Joint submission by AGE Platform Europe in collaboration with Irish Centre for Human Rights, University of Galway to Fourteenth Session of the United Nations Open-Ended Working Group on Ageing

Substantive inputs in the form of normative content for the development of a possible international standard of the protection of the rights of older persons to "Social inclusion" and "Right to health and access to health services"

12 April 2024

This submission focuses on the degrading and widespread practice of older people's deprivation of liberty in the context of care, and the need to understand older people's rights to **social inclusion** and to **health and access to health services** as (i) prohibiting forced institutionalisation and deprivation of liberty for care purposes and (ii) requiring the provision of consensual home and community-based care services and supports to older people (and those from whom older people wish to receive care) who depend on such assistance.

We respectfully suggest that a future Convention could and should conceptualise as *essential measures of protection against arbitrary detention and inhuman or degrading treatment* the substantive provision of, and legislative entitlement to, care services and supports (including home and community-based care entitlements for older people; financial, educational and other entitlements for those from whom older people wish to receive care; and self-advocacy and decision-making assistance entitlements for all in the care environment) based on free and informed consent.

Thus, we suggest that future Convention provisions on **social inclusion**, the **right to health and access to health services** and a discrete provision on the **right to care and support should respect older people's autonomy and be based on free and informed consent.** In addition, these provisions should refer *inter alia* to the role of such norms in protecting older people's dignity and liberty. Such an approach would emphasise the indivisibility of rights under a future Convention and illuminate aspects of states' immediately applicable positive obligations under Articles 7, 9 and 10 ICCPR and the minimum core of Article 12 ICESCR.

Crucially, making explicit the connection between consensual care services and supports and protection from arbitrary detention and inhuman or degrading treatment would also inform and

galvanise the dedicated human rights machinery that exists to monitor and inspect places of deprivation of liberty and states' implementation of the anti-torture norm in these contexts. This would contribute to realising older people's rights to social inclusion, to health and access to health services, and to autonomy in access to care services and supports at the same time as guarding against violations of the right to freedom from abuse and degrading treatment and right to liberty.

A **right to social inclusion** might require states, among other things, to:

- Prohibit through legislation, regulation, and access to justice the forced institutionalisation or deprivation of liberty of older people for care purposes;
- Ensure inspection and oversight of care services to protect against all forms of arbitrary deprivation of liberty, abuseand denial of legal capacity; and
- Establish legislative, administrative and substantive entitlements to consensual, home and community-based care services and supports for older people and those from whom they wish to receive care, as vital measures of protection against institutionalisation and deprivation of liberty for care purposes.

A **right to health and access to health services** (and a Convention right to consensual care services and supports) might require states, among other things, to:

- Provide and ensure access to person-centred, care services and supports for older people and those from whom they wish to receive care based on free and informed consent, responding to individuals' dependency on the state;
- Ensure that all older people in need of care are treated with humanity and with respect for the inherent dignity of the human person;
- Prohibit and take all necessary measures to prevent the forced institutionalisation or deprivation of liberty of older people for care purposes;
- Ensure access to self-advocacy and decision-making supports and services in all contexts of care; and
- Take all necessary measures to ensure that care providers and care services respect, facilitate and develop older people's capacities.

Supporting arguments are set out in the following appendix, authored by Dr Maeve O'Rourke, Irish Centre for Human Rights, University of Galway. The arguments presented in the appendix are those of the author and do not necessarily reflect the official opinion of AGE Platform Europe or the University of Galway.

