affairs and involvement in decisions affecting life and access to health care (inter alia, arts. 25, 29, 34 (3)). Those provisions, in combination with article 19 (Living independently and being included in the community), can be used as a safety net against deprivation of legal capacity, lack of informed consent, forced institutionalization and other forms of involuntary treatment facing persons with disabilities.

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27 A/76/157, para. 55.

28 A/HRC/37/56.

29 CEDAW/C/GC/27, paras. 27 and 34.

30 See https://social.desa.un.org/issues/disability/disability-issues/ageing-and-disability.

31 Committee on the Rights of Persons with Disabilities, 2014, Statement on article 14 of the Convention on the Rights of Persons with Disabilities, available at http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=15183&LangID=E.

32 See CRPD/C/CHN/CO/1.

21. Protections under the Convention on the Rights of Persons with Disabilities extend to older persons with disabilities, including older persons who are perceived to have a disability. However, older persons with disabilities may "fall through the cracks" in the implementation of the Convention.[33] For example, the Convention does not address the fact that older persons with disabilities are offered fewer rehabilitation services than younger persons with disabilities[34] and that older persons with serious illness and physical and cognitive impairments who live in institutional settings can lack access to justice (art. 13 of the Convention) to enforce their rights owing to their lack of legal capacity, limited access to legal assistance and the complexity and cost of enforcement.[35]

Regional frameworks

22. Of all international and regional instruments, the Inter-American Convention on the Rights of Older Persons offers the most comprehensive protection on older persons' equal recognition before the law.[36] Article 30 stipulates the presumption of legal capacity of older persons and establishes the provision of necessary supports and safeguards for the exercise of legal capacity in old age. Article 7 refers to the right "to make decisions, to determine their life plans, to lead an autonomous and independent life in keeping with their traditions and beliefs on an equal basis, and to be afforded access to mechanisms enabling them to exercise their rights". The Inter-American Commission on Human Rights has interpreted this provision as encompassing the obligation for the adoption of measures that allow individuals to enjoy the capacity to make decisions that are necessary for leading their lives.[37]

23. The Inter-American Convention further includes a specific provision on free and informed consent on health matters. Article 11 includes the obligation to guarantee this right through specific mechanisms that can prevent abuse, but also strengthen individual capacity for the exercise of this right, including through legally binding advance directives. Article 12 on long-term care calls on States to establish mechanisms to ensure that older persons can express their free will with regard to the start and end of care provision. The Inter-American Convention in article 27, moreover, protects political participation, including right to vote and be elected, also imposing an affirmative duty on States "to facilitate the conditions and the means for exercising" older persons' political rights.

24. Article 4 of the Protocol to the African Charter on Human and People's Rights on the Rights of Older Persons in Africa establishes the right to receive access to justice and equal protection before the law. However, its scope is quite limited, referring to an obligation to develop and review laws to allow for equal treatment and protection; provide legal assistance; and ensure training of law enforcement bodies for the effective enforcement of rights. Article 5 of the African Protocol recognizes older persons' right to make decisions "without undue interference". It also stipulates that older persons can "appoint a party of their choice to carry out their wishes and instructions" and mentions that "in the event of incapacity, older persons shall be provided with legal and social assistance in order to make decisions that are in their best interest and well-being". These provisions, which do not cover all aspects of legal capacity in the context of old age, are a good basis for next steps in the development of the rights of older persons at the international level, although they are sometimes in conflict with the Convention on the Rights of Persons with Disabilities. The references to "incapacity" and the "best interest" of older persons reflect a medical and paternalistic model that stands in contrast to article 12 of the Convention, which guarantees respect of legal capacity of persons with disabilities and precludes the use of substitute decision-making.[38]

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[33] A/74/186, para. 6.

[34] See https://academic.oup.com/hrlr/article/23/2/ngad004/7083777?login=false.

[35] Ibid.

[36] Inter-American Convention on Protecting the Human Rights of Older Persons, art. 3 (c) on "the dignity, independence, proactivity, and autonomy of older persons".

