Submission to the Open Ended Working Group on Ageing – Overview of the Human Rights of Older People in Ireland

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1. Introduction and overview

Founded in 1992 Age Action is a non-government organisation that campaigns for better policies and services for older people and works to empower older people to live full lives as actively engaged citizens and to promote and protect their rights to comprehensive high quality services according to their changing needs. We also work on global ageing and draw attention to issues older people face in developing countries.

This submission outlines the human rights of older people in Ireland as it applies to certain issues namely:

- Elder abuse
- Dementia and assisted decision making
- The overuse of medication and detention of older people in nursing homes
- Protection of the family
- Employment and pensions
- Social security and the right to an adequate standard of living
- Health

We would like to draw the Open Ended Working Group on Ageing (OEWGA) members' attention to the gaps in protection of the rights of older people in Ireland under these issues.

We in Age Action have been following the progression of the OEWGA since its inception in 2010 and thank the Working Group, Member States and contributors for their work to date. We support the drafting of a Convention on the Rights of Older People and think a new Convention, should Ireland ratify it, would help bridge these gaps by the introduction of supporting legislation, where appropriate.

As the global population ages and projections show that this will continue[1] Age Action also supports the drafting of a new Convention to ensure there is protection for the rights of this growing cohort of people worldwide. We need a common minimum standard set of rights for older people that Governments can sign up to. These would not necessarily be new rights, but the articulation of how each human right specifically applies to older people and what measures Governments must take to comply with it.

In addition a new Convention would provide a welcome cultural shift in how older people in Ireland and globally are perceived. Ageism is rife and older adults are often seen as a burden rather than the bearers of rights who have helped build the infrastructure of their respective societies and economics,

[1] 11% of the global population was over 60 in 2012. This will rise to 22% by 2050. (Global Age Watch Index, HelpAge International , 2013 available here)

and continue to contribute even when they are no longer in employment. A new Convention would help increase the visibility of older people and move towards older people being viewed as rights holders rather than recipients of charity or welfare.

We thus urge Member States, including Ireland, in this upcoming session from 30 July – 1 August 2014 to move towards the drafting of a Convention in order to adequately address the protection of the rights of older people.

2. Elder Abuse

Elder abuse in Ireland is defined as a single or repeated act or lack of appropriate action occurring within any relationship where there is an expectation of trust, and which causes harm or distress to an older person or which violates their human and civil rights. Elder abuse may be subdivided into the following categories:[2]

(i) Physical abuse which includes hitting, slapping, pushing, kicking, misuse of medication and inappropriate restraint.

(ii) Psychological abuse which includes the use of threats, humiliation, bullying, intimidation, isolation, swearing and other conduct that result in distress to the older person.

(iii) Financial abuse which is the unauthorised or improper use of an older person's funds, property or resources. It may include theft, fraud, coercion or misuse of enduring powers of attorney.

(iv) Sexual abuse which is any sexual act to which an older person has not or could not consent, including talking to the person or touching them in a sexual way.

(v) Institutional abuse occurs in residential or acute care settings and may involve poor standards of care, rigid routines or inadequate responses to complex needs. It may include (i)-(iv) above and other forms of abuse such as discriminatory abuse or neglect.

Both men and women are affected by elder abuse in Ireland and the perpetrators are often family members. In a study of elder abuse in the community in Ireland 2.2% of people aged 65 and over said they had suffered some form of abuse in the previous 12 months. 4% said they had suffered some form of abuse since the age of 65. Women were more likely to suffer abuse than men, and people aged 70 and over experienced double the levels of abuse experienced by those in the 65 -69 age group. Those in poor physical and mental health were more likely to experience abuse.[3] Most elder abuse is perpetrated by family members or acquaintances.

Elder abuse does not stop when an older adult is admitted to a nursing home or other care institution: some perpetrators who are family members or acquaintances may continue to abuse the person after admission. Elder abuse is often undetected and unreported, so abusers could continue their activities even if their access to the person is restricted. Abuse may also be perpetrated by staff in residential care settings.

Elder abuse services are provided by the HSE, with designated elder abuse social workers in each area of Ireland.[4] They are responsible for investigating and dealing with allegations of elder abuse in

[2] Protecting our Future. Report of the Working Group on Elder Abuse. September 2002. Dublin. See www.ncpop.ie/whatiselderabuse

[3] Abuse and Neglect of Older People in Ireland. Report on the national study of elder abuse and neglect. 2010. National Centre for the Protection of Older People. University College Dublin. www.ncpop.ie

[4] O'Donell D et al. Managing Elder Abuse in Ireland: The Senior Case Worker's Experience. (2012) . NCPOP University College Dublin.

both community and residential settings. Considerably fewer instances of abuse are reported to the HSE elder abuse service than occur, as a study of older people's actual experience shows about 10,000 older people suffer some form of abuse in the preceding 12 months.[5] Case workers deal with under 1000 cases nationally.[6]

