Sage Advocacy

# Older Persons in Receipt of Care:

## Five Human Rights Concerns in Ireland

A SCOPING DOCUMENT

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# Introduction

**THIS scoping document identifies five areas relating to possible breaches of the human rights of older persons, which, it is suggested, require further analysis, consideration and public and policy discussion in the Irish context. These are:**

## FIVE RIGHTS ISSUES

1. **Deprivation of liberty**
2. **Inappropriate use of psychotropic medicine**
3. **(In)continence care and management**
4. **Physical restraint**
5. **The use of cameras in care**

The lack of a dedicated legally binding UN Convention on the Human Rights of Older Persons is likely to contribute to a lack of awareness by governments, health and social care providers and society generally about the need to respect the human rights of older persons, particularly those who require long-term care.

Importantly, since no International Convention expressly dealing with the rights of older persons has been adopted – as in the case of women (UN Convention on the Elimination of All Forms of Discrimination against Women), children (UN Convention on the Rights of the Child) and disabled people UN Convention on Rights of Persons with Disabilities (UNCRPD), there is a real danger that the human rights of older persons may remain somewhat under the radar. Indeed, a 2021 Update to the 2012 Analytical Outcome Study on the normative standards in international human rights law in relation to older persons highlights the “silences, neglect and relative invisibility” of human rights issues experienced by older persons.[1] The absence of a legally binding UN Convention could explain why, in international law or national law, differential treatment on the basis of age seems to be considered tolerable. This is in stark contrast to existing treaties that oblige States parties to take steps to eliminate racism, sexism and ableism.[2]

The UN Convention on Rights of Persons with Disabilities (UNCRPD) seeks to ‘ensure the full, effective and equal enjoyment of all human rights and fundamental freedoms by persons with disabilities. A large number of older persons are persons with disabilities. Many individuals acquire age-related sensory or physical disabilities or may experience reduced decision-making capacity. Individuals who acquired their disabilities at a younger age are likely to experience double discrimination as they become older, and also have particular needs and concerns as older persons, including a likelihood that they will experience concerns as older persons at a younger chronological age than others.

The right of choice in long-term care services is currently not explicitly protected by the international human rights framework. However, the argument can be made that older people do currently have the right to choose the care that they receive protected as a derivative of their legally enshrined right to health, specifically its acceptability in light of culture and community needs.[3]

There is no statutory right to alternatives to residential care in congregated settings (home care, community-based day support services and social work services) in Ireland. This has the effect of de facto arbitrary deprivation of liberty. Apart from the provisions of the Mental Health Acts 2001-2018, there are no requirements in Irish legislation for care providers to obtain informed consent (with supported decision-making where necessary)

1 https://www.ohchr.org/sites/default/files/2022-01/OHCHR-HROP-working-paper-22-Mar-2021.pdf p.5

2 Report of the Independent Expert on the enjoyment of all human rights by older persons, Violence against and abuse and neglect of older persons (Claudia Mahler), https://documents-dds-ny.un.org/doc/UN-DOC/GEN/G23/152/56/PDF/G2315256.pdf?OpenElement

3 Baer, B. et al, (2016), The Right to Health of Older People, https://academic.oup.com/gerontologist/article-pdf/56/Suppl_2/S206/17700727/gnw039.pdf

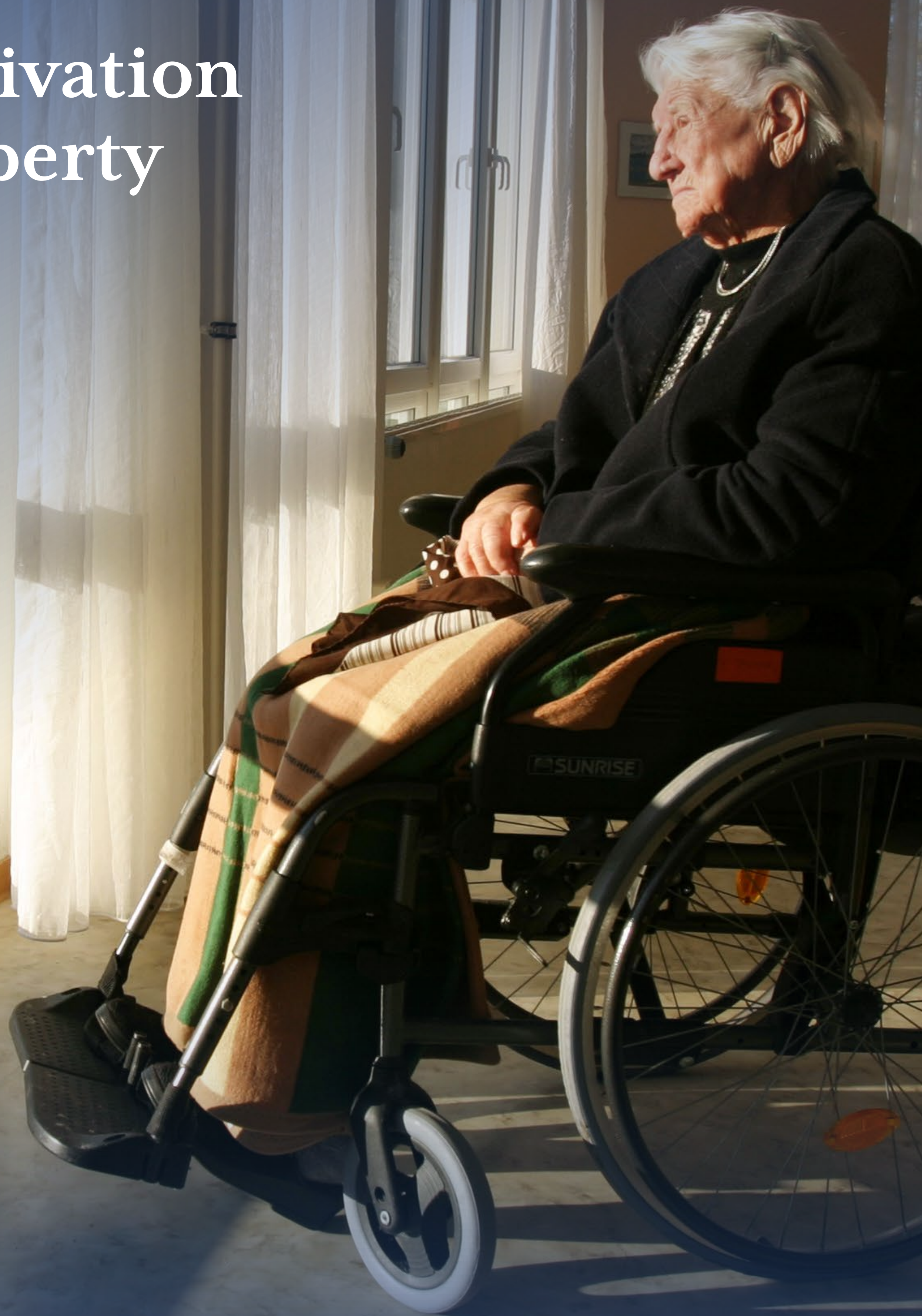
to all restrictive forms of care.

The World Health Organisation (WHO) estimates that one in six older persons have experienced some form of violence.[4] The Independent Expert on the enjoyment of all human rights by older persons has noted that violence against older persons remains overlooked and is not a priority at the national, regional or global levels.[5] The Independent Expert suggests that such violence has far-reaching consequences for the mental and physical wellbeing of millions of older persons worldwide and, because of its multidimensional impact, it is not easy to find sufficient interventions and appropriate solutions. She also notes that an increase in violence against older persons can be seen during ongoing crises such as Covid-19.

Five specific areas of concern in relation to the rights of older persons have been identified arising from Sage Advocacy casework and about which, it is suggested, more analysis and research is required in the Irish context – deprivation of liberty; (in)continence care and management; inappropriate use of psychotropic medication; physical restraint; and the use of cameras in care.

4 See https://www.who.int/news-room/fact-sheets/detail/abuse-of-older-people

5 https://documents.un.org/doc/undoc/gen/g23/152/56/pdf/g2315256.pdf (un.org)








# Deprivation of Liberty as a Fundamental Breach of Human Rights

**ALONG with the right to life, the right to personal liberty is one of the most fundamental human rights and, since the Universal Declaration of Human Rights (UDHR), every declaration of rights includes the right of liberty. It includes the right to freedom of movement and freedom from arbitrary detention by others.**

The European Convention on Human Rights (ECHR) Act 2003 obliges 'Organs of the State' to perform their functions in a manner compatible with the Convention. The UN Convention on the Rights of Persons with Disabilities (Article 14b) provides that there is an obligation on the State to ensure that a person is not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in accordance with the law.

