



A Human Rights-Based Approach to Long-Term Care

Age Action is Ireland's leading advocacy organisation promoting equality for all of us as we age.



Rialtas na hÉireann
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About Age Action

Age Action is the leading advocacy organisation on ageing and older people in Ireland. Age Action advocates for a society that enables all older people to participate and to live full, independent lives, based on the realisation of rights and equality, recognising the diversity of experience and situation. Our mission is to achieve fundamental change in the lives of all older people by eliminating age discrimination, promoting positive ageing, and securing the right for all of us to comprehensive and high-quality services.

Acknowledgements

Age Action derives expertise from our frequent interactions with older persons, through surveys, focus groups, one on one interviews, and informal methods. We have heard from many people about experiences accessing and receiving care. The concerns and perspectives of older persons with care needs inform this document, as well as domestic and international literature on the human rights of older persons. Moreover, an earlier version of this paper was shared with two experts in the field and invaluable feedback was received. We want to thank our peer reviewers for their contributions.

The Case for a Human Rights-Based Approach to Long-Term Care

A long-term care system must have human rights at its core. There is a growing movement, domestically and internationally, to articulate and implement a human rights-based approach to policy relevant to ageing and older persons, including or especially on long-term care.¹ A more detailed definition of long-term care is given below, but it should be noted at the outset that this is an expansive concept that covers many manifestations of care, from the informal to the formal and from the basic to the intensive. A human rights-based approach overcomes a long-standing issue in policy and services related to ageing and older persons, which is the presumption of vulnerability, neediness and incapacity. Human rights are empowering. They recognize and respect the autonomy and dignity of individuals and award them entitlements based on their humanity. Human rights serve as a coherent, authoritative, and well-developed framework in which to act, based on legal obligations and supported by a wealth of international guidance, analysis, and case law. Anomalous or arbitrary rules and practice will be ironed out under the rigorous application of a human rights-based approach to long-term care, and quality of care should improve.²

Ireland is beholden to many human rights agreements and has positive obligations to uphold rights in the delivery of its services and implementation of its laws and policies.

¹ For example see: <https://www.who.int/news-room/fact-sheets/detail/human-rights-and-health> <https://www.hiqa.ie/reports-and-publications/guide/guidance-human-rights-based-approach-health-and-social-care-services> <https://arrow.tudublin.ie/cgi/viewcontent.cgi?article=1060&context=jsoc> ; EU Charter of Fundamental Rights – Art 25 : “The rights of the elderly” (2000/2009) <https://fra.europa.eu/en/eu-charter/article/25-rights-elderly> ; <https://www.eesc.europa.eu/en/our-work/opinions-information-reports/opinions/european-strategy-older-persons> ; EU Council conclusions 2020 and 2021: <https://www.consilium.europa.eu/en/press/press-releases/2020/10/12/improving-the-well-being-of-older-persons-in-the-era-of-digitalisation-council-adopts-conclusions/> ; UN Special Rapporteur on Disability report on older persons with disabilities (2019) <https://www.ohchr.org/en/documents/thematic-reports/report-rights-older-persons-disabilities>

² Schulmann, K., Ilinca, S., Rodrigues, R. & Pateisky, D. (2017) *From disability rights towards a rights-based approach to long-term care in Europe: Building an index of rights-based policies for older people*, EURO.CENTRE.REPORT. Vienna: European Centre. <https://www.euro.centre.org/publications/detail/3092>

We ratified the Convention on the Rights of Persons with Disabilities, the substance of which is relevant to the lives of older persons receiving care. HIQA has discussed human rights-based approaches in health and social-care services,³ and the HSE has a National Office for Human Rights and Equality Policy.⁴ All of this means human rights and equality should be suffusing our care sector, yet the rights of older persons receiving care are often neglected or not fully respected.

Defining Long-Term Care

‘Care’ is difficult to define and covers a multitude of relationships and dynamics. It can be subjective, and people move in and out of care roles, both giving and receiving, and may give and receive care simultaneously. It is an integral part of any human society. Care should aim to improve and protect the well-being of those receiving it, which would necessarily involve empowering them and vindicating their rights.⁵ Long-term care includes social, healthcare and support services provided to older persons in all public and private settings, including at home, community-based services, day-care centres, residential institutions, hospitals, hospices, prisons or other settings. It is provided by both formal and informal caregivers or support providers including volunteers.⁶

In Ireland, there are three main options for people requiring assistance with care, each bringing different levels of supports, costs and regulatory requirements:

- Nursing home care for those needing intensive support,
- Formal home care for those needing support to live at home,
- Informal care from a family member or other support person.

Within each of these kinds of care there is great variation. A person may move between these kinds of care, or indeed receive multiple kinds simultaneously (e.g. formal home care and informal care from family). A human rights-based approach to long-term care can challenge and transform the boundaries between these kinds of care.

³ <https://www.hiqa.ie/sites/default/files/2019-11/Human-Rights-Based-Approach-Guide.PDF>

⁴ <https://www.hse.ie/eng/about/who/national-office-human-rights-equality-policy/>

⁵ For another human rights-based description of long-term care, see <https://www.sageadvocacy.ie/media/2026/choicematters2020.pdf> ; For further elaboration on how long-term care can be empowering, see <https://www.age-platform.eu/care-must-empower-us-throughout-our-lives-age-position-paper/>

⁶ UN General Assembly (2019) *Substantive Inputs in the form of Normative Content for the Development of a Possible International Standard on the Focus Areas “Autonomy and Independence” and “Long-term and Palliative Care”* Working document submitted by the Department of Economic and Social Affairs (DESA) in collaboration with the Office of the High Commissioner for Human Rights (OHCHR). Available at www.social.un.org.

Problems in Our Current Care System

Problem: Ageism and Lack of Respect for Rights

The World Health Organisation defines ageism as arising when “age is used to categorize and divide people in ways that lead to harm, disadvantage and injustice and erode solidarity across generations.”⁷ Age Action’s own polling has found ageist attitudes to be pervasive in Ireland,⁸ and many people Age Action has talked with are aware of how, as they age, they are increasingly deprioritized and pushed to the margins of society. One older person told Age Action that, “The system assumes that as you grow older you can do without being able to hear, or see, or having teeth.” Ageist opinions became more socially acceptable during the COVID-19 pandemic in which it was commonplace to argue that older persons should be deprioritized in healthcare contexts.⁹

At the same time, ageism is under-discussed and often poorly understood, and in older age we can ourselves internalize ageist attitudes that make us accept undignified living conditions and limits on our autonomy as a natural and inevitable consequence of growing old. Older persons can be less likely than other groups to agitate for their rights or against discrimination as there can be a shared perception that they are obligated to step aside for younger generations.¹⁰ The World Health Organisation demonstrates how ageism can be perpetrated by institutions, in laws and policy, service design, and practices and cultures that develop informally.¹¹ This includes institutions tasked with providing or facilitating care. Ageism is reinforced when institutions and services do not treat older persons with respect, and inversely, older persons will not be treated with respect until institutions and services are free of ageism.