[37] Inter-American Commission on Human Rights and Organization of American States, *Human Rights of the elderly and national protection systems in the Americas* (2022).

[38] Flynn, E., "Disability and ageing: Bridging the divide? Social constructions and human rights", *Routledge Handbook of Disability Law and Human Rights*, Routledge (2016), pp. 211–226.

25. In contrast, article 30 (2) (c) of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa restates the application of the right to legal capacity where a combination of older age and disability may be used to justify the restriction or denial of legal capacity and reiterates the obligation on States to provide older persons with disabilities with all the support they may require to exercise their legal capacity on an equal basis with others.[39] This provision recognizes the intersectional challenges in the enjoyment of this right and offers wider and better protection in line with the standards of the Convention on the Rights of Persons with Disabilities.

26. The non-binding recommendations of the Council of Europe also reflect a medical model that does not align with the Convention on the Rights of Persons with Disabilities. For example, recommendation CM/Rec(2009)6 allows for the loss of legal capacity due to the "worsening of a disability". The language of the recommendation "almost implies that the enjoyment of rights reduces naturally as persons grow older".[40] Recommendation CM/Rec(2014)2 on the protection of the human rights of older persons moves closer to the standards of the Convention, stating that older persons have a right to enjoy legal capacity "on an equal basis with others".[41] At the same time, the recommendation allows for "restrictions which may be required for protection purposes" and for the designation by older persons of a third party to decide on their behalf.[42] Additionally, it accepts that decisions may be taken without the consent of the older individual, such as in cases where "the person is becoming a danger to him/herself or third persons, is incapable of seeing to his or her basic personal needs or is becoming a threat to law and order".[43]

27. Case law from the European Court of Human Rights and the European Committee on Social Rights leave gaps in protections of the legal capacity rights of older persons. Both bodies reflect ambiguity in the understanding and protection of legal capacity in old age. Despite attempts to ensure the autonomy of older persons to make life choices, there is also recognition of legal incapacity, in which case procedural safeguards apply. While the European Court has stated that deprivation of legal capacity may constitute an interference with article 5 (Rights to liberty and security), article 6 (Right to a fair trial) and article 8 (Right to respect for private and family life) of the Convention for the Protection of Human Rights and Fundamental Freedoms (European Convention on Human Rights),[44] it states that limitations on legal capacity can be justified to safeguard the interests of individuals with mental impairments who are unable to take care of themselves.[45] Despite attempts to acknowledge the autonomy of older persons to make life choices, the European Union still recognizes legal incapacity, albeit with procedural safeguards,[46] in contravention to the Convention on the Rights of Persons with Disabilities.

C. Causes of restrictions on the legal capacity rights of older persons

Ageism and a narrative of decline

28. Gaps in protection for the legal capacity rights of older persons at the national level are impacted by multiple intersecting factors. Across countries, a life course narrative suggests that later life is characterized by weakness, decline and vulnerability. This narrative

[39] Flynn, E., "The rights of older persons with disabilities in the Protocol to the African Charter on Human and Peoples' Rights: A critical analysis", *African Disability Rights Yearbook*, vol. 9 (2021), p. 275.

[40] Quinn, G. and Doron, I., *Against Ageism and Towards Active Social Citizenship for Older Persons: The Current Use and Future Potential of the European Social Charter*, Council of Europe (2022), p. 39.

[41] Council of Europe, Recommendation CM/Rec(2014)2, para. 12 (https://rm.coe.int/1680695bce).

[42] Ibid., paras. 13 and 15.

[43] Ibid., Explanatory memorandum, para. 66.

[44] See European Court of Human Rights, *X and Y v. Croatia*, Application No. 5193/09, Judgment, 3 November 2011 (art. 6 of the European Convention).

[45] European Court of Human Rights, *Lashin v. Russia*, Application No. 33117/02, Judgment, 22 January 2013, paras. 80 and 92.