While it is noted that the term 'deprivation of liberty' has been the subject of criticism in international literature[6] in that it may lessen the required focus on the proactive protection of people's liberty, there is a strong argument for using the term 'deprivation' as it focuses attention on the actual liberty rights infringement per se.

It is generally acknowledged that Ireland does not have adequate legislation and procedures to ensure that the personal liberty of at-risk adults is fully protected at all times and in all situations. There are no adequate legal safeguards and procedures in place at present to prevent a person being de facto detained in a residential care setting/nursing home/ designated centre for people with disabilities/ hospital other than a High Court Habeas Corpus application. This is in marked contrast to provisions under the Mental Health Acts 2001 -2018,[7] which provide for everyone who is involuntarily admitted to an approved centre under the Acts to have their case reviewed by an independent Mental Health Tribunal within 21 days of the making of the admission or renewal order detaining the person.

The shortcomings of the current legislative situation in Ireland have been noted by a number of organisations in recent years, including Safeguarding Ireland, IHREC, Sage Advocacy, ICCL and the Citizens Information Board. Among the general points made in its Submission on Deprivation of Liberty legislative proposals, Sage Advocacy has stated that:

***Safeguards to protect the right to liberty should be for the equal benefit of all people who may be detained and deprived of liberty to ensure that the person has been fully informed, is made aware of all their options in a manner that is understandable to them and is making a decision to be in a place of residence where their liberty may be restricted. A person who is vulnerable and in need of care and treatment requires safeguards against coercion and undue influence.***[8]

There is currently no provision for a statutory right to the alternatives to residential care in congregated settings, which include, inter alia, appropriate housing, home care, community-based day support services and social work services. The procedures intended to prevent arbitrary deprivation of liberty and the need to obtain valid consent (with Supported decision-making where appropriate) may not be upheld in all scenarios.

The UN Special Rapporteur on torture and the UN Special Rapporteur on health have both highlighted that "while informed consent is commonly enshrined in the legal framework at the national level, it is frequently

6 Eg, https://basw.co.uk/about-social-work/psw-magazine/articles/mca-liberty-deprivations-vs-social-work-values

7 https://revisedacts.lawreform.ie/eli/2001/act/25/revised/en/html

8 Sage Advocacy Submission, https://sageadvocacy.ie/wp-content/uploads/2023/12/sage-advocacy-submission-to-lrc-200520-final.pdf p.3.

compromised in the healthcare setting. Structural inequalities, such as the power imbalance between doctors and patients, exacerbated by stigma and discrimination, result in individuals from certain groups being disproportionately vulnerable to having informed consent compromised'.[9]

The UN Independent Expert on the enjoyment of all human rights by older persons has stated that institutional care 'can often take the form of forced institutionalisation and compulsory placements, especially when no other form of care is available for the individual or when relatives are unable or unwilling to provide care'.[10]

Concerns have been expressed in submissions to the UN Committee Against Torture[11] regarding possible deprivation of liberty of adults in congregated care settings such as nursing homes, hospitals and other institutions. The Irish Human Rights and Equality Commission (IHREC)[12] has identified significant concerns regarding the lack of systematic safeguards, vulnerability assessment, and independent regulation across a range of institutional and quasi-institutional settings where people may be at risk – such as health and social care services, accommodation services for homeless people, drug treatment facilities, direct provision centres for applicants for international protection, and residential settings for older people and disabled people. It should, of course, be noted that HIQA monitors, inspects and registers designated centres (nursing homes) against regulations and standards and publishes reports on individual centres. If centres do not meet standards/regulations they may not continue in operation.

Many nursing homes residents experience deprivation of liberty to some extent, at least. The reality is that many so-called voluntary residents in nursing homes are de facto deprived of their liberty. They live in a closed unit and are not allowed to leave the institution without prior permission. Buildings are commonly secured by key code locks as a safety mechanism, requiring residents to ask permission to leave the premises. This deprivation of liberty can extend as far as limiting people's access to recreational grounds outside of the building, justified by an assessment that the resident is a 'falls risk' or likely to 'escape'.

## Valid consent as a core underlying component in protecting people's liberty

Valid consent to decisions affecting them is a key factor in the protection of a person's right to liberty. Many Sage Advocacy cases are indicative of a failure to afford due importance to valid consent in the decision-making process relating to long-term care, particularly in relation to people with reduced decision-making capacity. It is reasonable to suggest that this will have changed since the commencement of the assisted decision-making legislation.

The following matters have been identified by Sage advocates as relevant to valid consent:

- ***A person may consent to receive care and treatment in a residential care service but not consent to the restrictions on liberty that the place of residence has in place;***
- ***A person may consent to receive care and treatment but not consent to be in a particular place of residence;***
- ***It is likely that in many instances, people may not be advised that consent to a residential placement may also involve consent to loss of autonomy, deprivation of liberty, loss of functional independence and loss of privacy.***
- ***A person may consent to receive care and treatment in a particular place of residence and may subsequently change their mind;***
- ***A person may consent to receive care and treatment in a residential unit 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 to the person in a way that is understandable to them and in a manner that gives them choice;***
- ***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 liberty are clearly separate assessments and determinations but are not always treated as such.***

The UN Independent Expert on the enjoyment of all human rights by older persons has stated [13] that 'safeguards to free and informed consent should be adopted through legislation, policies and administrative procedures in conformity with international and regional standards. Particular attention should be given to older persons with underdeveloped literacy skills and persons with less formal education.[14] The Independent Expert has also stated that independent monitoring of places of deprivation of liberty is one of the most effective prevention strategies, especially against abuse of older persons.

It is important that legislation is formulated in Ireland in order to comply with the Constitution and the State's international human rights obligations, for example, the European Convention on Human Rights and the UNCRPD. The National Disability Inclusion Strategy 2017-2022[15] committed to introduce statutory safeguards to protect residents of nursing homes and residential centres, and ensure that they are not deprived of liberty, save in accordance with the law as a last-resort measure in exceptional circumstances.[16]

A key underlying issue is that there is grossly inadequate home care support provision in some areas and, to compound the matter, nursing home residents tend not to be prioritised for home support, which means their liberty continues to be compromised by the fact that they must remain in a nursing home setting against their wishes.

The issue of younger people with disabilities in nursing homes has been the subject of debate and public comment in recent years and has been reported on in HIQA inspection reports. The Ombudsman carried out an investigation into the placement of persons under 65 years of age in nursing homes. The Ombudsman's Report[17] (published in May 2021) identified systemic issues, which are compounded by a fractured funding model, which results in some disabled people having to reside in a facility that is totally inappropriate for their needs.

Sage Advocacy casework suggests that many, older people in particular, are living in residential care centres because there is no suitable alternate residence for them. There is a critical need in such instances to bring into the discussion the potential deprivation of liberty in a particular case and to facilitate a discussion on whether admission to residential care is absolutely necessary and if there is no appropriate, practicable and less intrusive alternative.

Ireland still has not ratified the Optional

9 http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf Par. 29

10 UN Human Rights Council, Report of the Independent Expert on the enjoyment of all human rights by older persons, Rosa Kornfeld-Matte, https://documents.un.org/doc/undoc/gen/g15/179/90/pdf/g1517990.pdf

11 See, for example, https://sageadvocacy.ie/wp-content/uploads/2023/12/submission_uncat-committee_follow-up-on-concluding-obervations-for-ireland_sage-advocacy_12112018.pdf

12 Submission to the UN Committee against Torture on the List of Issues for the Third Examination of Ireland https://www.ihrec.ie/app/uploads/2020/01/Submission-to-the-UN-Committee-against-Torture-on-the-List-of-Issues-for-the-Third-Examination-of-Ireland.pdf

13 UN Human Rights Council, Report of the Independent Expert on the enjoyment of all human rights by older persons, Rosa Kornfeld-Matte, https://documents.un.org/doc/undoc/gen/g15/179/90/pdf/g1517990.pdf

14 *Ibid.* Par. 101.

15 https://assets.gov.ie/162923/96990962-f41f-4844-b784-e9ccf8cbfa42.pdf P.13

16 The Department of Health has been engaging in work on Protection of Liberty safeguards and a draft Heads of Bill was developed and published for public consultation in 2018/2019. It is noted that in 2023 the Department of Health reconstituted a Protection of Liberty Safeguards Experts Advisory Group to support the Department in establishing a policy direction and a preliminary policy proposal.

17 https://ombudsman.ie/pdf/?file=https://assets.ombudsman.ie/media/285419/5257c89f-1242-4741-a3de-1588e12cb5a5.pdf#page=null

Protocol to the United Nations Convention against Torture (OPCAT)[18], which requires States to establish a National Preventive Mechanism (NPM) to inspect and monitor all places of deprivation of liberty in order to prevent arbitrary detention or torture or ill-treatment. This is of critical importance since residential care settings are places where there may be heightened risk of arbitrary deprivation of liberty. Indeed, Ireland is now the only EU country without a law to create an NPM.