The way in which services are made available and delivered to older persons can contribute to their segregation from society¹² and there is an inappropriate focus on their ‘needs’ and framing their presence in society as burdensome. This comes at the expense of recognizing the rights of older persons and the obligations that flow from them.¹³ Respect for older persons and their rights needs to be embedded in care, and it needs to be understood as a means of resisting ageist attitudes and behaviours.

⁷ <https://www.who.int/publications/i/item/9789240016866>

⁸ https://www.ageaction.ie/sites/default/files/are_we_ageist_poll_findings_december_2022.pdf

⁹ D’cruz, Migita, and Debanjan Banerjee. “An invisible human rights crisis’: The marginalization of older adults during the COVID-19 pandemic—An advocacy review.” *Psychiatry research* 292 (2020): 113369. Also see statement from the UN Independent Expert on Rights of Older Persons <https://www.ohchr.org/en/press-releases/2020/03/unacceptable-un-expert-urges-better-protection-older-persons-facing-highest>

¹⁰ D’cruz, Migita, and Debanjan Banerjee. “An invisible human rights crisis’: The marginalization of older adults during the COVID-19 pandemic—An advocacy review.” *Psychiatry research* 292 (2020): 113369.

¹¹ <https://www.who.int/publications/i/item/9789240016866>

¹² D’cruz, Migita, and Debanjan Banerjee. “An invisible human rights crisis’: The marginalization of older adults during the COVID-19 pandemic—An advocacy review.” *Psychiatry research* 292 (2020): 113369.

¹³ D’cruz, Migita, and Debanjan Banerjee. “An invisible human rights crisis’: The marginalization of older adults during the COVID-19 pandemic—An advocacy review.” *Psychiatry research* 292 (2020): 113369. The UN discusses the consequences of the failure to apply a rights framework to older persons:

<https://www.ohchr.org/en/documents/outcome-documents/ohchr-working-paper-update-2012-analytical-outcome-study-normative>

Problem: Inadequate Safeguarding against Abuse and Mistreatment

International research shows that one in six persons aged 60+ in community settings experienced abuse in 2020, and that two-thirds of nursing home or long-term care facility employees admitted to having committed abuse against older persons.¹⁴ This is indicative of how normalized certain practices can become so that they are understood as part of care rather than antithetical to it, such as over-medicalization or people being made to sit in chairs that they are unable to get out of themselves. Abuse can thus be institutionalized and facilitated by routines and practices that often emerge due to under-resourcing.

Persons in institutional settings or in care relationships with power imbalances are at particular risk of rights abuses and this risk can be further exacerbated by social isolation or situations in which the person's decision-making capacity is limited.¹⁵ Persons receiving care in the community can also be at risk of abuse without access to safeguards, including because this abuse can be "hidden" in the home, there are no formalized systems for monitoring or reporting, and that it may be perpetrated by family members who the victim is reluctant to report, including due to a relationship of dependency.

Older people in long-term care are thus at high risk of abuse and mistreatment.¹⁶ The degree of its prevalence in our society is hard to estimate, as abuse is under-reported and there is a lack of data in this area. Examples of safeguarding issues that are documented include: the situation of older people in nursing homes during the COVID-19 lockdowns,¹⁷ cultures of abuse, neglect, and exploitation of older persons,¹⁸ and the failure to meet older people's care needs due to inadequately resourced services, creating unsafe and undignified living conditions.¹⁹

The HSE's annual adult safeguarding report provides a minimum estimate of abuse, as it only includes cases reported to them, which are typically cases where someone is a resident in a HSE facility or otherwise in contact with HSE staff. In 2022, there were 15,464 cases of abuse reported, including 2,670 cases affecting people aged 65-79 and 2,217 cases affecting people aged 80 or older. A third of all cases (31.6%) affected older persons, especially those aged 80 or older who are more likely to have care needs, including the need for residential care. The cases affecting older persons

¹⁴ <https://www.ohchr.org/sites/default/files/2022-03/UN-Advocacy-Brief-Older-Women.pdf>

¹⁵ Equality and Human Rights Commission. 'Close to Home: An inquiry into older people and human rights in home care.' Available at https://www.equalityhumanrights.com/sites/default/files/close_to_home.pdf

¹⁶ Phelan, A. (2023), "Adult safeguarding in Ireland: a critical review of context and gaps", The Journal of Adult Protection. <https://www.emerald.com/insight/content/doi/10.1108/JAP-10-2022-0025/full/html>

¹⁷ A description of such is provided here:

<https://www.universityofgalway.ie/media/irishcentreforhumanrights/files/reports/Care-Champions-letter-to-IHREC-22-2-23.pdf>

¹⁸ In the nursing home context, see the National Care Experience Programme's Survey of Residents 2022, in which the five lowest scoring questions pertained to safeguarding, in that they express the lack of control residents' have over their lives. <https://yourexperience.ie/wp-content/uploads/2022/11/Nursing-Home-Resident-Report-2022-V3.pdf>

¹⁹ At the end of March 2022, there were 286 people assessed and waiting for funding for new or additional home support, while 5,458 people were assessed and approved for Home Support but are awaiting a carer to be assigned. As of 17 May 2022, the HSE reported 90 patients nationally who are waiting to be discharged with home support. https://www.oireachtas.ie/en/debates/question/2022-05-26/378/#pg_378 Also see a description of the limits of long-term care in Ireland in <https://op.europa.eu/en/publication-detail/-/publication/b39728e3-cd83-11eb-ac72-01aa75ed71a1>

included 1,183 cases of physical abuse, 850 cases of financial abuse, 634 cases of neglect, and 165 cases of sexual abuse.²⁰

Problem: Institutionalization

Too many older persons with care needs are placed in institutional settings instead of being supported to remain in their homes—in part because such supports often don't exist.²¹ Those in institutional settings often remain there too long before being transferred to community settings.²² UCC research, supported by Age Action, demonstrated the strong attachment to home and place shared by older persons, and the extreme reluctance to leaving.²³ Countless older persons have expressed this view to Age Action, and anger toward the practice of “warehousing” people in “the last years of their lives.” Moreover, institutional settings can give rise to abuse, exploitation, and neglect, as described in the section above on safeguarding issues. Many reports emerged during pandemic lockdowns highlighting the difficult situations endured by nursing home residents. Living in institutions can be detrimental to psychological well-being, social inclusion, and independence. It too often interferes with a resident's right to privacy and family life, such as by separating spouses or limiting visitation. For older persons' human rights to be honoured when care needs emerge, policy and services must be designed to support them to remain in their homes and communities, to deliver community care in a rights-affirming manner, and to minimize the role of institutions in our society, in line with article 19 of the Convention on the Rights of Persons with Disabilities.