Appendix to Submission by AGE Platform Europe in collaboration with Irish Centre for Human Rights, University of Galway to Fourteenth Session of the United Nations Open-Ended Working Group on Ageing

authored by Dr Maeve O'Rourke, Irish Centre for Human Rights, University of Galway; includes material in pre-publication draft form which will be published open access in Maeve O'Rourke, *Human Rights and the Care of Older People: Dignity, Vulnerability, and the Anti-Torture Norm* (OUP 9 May 2024)

Evidence and recognition of older people's widespread deprivation of liberty for 'care'

In recent years, and particularly since the COVID-19 pandemic's onset and in response to the UN Independent Expert on Older Persons' (Independent Expert) work, international human rights norm appliers have increasingly recognised that older people's deprivation of liberty for 'care' purposes is common practice. The numerous types of setting in which older people are deprived of their liberty are being steadily identified, along with the many non-state actors and state actors involved.[1] This emergent recognition is a significant development in legal interpretation and monitoring practice bearing in mind the traditional paradigm of deprivation of liberty in international human rights law, which is state custody through arrest or detention by police, military, or prison authorities.

The Independent Expert has drawn attention to the 'coerced institutionalization of older persons in private and public institutions such as residential care establishments and long-term care or nursing homes; in hospitals and psychiatric facilities; in restrictive community-based detention; or in forced home confinement, usually by relatives or caregivers'.[2] In December 2020, for the first time the European Committee for the Prevention of Torture (CPT) published Standards on 'persons deprived of their liberty in social care establishments'.[3] The Standards open by recognizing that 'elderly persons (including those suffering from dementia)' may be cared for in such settings.[4] The document notes that since 1990 the CPT has visited 'over 100 social care establishments in various Council of Europe member states',[5] and it gives a striking insight into the frequency with which such establishments deprived people of their liberty: 'more often than not' when visiting these environments CPT 'delegations observed that residents were *de facto* deprived of their liberty'.[6] In late 2022, the UN Working Group on Arbitrary Detention (WGAD) summarized its position on the deprivation of liberty of older persons in a report[7] coinciding with the UN Independent Expert on Older Persons' report on

[1] For example, Council of Europe (COE), CPT Factsheet: Persons deprived of their liberty in social care establishments (21 December 2020) CPT/Inf(2020)41 para 1.
[2] UN General Assembly (UNGA), Report of the Independent Expert on the enjoyment of all human rights by older persons, Claudia Mahler, on Older persons deprived of liberty (9 August 2022) UN Doc A/HRC/51/27 para 54.
[3] CPT Factsheet: Persons deprived of their liberty in social care establishments (n 1).
[4] ibid para 1.
[5] ibid.
[6] ibid para 2.
[7] UNHRC, Report of the Working Group on Arbitrary Detention (21 July 2022) UN Doc A/HRC/51/29.

the subject for the same UN Human Rights Council session.[8] The WGAD observed that it had 'come across numerous instances where older persons have been deprived of their liberty in a wide variety of settings',[9] noting 'health-care and social care contexts' as examples of such settings.[10] In 2021, the regional meeting of National Preventive Mechanisms (NPM) in the OSCE region focused on the theme of 'Monitoring the situation of older persons deprived of liberty in the context of the COVID-19 pandemic'.[11] The ensuing report recognized 'a growing tendency across the OSCE region to include nursing homes and social care institutions as part of the NPMs' mandates, as these places are increasingly being understood in law and practice as places where people may be *de facto* deprived of their liberty'.[12]

In a review of NPMs' reports from 26 Council of Europe (COE) member states between 2007 and 2018, all of which mentioned older people's deprivation of liberty in care homes, Nick Hardwick and others found that '[l]ocked doors were widely reported but less common features included darkened corridors (Austria), wire fencing (Serbia), bars on windows (Ukraine) and surveillance systems (Serbia, Spain)'.[13] Administrative barriers can also prevent an older person from leaving a care setting: for example, the Czech Republic's NPM has reported 'typical' practices of identity cards and insurance cards being taken away, and a requirement that clients give all of their income to the facility.[14] It further appears that older people are frequently medicated (usually with anti-psychotic drugs) for sedation purposes or otherwise to control their behaviour.[15] Hardwick and others' recent study of twenty-six European NPMs' reports dealing with older people's care homes reveals that '[m]edical restraint through sedation was commonly referenced, as were excessive use of sedation (Austria, UK), poorly supervised sedation practices (Czech Republic, Finland, North Macedonia) and unexplained use of sedation (Austria)'.[16] Hardwick and others also found that: 'Physical restraints were mentioned in a number of NPM reports, such as binding the hands of a resident (Austria, Serbia) or tying residents to beds (Lithuania, Norway), chairs (Austria) or even railings in