## Key points

The foregoing analysis points strongly to a need for focused research on deprivation of liberty of at-risk adults generally and, specifically, on the area of deprivation of liberty for older persons in nursing homes in Ireland.

## Key questions are:

1. ***How are the provisions of Article 14 of the UNCRPD (Liberty and security of person) being given effect in Ireland?***
2. ***How are the provisions of the ADMC legislation being applied in the context of the need to obtain valid consent to a place of care decision?***
3. ***What additional regulatory provisions are required to address situations where there is any question, direct or indirect,***

18 Optional Protocol to the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment, https://www.ohchr.org/EN/ProfessionalInterest/Pages/OPCAT.aspx

# Inappropriate use of psychotropic medicine





# Inappropriate use of Convenience Medication/ Chemical Restraint

**SAGE Advocacy case evidence points to the need for a more detailed consideration of the inappropriate use of psychotropic medicine in nursing homes since the practice raises very serious questions about the potential impact on a person's liberty and on their right to self-determination. This is particularly relevant where a person is de facto detained in a facility in the first instance due to a lack of appropriate alternatives in the community.**

Sage Advocacy casework over the years has highlighted concerns about the possible use of chemical restraint in nursing homes for containment in order to, for example, manage a person's tendency to wander, rather than for therapeutic reasons. Sage advocates have observed instances in some residential care facilities where the use of chemical restraint had become normalised in that it sometimes appeared to be used as a first rather than a last resort. It should be noted that this area is subject to inspection by HIQA and that HIQA can undertake a themed inspection where concerns are brought to their attention.

Chemical restraint is more difficult to measure because the administration of a psychotropic drug (e.g. an antipsychotic) does not necessarily equate to it being used as a restraint. International studies have reported the prevalence of use of drugs associated with chemical restraint. For example, the authors of a Finnish study found a prevalence of regular psychotropic medication use in nursing homes of 60.9% in 2017, having fallen from 81.3% in 2003.[19]

The blurring of the clear distinction between medication being used for therapeutic reasons and medication used to control behaviour is almost certainly a violation of basic human rights. HIQA Guidance is clear that administering sedatives to a person who wanders during the night primarily for the convenience of staff is an example of chemical restraint, which is not acceptable in any residential care centre. However, the status of guidance is not the same as that of regulations and standards.

The Sage Advocacy experience can be usefully considered in the context of international research that has pointed to the prevalence of potentially inappropriate medications in nursing homes and especially the use of multiple psychotropic drugs.[20] Irish-based research[21] has referred to inappropriate use of antipsychotic medications, as judged by American legislative guidelines, as common in long-stay units in the West of Ireland. A more recent 2018 study[22] has noted that despite the existence of guidelines for over a decade and national level efforts to improve dementia care, antipsychotic prescribing is still common, especially in nursing home settings. That report noted that nursing home staff struggled with the daily management of behavioural and psychological symptoms of dementia (BPSD) and the authors suggested that much more research was required into this complex area.

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19 See https://bmcgeriatr.biomedcentral.com/counter/pdf/10.1186/s12877-022-03450-4.pdf

20 See, for example, Potentially inappropriate medication use in nursing homes: an observational study using the NORGEP-NH criteria - PubMed (nih.gov)

21 Murphy, J., O'Keeffe, S.T. Frequency and appropriateness of antipsychotic medication use in older people in long-term care, https://link.springer.com/article/10.1007/s11845-008-0121-7

22 Walsh, Kieran A.; Sinnott, Carol; Fleming, Aoife; Mc Sharry, Jenny;Byrne, Stephen; Browne, John P.; Timmons, Suzanne, *Exploring antipsychotic prescribing behaviors for nursing homeresidents with dementia: a qualitative study* https://pubmed.ncbi.nlm.nih.gov/30241987/

Internationally, Inappropriate use of psychotropic medicines has been recognised as a safety and quality issue in health care. The Office of Inspector General of the U.S. Department of Health and Human Services has reported[23] that from 2011 through 2019, about 80 per cent of Medicare's long-stay nursing home residents were prescribed a psychotropic drug. In 2019, higher use of psychotropic drugs was associated with nursing homes that have certain characteristics. Nursing homes with lower ratios of registered nurse staff to residents were associated with higher use of psychotropic drugs. Nursing homes with higher percentages of residents with low-income subsidies were also associated with higher use of psychotropic drugs.

In Australia, the Royal Commission into Aged Care Quality and Safety and the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability[24] identified that psychotropic medicines are being overprescribed, misused and overused, particularly with older people and people with disability. The joint report found that there is little evidence that psychotropic medicines are effective for managing behaviours of concern. It also found evidence that psychotropic medicines can diminish the wellbeing and quality of life of older people and people with disability and that they can contribute to risks of harm, including by contributing to risk of falls, weight gain, hypertension and diabetes, by adversely affecting the person's ability to swallow, and by increasing the risk for aspiration pneumonia and other respiratory complications.

The Aged Care Quality and Safety Commission, the NDIS Quality and Safeguards Commission and the Australian Commission on Safety and Quality in Health Care have agreed to work together to reduce the inappropriate use of psychotropic medicines through:

- ***Raising awareness of the risks associated with inappropriate use of psychotropic medicines amongst healthcare, aged care and disability workforces;***
- ***Supporting improvements to the availability and quality of behaviour support planning, and preventative and de-escalation strategies;***
- ***Strengthening understanding and capacity for appropriate informed consent, prescribing, dispensing, administration and cessation of psychotropic medicines.***

Research[25] has also shown that, for all adults, prevalence of potentially inappropriate prescribing (PIP) and polypharmacy increases with advancing age and morbidity. This has been associated with adverse drug reactions and poor outcomes. There are even greater concerns among older adults with intellectual disability who are living longer.

It has been noted[26] that there has been substantial controversy internationally relating to extensive use of psychotropic medicines for people with an intellectual disability, particularly use for challenging behaviours. These medicines have been used to treat mental health conditions, but also – controversially – to treat behaviours in the absence of a diagnosis. It has also been noted that people with intellectual disability have unique medication needs and frequently report high levels of psychotropic use, including antipsychotics.[27]

Widespread, and sometimes inappropriate use of psychotropics in adults with intellectual disability has been identified as an international concern [28]. Despite the mounting evidence and concerns about the impact of potentially inappropriate prescribing (PIP) on quality of life, health and safety for people with ID, this issue has not been adequately researched, which is seen as representing an important gap in the research literature.

## Key points for consideration

While, from an evidential perspective, it is hard to prove that a psychotropic medication has been used for an improper purpose, there is some clear evidence internationally and in Ireland of inappropriate use. It may also be the case that in some instances, clinical governance is not sufficiently robust. There is also some evidence from Sage Advocacy casework of medication being prescribed as the only method of dealing with challenging, sexualised behaviour.

These are matters of serious concern from a human rights perspective and further analysis and debate is required.

23 https://oig.hhs.gov/oei/reports/OEI-07-20-00500.pdf

24 Joint Statement on the Inappropriate Use of Psychotropic Medicines to Manage the Behaviours of People with Disability and Older People, https://www.safetyandquality.gov.au/sites/default/files/2022-03/joint_statement_on_the_inappropriate_use_of_psychotropic_medicines_to_manage_the_behaviours_of_people_with_disability_and_older_people.pdf

25 Medication use and potentially inappropriate prescribing in older adults with intellectual disabilities: a neglected area of research, https://pubmed.ncbi.nlm.nih.gov/30181861/

26 *Ibid*.

27 *Ibid*.

28 July TCAID: In Focus - Introduction to the Medicines Optimisation and Innovation theme, TCAID - Trinity Centre for Ageing and Intellectual Disability - Trinity College Dublin (tcd.ie)

# (In)continence Care and Management





## (In)continence Care

**THE term 'continence care' refers to the range of activities that are typically performed by nurses and care workers to assist care-dependent individuals to maintain continence or to manage incontinence.**[29]

Although codes of conduct, guidelines and standards call for healthcare practitioners to protect patients' dignity, there are widespread concerns about a lack of attention to the dignity of older people who need assistance with toileting, incontinence or bladder or bowel care in health or social care settings that provide long-term care.

Research shows that one of the most common problems for older persons with limited mobility regarding their personal hygiene is that they may not always receive the physical assistance they require for toileting. This can affect older people in nursing homes, in hospitals and, in some, instances, those living at home. Clearly, this impacts negatively on their sense of wellbeing and undermines their self-esteem.[30] The reported physical effects of prolonged use of incontinence pads have been noted and include dermatitis, breakdown of skin integrity, pressure ulcers, urinary tract infections and the development of long-term incontinence.[31]

Managing (in)continence in older people is a major problem in nursing care that presents significant challenges if carried out appropriately and with due respect for each individual. The use of incontinence pads for people who are not clinically incontinent is reported as being accepted practice in some social services in the UK.[32] There is some evidence from Sage Advocacy casework of use of incontinence wear in nursing homes to discourage requests by persons for assistance with toileting, instances where incontinence pads are used to avoid trips to the bathroom and thus minimise falls risk and instances where pads are used in people's homes because there is no stairlift or carer available to bring the person to the bathroom located upstairs.