[46] A/HRC/30/43, paras. 16 and 100.

overshadows narratives of strengths in later life, such as the wisdom and emotional stability of older persons and their contributions through family caregiving.[47]

29. Structural or institutional ageism is evident in policies and laws that include age limits and offer fewer opportunities for older persons. Ageism has led to policies and practices suggesting a general acceptance that the rights of older persons can be violated, as needed, to provide special protections, even when violating those same rights of younger persons would not be tolerated.[48] For example, national and subnational laws use old age indirectly as a reason for denial or restriction on legal capacity, for instance by referring to "senility", "age-related illness", or "functional limitations connected with advanced age".[49] Mandatory retirement age is another example of institutional ageism.[50] The coronavirus disease (COVID-19) pandemic revealed a willingness to isolate older persons at higher rates than younger persons and the use of age in triaging access to care.[51] Some countries prevent older persons with disabilities from accessing community-based services and support available to younger persons.[52]

30. This negative narrative and ageism justify an emphasis on protecting older persons from themselves and others by limiting their legal capacity, which leads to a belief that courts, medical providers, families, and others in authority can make better decisions on behalf of older persons than older persons can make for themselves. Paradoxically, this deprivation of rights is anchored in the doctrine of informed consent, which arose out of a recognized need to move away from medical paternalism and toward personal autonomy.

Social and economic factors

31. Loss of income, negative preconceptions and family abandonment can become grounds for the restriction of capacity in old age.[53] In addition, when older persons are no longer engaged in paid employment, there is often a change in family dynamics and roles. Further, States may also impose restrictions on the legal capacity to access their financial assets, including pensions and savings, to maintain control over how those resources are to be used.[54]. Absence of community-based care and supports can force people to live in residential facilities even when they prefer not to, subjecting them to the multiple threats to their legal capacity inherent in such settings.[55]

32. In practice, wealthy older persons may also be subject to restrictions on their legal capacity or their will and preferences may not be acknowledged by those close to them in instances where those close to them are seeking to take control of their resources. The preferences of older persons as to where and with whom they wish to live may be ignored and such situations can lead to economic exploitation by family members or caregivers taking control of their pensions, fortune or property. Older women are particularly at risk of losing their property in later life.[56]

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[47] WHO, *World Report on Ageing and Health* (2015), p. 174, available at https://www.who.int/publications/i/item/9789241565042.

[48] A/HRC/48/53.

[49] Open-ended Working Group on Ageing, "Substantive inputs in the form of normative content for the development of a possible international standard on the focus areas 'right to work and access to the labour market' and 'access to justice'", available at https://social.un.org/ageing-working-group/eleventhsession.shtml.

[50] Jecker, N. S., "The dignity of work: An ethical argument against mandatory retirement", *Journal of Social Philosophy*, vol. 54, No. 2 (2023).

[51] A/HRC/48/53; see also Jecker, N. S., "Too old to save? COVID-19 and age-based allocation of lifesaving medical care", *Bioethics*, vol. 36, No. 7 (2022), pp. 802–808.

[52] Jönson, H. and Larsson, A. T., "The exclusion of older people in disability activism and policies—a case of inadvertent ageism?", *Journal of Aging Studies*, vol. 23, No. 1, (2009), pp. 69–77.

[53] Dabove, M. I., "Autonomy and capacity: about human rights of older persons in dependency situations", *Ageing International*, vol. 42, No. 3 (2017), pp. 335–353.

[54] Age UK, Discussion Papers, Allen, R, "Legal issues for strengthening international legislation on the rights of older persons", para. 30.

[55] Submission by Sage Advocacy.

[56] A/76/157.

33. Older persons living in the community face high rates of violence, abuse and financial exploitation.[57] This is "a major public health problem that results in serious health consequences for the victims, including increased risk of morbidity, mortality, institutionalization and hospital admission, and has a negative effect on families and society at large".[58] Abuse includes confinement by family members or caregivers,[59] even if the confinement is meant to protect the older person. Victims of abuse may experience fear, guilt or shame. These emotions can prevent them from accessing justice and may be misinterpreted as lack of decision-making capacity.[60]