Problem: Barriers to Procedural Justice

Access to justice does not just mean the right to have one's case heard before a court. It also relates to complaint, reporting, and oversight procedures across state actors. Older persons receiving care often cannot access justice, due to these procedures in the care context being inadequate. For example, independent advocates for older persons lack supports and entitlements to fulfil their roles, and there exists no state authority tasked with taking on individual complaints regarding care. As it stands, complaints procedures can be unclear, inadequately impartial, overly formal, overly narrow in their remit, and intimidating. Complaints may be responded to but not treated as seriously as they should be, for example if someone is making allegations of abuse.²⁴ There may be no option for appealing the outcome of a complaints process. Making a complaint or appealing might be particularly prohibitive for persons with certain disabilities or impairments. Often access to justice is not realized in a care context due to a lack of information.²⁵ Many people receiving care feel uncomfortable raising concerns and can even fear retaliation. Where complaints are made, they can be handled improperly due to cultures of ageism that normalize mistreatment or that disregard the perspectives of older persons. Sage Advocacy has reported on cases where persons are directly discouraged by nursing home staff members from lodging

²⁰ <https://www.hse.ie/eng/about/who/socialcare/safeguardingvulnerableadults/nationalsafeguardingreport2022.pdf>

²¹ <https://www.ohchr.org/en/calls-for-input/report-rights-older-persons-disabilities>

²² <https://www.ihrec.ie/app/uploads/2023/07/Policy-Statement-on-Care.pdf>

²³ https://www.ageaction.ie/sites/default/files/agency_and_ageing_in_place_in_rural_ireland_report_2022.pdf

²⁴ https://www.sageadvocacy.ie/media/1124/report_of_forum_on_ltc_for_older_people.pdf

²⁵ https://ennhri.org/wp-content/uploads/2019/10/ennhri_hr_op_web.pdf

complaints.²⁶ Where the right to access justice is not upheld, all other rights are put in jeopardy.

Problem: Profit Motive

In 2021, 84% of nursing home beds were provided by private or voluntary nursing homes.²⁷ Between 2009 and 2021, there was a net growth of 45 private nursing homes per year.²⁸ In 2020, it was estimated that 75% of the revenue in the private homecare sector was obtained from public sources, including tax allowances.²⁹

The Irish state treats care as a product. This defies its social role and inherently human elements, and worsens the quality of care, as the incentive for profit-driven private providers becomes reducing costs, rather than improving care or protecting human rights. It also produces a framework which makes no room for valuing informal, family, or community carers. As one older person wrote to Age Action regarding nursing homes, “They should be nonprofit by law. A resident's needs will always impact the profit margin leading to questionable decisions. This is a moral issue.” If private institutions are to continue to have a role in the care sector, the state must ensure they are guided by human rights principles first and foremost, rather than profit.

The Irish Human Rights and Equality Commission has said, “Seeking to make a profit from care is antithetical to its values.”³⁰ Human rights and equality cannot be adequately safeguarded in a system that is dependent on making profit, particularly in sectors such as care where rights and equality are more easily interfered with.

Problem: Feminization of Care

Gender complicates care in many ways. One dynamic in play is that men provide less care than women. Another is that, because of the strong association between care and women, care is under-valued, disregarded, and rendered invisible.

For example, in Census 2016, fewer than 27,500 men gave their principal economic status as ‘looking after home/family’ whereas 245,000 women reported that status—nearly nine times as many as men. Census 2022 also found that women are not only more likely to provide unpaid care, but they typically provide more hours per week than men. Women are nearly twice as likely as men to be full-time carers and provide over 43 hours per week in unpaid care. At the same time, legal supports and entitlements for carers are limited, such as to respite care.

²⁶ See page 30 <https://www.sageadvocacy.ie/media/2026/choicematters2020.pdf>

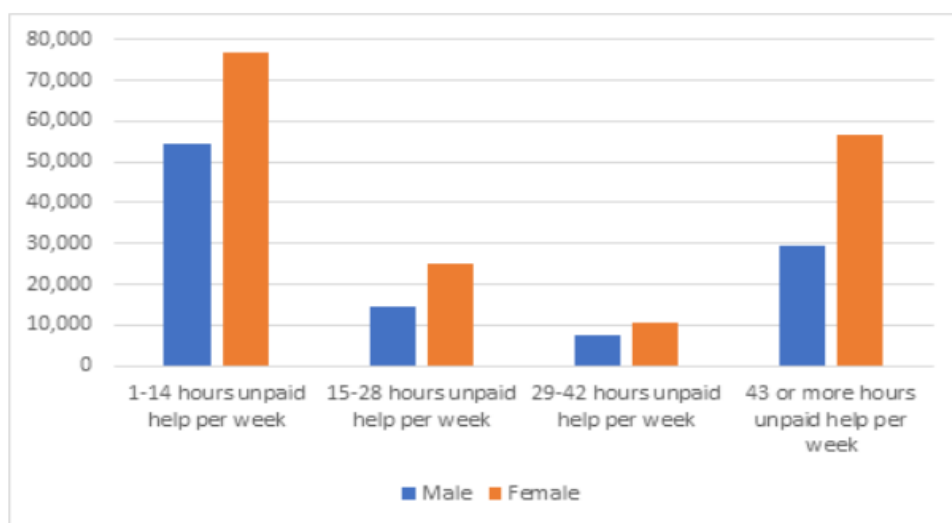
²⁷ Nursing Homes Ireland, ‘Private & Voluntary Nursing Home Survey Results 2020/2021’ (2021) [https://www.bdo.ie/getattachment/Insights/2022/BDO-Private-Voluntary-Nursing-Home-results-2020-21/Private-Voluntary-Nursing-Home-Survey-Results-2020-21-v4-\(1\).pdf.aspx?lang=en-GB](https://www.bdo.ie/getattachment/Insights/2022/BDO-Private-Voluntary-Nursing-Home-results-2020-21/Private-Voluntary-Nursing-Home-Survey-Results-2020-21-v4-(1).pdf.aspx?lang=en-GB)