Sage Advocacy has come across instances where a nursing home supplied incontinence wear of unsuitable size/type (as this was the free/cheaper option) and the clients could not afford the extra charge for higher quality pads. Sage Advocacy has also encountered instances where there is a crossover between the management of incontinence and restraint, e.g., mittens used for clients in order to limit their ability to pull off the pads and belts used on chairs to prevent freedom of movement. Sage Advocacy has also encountered instances where people prefer to live at home and tolerate longer waiting periods before a carer is available to provide personal care rather than move to a nursing home.

Older people's lack of assistance with continence care is a commonly reported form of neglect. Such neglect may arise through the absence of any form of care provision to a person living at home, for example. However, lack of assistance with continence care also manifests in formal care settings – where the treatment of older people is frequently dominated by factors other than a focus on the individual in need of care. This practice may be masked by non-consensual practices that are portrayed or accepted as 'care' by institutional care providers and by individual care personnel, and which may feed negative stereotypes that are then used to justify non-consensual care management.

Providing continence care necessarily involves transgressing people's personal space and infringing social norms about privacy and touch and places them at high risk of violation of their personal dignity, particularly if they are also care-dependent or have reduced decision-making capacity.

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29 Ostaszkiewicz J., Reframing continence care in care-dependence, https://www.sciencedirect.com/science/article/abs/pii/S0197457217300861?via%3Dihub

30 Maeve O'Rourke, (2017), 'Poor Continence Care: A Question of Dignity' Working Paper

31 *Ibid.*

32 *Ibid.*

O'Rourke (2024)[33] has applied the concept of a dignity violation to the problem of inadequate continence care. She suggests that this is an exemplar of the care-related suffering experienced by many older people at home, in hospital, in institutional long-term care settings, and in other care environments. This focus on dignity violation hones in on the human impact of coercive and neglectful 'care' practices that older people commonly suffer – which are frequently prescribed or accepted as professionally appropriate. It has been argued[34] that an understanding of the essential attributes of dignity-protective continence care could allow caregivers and healthcare professionals to challenge practices that violate dignity, and recognise caring opportunities for protecting the dignity of vulnerable and care-dependent older citizens. It could also inform the development of an instrument to evaluate whether or not continence care is delivered in a way that protects the person's dignity.

O'Rourke suggests that focusing on personality highlights various aspects of degradation:

- ***The individual's reduction to pleading, crying and otherwise begging for help to keep clean or to use the toilet;***
- ***Their physical and psychological degradation through the acquisition of sores, infections and lasting incontinence; and***
- ***Their loss of control over their sense of self and others' relation to them arising from how they are forced to present to the world.***

There is a strong case to be made that all these factors should be regarded as degrading treatment[35] and dealt with accordingly. The right to freedom from torture and ill-treatment has been recognised by the Irish Courts as an unenumerated right and part of the right to bodily integrity under Article 40.3 of the Constitution.[36] The right to freedom from torture and other cruel, inhuman or degrading treatment or punishment is also expressly guaranteed by a wide range of European and international treaties to which Ireland is a party.

People living with dementia (a growing proportion of the population) often experience continence problems, which can have a profound impact on their lives and on the lives of their carers. It has been suggested[37] that there is a misconception that nothing can be done if a person living with dementia experiences episodes of incontinence of urine or faeces, or both, when continence can actually be promoted through activities and care practices, including a balanced diet, exercise, and a clear routine. Encouragement and help to use the toilet may involve 'signposting' the toilet and mobility aids. A growing range of products, including assistive technology, can help some people at some times. Even so, the progressive nature of dementia means that there will come a point where containment might be the best approach. In which case, carers and practitioners need support and advice to provide this intimate care in the best way possible.

It has also been suggested[38] that many people living with dementia have continence problems that are fundamentally different to the continence problems of people without dementia. People living with dementia need high quality, personalised continence care to have a good quality of life. This should be a high priority in all settings. Research has found deficits in professionals' assessment and management of continence in people living with dementia at home, in care homes and in hospitals. Both dementia and continence are associated with stigma and shame; people with both can suffer a double indignity. This can delay seeking or offering help, and leave underlying problems unaddressed. Professionals often focus on "containing" the problem through pads and other incontinence products, rather than actively promoting continence. This is particularly true in hospitals where organisational sensitivity to individual needs may be lacking.

By examining health and social care literature on poor continence care, O'Rourke identifies a range of sources of older people's situational powerlessness, which impacts on their wellbeing in respect of (in)continence care, including:

- ***The unavailability of consensual care services and supports;***
- ***Paternalistic culture and an accompanying denial of communication avenues or support that would insist on the person's views and preferences being acknowledged;***
- ***The related inaccessibility of complaints and other accountability mechanisms, institutional priorities that are not concerned with the individual in need of care; and***
- ***Modes of resourcing that do not have the human rights of those giving or receiving care at their centre.***

## Key points for consideration

(In)continence problems can have a profound and distressing impact on the lives of people. A very preliminary analysis of relevant literature suggests that:

- ***There is evidence of an over-reliance on "containment" and the use of pads;***
- ***Staff in all settings often lack training, not only to promote continence but to manage incontinence sensitively and well;***
- ***There is a lack of research about what works and therefore a lack of evidence-based guidance;***
- ***Action is needed at all levels to ensure that people living with dementia receive high quality and individually-tailored continence care;***

There is a clear need for the quality of (in) continence care in Ireland to be routinely audited. More research is needed to identify effective interventions to promote personalised care and independence. There is a need to invest in evidence-based training for staff to provide them with skills in continence care and the care of people living with dementia.

Getting (in)continence right is critical in maintaining people's dignity and wellbeing and protecting their basic human right to bodily integrity. It would appear that there are frequent instances where this does not happen and this is a matter that requires further research and analysis in Ireland.

"Improving the identification, assessment and management of continence issues can not only enable people with dementia to maintain their dignity and improve their health, but also their sense of wellbeing and quality of life. There is also the possibility to improve relationships, reduce carer burden, and reduce the risk of a premature transition into a residential care setting."[39]

33 Maeve O'Rourke (2024), *Human Rights and the Care of Older People: Dignity, Vulnerability, and the Anti-Torture Norm,* Oxford University Press https://fdslive.oup.com/www.oup.com/academic/pdf/openaccess/9780192859716.pdf *Human Rights and the Care of Older People: Dignity, Vulnerability, and the Anti-Torture Norm*https://ichrgalway.org/2024/05/16/human-rights-and-the-care-of-older-people-dignity-vulnerability-and-the-anti-torture-norm/

34 A concept analysis of dignity-protective continence care for care dependent older people in long-term care settings | BMC Geriatrics | Full Text (biomedcentral.com)

35 Degrading treatment includes treatment that is *"such as to arouse in its victims feelings of fear, anguish and inferiority capable of humiliating and debasing them and possibly breaking their physical or moral resistance".* Cited in https://www.iccl.ie/her-rights/torture/

36 https://www.iccl.ie/her-rights/torture/

37 Candace Imison, and Jemma Kwint https://evidence.nihr.ac.uk/collection/continence-dementia-and-care-that-preserves-dignity/

38 *Ibid.*

39 *Aldridge and Dening, 2021,* https://www.ucc-today.com/journals/issue/launch-edition/article/dementia-and-continence-issues-ucct *p.58*

# Physical Restraint





## Use of Physical Restraints

**USE of physical restraint in a care context is a complex and challenging issue both in residential care settings and in home care. Research has pointed to an increasing demand worldwide from informal caregivers and healthcare providers for use of various types of restraints in different care settings.**

The Department of Health's *Towards a Restraint Free Environment in Nursing Homes*[40] policy document describes restraint as "the intentional restriction of a person's movement or behaviour". Such practices may be physical or environmental in nature. Physical restraint is any manual method or physical or mechanical device, material or equipment attached or adjacent to a person that the individual cannot easily remove and that restricts freedom of movement or normal access to one's body.

Environmental restraint is the intentional restriction of a person's normal access to their environment, with the intention of stopping them from leaving, or denying a person their normal means of independent mobility, means of communicating, or the intentional taking away of ability to exercise civil and religious liberties. Environmental restraint may also seek to limit a person's choices or preferences (for example, access to alcohol, tobacco or certain foods).

Examples of restraints are bedrails, bed-against-the-wall (positioned in a way that the person will not fall out of bed), locked room or house doors, deep chair that prevents rising, and restrictive clothing and belts. There is some evidence from Sage Advocacy casework of mobility aids not being left beside residents and batteries in motorised wheelchairs not being charged in order to discourage free movement around their place of residence.