The Health Information and Quality Authority (HIQA) inspect and regulates nursing homes: as part of their regulation they expect staff to receive training in elder abuse. Staff in nursing homes may be the perpetrators of elder abuse. Elder abuse may be physical, psychological, financial or sexual. Physical abuse in nursing homes may include slapping and hitting the person or restraining them beyond what was necessary. In a recent case at St John's Community Hospital in Sligo a nurse taped a patient's mouth shut.[7] This was reported to HIQA and the Gardai and the nurse was found guilty of assault and given probation.[8] The judge noted that he had an extremely high workload due to poor staffing levels at the home and appeared to consider this a mitigating factor. HIQA had warned the home about its poor staffing on several occasions since 2011 but no action had been taken to correct staffing levels.

In a recent study of elder abuse in institutional settings 3.2% of staff reported observing a colleague in an act of physical abuse in the preceding 12 months, most commonly restraining the person beyond what was required, or slapping or hitting the person. 57.6% observed neglectful behaviour by others, most commonly not responding when a resident called for help or not bringing a resident to the toilet when they asked. About 6% of staff reported not changing an older person after an episode of incontinence. 5.6% reported giving a resident too much medication to keep them sedated or quiet. 1.2% had observed financial abuse and 0.2% reported observing sexual abuse.[9] The affront to older people's dignity is particularly marked in instances of repeated psychological abuse and neglect, often centring around intimate bodily functions. Such treatment is degrading for those who are so reliant on others for care. Arguments that people who are cognitively impaired do not suffer any lasting effects from such treatment have not been accepted by the European Court of Human Rights. In *Keenan v United Kingdom* it was held that "there are circumstances where proof of an actual effect on a person may not be a major factor…Treatment of a mentally ill person may be incompatible with the standards imposed by Article 3 in the protection of fundamental human dignity, even though the person may not be able, or capable of, pointing to any specific ill effects."[10]

In England the superior courts have considered the matter of degrading treatment of those who lack decision making capacity on a number of occasions. In *R (Burke)v General Medical Council* Munby J made an *obiter* comment that: "…treatment is capable of being degrading whether or not it arouses feelings of fear, anguish and inferiority in the victim. It is enough if it is judged by the standards of right

[5] Abuse and Neglect of Older People. Report on the National Study of Elder Abuse. 2010 National centre for the Protection of Older People. University College Dublin. www.ncpop.ie
[6] Open Your Eyes. HSE Elder Abuse Services April 2012. at p 36 www.ncpop.ie
[7] Irish Independent. 20/2/14. Paddy Clancy. "Nurse 'taped patient's mouth shut to keep him quiet', court hears.
[8] Section 1 of the Probation Act
[9] Older people in residential care settings: results of a national survey of staff-resident interactions and conflicts. NCPOP 2011. see www.ncpop.ie
[10] *Keenan v United Kingdom* [2001] 33 EHRR 903

thinking bystanders- human rights violations obviously cannot be judged by the standards of the perpetrators- it would be viewed as humiliating and debasing for the victim, showing lack of respect for, or diminishing his human dignity."[11]

In *R (On the application of Wilkinson) v Responsible Medical Officer Broadmoor Special Hospital Authority* Hale LJ said more succinctly: "the degradation of an incapacitated patient shames us all even if that person is unable to appreciate it."[12]

The misuse of sedative medication is also of concern because it not only violates the older person's dignity and bodily integrity but facilitates further abuse.

There is no Irish legislation defining elder abuse and there is no mandatory reporting of elder abuse in Ireland. Many professional groups such as doctors, nurses and social workers have a contractual and ethical obligation to report suspected elder abuse. Recently the Criminal Justice (Withholding of Information on Offences Against Children and Vulnerable Persons) Act 2012 made it an offence for prescribed groups of persons and organisations to fail to report suspicions of offences against children and vulnerable adults. A vulnerable adult is defined in the Act in section 1(1)(a) as a person suffering from a disorder of the mind, whether mental illness, dementia or intellectual disability who is unable to protect themselves against exploitation or abuse, whether physical or sexual by another person.

Older adults may suffer financial abuse but the Act does not recognise this, nor is any form of financial crime against older adults listed in the schedule of offences in the Act. Offences against vulnerable adults are virtually identical to those against children, although financial abuse is one of the areas of elder abuse which occurs.

As already mentioned staff of nursing homes should receive training in elder abuse, but it is clear from HIQA's inspection reports that some do not.[13] Elder abuse may be reported to special elder abuse senior case workers. If elder abuse occurs in a nursing home HIQA should be informed.[14] HIQA regulates and inspects nursing homes in Ireland. In their overview of nursing homes for older people HIQA reports 373 reports of episodes of abuse in 195 centres in 2013.