Institutionalization

34. In addition to an increased risk of abuse, neglect and exploitation, older persons are deprived of their liberty in institutional settings such as nursing homes, hospitals and other care facilities,[61] environments that sometimes lack adequate safeguards, vulnerability assessments and independent oversight. Notably, issues with obtaining genuine informed consent are prevalent in long-term care facilities. Older persons may: consent to receive care and treatment in residential facilities without fully consenting to associated restrictions on their freedom; initially consent but later change their minds; or agree to short-term care without intending that it become a long-term arrangement. The issue of voluntariness is further complicated by the lack of choices. Consent without alternatives is essentially coercive. Insufficient resources for community care and the absence of a legal right to home care can force older persons into residential facilities against their will. Additionally, many older persons are not informed that consenting to residential care might entail losing their autonomy, functional independence and privacy.

Intersecting forms of discrimination

35. Older women are more vulnerable than men to loss of legal capacity.[62] They may lack the right to inherit and administer marital property on the death of a spouse or their legal capacity may be deferred to lawyers or family members without their consent.[63] The plight of older women with disabilities to retain and exercise legal capacity has been discussed in a previous report of the Independent Expert.[64] Older women with psychosocial disabilities reporting abuse are often seen as unreliable witnesses owing to memory issues, sometimes leading to denial of their legal capacity.[65] Older women often face higher levels of poverty and less access to pensions, exacerbated by the cumulative effect of the gender pay gap over their working lives, which limits their choices and may impede their ability to effectively exercise their legal capacity.

36. Older persons with disabilities are more likely than others to face formal and informal denial or limitations of legal capacity attributable to "prejudices and assumptions based on both age and disability", leading to many being institutionalized, confined at home or dependent on family members' consent to exercise their legal capacity.[66] Consequently, many older persons with disabilities experience "loss of control over their lives" and exposure to "high levels of violence, abuse and neglect".[67] Older persons with disabilities are particularly at risk of "explicit or implicit pressures arising from their context, including

[57] A/HRC/54/26.
[58] Yon, Y., Mikton, C. R., Gassoumis, Z. D. and Wilber, K. H., "Elder abuse prevalence in community settings: a systematic review and meta-analysis", *The Lancet Global Health*, vol. 5, No. 2 (February 2017), pp. e147–e156.
[59] Dong, X. Q., "Elder abuse: Systematic review and implications for practice", *Journal of the American Geriatrics Society*, vol. 63, No. 6, (2015), pp. 1214–1238.
[60] A/HRC/54/26.
[61] Submission by Sage Advocacy.
[62] Age UK, Discussion Papers, Allen, R, "Legal issues for strengthening international legislation on the rights of older persons"; see also CEDAW/C/GC/27.
[63] CEDAW/C/GC/27, para. 27.
[64] A/76/157, paras. 43 and 53.
[65] Submission by Transforming Communities for Inclusion.
[66] A/74/186 and A/HRC/37/56, para. 18.
[67] A/HRC/37/56, para. 18.

expectations from family members, financial pressures, cultural messages and even coercion”.[68]

37. At the intersection of ageism and the ableism, older persons with mental illness and dementia experience specific challenges. Despite their right to equal legal recognition and capacity, they often experience systematic discrimination[69] and face increased risks of forced institutionalization and neglect.[70] Institutional biases within medical, legal and social systems contribute to such prejudice. In addition, these populations often lack information and access to tools such as advance care planning, which may help to protect their autonomy.[71]

38. Ageing and dementia are threats to legal capacity, with risks exacerbated by widespread ignorance about the various forms of dementia and the diverse ways individuals are affected by it. While some older persons with dementia may require significant assistance in decision-making, others can make decisions independently. Nonetheless, the diagnosis of dementia may lead to the unwarranted removal of a person’s decision-making rights, regardless of their capabilities.[72] The fact that dementia entails gradual cognitive decline complicates the assessment of ability. Individuals may be judged as lacking capacity if they express preferences different from those they expressed when younger. However, even among people without dementia perceived preferences often change dramatically, depending on one’s health situation. It is hard to make clear predictions that cover multiple situations and it is hard to predict whether such decisions will remain constant over time.[73] This raises concerns about whether advance directives can be the answer to concerns about legal capacity and dementia.