### Use of bed rails

Bed rails, also known as side rails or cot sides, are widely used to reduce the risk of falls. While they are widely used in various care settings, and can be effective when used properly in the right way, for the right person. accident data shows that bed rails sometimes do not prevent falls and can introduce other risks. Poorly fitting bed rails have been reported as causing deaths where a person's neck, chest or limbs become trapped in gaps between the bed rails or between the bed rail and the bed, headboard, or mattress. Other risks identified[41] are:

- ***Rolling over the top of the rail***
- ***Climbing over the rail***
- ***Climbing over the footboard***
- ***Violently shaking and dislodging rails***
- ***Violent contact with bedrail parts***

A person can also experience physical restrictions through inaction. This means that the care and support a person requires to partake in normal daily activities are not being met within a reasonable timeframe.

HIQA general principles and guidance for consideration in relation to restrictive practices include the following:[42]

- Restrictive practices are an infringement of a person's constitutional right to liberty and bodily integrity and should only be used when absolutely necessary.
- Providers should, in so far as is practicable,

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40 **Department of Health. Towards a Restraint Free Environment in Nursing Homes.** https://assets.gov.ie/18830/9ef5610bf0814bf792263e844e0d9378.pdf

41 https://www.nursingdirect.co.uk/index.php?option=com_docman&view=download&alias=94-policy-87-language-policy&Itemid=6678#:~:text=Bed%20rails%20are%20'medical%20devices,medical%20devices%20are%20acceptably%20safe.

42 https://www.hiqa.ie/sites/default/files/2019-03/Restrictive-Practice-Guidance_DCOP.pdf

seek to reduce or eliminate the use of restrictive practices.

- Where restrictive practices are assessed as necessary, they should be implemented, where possible, in consultation with the person receiving care and with their informed consent.
- Assessments should identify any physical, medical, psychological, emotional, social and environmental issues that may be contributing to the use of restrictive practices.
- Any restrictive practice should be proportionate to the identified risk(s).
- The use of restrictive practices should be subject to ongoing review to determine if they continue to be necessary and should be removed as quickly as possible when no longer required. Reviews should also be used as an opportunity to trial alternatives that are less restrictive and or for a shorter period of time.
- Providers should be: (a) aware of the use of restrictive practices in their centres; (b) assured that they are used in compliance with the regulations and National Standards; and (c) have a senior manager or a committee in place whose goal it is to reduce and or to eliminate the use of restrictive practices.
- Staff should have access to appropriate training on the use of restrictive practices, including prevention and alternatives, and be supported in getting to know each person's needs and preferences.
- Providers should collect and analyse data on the use of restrictive practices in order to identify patterns or trends.[43]

Physical restraint is clearly a factor in mental health facilities and in prisons. It would appear that the issue of the use of physical restraint receives greater attention in discourse on prisons and mental health facilities than it does in relation to residential care facilities for older persons and people with an intellectual disability or, indeed, in relation to older persons or people with an intellectual disability being cared for in their own homes. It is noted that a new human rights model for mental health treatment aims to reduce use of physical restraint in mental health facilities.[44] It is noted that Germany has very stringent laws governing restraint, including a requirement for court approval of restraint, other than in emergencies, where a nursing home resident lacks capacity to consent.[45]

While people have the right to live as independently as possible without unnecessary restriction, there is often a challenge to balance the right to autonomy and liberty with the need to ensure people's health and safety and the safety of others. Department of Health Guidelines[46] stipulate that any potential episode of restraint must be considered only where there is clear evidence that the potential benefit of restraint to the individual person, and the risk involved if restraint is not used, outweigh the possible negative effects on the person subject to the restraint. The typical 'closed unit' model operating in many nursing homes is clearly at odds with this thinking.

While patient safety is the most commonly indicated reason for using (physical) restraints, it has been pointed out[47] that, despite decades of concern about their safety, effectiveness and appropriateness, physical restraints remain widely used in nursing homes particularly for residents with poor mobility, high dependency or dementia. Some of the issues reported with physical restraints internationally include, death by asphyxiation or mechanical compression. Research has shown how the frequency of restraint can be cut dramatically without significant increase in psychoactive drug use or in falls-related injuries.[48]

The 2017 Cochrane Literature Review on Restrictive Practices[49] questioned whether physical restraint (PR) use is an effective way of preventing falls or fall-related injuries. The review suggested that by making people spend more time immobile, they may worsen walking problems and actually increase the risk of falling. They may also increase feelings of fear, anger and discomfort, and decrease wellbeing. Other unintended consequences include an increased risk of pressure ulcers and incontinence, and injuries directly related to the use of PR.

The review also suggested that interventions aimed at reducing use of PR through changing policy and practice in care homes are likely to be effective at reducing the number of people restrained overall and especially with belts. The review found that reducing restraints did not lead to a higher number of people with falls.[50]

A 2024 study[51] noted that, although professionals involved in nursing care agree that improvements have been made, they highlight the negative impact of restraints and the need for a change in culture about their use. All stakeholders highlighted the need for a change in culture when applying restraints, ensuring that their use is exceptional and limited to situations related to protection.

Experts on ethics and human rights defenders stated that the culture of 'zero restraints' should be promoted with the support of scientific evidence and the utmost respect for existing human rights. They claim that restraints potentially violate human rights and can be abusive, and talk about the impact on older people's emotional wellbeing.

The negative impact of restraints was recognised by all participants and linked to the potential violation of residents' rights. Many study participants highlighted the progressive improvements in the use of restraints observed in recent decades: in terms of awareness of their negative impact, limitations on use, approved devices and consensus on restraint procedure.

Healthcare professionals emphasised that there are guidelines and protocols to ensure good practice, that restraints are necessary in certain cases, and that there is resistance from professionals to eliminate the use of restraints to zero. They have concerns about the 'zero restraints' feasibility and urged more resources to preserve the exceptionality of this measure.

There is a need for further research to carefully document and understand the use of restraints in nursing homes and the experiences of all individuals and organisations involved.

A 2023 review[52] of empirical studies on physical restraint found that the most common reasons given by nursing home staff for using physical restraint are safety, such as preventing falls or self-injury or harm to others, residents' inappropriate behavior, such as agitation and wandering, the convenience of the staff, shortages of nurses, the complexity of care, high workloads, lack of knowledge about physical restraint, absence of person-centered care, and lack of legislation/guidelines. The review further noted that there is little information on the prevalence of and methods used in physical restraint, reasons for using restraints in nursing homes, and interventions to reduce restraint use. The evidence shows that a decrease in physical restraint use does not result in more falls or fall-related injuries.

The review also highlighted the fact that physical restraint use is recognised as a violation of human rights – an infringement of an individual's autonomy, dignity and

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43 **It is important to distinguish between regulations, national standards and guidance – the latter does not have a standing in court.**

44 **Irish Examiner article, 23 January 2024, New human rights model for mental health treatment aims to reduce use of physical restraint (irishexaminer.com)**

45 *Ibid.*

46 **Department of Health. Towards a Restraint Free Environment in Nursing Homes. https://assets.gov.ie/18830/9ef5610bf0814bf792263e844e0d9378.pdf**

47 **Shaun T. O'Keeffe, Physical restraints and nursing home residents: dying to be safe? | Age and Ageing | Oxford Academic (oup.com)**

48 *Ibid.*

49 **Restrictive-Practices_Literature-Review.pdf (hiqa.ie)**

50 **It should be noted that all the evidence in the review came from studies in institutions and it may not apply to care in people's own homes.**

51 **Physical restraints in nursing homes: A qualitative study with multiple stakeholders - PubMed (nih.gov)**

52 **Hakverdiolu Yönt G, Kisa S, Princeton DM. Physical Restraint Use in Nursing Homes-Regional Variances and Ethical Considerations: A Scoping Review of Empirical Studies. Physical Restraint Use in Nursing Homes-Regional Variances and Ethical Considerations: A Scoping Review of Empirical Studies - PubMed (nih.gov)**

liberty. The ongoing use of physical restraints for fall prevention, despite lacking scientific evidence, raises ethical concerns. To address this, it is recommended that clear directives are provided to nursing home staff based on the latest evidence-based practices and interventions for fall prevention. These directives should emphasise the safety, rights, and dignity of the residents, ensuring that physical restraints are only considered as a last resort when no alternatives are available.

The review also noted that international guidelines and recent studies suggest that a restraint-free nursing home and model of care with reasonable levels of safety is possible. Implementing mandatory training programmes for nursing home staff is essential in this regard.

