

Submission to UN Independent Expert on the Enjoyment of All Human Rights by Older Persons

Sage Advocacy welcomes the opportunity to make a submission for consideration by the UN Independent Expert on the enjoyment of all human rights by older persons on the topic of *Autonomy, dignity and human rights in situations of dependency in older age*.

Sage Advocacy is the National Advocacy Service for Older People and Survivors of Institutional Abuse in Ireland. It also supports vulnerable adults and healthcare patients in certain situations where no other service is able to assist.

Sage Advocacy provides information, support and advocacy and its work on behalf of clients is independent of family, service provider, or systems interests. The Sage team of experienced advocates is available right across the Republic of Ireland and the service is free of charge and confidential. Sage Advocacy ensures that a person's voice is heard, that their wishes are taken into account and that they are involved in decisions that affect them. Based on its motto, *Nothing About You/Without You*, Sage Advocacy seeks at all times to uphold the human rights of its clients and consistently identifies blockages to protecting the human rights of older persons.

This submission is based on Sage's extensive advocacy casework. It is also informed by its participation in Erasmus Plus Project involving four EU countries, *Safeguarding older persons' legal and human rights through an active citizenship inter-generational approach*.¹

Issues relating to dignity, autonomy, deprivation of liberty and financial abuse of older persons feature regularly in casework. Coercive control by relatives of older persons is a constant feature in Sage Advocacy casework. There is also regularly a failure in practice by professionals to make a clear distinction between a person's ability to make a decision and their ability to execute that decision, for example, because of mobility difficulties, frailty associated with the ageing process or difficulties in communicating or because of an absence of decision-making supporters in their lives.

¹See, for example, <https://sageadvocacy.ie/wp-content/uploads/2023/12/intergenerational-solidarity-a-position-paper-april-2023.pdf>

Positive developments in Ireland

Assisted-decision-making legislation

The introduction in law in Ireland (through the Assisted Decision Making (Capacity) (ADMC) Act 2015 which commenced in 2023) of the statutory presumption of capacity and the legal requirement for people (including older persons) whose decision-making capacity may be in question to be provided with whatever support they require to maximise their decision-making capacity was a significant point of departure. It introduced a fundamental change in how older people with reduced decision-making capacity (for whatever reason) are to be supported with a range of legal mechanisms available to support decision-making by individuals to the greatest extent possible. Also, a central tenet of the legislation is that capacity assessment has to be time and issue specific as distinct from a 'blanket' decision covering all matters. This approach is central in the context of protecting older persons' human and legal rights and their right to equality of treatment.

A proposed framework relevant to equality of access by older persons to health and social care

Protecting the human rights of older persons requires a balance between independence, participation, and protection. In this regard, the Law Reform Commission² in Ireland has proposed a number of guiding principles for adult safeguarding legislation which are relevant to the autonomy, dignity and human rights protection of vulnerable older persons.

- Equal treatment in respect of access to basic goods and services;
- The presumption of decision-making capacity and the facilitation of supported decision-making;
- Ensuring informed consent;
- The right to autonomy and the right to full and effective participation in society;
- The realisation of the right to independent advocacy;
- Respect for will and preferences;
- The right to have risks and options explained;
- The right to be consulted at every step of an action or intervention;
- Responding effectively to actual or suspected abuse or safeguarding concerns
- Ensuring that actions or interventions are the least intrusive and restrictive of individual freedom;

Specific areas that require attention

The human rights of older people resident in nursing homes

Older people resident in nursing homes in Ireland are at greater risk of having their human rights violated than people who live in their own homes. Sage Advocacy has identified five areas where there may be a violation of people's human rights in nursing homes – deprivation of liberty; inappropriate use of psychotropic medicine; (In)continence care and management; physical restraint; and the use of cameras in

² <https://www.lawreform.ie/news/the-law-reform-commission-publishes-report-on-a-regulatory-framework-for-adult-safeguarding.1141.html>

private spaces.³ These issues combined point to a dismal scenario in the protection of human rights of older persons in nursing homes which need to be acknowledged and addressed.

The European Union Agency for Fundamental Rights report, '*Places of Care - Places of Safety? Violence against persons with disabilities in institutions*'⁴ confirms that people living in such institutions are more likely to experience neglect, abuse and violence coupled with barriers to reporting and lack of effective monitoring.⁵

Consent by older persons to long-term care in a nursing home

While the context in Ireland relating to consent to nursing home care has changed fundamentally with the commencement of the ADMC legislation, a significant issue arises in relation to valid consent because of the lack of availability of choice. In effect, consent without choice is meaningless as then it becomes a form of coercion.