[8] UNGA, Report of the Independent Expert, Claudia Mahler (n 2).
[9] UNHRC, Report of the Working Group on Arbitrary Detention (21 July 2022) UN Doc A/HRC/51/29, para 56.
[10] ibid para 57.
[11] Organization for Security and Co-operation in Europe (OSCE) and Association for the Prevention of Torture (APT), *Monitoring the situation of older persons deprived of liberty in the context of the COVID-19 pandemic: Report on the regional meeting of National Preventive Mechanisms (NPMs) and civil society organizations (CSOs) of the OSCE region, 16–17 June 2021* (OSCE, 25 May 2022).
[12] ibid 15.
[13] Nick Hardwick, Jane Marriott, Karl Mason, and Marie Steinbrecher, 'Human Rights and Systemic Wrongs: National Preventive Mechanisms and the Monitoring of Care Homes for Older People' (2022) *14*(1) *J Hum Rights Pract* 243, 256.
[14] Czech Republic, Public Defender of Rights (Ombudsman), 'Protection against Ill-treatment: Report on the Activities of the Public Defender of Rights as the National Preventive Mechanism in 2014' (2014).
[15] Sube Banerjee, *The Use of Antipsychotic Medication for People with Dementia: Time for Action* (An independent report commissioned and funded by the United Kingdom Department of Health, 2009) 5–6; Zhanlian Feng and others, 'Use of Physical Restraints and Antipsychotic Medications in Nursing Homes: A Cross-National Study' (2009) *24 Int J Geriatr Psychiatry* 1110, 1113; UNHRC, Report of the Independent Expert on the enjoyment of all human rights by older persons, Rosa Kornfeld-Matte (8 July 2016) UN Doc A/HRC/33/44 para 48; UNGA, Report of the Independent Expert, Claudia Mahler (n 2) para 57.
[16] Hardwick and others (n 13) 256–57.

corridors (Bulgaria). Additionally, nets and "cage" type apparatuses around beds (Austria, Hungary) or in rooms (Ukraine) or corridors (Slovenia) were indicated.'[17]

In addition to overt forms of confinement and restraint such as those noted above, the Independent Expert has recognised the absence of home and community-based care services and supports[18] and a 'lack of age-friendly housing solutions'[19] as structural sources of coercion that deprive older people of choice regarding their care and place of residence. Importantly, international human rights treaty bodies tend to focus not on specific types of barrier or forms of physical environment when defining deprivation of liberty; the key question is whether the person is in reality free to leave.[20] As the Inter-American Court of Human Rights (IACtHR) has clarified: 'the particular element that allows a measure to be identified as one that deprives a person of liberty, regardless of the specific name it is given at the local level, is the fact that the person . . . cannot or is unable to leave or abandon at will the place or establishment where she or he has been placed'.[21] Significantly, the CPT's report of its 2022 visit to Italy found a combination of social isolation and lack of access to care in the community to indicate deprivation of liberty of older people in nursing homes.[22]

Social isolation is a frequently observed consequence and feature of institutionalised care for older people. Institutionalisation, meanwhile, is a natural consequence of compulsory placement—which as an overriding matter characterizes the person's chosen manner of living as not the care system's primary concern. Martin Knapp and others acknowledge that congregate living settings are not automatically places of institutionalisation but frequently operate as such.[23] Equally, institutionalisation can occur in community-based settings where

[17] Hardwick and others (n 13) 256. In 2003, the Mental Disability Advocacy Center reported the routine use of cage beds to restrain older people with dementia in Hungary, the Czech Republic, Slovakia and Slovenia: Mental Disability Advocacy Center (MDAC), 'Cage Beds: Inhuman and Degrading Treatment or Punishment in Four EU Accession Countries' (Budapest, 2003).