39. For older persons from diverse backgrounds, including Indigenous persons, minorities and migrants, culturally accessible services and culturally informed medical care may be lacking. This can lead to incorrect assumptions being made about their legal capacity in instances where providers misunderstand how religious or cultural factors influence their decisions.

40. Older LGBTQ+ persons may experience additional barriers in exercising their legal capacity.[74] The lack of marriage equality in numerous countries means that many older LGBTQ+ persons cannot make legal decisions if their partners become incapacitated nor can they delegate their legal capacity to their partners. This means that third parties, such as estranged biological relatives, may make those decisions on their behalf, against their wishes and advance directives. In addition, older LGBTQ+ persons and couples may face discrimination, based on their sexual orientation and gender identity, in seeking to live independently, either in private housing or in an institutional setting. In the absence of alternatives, they may be obliged to return to their families of origin, where their legal capacity may be further restricted.

D. Good practices to safeguard the legal capacity rights of older persons

Supported decision-making as an alternative to guardianship

41. Supported decision-making is the alternative to the removal of rights when a person requires support in decision-making. As noted by the Committee on the Rights of Persons with Disabilities, in its general comment No. 1 (2014), “support” is a broad term that encompasses both informal and formal support arrangements, of varying types and intensity. Supported decision-making is an emerging practice and policy with potential to empower and support older persons facing cognitive decline, including dementia. Many countries have

[68] A/HRC/43/41, para. 37.
[69] Submission by Austria.
[70] Submission by Cyprus.
[71] Submission by World Psychiatric Association, International Psychogeriatric Association, Capacity Australia, International Longevity Centre Canada and the Canadian Coalition Against Ageism.
[72] Submission by Older Persons Advocacy Network.
[73] Submission by World Psychiatric Association, International Psychogeriatric Association, Capacity Australia, International Longevity Centre Canada and the Canadian Coalition Against Ageism, p. 10.
[74] See A/HRC/54/26/Add.3, para. 29; A/HRC/54/26/Add.2, para. 28; and A/HRC/54/26/Add.1, para. 34.

recognized supported decision-making in legislation. Typically, it enables persons in need of support to identify one or more persons they trust to assist in obtaining and understanding information, evaluating alternatives and expressing and implementing decisions.[75] It is essential that the will and preferences of the person concerned, rather than their perceived well-being, be at the centre of supported decision-making processes.

42. The Austrian Adult Protection Law provides mechanisms for supported decision-making and assistance, allowing individuals to appoint trusted persons to assist them in making decisions regarding their personal and financial matters, and prioritizes assisted decision-making over proxy decision-making.[76] In Cuba, persons who need assistance exercising legal capacity may designate a support-person according to his or her free choice, and can legally specify the nature, identity, scope, duration and guidelines of such support. Supporters can only act on behalf of a person in exceptional circumstances and must respect their previously expressed will and preferences.[77] In 2016, Costa Rica adopted Law No. 9379, by which it abolished all forms of guardianship and introduced the legal role of a guarantor for persons with disabilities to ensure their equality and full legal capacity before the law.[78] In Sweden, "personal ombudsmen" act as independent advocates for persons with cognitive impairments, building trust and offering support in different areas of life, including decision-making.[79]

43. The Assisted Decision-Making (Capacity) Act, in force in Ireland since 2023, includes a complaint mechanism related to decision-making assistants as a safeguard to prevent abuse and undue influence, and further states that relevant persons shall not be considered as unable to make decisions unless all practicable steps have been taken, without success, to help them to do so.[80] In Mexico, all adults possess full legal capacity, although support can be provided for persons who need assistance as regulated by the National Code of Civil and Family Procedures. Support may only be designated by a third party if it is impossible to determine the will and preferences of individuals and they have not left advance directives.[81]