A 2022 study on the incidence and type of restrictive practice (RP) use in nursing homes in Ireland[53] found that nursing homes in Ireland regularly use RP; only 9.5% reported no RP use in the 12-month period. A wide variety of types of RP were reported. Matters that are required to be notified to the HIQA Chief Inspector include the use of restraint, including the use of bedrails etc to confine a person. A centre may be asked by HIQA to identify what other methods were employed before using restraint.

It has been suggested[54] that there is a risk that focusing primarily on the risks and physical complications of restraint, i.e., health and safety, while important, will lead to an emphasis on the better design of restraints or on improvement of staff training in how to restrain rather than a more fundamental questioning of the use of restraints and the perspective and experience of people who are restrained.

Decision-making related to restraint use is a complex process that is influenced by various factors relating not only to patient characteristics such as cognitive decline and poor mobility but also non-patient related factors such as the attitude and knowledge of healthcare providers and what is allowed by regulation. The context-specific factors influencing restraint use include insufficient supervision, staff shortages, a lack of understanding of the potential impact of restraint on an individual in terms of their liberty and related wellbeing and, in some instances, relatives requesting that restraints be put in place.

## Key questions requiring further analysis in the Irish context

A prima facie question arises as to how well HIQA national standards, principles and guidelines are implemented in all care settings. It is reasonable to suggest that the typical 'closed unit' model operating in many nursing homes is clearly at odds with Department of Health thinking and HIQA Guidance.

Key questions relating to physical restraint in care settings requiring attention in Ireland that require further consideration are:

1. How is physical restraint understood by professional staff in residential care facilities, nursing homes and hospitals and by both paid and 'informal' carers in people's homes?
2. What are the consequences and impact on individuals of physical restraint use in various residential care settings?
3. To what extent are there restraint practices in existence in respect of people being cared for in their own homes?[55]
4. Are the ethical and legal frameworks guiding healthcare providers in decisions about the use of physical restraint in various care settings sufficiently robust from a human rights perspective?
5. Are the provisions of the Assisted Decision-Making (Capacity) Act[56] given effect in decisions about the use of physical restraint?
6. How can healthcare workers reduce the use of physical restraint?
7. Is the process for deciding to use physical restraint sufficiently clear and robust?
8. To what extent do practices such as non-availability of staff to assist people with mobility problems and locked doors constitute a form of physical restraint?
9. What factors should be taken into account when there are divergent views between residential care facilities and residents' relatives in instances where a person lacks decision-making capacity?
10. To what extent is the will and preference of an individual, particularly those with reduced decision-making capacity, taken into consideration when decisions are being made about using restraints?
11. While physical restraints are often considered by healthcare and family carers as safety measures, is this always the case?
12. What are the consequences and the impact of the use of physical restraints on individuals, particularly those with reduced decision-making capacity?
13. Where physical restraint is used or considered, do the anticipated benefits of the restraint use outweigh the associated risks?
14. Is the permission of the person, or their legal representative in the case of a person who lacks decision-making capacity, sought prior to applying physical restraints on an ongoing basis?

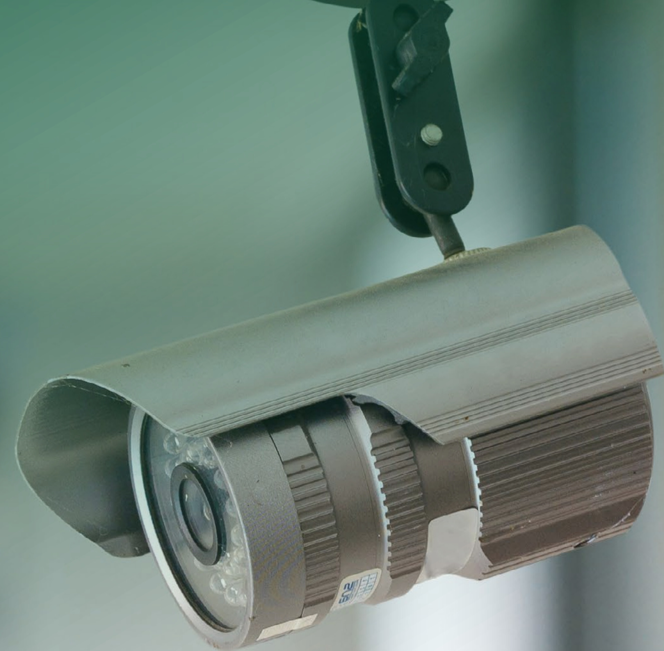
53 https://bmcgeriatr.biomedcentral.com/counter/pdf/10.1186/s12877-022-03450-4.pdf

54 *Ibid.*

55 International research has suggested that that there are no guidelines specific to restraint use in home care and that research on restraint use in home care settings was scarce.

56 It should be noted that there are now no provisions in the ADMC Act in relation to physical restraint. Sec.37 of the 2022 Act deleted Sec.43(3) to (5) of the 2015 Act, which provided for restraint by DMR. Sec.3 of the 2022 Act repealed Sec.62 of the 2015, which provided for restraint by an Attorney.

# The Use of Cameras in Care







# The Use of Cameras in Care

## Introduction

**THE question of whether the use of surveillance cameras in nursing homes is an acceptable practice has been subject to regular debate internationally by both the care home sector and the media. This often takes place in the context of cases where residential care services have been seen to have failed their residents, as in the Áras Attracta situation in Ireland.**

While there is a lot written about enabling technologies for older people and people with disabilities and the use of sensors to identify patterns and potential need for urgent intervention, there is little written about the use of cameras for surveillance purposes in respect of at-risk adults.

There are diverging views about the use of surveillance. Some supporters of the use of CCTV have welcomed it as a way of providing an additional protection to vulnerable residents. Opponents have expressed concerns about the adverse implications for the privacy and dignity of residents, particularly if it includes surveillance in bedroom areas. The debate has included discussion on whether covert surveillance can ever be appropriate in care homes.

A distinction is usually made between surveillance in public care home spaces and private/personal spaces within the facility, especially bedrooms. However, this distinction may be somewhat artificial in that the residential care facility is in effect the private space of residents (their home) and in that sense should not be regarded as a public space.

Internationally, surveillance technology (CCTV, cameras and microphones) is increasingly being deployed in nursing homes and assisted living facilities and it has been suggested that there is insufficient attention to a range of ethical considerations.[57] Most residential care facilities routinely use security cameras to monitor common areas, parking lots, and exits. A centrally important issue arises, however, relating to a trend in some countries towards installing cameras in residents' rooms.

In Nordic countries, the use of surveillance cameras is widely recognised as a type of welfare technology that can be used as support in the care of older people.[58] Welfare technology is defined as knowledge and use of a technology that can maintain and/ or increase the feeling of safety, activity, participation and independence for a person of any age who has or is at an increased risk of having or developing a disability.[59] The definition of welfare technology describes its capabilities (e.g., maintain and/or increase the feeling of safety, activity, participation and independence).

Related to health and wellbeing, welfare technology can be used at a distance or at the physical place. Such technologies have the potential to provide high-quality care services to older people, and lessen the burden on elder care personnel in the context of shortages of staff commensurate with need.

The concept of welfare technology in Swedish municipal eldercare is based on the belief that it can provide around-the-clock surveillance and quick 'check-ups' through digital-supervision that would not otherwise be made. Digital night camera supervision was also mentioned as an advantage to physical night visits. This is because digital "sightings" do not disturb the sleep of the care receivers as much as physical visits do.

The Care Quality Commission (CQC) – the independent regulator of health and social care in England – has agreed that the use of CCTV cameras may be the best way to ensure safety or quality of care.[60] However, it has highlighted the need to consider whether less intrusive steps can be taken by providers to ensure the same aims are achieved.

57 https://pubmed.ncbi.nlm.nih.gov/30794112/

58 Full article: The concept of welfare technology in Swedish municipal eldercare (tandfonline.com)

59 *Ibid.*

60 https://www.cqc.org.uk/guidance-providers/all-services/using-surveillance-your-care-service

In Ireland, following the exposure by an RTÉ Prime Time investigation of significant abuses of residents in Áras Attracta,[61] the HSE actively considered the installation of surveillance and security systems to protect vulnerable clients, patients, service users and staff members. However, this was not proceeded with on the basis that the installation of cameras in residential facilities would impinge on the privacy of residents.

Notwithstanding this, in 2021, a HIQA inspector found "significant use of restrictive practices" at a Dublin disability care home, including the use of CCTV cameras in resident apartments and in one resident's bedroom.[62]

An emerging scenario involves adult children monitoring activity inside people's homes (especially of home care providers). The HSE took a case in 2018 to safeguard a woman from her children placing cameras in different areas of the home (e.g., showers). The then President of the High Court refused it.

There is also the matter of surveillance in instances where people are being cared for in their own homes. In 2018, the President of the High Court dismissed concerns by the HSE that a family's installation of CCTV cameras in their mother's home, with a view to ensuring appropriate care of her, amounted to abuse. The HSE had applied for a declaration under the Enduring Powers of Attorney Act that cameras are not an appropriate personal care decision and also sought orders for destruction of footage taken prior to its application. However, the High Court judgement stated that there was "nothing surreptitious" about installation of the cameras, given that the family had informed the HSE of the fact.