[18] UNGA, Report of the Independent Expert, Claudia Mahler (n 2) para 56. Also UN Human Rights Council (UNHRC), 'Report of the Independent Expert on the enjoyment of all human rights by older persons, Rosa Kornfeld-Matte' (13 August 2015) UN Doc A/HRC/30/43 para 74, citing UN Economic and Social Council (ECOSOC), 'Report of the United Nations High Commissioner for Human Rights on the human rights situation of older persons' (20 April 2012) UN Doc E/2012/51 para 25. Also a 2012 study of 1,300 nursing home staff in Ireland (one of the largest study undertaken internationally) that found that 73.4% of staff had been involved in arguments with residents about leaving the institutional setting: Jonathan Drennan and others, *Older People in Residential Care Settings: Results of a National Survey of Staff-Resident Interactions and Conflicts* (National Centre for the Protection of Older People, University College Dublin, 2012).

[19] UNGA, Report of the Independent Expert, Claudia Mahler (n 2) para 30. Also Commonwealth of Australia, Royal Commission into Aged Care Quality and Safety, Final Report: Care, Dignity and Respect, Volume 2: The current system (2021) 25.

[20] For example, UN Human Rights Committee (HRC), General Comment No 35, 'Article 9 (Liberty and Security of Person)' (16 December 2014) UN Doc CCPR/C/GC/35 paras 5, 6; UNHRC, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment on migration-related torture and ill-treatment, Nils Melzer (23 November 2018) UN Doc A/HRC/37/50 para 17; UNHRC, Report of the Working Group on Arbitrary Detention (n 72) paras 58, 59.

[21] Inter-American Court of Human Rights (IACtHR), *Rights and Guarantees of Children in the Context of Migration and/or in Need of International Protection*, Advisory Opinion OC-21/14, 19 August 2014, para 145.

[22] CPT, *Report to the Italian Government* (n 46) para 227.

[23] Martin Knapp, Eva Cyhlarova, Adelina Comas-Herrera, and Klara Lorenz-Dant, *Crystallising the Case for Deinstitutionalisation: COVID-19 and the Experiences of Persons with Disabilities* (Care Policy and Evaluation Centre, LSE, May 2021) 9.

older people are detained.[24] The UN Committee on the Rights of Persons with Disabilities explains institutionalisation to involve 'certain defining elements' including a lack of influence over whom one has to accept assistance from, social isolation, lack of control over day-to-day decisions, the imposition of a rigid routine regardless of individuals' will and preferences, identical scheduled activities for all, and constant supervision.[25]

Older people's separation from their partners and other loved ones through institutionalisation for care purposes is commonly highlighted and found to cause 'stress, anxiety and depression'.[26] In a recent wide-ranging review of research on loneliness, Clare Gardiner and others concluded that 'the prevalence of both moderate loneliness and severe loneliness amongst care home residents is high enough to warrant concern'.[27] The Independent Expert has highlighted the 'devastating impacts of contact restrictions, quarantine and isolation' routinely imposed on older people living in nursing homes during the COVID-19 pandemic.[28] Among other forms of restraint (all of which affect the person's ability to act according to their will and to relate to others), chemical restraint is an overwhelming interference with the personality. In Rosie Harding and Elizabeth Peel's qualitative study of informal carers' experiences of the administration of antipsychotic medication to their older relatives with dementia in the United Kingdom, several carers described the medication as leaving the person like a 'zombie' or 'catatonic'.[29] Such descriptions are supported elsewhere.[30]