²⁸ Nursing Homes Ireland, ‘Private & Voluntary Nursing Home Survey Results 2020/2021’ (2021) [https://www.bdo.ie/getattachment/Insights/2022/BDO-Private-Voluntary-Nursing-Home-results-2020-21/Private-Voluntary-Nursing-Home-Survey-Results-2020-21-v4-\(1\).pdf.aspx?lang=en-GB](https://www.bdo.ie/getattachment/Insights/2022/BDO-Private-Voluntary-Nursing-Home-results-2020-21/Private-Voluntary-Nursing-Home-Survey-Results-2020-21-v4-(1).pdf.aspx?lang=en-GB)

²⁹ Julien Mercille and Nicholas O’Neill, The Growth of private home care providers in Europe: The case of Ireland (2020), Social and Policy Administration, 1-16, p. 2; cited in the Irish Human Rights and Equality Commission’s Policy Statement on Care (2023). <https://www.ihrec.ie/app/uploads/2023/07/Policy-Statement-on-Care.pdf>

³⁰ <https://www.ihrec.ie/app/uploads/2023/07/Policy-Statement-on-Care.pdf>

Figure 1. Men and Women Providing Unpaid Care by Hours/Week (Census 2022)³¹



Most carers are women, and women spend more time caring than men.³² This is due to a set of values in which men are seen as public actors, active in civic society and the economy, whereas women are relegated to the realm of the domestic. This arrangement underpins patriarchy. Much of gender inequality, and misogynistic attitudes towards and treatment of women, is enabled by women being assigned domestic and familial duties which men are exempt from in society's division of labour.

The feminization of care exists not only within our culture but also our legal order, with the Irish Constitution positioning women as unique in their possession of lives and duties within the home, necessary to the functioning of society.³³ This is antithetical to any commitment to gender equality and the human rights of women.

Another gender dynamic at play in the care context is that women are more likely than men to be resident in nursing homes.³⁴ Because women live longer, are less likely to remarry after divorce or spousal bereavement, and are less likely than men to have married someone younger, women in older age are more likely than men to live alone.³⁵ Older women also have significantly lower incomes than men. All of this means that where care needs emerge women are more likely to be institutionalized, as they are not living with someone who can support them, and thus the issues of safeguarding and ageism present for residents in institutional settings also often intersect with sexism, and can lead to gendered forms of abuse and mistreatment such as rape or sexual harassment. Sexual abuse against older women in care contexts is deeply misunderstood and under-recognized, and older women are not trusted to understand

³¹ <https://data.cso.ie/table/F3057>

³² <https://www.cso.ie/en/releasesandpublications/ep/p-ihsc/irishhealthsurvey2019-carersandsocialsupports/carers/>

³³ Article 41.2 of the Irish Constitution. There is a forthcoming referendum to replace this provision with a gender neutral alternative that recognizes the importance of care within the family.

³⁴ Hennessy, O., and McGauran, A-M. 2021. Gender and Covid-19 in Ireland. NESC Secretariat Covid-19 Working Paper Series. Paper No. 21. March 2021.

³⁵ http://files.nesc.ie/nesc_research_series/Research_series_paper_21_Gender.pdf

³⁵ data.cso.ie/table/E9089

or accurately communicate their own experiences, as was shown in the recent ‘Emily case’.³⁶

Problem: Implementation Gap

Human rights in the Irish care system are interpreted too narrowly, are not adequately prioritized as a guiding principle, and their relevance has not been adequately explored or explicated. Yet even to the degree that human rights have been fleshed out at a legal or political level in the care context, they fail to translate into practice. This is evidenced in the European Centre for Social Welfare Policy and Research’s “Rights of Older People Index” and “Scoreboard of Outcome Indicators”. While Ireland performed well relative to other countries in its human rights law and policy, its actual ability to deliver and protect human rights was markedly poorer. Ireland was joint last out of 12 countries for providing remedy and redress, and joint second last for freedom from restraint.³⁷ This shows that part of committing to a human based approach to long-term care will be installing an infrastructure capable of transforming culture and translating high level policy and law into practice.

In its 2019 overview report of older persons services, the last prior to COVID-19, HIQA found that only 21.5% of nursing homes were fully compliant with relevant regulations, for example to do with insurance, food and nutrition, or visits.³⁸ Even then, the regulations which HIQA monitors are generally limited to matters of health and safety, rather than rights.

This “implementation gap” needs to be closed off. Effective monitoring and enforcement mechanisms must accompany formal legal commitments to a more thorough and expansive human rights-based approach to long-term care, and those delivering care must be supported through the culture change with adequate resources and training.³⁹

Problem: Disjointed System

Long-term care in Ireland is disjointed.⁴⁰ There is a lack of coordination and harmonization between the different kinds of care available and the different providers of care operating within the sector, and transitioning from one phase of care to another can be needlessly difficult and slow-moving. Moreover, the disjointed nature of the current care system (between residential and home care, and public, voluntary, and private care) creates rights violations in terms of equality of access. Stakeholders who

³⁶ <https://www.hse.ie/eng/services/publications/independent-review-of-the-governance-arrangements-in-a-hse-nursing-home.pdf>

³⁷ Birtha, M., Sandu, V., Zólyomi, E., & Rodrigues, R. (2019). Taking a human rights-based approach in monitoring policies for older people in Europe, Policy Brief 2019/10. Vienna: European Centre. <https://www.euro.centre.org/publications/detail/3519>

³⁸ HIQA (2020). *Overview report on the regulation of designated centres for older persons – 2019*. Available at https://www.hiqa.ie/sites/default/files/2020-12/DCOP_Overview_Report_2019.pdf

³⁹ Schulmann, K., Ilinca, S., Rodrigues, R. & Pateisky, D. (2017) *From disability rights towards a rights-based approach to long-term care in Europe: Building an index of rights-based policies for older people*, EURO.CENTRE.REPORT. Vienna: European Centre. <https://www.euro.centre.org/publications/detail/3092>

⁴⁰ UN General Assembly (2019) *Substantive Inputs in the form of Normative Content for the Development of a Possible International Standard on the Focus Areas “Autonomy and Independence” and “Long-term and Palliative Care”* https://social.un.org/ageing-working-group/documents/tenth/A_AC.278_2019_CRP.4.pdf and Sage Advocacy (2019) *Financing Long-term Care in an Ageing Society The Challenge Facing Ireland Summary*. https://www.sageadvocacy.ie/media/1538/sage-advocacy_summary-financing-long-term-care-in-ireland_2002019.pdf

engaged with IHREC referred to the care system as a “postcode lottery.”⁴¹ To some older people with whom Age Action has engaged, who gets access to quality care and who doesn’t feels like “the luck of the draw.” One respondent to our 2022 Lived Experience Survey wrote, “Why at the end of your life is the care you can expect so uncertain. Like a weight on one’s shoulders...”