The following factors are identified⁶ in the context of consent to long-term care in Ireland and which may be replicated in other jurisdictions.

- In many instances, consent to a residential placement may also involve consent to loss of autonomy, deprivation of liberty and loss of privacy.
- A lack of resources for appropriate care and supports in the community, and a lack of a statutory right to homecare can result in a person being forced to live in a residential facility against their wishes.
- A person may consent to receive care and treatment for a respite period but not to this becoming a long-term arrangement;
- A person may consent to receive care and treatment without having all relevant information and all options being explained in a way that is understandable to them;
- While an assessment of care needs, an assessment of capacity to consent to care and an assessment of capacity to consent to a living arrangement where there is a potential deprivation of

³ <https://sageadvocacy.ie/wp-content/uploads/2025/03/Five-Rights-Issues-210225.pdf>

⁴ <https://fra.europa.eu/en/publication/2025/institutions-places-care-and-places-safety>

⁵ This report considered qualitative research based on 10 of the 27 Member States (one of which was Ireland) https://fra.europa.eu/sites/default/files/fra_uploads/ireland_desk_research_violence_against_persons_with_disabilities_in_institutions_en.docx

⁶ See Sage Advocacy *Access to Justice by At-Risk Adults*, <https://sageadvocacy.ie/wp-content/uploads/2023/12/sage-access-to-justice-report.pdf>

liberty are separate assessments and determinations – in practice, these may not always be treated separately;

Impact of undue influence and power imbalances

The matter of undue influence has been raised in the context of giving consent in Irish law.⁷ This phenomenon has been described⁸ as ‘hostage bargaining syndrome’ whereby people tend not to speak up to assert their views in the presence of clinicians whom they would view as a higher authority. In such situations, an individual may become disempowered and unable to control their own situation thus allowing significant decisions to be made by others on their behalf.

Need for a stronger focus on safeguarding vulnerable older persons

High levels of dependency and/or a lack of decision-making capacity almost certainly results in some vulnerable older people currently not being adequately safeguarded in Ireland. There is a clear need to reaffirm Article 16 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD), which provides that state parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.

Intersectionality

The main intersectional factor impacting on the human rights of older persons in Ireland is disability. While disabled people have achieved a level of visibility through the UNCRPD, this may not be the case in relation to older persons with long-term care and support needs. The Council of Europe Statement on the Rights of Older Persons⁹ urges Member States to provide for appropriate and effective safeguards to prevent abuse in all areas that relate to decision-making and the exercise of legal capacity of older persons, including possible restrictions which may be required for protection purposes.

It is noted that the 2019 Report of the UN Special Rapporteur on the Rights of Persons with Disabilities¹⁰ has stated that the UNCRPD applies to disability experienced at any age but medical definitions and approaches dominate international discussions of ageing, with older people still largely perceived as “mere

⁷ *Ibid.*

⁸ Berry L., Danaher T., Beckham D., Awdish R. and Mate S. (2017) *When Patients and Their Families Feel Like Hostages to Health Care*, <https://www.mayoclinicproceedings.org/action/showPdf?pii=S0025-6196%2817%2930394-4>

⁹ Recommendation CM/Rec (2014)2 of the Committee of Ministers to member States on the promotion of the human rights of older persons. (Adopted by the Committee of Ministers on 19 February 2014 at the 1192nd meeting of the Ministers’ Deputies).

¹⁰ United Nations (2019) *Report of the Special Rapporteur on the rights of persons with disabilities: General Assembly 74th Session*. (A/74/186, 17 July 2019) <https://undocs.org/en/A/74/186> p.5.

beneficiaries of care and welfare with human rights violations against older disabled people often neither monitored nor categorised as such”.¹¹

Enshrining the right to equality of treatment

The manner in which support is provided can place vulnerable older persons at greater risk of inhuman or degrading treatment, violence, abuse and neglect. A study by the European Network of National Human Rights Institutions found that although there were no clear signs of torture or deliberate abuse or ill treatment, several practices witnessed in all six countries [covered in the study] raised concerns, particularly in upholding dignity, the right to privacy, autonomy, participation, and access to justice”.¹²

There is a need for greater attention to be paid to enshrining equality of treatment of older persons in EU and national legislation with particular reference to marginalised older people – nursing home residents, older women, older people with immigrant or ethnic minority background, older disabled people and older persons who are survivors of childhood institutional abuse.