Assessing capacity in the context of preserving autonomy

44. Removal of legal capacity rights owing to disability is inconsistent with the Convention on the Rights of Persons with Disabilities, which shifted the framing of legal capacity to autonomy as the foundational principle and protection as the exception,[82] premised on the notion that legal capacity is inherent to all persons by virtue of their humanity. Nonetheless, decision-making capacity assessments and judgments are widely used to deny older persons their legal capacity rights.[83] Whether based on a guardianship, a medical assessment or a family's opinion that relevant persons need protection, government and local authorities, policymakers, health-care professionals, family and friends may exclude individuals with conditions affecting cognition from making decisions about their own affairs and fail to support their involvement and empowerment.[84]

[75] A/HRC/37/56, para. 41.
[76] Submission by Austria.
[77] Submission by Cuba.
[78] A/HRC/37/56, para. 39.
[79] Ibid., para. 46.
[80] Available at https://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html; see also A/HRC/37/56, para. 47.
[81] Submission by Dr. Cesar Aranda.
[82] Quinn, G. and Doron, I., *Against ageism and towards active social citizenship for older persons: the current use and future potential of the European Social Charter*, Council of Europe, available at https://rm.coe.int/against-ageism-and-towards-active-social-citizenship-for-older-persons/1680a3f5da.
[83] Doron, I., Numhauser-Henning, A., Spanier, B., Georgantzi, N. and Mantovani, E., "Ageism and anti-ageism in the legal system: A review of key themes", *Contemporary perspectives on ageism* (2018), pp. 303–319.
[84] Submission by HelpAge International.

45. The adoption in law of "a presumption of autonomy (with support where needed) at its core",[85] which rejects, in accordance with article 12 of the Convention on the Rights of Persons with Disabilities, the need to emphasize protection over autonomy, is an alternative to focusing on decision-making capacity. Instead, protection can be conceptualized as requiring support for autonomy.[86] This approach is reflected in the Irish Assisted Decision-Making (Capacity) Act, which is driven by the following guiding principles: all persons are presumed to have capacity; capacity is assessed individually, not by group; all practical steps are taken to support decision-making; respect for a person's right to make an unwise decision; intervention only when necessary; intervention, where required, to be the least restrictive possible, with respect for individual rights; facilitation of participation and the articulation of a person's will and preferences; consideration of the views of others who have a bona fide interest in the welfare of the individual; consideration of the likelihood of recovery of an individual's capacity and urgency of intervention; and maintenance of strict confidentiality in the collection and use of personal information.[87]

46. Capacity Australia has educated health-care professionals about the importance of capacity assessment, resulting in best practices being integrated into the National Safety and Quality Health Service Standards for hospital accreditation as well as in the policies of the Australian Government Aged Care Quality and Safety Commission.

Engaging older persons in decision-making processes and respecting their decisions

47. The legal capacity rights of older persons are likely to be more effectively protected if older persons and their advocates are engaged in the development of policies and frameworks that govern legal capacity; this is already an emerging practice in many contexts. In Chile, efforts to establish a legal framework for autonomy and informed consent in health matters have included regular consultations with advisory bodies made up of older persons.[88] In Austria[89] the development of legal standards for the protection and support of adults included organizations representing older persons, guardianship associations and care-home representatives, while in Portugal[90] it entailed the engagement of organizations representing persons with disabilities. Similarly, Nigeria developed its national policy on ageing in consultation with older persons,[91] while Cuba consulted civil society organizations that advocate for older persons in the revision of its Family Code.

48. Legal systems often include advance directives, allowing individuals to state their preferences in advance, so they can be followed at a time when they may not be in a position to communicate them. Such directives usually cover health-care decisions but may include personal, financial or property matters (for example, appointment of an enduring power of attorney). However, the validity and enforcement of such directives, which often depend on the person being declared legally incapacitated, may not be universally binding or subject to exceptions in certain situations.[92]

Strengthening community-based support systems

49. The Special Rapporteur on the rights of persons with disabilities stressed the important role of communities in developing networks and providing support for the exercise of legal capacity.[93] Insofar as older persons tend to be more isolated or lack other sources of family or community support, they may be less likely to rely on formal or informal support

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[85] Quinn, G., Gur, A. and Watson, J., "Ageism, moral agency and autonomy: Getting beyond guardianship in the 21st century", in *Ageing, ageism and the law*, Edward Elgar Publishing (2018), pp. 50–71.