Elder abuse rarely results in the prosecution of perpetrators as it is rarely reported to Gardai. Elder abuse is often perpetrated by people who know the older person and are able to exert considerable control over them, usually because they live with the older person or provide care for them. Older people suffering from physical or mental illness may be unable to report what has happened to them,

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[11] *R (Burke) v General Medical Council* [2005] QB 424 at para 149
[12] *R (On the Application of Wilkinson) v Responsible Medical Officer Broadmoor Special Hospital Authority* [2001]All ER 294 at 79
[13] Annual Overview Report on the Regulation of Designated Centres for Older People-2013. May 2014. Health Information and Quality Assurance (HIQA) at p 34. See Publications www.hiqa.ie
[14] HIQA was created by the Health Act 2007

and if they do they may not be believed. Their complaints may be dismissed as part of the paranoia of dementia. Although the courts may regard the age of the victim as an aggravating factor when sentencing those who have committed crimes against older adults, there are no specific penalties for those who offend against older people as there are in the state of California, for instance.

3. Dementia and assisted decision making

The Assisted Decision Making (Capacity) Bill 2013 was introduced in order to promote and protect the rights of those who may have difficulties making decisions for themselves as part of the ratification process of the International Convention on the Rights of Persons with Disabilities. These groups include those with mental illness, those with intellectual disabilities, and those suffering from dementia and other neurological disorders. The new legislation does not address the issue of detention/ deprivation of liberty, especially among older people who are admitted to nursing homes, which is of particular concern to Age Action.

(a) Dementia

Most people over the age of 65 do not suffer from any impairment of their ability to make decisions, but some do. Dementia is not a normal part of ageing, but it commonly affects older people. The World Health Organisation defines dementia as a syndrome due to a disease of the brain, usually of a chronic and progressive nature, in which there is a disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capability, language and judgement. Consciousness is not impaired. Impairments of cognitive function are commonly accompanied, occasionally preceded, by deterioration in emotional control, social behaviour and motivation.[15]

Dementia is most often due to Alzheimer's disease, but cerebrovascular disease is a frequent cause and the two conditions may co-exist in the same individual. Many other illnesses including Parkinson's disease and AIDS may cause dementia. Most forms are irreversible, although some drugs may slow the progress of dementia.

Those in the early stages of dementia can plan for the future, for example by donation of an enduring power of attorney[16] which would allow another person to make decisions about financial and some welfare matters when they lack the ability to make these decisions for themselves. They can tell their families of their wishes for their future care.

Older people with dementia face the prospect of deteriorating cognitive abilities which will shorten their lives and make them dependant on others for care. There is considerable stigma attached to dementia, which often results in depression and denial on the part of the older person and their families. As a result it is not uncommon for those with dementia to present to doctors and social

[15] International classification of diseases (ICD10) World Health Organisation
[16] Powers of Attorney Act 1996

workers late in the course of their illness when their decision making abilities are seriously impaired over many areas, and their families are struggling to cope with their physical and psychological needs.

Those in the late stages of dementia lose the ability to speak, swallow and move. They lose the ability to make or communicate most decisions and must have 24 hour care from others.

Family members, often elderly spouses or adult children, may face enormous challenges when caring for older people with dementia at home. The decision to seek admission to a nursing home is not taken lightly and is often seen as deeply stigmatising: they feel they should continue to care for the person at home, and institutional care is viewed as an admission of failure on their part. Acknowledging that they are no longer able to care for an elderly relative or spouse at home is often accompanied by feelings of guilt and sorrow which generate considerable conflict within families. Family members may feel anxiety about the quality and safety of the care offered by institutions.[17]

(b) Concepts of capacity

The ability to make a decision is often referred to as mental capacity. It consists of the ability to receive, understand and weigh information in order to arrive at a decision; and the ability to communicate the decision made. There is a rebuttable presumption of mental capacity. Capacity is assessed in relation to the nature of the particular decision at that particular time. It is known as the functional test of capacity.[18] A person may have the capacity to decide that they need to buy a new coat, but lack the capacity to make decisions about investment of their money. The ability to manipulate financial information is often impaired early in the course of dementia.[19] The inability to make major financial decisions may co exist with the ability to make decisions about medical care or residence.