According to the 2021 report of the OSCE NPM meeting on older people deprived of liberty, NPMs present 'noted that often social care institutions and nursing homes do not offer a programme of meaningful activities to older residents', and denied opportunities for physical exercise.[31] In the context of the COVID-19 pandemic the OSCE countries' NPMs highlighted 'a worrying lack of efforts to enable the residents to maintain their ability to function in their daily life'.[32] Older people's social isolation in care facilities during the pandemic seems also to have resulted in their frequent ouster from emergency public health planning and operational measures. Knapp and others describe nursing home residents' difficulties accessing hospital

[24] ibid 65.
[25] CRPD, General Comment No 5 on living independently and being included in the community (27 October 2017) UN Doc CRPD/C/GC/5 para 16(c).
[26] UNGA, Report of the Independent Expert, Claudia Mahler (n 2) para 59.
[27] Clare Gardiner, Pete Laud, Tim Heaton, and Merryn Gott, 'What Is the Prevalence of Loneliness amongst Older People Living in Residential and Nursing Care Homes? A Systematic Review and Meta-Analysis' (2020) *49 Age and Ageing* 748, 756.
[28] UNGA, Report of the Independent Expert, Claudia Mahler (n 4) para 59. Also HRW, 'Submission to the Independent Expert on the enjoyment of all human rights by older persons: Older persons deprived of their liberty' (1 April 2022) 5.
[29] Rosie Harding and Elizabeth Peel, '"He Was Like a Zombie": Off-label Prescription of Antipsychotic Drugs in Dementia' (2013) *21 Medical Law Review* 243, 265. Also Human Rights Watch (HRW), Hannah Flamm, Megan McLemore, and Bethany Brown, *'They Want Docile': How Nursing Homes in the United States Overmedicate People with Dementia* Human Rights Watch Report (5 February 2018) 36.
[30] For example HRW, *'They Want Docile'*, ibid.
[31] ibid.
[32] Organization for Security and Co-operation in Europe (OSCE) and Association for the Prevention of Torture (APT), *Monitoring the situation of older persons deprived of liberty in the context of the COVID-19 pandemic: Report on the regional meeting of National Preventive Mechanisms (NPMs) and civil society organizations (CSOs) of the OSCE region, 16–17 June 2021* (OSCE, 25 May 2022) 14.

care and palliative care, and nursing homes' de-prioritization for disbursement of personal protective equipment, in some countries during the pandemic.[33] In her concluding analysis in the Final Report of the Australian Royal Commission into Aged Care Quality, Commissioner Lynelle Briggs reflected on the generalized denial of ordinary medical care and allied health services (such as physiotherapy, occupational therapy, and psychology) to older people living in residential care institutions arising from how the state organizes its services—not just during the pandemic. Briggs reflected: 'At various times during our inquiry, I found myself asking 'why are we as a community prepared to accept this?' and 'have we lost our moral compass?'—and I expect some of the answer lies in the fact that most aged care is largely hidden and out of sight of the rest of the community, so the community is unaware of what has been going on.'[34]

The impermissibility under international law of deprivation of liberty for social care purposes and the need for comprehensive prohibition

International human rights law does not permit deprivation of liberty for the purpose of social care, or, assistance with the tasks of daily living. That numerous international human rights actors have particularly recognised older people's *de facto* deprivation of liberty as a widespread problem indicates that many domestic legal systems do not recognise daily personal care or assistance as a lawful justification for deprivation of liberty—lending credence to the notion that such justification does not exist in international law.

Worryingly, in the 2002 European Court of Human Rights (ECtHR) case of *HM v Switzerland*,[35] the Swiss government sought to rely on the practically obsolete[36] ground of 'vagrancy' under Article 5 ECHR to justify an older woman's forcible placement in a nursing home.[37] The ECtHR found in Switzerland's favour—not on the ground of vagrancy, but on the basis that HM's placement was not a deprivation of liberty within the meaning of Article 5 ECHR (such that it did not fall to be justified as lawful detention). Although the police had taken HM to the nursing home pursuant to a court order, the ECtHR held that the placement was not a deprivation of liberty because it was in HM's best interests[38] and allowed her freedom of movement *within* the institution and to 'entertain social contacts with the outside world'.[39] The ECtHR further found that after more than a year in the nursing home under a placement order, 'she agreed to stay there'.[40] The majority's decision in *HM v Switzerland* prompted strongly dissenting judgments. In my respectful submission, *HM v Switzerland* is a clarion call for clear and comprehensive articulation, in a future Convention (and elsewhere), of older