Recognition of human rights will require an adoption of a whole-of-government approach to care. This is because human rights are indivisible, interdependent, and interrelated, which means that siloed efforts towards upholding rights are inherently flawed and holistic systems are required.

Solution

To support older persons to live with dignity and autonomy and protect them from abuse and mistreatment, a far-reaching transformation of our care system is needed. This is what a human rights-based approach offers. Though not a panacea, human rights have transformative potential. When a person is attempting to access long-term care, a human rights-based approach should ensure it is affordable, equitable, suitable, and timely.⁴² Once a person is in long-term care, a human rights-based approach encompasses all aspects of their experience. At a high level, it means putting older persons’ preferences at the centre of the system. It means moving away from a strictly medical lens toward a holistic perspective of well-being. This will involve a rejection of rigidity and adopting a flexible approach to care that reflects the circumstances, preferences, and aspirations of the individual recipient. The following section goes into further detail on what a human rights-based approach to long-term care would look like.

⁴¹ <https://www.ihrec.ie/app/uploads/2023/07/Policy-Statement-on-Care.pdf>

⁴² HIQA (Nov 2019). *Guidance on a Human Rights-based Approach in Health and Social Care Services*. Available at: <https://www.hiqa.ie/reports-and-publications/guide/guidance-human-rights-based-approach-health-and-social-care-services>

Describing a Human Rights-Based Approach to Long-Term Care

Human Rights, Care, and Carers

Care is a relationship between two or more people, and the rights of all involved are interdependent.⁴³ A good relationship with their carers is integral to older persons' ability to enjoy their human rights.⁴⁴ One older person told Age Action, regarding carers: "they're not treasured the way they should be. Not just in a moral sense but in a practical sense, given the amount they contribute."

Carers, both professional and informal, are disadvantaged in our society, in part due to their work being under-valued as a woman's pursuit, combined with ageism leading to care of older persons being de-prioritized. Due to poor work conditions and inadequate incomes, the rights of carers are often at risk. This is an important policy issue that urgently needs to be addressed but is largely outside the scope of this paper. What is relevant is that where carers are not supported, their ability to protect the human rights of those for whom they care will be gravely jeopardized.⁴⁵ Much of the existing material on human rights in care is concerned with promoting good practice within the existing system. However, this attempt to translate high level commitments into daily behaviours can be met with resistance from staff, particularly if they feel it is additional bureaucracy or if they do not have the required supports to undertake what they believe to be a more arduous approach to care.⁴⁶ Informal carers, who deliver the bulk of care in Europe, have even less opportunity to develop a human rights-based approach to care.

To uphold the human rights of those in receipt of care, carers (including informal carers) must be adequately trained and resourced and there needs to be strong continuity across staff. Carers and related staff must be capable of effectively involving older people in decisions regarding their care and other aspects of their life over which the carer or staff member exercises influence.⁴⁷ This will involve formal and informal networks of communication with relevant parties, including the care recipient's family. Informal carers must also be supported, including in terms of the psychological and emotional impact caring can have and to help them reconcile their care obligations with their family/personal life, and they must have access to information and training to help

⁴³ Schulmann, K., Ilinca, S., Rodrigues, R. & Pateisky, D. (2017) *From disability rights towards a rights-based approach to long-term care in Europe: Building an index of rights-based policies for older people*, EURO.CENTRE.REPORT. Vienna: European Centre. <https://www.euro.centre.org/publications/detail/3092>

⁴⁴ ENNHRI Human Rights of Older Persons and Long-Term Care Project: The Application of International Human Rights Standards to Older Persons in Long-Term Care February 2017 http://ennhri.org/wp-content/uploads/2019/10/ennhri_application_of_human_rights_to_ltc_feb_2017.pdf; also Michael A West and Jeremy F Dawson, Employee engagement and NHS performance (2012), p. 20, cited in IHREC's Policy Statement on Care (2023) <https://www.ihrec.ie/app/uploads/2023/07/Policy-Statement-on-Care.pdf>

⁴⁵ ENNHRI Human Rights of Older Persons and Long-Term Care Project: The Application of International Human Rights Standards to Older Persons in Long-Term Care February 2017 http://ennhri.org/wp-content/uploads/2019/10/ennhri_application_of_human_rights_to_ltc_feb_2017.pdf

⁴⁶ HIQA (Nov 2019). *Guidance on a Human Rights-based Approach in Health and Social Care Services*. Available at: <https://www.hiqa.ie/reports-and-publications/guide/guidance-human-rights-based-approach-health-and-social-care-services>

⁴⁷ ENNHRI Human Rights of Older Persons and Long-Term Care Project: The Application of International Human Rights Standards to Older Persons in Long-Term Care February 2017 http://ennhri.org/wp-content/uploads/2019/10/ennhri_application_of_human_rights_to_ltc_feb_2017.pdf

them develop as a carer. Carers in good situations will have significantly greater capacity to adapt their work to be compliant with a human rights-based approach to care.

Values and Principles Underlying Human Rights

“Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world...”

Preamble to the Universal Declaration of Human Rights.

The human rights system is built on foundational values that are not necessarily rights in and of themselves. Rather, these values serve as the ethical rationale for rights and are at the core of binding human rights conventions. Some of these words may not be explicitly used in the formulation of rights, despite clearly underpinning them. For example, the right to privacy and family life does not mention freedom, respect, dignity, or autonomy. Therefore while dealing with specific rights it is important to keep in mind the underlying values and principles and to understand that rights are intended to uphold them and protect them from assault. These values and principles are often contained in preambles of human rights conventions, or supplementary material produced to support the interpretation and implementation of human rights. They can also be found in the case law of authorities like the European Court of Human Rights. Various bodies in Ireland and Europe have engaged in exercises to develop a set of principles to guide human rights-based approaches. These include the PANEL principles⁴⁸ and the FREDa principles, the latter of which are specifically intended for use in the health and care context and have often been cited by HIQA.⁴⁹ The following is a list of values established in human rights practice and doctrine that are at stake for older persons with care needs:

- Freedom
- Respect
- Equality/non-discrimination
- Dignity
- Autonomy/self-determination/agency
- Participation
- Accountability
- Empowerment
- Fairness

⁴⁸ For a description see: <https://www.scottishhumanrights.com/projects-and-programmes/human-rights-based-approach/>

⁴⁹ See <https://www.higa.ie/sites/default/files/2019-11/Human-Rights-Based-Approach-Guide.PDF> which cites, Curtice M, Exworthy T. FREDa: a human rights-based approach to healthcare. *The Psychiatrist*. 2010;34(150-156).