[86] Ashcroft, R. E., Dawson, A., Draper, H. and John McMillan, J. eds., *Principles of Health Care Ethics*, John Wiley and Sons, 2007, chap. 3, Cullity, G., "Beneficence".

[87] See https://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html.

[88] Submission by Chile.

[89] Submission by Austria.

[90] Submission by Portugal.

[91] A/HRC/54/26/Add.1, para. 13.

[92] A/HRC/37/56, para. 44.

[93] Ibid., para.28.

for decision-making.[94] Supportive networks could serve as an alternative to guardianship. For example, the Government of Armenia has established groups in 10 communities that are involved in the decision-making process concerning community residents and provide support to lonely and disabled elderly people living in the community.[95]

50. Support for independent living can help older persons to stay in their communities and to avoid any additional restriction on their legal capacity associated with institutionalization. The Dominican Republic has launched a comprehensive multidimensional programme to support older persons' autonomy and independence, which includes a home-based "preventive, progressive, coordinated and integrated model", including respite care for caregivers and day-care programmes for older persons.[96]

E. Conclusions and recommendations

51. **Structural ageism and discrimination against older persons enable the continuation of policies and practices that restrict their legal capacity. Paternalistic measures to protect older persons may have the opposite result by imposing undue limits on their autonomy. Social and economic factors also play a role. The financial situation of older persons may determine the extent to which they are subjected to restrictions on their legal capacity, while older persons who are victims of violence, abuse and neglect may face additional barriers to exerting their autonomy. Lack of digital literacy or information that is provided in a manner not accessible to older persons may be conflated with a lack of capacity. Older persons facing intersecting forms of discrimination, including women, persons with disabilities, including dementia, Indigenous persons and LGBTQ+ persons often face additional restrictions on their legal capacity.**

52. **The denial of older persons' rights to full legal capacity has myriad impacts on their daily lives and their enjoyment of other human rights. They may be unable to freely choose their living arrangements, make basic decisions regarding their health, their care or their finances or participate fully in society. Older persons subjected to practices such as guardianship or institutionalization face even greater fundamental restrictions, including on their liberty and freedom of movement. It is crucial to move towards approaches that support older persons experiencing cognitive decline or other limitations without infringing upon their human rights. Such approaches may include measures to strengthen supported decision-making, expand community-based support systems and meaningfully engage older persons in the development of policies related to legal capacity.**

53. **The absence of a unified international legal framework to protect the rights of older persons has led to the fragmentation of approaches towards their legal capacity rights and the persistence of medical and social models that limit their autonomy. While regional standards help address this gap, their scope is limited and they lack the authority of a binding international convention. The Convention on the Rights of Persons with Disabilities ushered in a paradigm shift for persons with disabilities, away from medical and social approaches, emphasizing their vulnerabilities and need for protection towards a human rights-based approach that privileges their inherent dignity and individual autonomy as rights-holders and under which they are supported in the exercise of their legal capacity. It is imperative for the international community to achieve the same paradigm shift and establish the same legal protections for older persons.**

54. **The Independent Expert makes the following recommendations to Governments, as the primary duty-bearers, and to other stakeholders, in line with their respective**

[94] Diller, R., "Legal capacity for all: Including older persons in the shift from adult guardianship to supported decision-making", *Fordham Urban Law Journal*, vol. 43, No. 3 (2016), p. 495.

[95] Submission by Armenia.