## Perceived benefits of in-room surveillance

Research has shown that care personnel have reported that nocturnal digital surveillance technology had several benefits for the residents, such as giving them a better night's sleep, reducing the use of sedatives and sleeping pills, and making them more alert during the day. The cameras also facilitated the care personnel's work by making it easier for them to help each other across departments, prioritise, and create a better work environment. There is also an argument that in-room cameras provide an extra layer of security for family members who may have concerns about potential abuse of their loved ones. Cameras can reassure families that their loved ones are being cared for properly and can help identify poor care or abuse where such exists.

Another argument for in-room cameras is that the workforce in residential care facilities for older persons cannot increase at the rate required to match the needs. The argument is that welfare technologies, such as surveillance cameras, can replace physical visits and be used at night to monitor residents in order to keep them safe, while not disturbing their sleep.[63]

A further argument is that in-room surveillance would provide undisputable evidence of poor care and abuse, making it easier to secure prosecutions, and would remove the need for care staff to blow the whistle on perpetrators – something that many workers may find difficult and stressful.

In addition to the implications for residents' privacy, a downside to the perceived benefits and efficiency of surveillance cameras is the risk for abuse. In the event of staff shortages and budget cuts, cameras could become a tool that is used to replace staff. Care staff need to be physically present to smell, feel the body temperature, see the face colour, and hear the breathing. Likewise, physical contact such as holding a person's hand cannot be done via a camera. Hence, irrespective of its perceived benefits, no technology can ever fully replace personal contact.

Three ethical issues have been identified in respect of in-room cameras[64] – (i) the invasion of residents' privacy and dignity; (ii) the risk of undermining care workers' sense of being persons trusted by residents; and (iii) the likely extension of camera use by facilities to monitor both staff and residents. There is a very strong argument that, even if a resident agrees to in-room surveillance, it is a violation of privacy for anyone else who comes to visit them, in particular, staff. A critical question that arises is whether any person, irrespective of their decision-making capacity, would be happy with their every private moment being recorded for others to view (including by family members).

## Where a resident lacks decision-making capacity

Given that any use of in-room surveillance would typically give rise to 'continuous supervision' of a resident, ethical dilemmas can arise when consent is needed from a person with reduced decision-making capacity. Even if the person receives adequate information and (with supported decision-making) understands it at that moment, the person may forget it shortly afterwards. Therefore, people with reduced decision-making capacity who have been offered and consented to a surveillance camera in their room must be provided with meaningful opportunities to review and renew that consent.

The Care Quality Commission has emphasised the need to consult with the people who use care services, including residents, families and other visitors to care homes and also staff when deciding about whether and how to use surveillance.

## Surveillance in nursing homes and GDPR

Any visual images such as photographs and video recordings are defined as data and are covered in the same way as written records by data protection principles in organisations, where data protection laws apply. If cameras are to be used, nursing home managers should by law have to make decisions about various matters relevant to the GDPR, including who has access to the CCTV and for what reasons. Clearly, CCTV footage of nursing home residents and staff falls under personal data, so it is imperative for the nursing home to adhere to the GDPR guidelines.

The UK CQC has stated that where a decision has been made to use surveillance, the obligations placed on data controllers under GDPR to ensure that personal data is collected for "specified, explicit and legitimate purposes" must be adhered to.

CCTV law in Ireland is governed by the Data Protection Acts of 1988 and 2003, as well as the General Data Protection Regulation (GDPR), which came into effect in May 2018. These laws set out the framework for the use of CCTV cameras in Ireland and aim to strike a balance between the need for security and the protection of individuals' privacy rights.

Transparency is at the heart of the GDPR and residential care services that propose to use CCTV, particularly in bedroom areas, should evidently do so on the basis of consent and agreement by residents and staff. Consent, in order to be lawful, must be express and not inferred and there must be simple and clear ways by which the data subject can withdraw consent. Under the GDPR, the processing of any personal data can only be done if one or more of the various lawful means whereby data can be shared (including explicit consent by the data subject in this case the resident) are met, as set out in detail in Article 9(2) of the GDPR.[65] Where cameras are placed in residents' bedrooms, this will require an additional level of attention and clear data protection protocols.

Generally speaking, under Irish law[66], individuals and organisations using CCTV surveillance must adhere to several key principles:

***Purpose and Consent:*** CCTV systems should be used for legitimate purposes such as security, crime prevention, or health and safety. Individuals must be informed if they are being recorded, and their consent should be obtained in certain situations.

***Data Minimisation:*** The data collected by CCTV cameras should be limited to what is necessary for the intended purpose. Unnecessary or excessive recording is generally prohibited.

***Data Retention:*** Data should not be retained for longer than is necessary for the purpose

61 Inside Bungalow 3 - Áras Attracta (rte.ie)

62 https://www.irishtimes.com/news/health/cctv-used-in-resident-s-bedroom-at-disability-care-home-watchdog-finds-1.4544710

63 https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-023-09130-2

64 https://pubmed.ncbi.nlm.nih.gov/30794112/

65 https://gdprhub.eu/Article_9_GDPR

66 https://www.dataprotection.ie/sites/default/files/uploads/2023-12/CCTV%20Guidance%20Data%20Controllers_November%202023%20EN.pdf

for which it was collected. Clear retention policies must be in place.

***Security Measures:*** Adequate security measures should be in place to protect the data from unauthorised access or disclosure.

***Access and Rights:*** Individuals have the right to request access to CCTV footage in which they appear. They also have the right to request the erasure of their data under certain circumstances.

***Signage:*** There should be clear signage in areas where CCTV is in operation, notifying individuals that they may be recorded.

***Registration:*** In some cases, organisations using CCTV may need to register their systems with the Data Protection Commissioner.

To ensure compliance with data protection laws, several key requirements must be met, including, in particular, establishing a legal basis, transparency in operation and secure data handling. While these requirements should clearly apply in all residential care settings, the extent to which they are adhered to in practice in Ireland is not entirely clear. This is an area where, it is suggested, more research is required.

## GDPR Storage and use of footage

There is an express requirement under the GDPR that personal data is to be processed for only as long as its purpose requires it to be. The care home operator will therefore need to consider for what period footage should be stored by the home and any policy on CCTV should reflect this.

As with other forms of data processing, care home operators will need to consider the specific arrangements that they make for processing the CCTV images and the implications of using third party processors, such as cloud storage services. There needs to be specific consideration given to who will have access to the CCTV and for what reasons and it will be essential that security measures are in place to prevent unauthorised access. Where cameras are placed in residents' bedrooms, this will require an additional level of security.

There is an express requirement under the GDPR that personal data is to be processed for only as long as its purpose requires it to be. This is an important consideration.

Since obtaining valid consent to the use of surveillance will present significant challenges, given that some residents will have reduced decision-making capacity affecting their ability to comprehend information relevant to the consent process, this is a matter that would require very careful consideration in the Irish context with particular reference to requirements under ADMC legislation.

The CQC has identified[67] the following aspects of surveillance that need to be documented and available for inspection and that would be relevant in the Irish context:

- An assessment of the need for surveillance, the reasons behind the idea and why CCTV or similar would seem to be the best option out of the options available;
- A statement of the purpose, including specific goals and the outcomes sought from the use of the preferred surveillance method;
- The timescales involved: starting, periods of use (if not continuous);
- How the decision to use CCTV in a specific place has been arrived at;
- Confirmation that the surveillance methods proposed or used are lawful and the steps taken to establish their legal basis;
- The steps taken to obtain consent of all whose personal information is being captured; not least where surveillance methods are being installed in communal areas resulting in the exposure of a wide range of people;
- How consent from people who might lack decision-making capacity has been obtained;
- Any deprivation of liberty safeguarding issues that have arisen;
- How the service has addressed concerns about possible loss of privacy, dignity and respect and the concerns of staff and others;
- The scope, methods and results from the consultation process followed;
- A statement of the information that will be/has been captured and the steps to ensure that its capturing is legitimate and complies with data protection requirements;
- How the data is or will be kept secure;
- How people are informed, e.g., by signage that they might be subject to surveillance in certain areas of the home;
- If covert surveillance is to be used, a statement of the overriding reason for it and when and how it can be minimised and discontinued at the first opportunity;
- The personnel responsible for the operating of the system, including the processing of the information captured, their accountability and the systems for monitoring, reviewing and auditing the surveillance process.

## Key points for consideration

Central to whether the use of CCTV is justified will be how it will support the needs and interests of nursing home residents. It would appear that surveillance cameras are increasingly being deployed in nursing homes and residential care facilities, without sufficient attention being given to ethical considerations, in particular people's right to privacy. It is critically important from a human rights perspective to consider the ethical implications of how technology is used in care settings.