As well as these values, human rights are also underpinned by the principle of non-regression. This means that a state cannot roll back progress it has made in the realization of rights.⁵⁰ Such a guarantee is important in long-term care, which has many implications for resources, and thus is at risk of having its human rights protections weakened in times where less funding is available. A human rights-based approach to long-term care should include a commitment to guard against backsliding. As a duty bearer to rights holders, the Irish state must be vigilant not only against the human rights abuses that we know have occurred historically in the care sector but also ones that may occur in the future.

PANEL Principles

The PANEL Principles are a well-established set of principles designed to underpin human rights-based approaches, with direct relevance to the long-term care context and the situation of older persons. These principles are participation; accountability; non-discrimination and equality; empowerment; and legality. In developing a human rights-based approach to long-term care we must look not only at the text of human rights, but whether processes and decisions are participatory, subject to accountability, non-discriminatory and equitable, empowering, and compliant with the law. These principles are a useful framework for decision makers at all stages of the policy process, enabling the fulfilment and protection of human rights.

Human Rights of Older People Relating to Long-Term Care

Older people in long-term care have civil, political, economic, social, and cultural rights that need to be protected, and that they need to be supported to fulfil. Human rights, and interpretations thereof, are dynamic. Many binding legal human rights covenants, such as the ECHR, are seen as living documents. As issues around ageing and older persons become more highly prioritized in human rights discourse and practice, we may see rights expanding or being applied in new ways. While this document provides detail on what a human rights-based approach to long-term care looks like, it is not the last word on the matter. New rights issues and concerns may emerge in the changing care landscape that will need to be addressed.

Rights enshrined in international documents which Ireland has signed or ratified provide useful signposting for the establishment of a human rights-based long-term care model. However, binding human rights covenants are intended as a floor rather than a ceiling. While they serve as a starting point, the Irish government should set a more ambitious aim than upholding explicit obligations. Human rights are a practice that needs to be ingrained into our processes and our thinking, becoming the normative framework for our actions. Every time the state makes a decision or interacts with a member of the public, human rights must be the starting point. Further guidance for the development of a human rights-based approach should be sought from soft law and other authoritative non-binding sources.

⁵⁰ See for example the ICESCR.

Relevant sources of human rights are listed below. All of these, other than the UDHR and MIPAA, are binding:

- The Universal Declaration of Human Rights (UDHR),
- The European Convention on Human Rights (ECHR),
- The International Covenant on Civil and Political Rights (ICCPR),
- The International Covenant on Economic, Social, and Cultural Rights (ICESCR),
- The European Union Charter of Fundamental Rights (EUCFR),
- The European Social Charter (ESC),
- The Convention on the Rights of Persons with Disabilities (CRPD),
- The United Nations Convention Against Torture, and Other Cruel, Inhuman or Degrading Treatment or Punishment (UNCAT),
- The Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW),
- The International Convention on the Elimination of All Forms of Racial Discrimination (ICERD),
- The Madrid International Plan of Action on Ageing (MIPAA).

Older people do not have an explicit human right to long-term care, yet many rights would be impossible to deliver through any other means. Furthermore, because older people in care or in need of care face unique challenges to their rights, they require unique safeguards and supports. In the European Commission's communication to the EU Parliament on the EU Care Strategy, a clear connection is made between the rights of older persons and the required improvements in long-term care.⁵¹ The care sector interacts with human rights in two main ways. Firstly, receiving care may be the only or the most practical means of guaranteeing the rights of older people, such as to life or an adequate standard of living. In this way, access to long-term care is a human rights concern. Secondly, when older persons are receiving care, this care must be delivered in such a way that protects and supports them to fulfil their rights. In this way, the *delivery* of long-term care is a human rights concern.

⁵¹ <https://ec.europa.eu/social/main.jsp?langId=en&catId=89&furtherNews=yes&newsId=10382#navItem-1>

The following is a list of rights considered relevant to older persons in or seeking long-term care. All these rights are contained within at least one human rights agreement that Ireland has ratified. The Appendix contains a table of these rights along with the stage of care at which they are relevant and their sources in international human rights law. This is non-exhaustive and is alphabetized and thus not presented in any order of priority.

- Access to Justice/Due Process/Right to Remedy and Redress.
- Freedom from Discrimination.
- Freedom from Deprivation of Liberty.
- Freedom of Expression and Information and Freedom of Thought, Conscience, and Religion.
- Freedom from Torture and Inhuman or Degrading Treatment.
- Right to an Adequate Standard of Living.
- Right to Health.
- Right to Inclusion or Participation in the Community.
- Right to Life.
- Right to Respect for Privacy and Family Life.

These rights are derived from a number of sources that attempt to compile a list of rights relevant to older people in long-term care, including the European Centre for Social Welfare Policy and Research's Rights of Older People Index,⁵² and the European Charter of the rights and responsibilities of older people in need of long-term care and assistance.⁵³ The rights of older persons also significantly interact with theory and practice around disability rights, with disability rights applying to older persons with care needs.

Characteristics of a Human Rights-Based Approach to Long-Term Care

This section serves as a non-exhaustive demonstration of how human rights manifest in the design and implementation of long-term care. It is non-exhaustive both in which rights may come into play in long-term care and the characteristics they may have. As human rights doctrine acknowledges, the interpretation of human rights is dynamic and evolving, and as the care sector shifts so too may which rights are relevant and how they manifest.

Many characteristics of long-term care that we may already assume are good policy and practice are in fact derived from human rights. Consistently and explicitly framing these measures as human rights protections reinforces how vital they are. It further

⁵² See Schulmann, K., Ilinca, S., Rodrigues, R. & Pateisky, D. (2017) *From disability rights towards a rights-based approach to long-term care in Europe: Building an index of rights-based policies for older people*, EURO.CENTRE.REPORT. Vienna: European Centre. <https://www.euro.centre.org/publications/detail/3092>

⁵³ Available at <https://www.age-platform.eu/publications/eu-charter-rights-and-responsibilities-older-people-need-long-term-care-and-assistance>

demonstrates that they are entitlements rather than privileges, which is fundamental to upholding the dignity and well-being of older persons in care.