[96] Submission by Dominican Republic.

mandates, including civil society, health and care providers, equality bodies and rights institutions:

(a) **States should ratify and implement regional conventions and protocols for the protection of the human rights of older persons and include specific standards on autonomy, legal capacity, full informed consent and supported decision-making, in alignment with the standards of the Convention on the Rights of Persons with Disabilities;**

(b) **The implementation of exiting norms must be strengthened and remaining gaps closed to ensure the enjoyment of legal capacity of older person and the support for older persons in decision-making processes;**

(c) **Develop, finance and implement laws, policies and programmes that ensure that older persons' full autonomy is protected and support their autonomous decision-making capacity;**

(d) **Develop measures and programmes to combat ageism and change negative stereotypes that intrinsically link ageing to decline;**

(e) **Ensure that older persons have access to all relevant information necessary to exercise their legal capacity in accessible and understandable formats;**

(f) **Promote the participation of older persons in decision-making processes that affect them, in particular the development of laws and policies related to legal capacity and informed consent;**

(g) **Strengthen contributory and non-contributory pension and social protection systems to ensure that older persons experiencing poverty and in retirement can effectively exercise their legal capacity and avoid financial dependency;**

(h) **Adequately monitor conditions for older persons in situations of dependency, including institutional settings and familial settings, to ensure they are not subject to exploitation or undue restrictions on their legal capacity;**

(i) **Promote supported decision-making models that enable older persons experiencing cognitive decline or other challenges to continue exercising their legal capacity;**

(j) **Promote alternatives to institutionalization, guardianship and other extreme restrictions on legal capacity and ensure adequate monitoring for individuals subject to those restrictions in order to ensure that the legal capacity, will and preferences of older persons are protected;**

(k) **Implement adequate safeguards to prevent forced institutionalization;**

(l) **Ensure that older persons who consent to receive care in institutional settings are able to live autonomous lives and are not coerced to stay longer or expend more of their financial resources on care than they would wish to;**

(m) **Develop and strengthen infrastructure to support independent living in the community as part of an inclusive environment and an option for older persons, ensuring that they have the autonomy to take the decision to live independently;**

(n) **Strengthen the right to receive support and care at home;**

(o) **Develop preventive measures to raise awareness of all different forms of violence, including financial exploitation, which may negatively impact the autonomy and independent living arrangements of older persons;**

(p) **Ensure that older persons have access to justice and remedies to challenge restrictions to their autonomy and assert their agency in relation to where and with whom they wish to live;**

(q) **Undertake additional precautions to ensure that the legal capacity of older persons in all their diversity is protected, in particular for older persons facing intersecting forms of discrimination, including older women, older persons with**

disabilities, older Indigenous persons and LGBTQ+ persons facing restrictions on their legal capacity;

(r) **Older women, in particular, should enjoy equal access to property and inheritance rights, as well as to income through pensions or social protection systems to avoid undue impacts to their legal capacity;**

(s) **Older persons with disabilities must be protected from the loss of control over their lives through implicit or explicit measures on the part of family members or others who make decisions on their behalf;**

(t) **Ensure that older persons with dementia receive the same support as other persons with disabilities, that the standards to protect their autonomy are on equal basis as others and that their legal capacity is not challenged owing merely to their preferences changing over time;**

(u) **Ensure that services for older Indigenous persons, minorities and migrants are culturally adapted in order to better protect their legal capacity and prevent that capacity from being undermined owing to cultural barriers;**

(v) **Monitor the additional barriers faced by older LGBTQ+ persons when decisions need to be taken to support their partners, especially in countries without marriage equality, and to ensure that they have access to services that enable them to maintain their legal capacity, in line with their gender identity;**

(w) **Ensure that assessments of legal capacity and the ability to provide informed consent are applied equally across all age ranges and do not disproportionately target older persons;**

(x) **Promote approaches to capacity assessment that privilege the preservation of autonomy and are individually tailored rather than applied as a general approach to all persons of a certain age;**

(y) **States must ensure that older persons still have access to justice to regain their autonomy, including safeguards, especially when it is easy to deny legal capacity or refuse access to supported decision-making processes;**

(z) **Encourage key stakeholders to receive in training on issues of autonomy, legal capacity and full informed consent in order to understand the implications of those issues on older persons full enjoyment of their human rights;**

(aa) **States must support a paradigm shift, which ensures that older persons are treated as rights holders, including the participation of older persons regarding their right to make autonomous decisions, legal capacity and informed decision-making, based on their will and preferences; the decisions of older persons are key and cannot be ignored or overruled by governments, local authorities, family members or care professions in the light of the "best interest of the older person" or other patronizing behaviour.**