Appropriate regulatory frameworks

Legislation at national level has a central role to play in ensuring that there are appropriate regulatory frameworks in place for safeguarding vulnerable older persons. However, legislation and regulation on its own will not be sufficient. Also required is a major cultural and attitudinal change throughout society which:

- a) Acknowledges each individual older person’s legal capacity and their right to autonomous decision-making irrespective of their decision-making capacity;
- b) Recognises a presumption of capacity (unless formally assessed otherwise) and a person’s right to be provided with the least restrictive form of decision-making support;
- c) Shows zero tolerance for any ‘workarounds’ that do not have a clear legal basis;
- d) Recognises abuse of older persons in all of its multiple manifestations, including Inter-generational transfer of assets associated with coercive control;

Role of independent advocacy

Independent advocacy has a critical role to play in the protecting the human and legal rights of older persons with additional support needs.

¹¹ *Ibid.* p.10

¹² European Network of National Human Rights Institutions (2017), *We have the same rights: the human rights of older persons in long-term care in Europe*, http://ennhri.org/IMG/pdf/ennhri_hr_op_web.pdf

It is important that the underpinning principles of independent advocacy are well understood by society generally, by Government and by agencies delivering public services and by financial services.

- ✓ Helping to ensure that people have access to services and supports on an equal basis with others;
- ✓ Empowering people to assert their will and preferences and to self-determine;
- ✓ Identifying and addressing abuse and exploitation

It is critically important that each jurisdiction has legislation to adequately safeguard older persons at risk of abuse and exploitation – those in residential care settings, those with reduced decision-making capacity and those without trustworthy support networks. It is also the case that such legislation is necessary in order to comply with Article 16 of the UNCRPD, which requires that State Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.

Sage Advocacy strongly supports the transition from a policy-based approach to a statutory framework that ensures the rights, dignity, and safety of all older persons, particularly those in vulnerable situations are respected.

It is noted that there have been repeated calls in Ireland for the State to enact legislation on Deprivation of Liberty in accordance with international human rights standards and norms regarding use of detention and restraint including the UN Convention Against Torture (UNCAT), the UNCRPD and the ECHR.

Many older people in nursing homes are *de facto* detained due to doors being locked and keycode systems being used or being unable to leave without permission. In many instances, valid consent to living in a nursing home is often not obtained, especially where decision-making capacity is reduced. Placement in a nursing home must not be based on what a doctor or relative thinks is 'best', but rather on a person's expressed will and preference. Where this is unknown, an independent advocate should be appointed to reconstruct those preferences.

Concluding Points

There are three key issues that arise in Sage Advocacy casework in respect of the human rights of older persons – adult safeguarding, deprivation of liberty, and the lack of choice in health and social care.

The experience of Sage Advocacy is that the human rights of older persons are undermined by a range of inter-related factors:

- Absence of a legal entitlement to care based on individual needs assessment;
- A long-term care and support system that prioritises residential nursing home care over alternative community-based responses;
- A social and cultural milieu which does not always give due cognisance to the voice of individual older persons in respect of care choices and consent;

- A tendency to see older persons (over 75s) as a homogenous group with insufficient recognition of diversity, individual needs and individual contributions.

It is important that the Independent Expert Report on the Rights of Older Persons focuses on older people in terms of the challenges and opportunities faced at each stage of the life cycle as distinct from people as members of an older persons' identity group. A human rights approach does not contradict the reality of age-specific needs but, on the contrary, a rights-based approach enables society to better meet needs, as required, while framing them within a human rights-based narrative.

The introduction of Assisted Decision-Making legislation in Ireland has been a very important development in respect of promoting the rights of older persons where there is a question about their decision-making capacity.

This critical role for independent advocacy in ensuring that the human rights of vulnerable older persons are protected should be articulated in the Independent Expert Report. Recognition in law of independent advocacy is critically important in ensuring that the human rights of older persons are protected.

The UNCRPD marked an important shift from a traditional narrowed welfare state approach, based on 'deficits' compensation to a more comprehensive participatory approach based on dignity, autonomy and rights. It introduced the concept of "reasonable accommodation" that entails necessary and appropriate modifications in to ensure that persons with disabilities enjoy or exercise on an equal basis with others all fundamental rights. The Independent Expert Report should strongly reflect the need for such 'accommodation' of the multi-faceted needs of older persons requiring care and support in order to proactively vindicate their human rights.