Some characteristics of a human rights-based approach are not derived from a specific right but rather are necessary to honour human rights in general. Other characteristics do relate to specific rights. However, while they can be isolated from each other for the purpose of analysis, rights are inter-related, inter-dependent, and indivisible. Any action which threatens or strengthens one right will threaten or strengthen others.

This table’s descriptions of what rights look like in practice is compatible with authoritative sources, including jurisprudence from the European Court of Human Rights, the report “Against Ageism and Towards Active Social Citizenship for Older persons”, which builds on ECHR jurisprudence,⁵⁴ and the Accompanying Guide of the European Charter of the rights and responsibilities of older people in need of long-term care and assistance.⁵⁵

Right	Characteristics
Foundational to All Human Rights	<ul style="list-style-type: none"> • Long-term care systems are designed to be implemented in a flexible and person-centred manner. • There is an explicit and foundational commitment to human rights in government care policy and elaboration on how this will be delivered. • Older people maintain independence and are meaningfully including in making decisions relevant to their life and care. The Assisted Decision-Making scheme is operational, accessible, and effective. • Staff are adequately trained and supported, including to ensure that their level of English is adequate for safe and effective communication. • Informal carers are adequately supported, including through provision of respite care, and have access to training and information. • Long-term care is adequately and sustainably funded. • There are clear quality standards for care that take a rights-based approach. • Information is clearly communicated to people in care, their family, and carers about their human rights and related obligations. • There is greater awareness of ageism in the care sector and society generally. • Legal provisions are made to combat age discrimination.

⁵⁴ <https://rm.coe.int/against-ageism-and-towards-active-social-citizenship-for-older-persons/1680a3f5da>

⁵⁵ <https://www.age-platform.eu/publications/eu-charter-rights-and-responsibilities-older-people-need-long-term-care-and-assistance>

Right	Characteristics
<p>Access to Justice; Due Process; Right to Remedy and Redress</p>	<ul style="list-style-type: none"> • There exists adequate monitoring and oversight, adequate internal and independent formal and informal complaints and appeals procedures, and adequate remedies. • Punishment and intimidation of older people in care for actually or intending to complain about rights breaches is effectively prevented. • There exist legal protections and empowerment of independent advocates. • Older people in long-term care are treated fairly before the law and are not intimidated or discouraged from taking legal action against care providers, including the state. • Legal procedures and remedies are delivered in a timely manner, cognisant of the particular importance of making justice expeditious when it comes to older persons.
<p>Freedom from Deprivation of Liberty</p>	<ul style="list-style-type: none"> • Older persons live free from the use of restraints. They are not forced into medical or other procedures. • Older persons receiving care are never locked into rooms or premises. • Older persons are not institutionalized against their will or under false pretences (e.g. being told it will only temporary when it is intended to be permanent).
<p>Freedom from Discrimination</p>	<ul style="list-style-type: none"> • Older people have the same level of access to care regardless of age, nationality, disability, ethnicity, religion, sexuality, gender, family status, or other statuses. • Care settings and organisations have effective policies and procedures for preventing discrimination and redressing it where it occurs. • The policies and systems designed to ensure older people have access to justice and redress apply where the complaint is regarding discrimination.
<p>Freedom of Expression and Information and Freedom of Thought, Conscience, and Religion</p>	<ul style="list-style-type: none"> • Older people have access to religious services to practice their faith. • Older people can exempt themselves from religious services, practices, and settings if they so choose. • Older people have affordable and timely access to technology, suitable for every level and kind of ability, for receiving and imparting information. • Older people can participate in public discourse and other civic activities. • Older persons can access cultural resources, participate in cultural activities, and make cultural contributions. • Nursing homes are community spaces.

Right	Characteristics
Freedom from Torture and Inhuman or Degrading Treatment	<ul style="list-style-type: none"> • Older people are adequately safeguarded against all forms of neglect, abuse, and exploitation, including through the enactment of adult safeguarding legislation. • Older people are aware of how to and supported to report abuse and mistreatment, formally and informally. • The public, caregivers, and social workers are able to identify abuse and mistreatment of older people and know how they should respond to it. • Older people have control over their day to day lives, including through access to independent advocates and decision-making supports, and do not have their autonomy unnecessarily curtailed. • Older persons live free from the use of restraints. They are not forced into medical or other procedures. • Older persons receiving care are never locked into rooms or premises.
Right to an Adequate Standard of Living	<ul style="list-style-type: none"> • Older people are provided with necessary services in care contexts, including food, medicine, social security, and shelter. • Older people have access to nutritious food, malnutrition is combated. • Adequate medical care is delivered in a timely manner. • The income of older people in care is protected. Care recipients are protected from financial abuse, are not subject to undue fees and charges, and are entitled to adequate state pensions in older age. • Standards of living in long-term care contexts are continuously improved.
Right to Health	<ul style="list-style-type: none"> • There is a joined up long-term care system on statutory footing, under which everyone who needs care is entitled to it. • There are a range of options available to those seeking care that allow the individual to exercise choice based on free and informed consent. • Older people have autonomy over their care arrangements and care is tailored to the person receiving it. • Standards and safeguards exist to ensure that older people's bodily autonomy and decision-making capacity is respected in healthcare and social care contexts. • Rather than simply mitigating health concerns, care is designed to support the physical and psychological well-being of older people and the full realization of rights. • There are tailored mental health services and programmes for older people in care, and general mental health

Right	Characteristics
	<p>services and programmes are accessible to older people in care.</p> <ul style="list-style-type: none"> • Older people have access to nutritious food, malnutrition is combated. • Older people have access and entitlement to adequate palliative and end-of-life care, including the right to make Advance Healthcare Directives.
<p>Right to Inclusion and Participation in the Community</p>	<ul style="list-style-type: none"> • Nursing homes are community spaces, in which community activities happen and members of the community visit and spend time. • Older people in care can participate in public discourse and decision-making and other civic activities, including voting. • Non-digital options for cultural and civic contributions are available, including for accessing information, communicating with people, and reporting. • Intergenerational contact is encouraged and facilitated. • Older people have access to information about their communities and wider society. • Older people can remain in their homes for as long as they so desire. • Opportunities for lifelong learning are available in care settings, in the form of education and training, that meet the needs and preferences of care recipients. Older persons also have opportunities to act as teachers, trainers, and mentors.
<p>Right to Life</p>	<ul style="list-style-type: none"> • Physical environments are safe, including when older people remain at home, meaning that older persons are able to adapt their home. • Older people have access to required medical and care services.
<p>Right to Respect for Privacy and Family Life</p>	<ul style="list-style-type: none"> • Older people are supported to age in place in their own homes and among their community. • Older people are supported to remain with spouses, other family members, friends, and loved ones, and where this has not happened, they are supported to remain in frequent and meaningful contact with them. • Older people have their own individual space and can maintain their modesty. • Older people can spend time alone. • Procedures are in place to protect older people’s personal information when they are in the care system.