[33] Knapp and others (n 23) 37–38, 45–46.
[34] Commonwealth of Australia, Royal Commission into Aged Care Quality and Safety, Final Report: Care, Dignity and Respect, Volume 2: The current system (2021) 26.
[35] *HM v Switzerland* (2004) 38 EHRR 17 para 24.
[36] ECHR, *Guide on Article 5 of the European Convention on Human Rights: Right to Liberty and Security* (31 August 2022) para 137.
[37] *HM v Switzerland* (2004) 38 EHRR 17 para 38.
[38] ibid para 48.
[39] ibid para 45.
[40] ibid para 47.

people's right to liberty which must be secured through the substantive provision of and legal entitlements to consensual care services and supports.

The ECtHR's 2014 judgment in *KC v Poland*[41] further demonstrates the need for a future Convention to reinforce Articles 12 and 14 UNCRPD and to ensure that long-term care/personal care/social care do not proliferate as justifications for deprivation of liberty of older people—crucially, by requiring states to substantively provide and legally entitle older people to consensual care services and supports in the home and community. The ECtHR's judgment in *KC v Poland* illustrates the societal and legal tendency to mask the denial of care to older people and people with disabilities by portraying it as self-neglect and therefore evidence of their purported 'incapacity' to understand their own care needs.

KC v Poland concerned the detention of a seventy-one-year-old woman in a social care home by court order. Successive psychiatrists had advised the domestic courts that although they had diagnosed KC with a 'mental disorder' there was no need for KC's hospitalisation and she did not pose a threat to her own or others' life or health. Despite KC's clear objections, made known at the time of the domestic court hearing and through her determined litigation thereafter, the ECtHR found KC's initial compulsory placement justified on the ground of 'unsound mind' because the state's social services authority and assessing psychiatrists determined that she needed ongoing assistance with the tasks of daily living including hygiene and nutrition. Full-time home care was not available from the state authorities, nor from her daughter. The Court observed that KC 'had neglected herself and her apartment and failed to observe the basic principles of hygiene and nutrition' and therefore 'the domestic court's decision to confine the applicant in a social care home was properly justified by the severity of disorder'.[42] (Ultimately, the ECtHR found a violation of Article 5 ECHR due to the fact that the domestic law did not require regular reviews of the justification for the deprivation of liberty: KC had been detained for over six years and her last examination by a psychiatrist had taken place more than five years previously as part of her daughter's failed appeal on her behalf against her detention.[43])

The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa does not contain an explicit statement of the right to liberty but provides in its Article 11 that 'States Parties shall enact or review existing legislation to ensure that residential care is *optional* and affordable for Older Persons'[44] (my emphasis). Article 13 of the Inter-American Convention on the Rights of Older Persons includes in its statement of the right to personal liberty that 'in no instance shall age be used to justify the arbitrary denial or restriction of liberty'.[45]

[41] *KC v Poland* App no 31199/12 (ECtHR, 25 November 2014).
[42] ibid para 69.
[43] ibid para 70.
[44] Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa (adopted 31 January 2016) rt 11.
[45] Inter-American Convention on Protecting the Human Rights of Older Persons (adopted 15 June 2015, entered into force 11 January 2017) (2016) 55(5) ILM 985 art 13.

The above submission argues that a future UN Convention on the rights and dignity of older persons should both prohibit older people's deprivation of liberty for care purposes and comprehensively require states substantively to provide and legislatively to entitle older people to a range of consensual care services and supports: in order to protect against arbitrary detention and violations of the anti-torture norm in practice, and to further the rights to social inclusion, and to health and access to health services.