Central to the question of whether the use of cameras in care is justified will be how it will support the needs and interests of the residents of the home. Particular attention will need to be given to whether CCTV can be used in bedroom areas having regard to the legal requirements relating to sensitive personal data, including data concerning a person's health.

While there is currently no regulatory provision in Ireland for the use of in-room camera surveillance, as more pressures come on the care workforce, there may well be a push for it to be allowed in the future. It is important, therefore, that the ethical dimensions of any such potential decisions be fully acknowledged and exposed.

There would appear to be insufficient attention given in policy and regulatory discourse in Ireland to date to the use of cameras in care, either in terms of what is legally permissible and its operation in practice, particularly in relation to consent; and access to and retention of surveillance data. This is a matter of some concern from a human rights perspective.

Clearly, any decision to install surveillance should only be taken with the support and consent of residents, their families and staff, and with clear policies on how the data will be used. For example, where residents consent to surveillance, they should have the option of turning the cameras off in private spaces whenever they wish.

It has been suggested that, with an ageing population, intensifying strain on the care workforce, and ease of access to web-connected cameras, this is a critical moment to address the various ethical challenges involved.[68] A critical question from a human rights perspective is: Are cameras in care the ultimate deterrent to abuse of at-risk adults or are they a massive invasion of people's right to privacy and personal dignity?

67 https://www.cqc.org.uk/guidance-providers/all-services/using-surveillance-your-care-service

68 https://pubmed.ncbi.nlm.nih.gov/30794112/

# Some Overarching Considerations

**THE five issues outlined in this document raise important concerns about the protection of rights of at-risk adults and clearly point to the need for a proactive engagement with these issues. This would be necessary in order to strengthen the case for the introduction of adult safeguarding and protection of liberty legislation as a matter of some urgency.**

The human rights of at-risk older persons continue to be undermined by a lack of resources for appropriate care and supports in the community, and a lack of a statutory right to homecare. The result is that the principle of valid consent is compromised and people are effectively deprived of their liberty as a result of lack of choice. As is the case with mental health legislation, there is no comparable legislation in Ireland to protect people with high care needs who are forced to remain in a residential care setting against their will. This current lack of legislative safeguards and the absence of a process of automatic review to determine if a person admitted to a residential care centre has consented to be there adds to the rights infringement issue in that it can result in people being effectively detained against their will.

It is important to note that from a human rights perspective, deprivation of liberty can take many forms and that there are different settings in which deprivation of liberty can occur. These include in people's own homes where people are subjected to coercive control or dependent on the goodwill of others to enable them to get out of their homes. For example, a person's inability to leave a place or escape a situation may arise due to non-physical forms of coercion, including the exercise of power over a person who is dependent on another for care.

There are also serious concerns about the use of physical constraint and psychotropic medicine in the context of people's basic right to freedom of movement. It is also noted that research has tended to focus largely on physical and chemical restraint in nursing homes and, consequently, there is, perhaps, a lack of research into other forms of restraint such as social, psychosocial or psychological. The latter (sometimes referred to collectively as 'informal restraint') are more nebulous and difficult to accurately define. Examples of these type of restraint include diversion, persuasion, lies or threats.

In some countries, the use of physical restraint is illegal in most circumstances and guidelines recommend that its use should be reduced or stopped. This is a matter that requires further research and debate in Ireland. Awareness and knowledge of restraint use and its implications and the ethical challenges surrounding it are of crucial importance to its reduction.[69] Making a distinction between surveillance in public/shared spaces in nursing homes and in-room surveillance, while somewhat artificial because in each case it impinges on privacy, is clearly important.

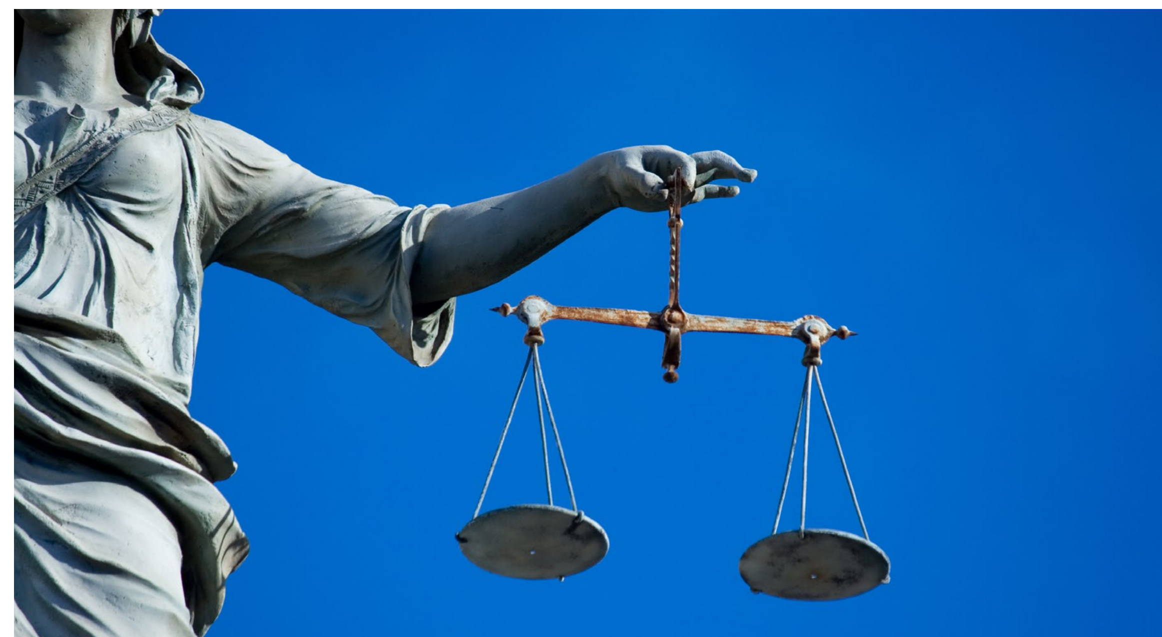
The prevalence of the inappropriate use of medication is a matter of ongoing concern. This is an area where more research could be carried out in Ireland in order to explore further the various reasons for this poor practice.

## Need for new adult safeguarding legislation

The five human rights issues discussed in this document need to be considered in the context of the absence of fit-for-purpose safeguarding legislation. The need for such legislation has been identified repeatedly in recent years by various agencies (statutory and NGO). The Law Reform Commission has noted that the provision of adult safeguarding legislation is underpinned by international human rights obligations as well as in the context of defending the personal rights of those whose capacity is in question as set out in Article 40.3.1 of Bunreacht na hÉireann.

69 https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-020-1499-y





It is important to acknowledge that Ireland has introduced various pieces of legislation and a number of regulations[70] and guidelines aimed at safeguarding older people in residential care, including restraint; managing behaviour that is challenging and residents' rights. HIQA clearly plays a hugely important safeguarding role by regulating health and social care services, inspecting services and investigating allegations involving service providers. However, HIQA currently has no role in regulating home care or investigating complaints by individual residents in congregated settings.

The Department of Health Policy Proposals on Adult Safeguarding in the Health and Social Care Sector[71] address a number of key shortcomings in adult safeguarding policy and practice to date, including, in particular, the fact that existing policy does not apply to much of the health and social care sector and insufficient emphasis on hearing the voice of service users who have reduced decision-making capacity or who communicate differently.

However, these policy proposals will be insufficient in the absence of legislation. The need for new safeguarding legislation arises primarily because of the need to broaden the issue of safeguarding vulnerable adults beyond the domain of health and social care and the need to ensure that vulnerable adults in nursing homes and in other residential care facilities are fully safeguarded and that their legal and human rights are protected.

As far back as 2017, HIQA, in its submission to the Oireachtas Select Committee on the Future of Healthcare[72], noted as follows:

> ***"We believe that now is the time to introduce safeguarding legislation to protect at risk adults from abuse and neglect. While national safeguarding protocols are in place following recent high-profile revelations of abuse, these do not go far enough to ensure the safety and rights of vulnerable people."***

The publication of the Law Reform Report on Adult Safeguarding provides a timely and useful context for considering the five issues outlined and discussed in this document. At the very core of each of these issues is an adult safeguarding concern. Also, of critical relevance is that failure to engage systematically and fully with these issues will inevitably result in ongoing breaches of the basic human rights of at-risk and highly vulnerable adults in Ireland.

70 See, for example, S.I. No. 415/2013 - Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2013. (irishstatutebook.ie)

71 https://assets.gov.ie/282259/c941dc0c-c220-4a3a-8da5-460ba6af51bd.pdf

72 https://www.hiqa.ie/sites/default/files/2017-02/Submission-Committee-on-the-Future-of-Healthcare.pdf

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