Right	Characteristics
	<ul style="list-style-type: none"> • Older people exercise control over their own affairs and influence decisions relevant to their lives, including possessing the freedom to make unwise decisions and to have a say in how a residential setting of which they are a resident is run. • Older people receive the kind of care or medical treatment most conducive to their privacy and dignity. Care is delivered in a manner conducive to privacy and dignity, and always based on free and informed consent, including personal or intimate tasks such as assistance with cleaning, dressing, or eating. • The moral, bodily and physical integrity of older persons is protected in care contexts.

Recommendations

The following recommendations to the state would contribute to a human rights-based approach to long-term care. They are organized in two stages: recommendations for establishing human rights as a normative framework and adopting a human rights-based approach to long-term care; and recommendations for ensuring that the policies, services, and standards developed under a human rights-based approach to long-term care are fully and effectively implemented.

To establish human rights as a normative framework and adopt a human rights-based approach to long term care:

1. Age Action is calling for the state to commit to a human rights-based approach to long-term care, which will require explicitly positioning all related laws, policies, services, processes, and interactions with the public in a human rights framework from the outset.
2. To establish human rights as a normative framework and adopt a human rights-based approach to long-term care:
 - Mainstream the PANEL principles in policy, practice, and service and programme design.
 - Implement gender mainstreaming.
 - Meaningfully involve older persons in policy decision making processes regarding care.
3. Develop a rights-based long-term care strategy.
 - This should support the development of an integrated long-term care system with cross-departmental responsibilities, and it should align with the WHO's guidance on Integrated Care for Older People (ICOPE). It should also commit to fulfilling the recommendations made under the EU Care Strategy.
 - The strategy should set out processes for reviewing and reporting on the long-term care system and its performance in the upholding of human rights.
4. Establish a Commissioner for Ageing and Older Persons.
 - This Commissioner would examine systemic issues affecting older people; investigate complaints from older people where their rights have been violated; review the adequacy of policy, legislation and services affecting older people; and advise Government on matters concerning older people. This would promote a culture of valuing human rights, care, and older people.
5. Establish universal healthcare by fully implementing Sláintecare.
 - This will include creating a statutory entitlement to home care, not dependent on a person's ability to afford it.

6. Ensure the equitable distribution of care resources across all regions of the country on the basis of need.
7. Support the introduction of an international convention on the rights of older persons, as recommended by the Office of the High Commissioner of Human Rights (OCHR).
8. Ratify the Optional Protocol to the Convention Against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (OPCAT).

To ensure the full and effective implementation of a human rights-based approach to long-term care:

9. Deliver training to carers and practitioners at all levels and in all contexts to understand human rights; identify rights breaches; and adopt a human rights-based approach in their day-to-day work.
 - This training should involve awareness raising around ageism, as well as the functioning of the Assisted Decision Making scheme.
10. Ensure access to independent advocates for care recipients.
 - These advocates should have appropriate access, entitlements, and supports.
11. Ensure effective remedy to care recipients where rights have been infringed or policy has otherwise been breached.
12. Expand the remit of HIQA to oversee human rights compliance in care contexts including homecare, and strengthen their powers.
 - HIQA should also have the capacity for receiving and addressing individual complaints of care recipients.
13. Mandate that both public and private providers of care uphold human rights and can demonstrate their adoption of human rights-based approaches.
 - This will involve adopting a human rights-based approach to the procurement process and regulations.
 - As a matter of contract, care providers should demonstrate compliance with the Public Sector Equality and the Human Rights Duty and the steps they have taken to prevent discrimination across all nine protected grounds under the Equality Acts.
14. Include human rights centrally in a statutory enquiry into COVID-19, with due focus given to the situation of older people in care, with a cross-party commitment to funding the implementation of resulting recommendations.

Appendix

Human Rights by Stage of Care and their Source in Human Rights Law

Right	Stage of Care	Source
Access to Justice/Due Process/Right to Remedy and Redress.	Delivery	Articles 14, 15, and 16 of the ICCPR; Articles 8 and 10 of the UDHR; Articles 6 and 13 of the ECHR; Article 13 of the CRPD.
Freedom from Discrimination.	Access and Delivery	Article 2 of the UDHR; Article 2 of the ICESCR; Article 14 of the ECHR; Article 5 of the CRPD; Article E of the ESC; Article 21 of the EUCFR.
Freedom from Deprivation of Liberty.	Delivery	Article 14 of the CRPD; Article 5 of the ECHR; Article 3 of the UDHR; Article 9 of the ICCPR; Article 6 of the EUCFR.
Freedom of Expression and Information and Freedom of Thought, Conscience, and Religion.	Delivery	Articles 18 and 19 of the ICCPR; Articles 18 and 19 of the UDHR; Articles 9 and 10 of the ECHR; Article 21 of the CRPD; Articles 10 and 11 of the EUCFR.
Freedom from Torture and Inhuman or Degrading Treatment.	Delivery	Article 15 of the CRPD; Article 7 of the ICCPR; Article 5 of the UDHR; Article 3 of the ECHR; Article 2 of the CAT; Article 4 of the EUCFR.
Right to an Adequate Standard of Living.	Access and Delivery	Article 11 of the ICESCR; Article 25 of the UDHR; Article 28 of the CRPD.
Right to Health.	Access and Delivery	Article 25 of the UDHR; Article 12 of the ICESCR; Article 25 of the CRPD; Article 11 of the ESC; Article 35 of the EUCFR.
Right to Inclusion or Participation in the Community.	Delivery	Article 19 of the CRPD; Article 15 of the ICESCR; Article 27 of the UDHR; Article 15 of the ESC; Article 13 of the CEDAW.
Right to Life.	Access and Delivery	Article 3 of the UDHR; Article 2 of the ECHR; Article 10 of the CRPD; Article 6 of the ICCPR; Article 2 of the EUCFR.
Right to Respect for Privacy and Family Life.	Access and Delivery	Article 8 of the ECHR; Articles 22 and 23 of the CRPD; Article 12 of the UDHR; Article 17 of the ICCPR; Articles 7 and 8 of the EUCFR.