An older concept of capacity is less nuanced and consists of an all or nothing approach: either the person has full capacity and can make all decisions for themselves or they do not. This global approach to capacity assessment means that an older person may be deemed to have no capacity to make any kind of decision, even if in reality they are perfectly capable of making some decisions. This concept of capacity is retained in the current Wards of Court system.[20]

(c) Legislative background

In Ireland there are currently two main forms of legislation which allow decision making on behalf of those who lack the ability to make decisions:

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[17] Annual overview report on the regulation of designated centres for older people-2013. Health Information and Quality Authority. May 2014 at p 4

[18] For example section 3 of the Assisted Decision Making (Capacity) Bill 2013(Ireland) . Section 2 of the Mental Capacity Act 2005 (England and Wales)

[19] Marson *et al*. Clinical Interview Assessment of Financial Capacity in Older Adults with Mild Cognitive Impairment and Alzheimer's Disease. *Journal of the American Geriatrics Society.* May 2009; 57(5):806-14

[20] Lunacy Regulations (Ireland) Act 1871

(i) Enduring Power of Attorney

The person, while they still have the ability, can donate an enduring power of attorney to another person.[21] In order to be activated, the attorney's powers must be registered when the person loses the ability to make their own decisions. There are two broad areas of decision making: finances and personal care. At present the Act does not confer the power to consent to or refuse medical treatment on behalf of the donor[22], but does allow the attorney to decide where the person should live, for example a nursing home.

(ii) Wardship

A person who is deemed to be of unsound mind and unable to manage his person or property may become a ward of court. Wardship is governed by the Lunacy Regulations (Ireland) Act 1871. A Committee makes decisions on behalf of the ward who is regarded as lacking any decision making ability and who is essentially stripped of his or her legal rights in that he or she cannot marry, make a will, decide where to live or manage their own affairs.

(d) Assisted Decision making (Capacity) Bill 2013

Ireland now proposes to introduce legislation recognising functional tests of capacity and repealing the Lunacy Regulations.

The legislation will allow a person who feels they may shortly lack capacity or whose capacity is in question to appoint a decision making assistant to help them make decisions, or a co decision maker. If a person is unable to make major decisions for himself a decision making representative may be appointed by the courts, or the court may make orders directly concerning the person. Informal decision makers have wide powers to make personal care decisions for those who cannot make these decisions for themselves. They are unregulated, and the powers granted to them under the Bill have been extensively criticised by NGOs working with the elderly, the mentally ill and the intellectually disabled. The new legislation will incorporate Enduring Powers of Attorney and extend the power of attorneys to allow them to make decisions regarding medical treatment. Those who have the capacity to do so will be able to make advance care directives regarding their future medical treatment. The legislation contains reference to restraint and deprivation of liberty and it is this part of the legislation which causes Age Action most concern (see 4(c))

4. The over use of medication and detention of older people in nursing homes

There are over 20,000 people aged 65 and over in residential care settings in Ireland, mostly nursing homes and hospitals. A high proportion suffer from strokes, dementia and other neurological disorders and are unable to consent to admission to residential care, or to medical treatment while in

[21] Powers of Attorney Act 1996, Part II.
[22] Personal care decisions are described in section 4 of the Powers of Attorney Act 1996

such institutions. They are essentially detained indefinitely, usually until the end of their lives. Staff may exert total and effective control over all aspects of their lives including when and if they can leave to visit relatives; medical care; who can visit them; their dress and diet. Antipsychotics, and other sedating medication may be prescribed to ensure compliance, which violates the right to security of person, since they have little therapeutic value, are often used as a means of restraint, and the person has not or cannot consent to their use. Other means of restraint such as the use of physical restraints for prolonged periods may also violate the right to security of person.
The right to liberty is the foundation on which other rights are based including the right to freedom from cruel inhuman and degrading treatment, and the right to be treated with humanity and with respect for dignity.

(a) Legal basis for detention

(i) Wards and Attorneys

If a person lacks the mental capacity to consent to admission, but nevertheless needs care, consent for admission and medical treatment may be given by the Committee of the Ward if the person is a ward of court. Currently about 2000 people are wards of court in Ireland. Some are older adults who lack decision making capacity; others are younger people or children. The number of Wards admitted to residential care settings for older people are relatively small.

Some older persons who donate an Enduring Power of Attorney, donate a power to make decisions on personal welfare which includes a power to decide where the person resides when they have lost the ability to make a decision for themselves. There is currently no power to consent to, or refuse medical treatment, including the administration of drugs such as antipsychotics.

There is no automatic review of a decision to confine an older person to a nursing home or hospital under either the Lunacy Regulations (Ireland) Act or the Powers of Attorney Act 1996. This is in contrast with the mechanisms designed to protect the rights of those confined in hospitals under the Mental Health Act 2001. The Mental Health Act 2001 does not allow the detention of the mentally ill (which may include those with severe dementia) in non approved institutions such as nursing homes; they can only be detained in hospitals. Only a very tiny proportion of older adults with dementia are detained under the Mental Health Act 2001 at any time.

(ii) Doctrine of Necessity

The common law doctrine of necessity forms the legal basis for the detention of most older persons in residential care settings. The doctrine of necessity in relation to an adult who was compliant but lacked the capacity to consent to admission was discussed by the European Court of Human Rights in *HL v United Kingdom*[23], often called the *Bournewood* case after the hospital involved. It was held that the common law doctrine of necessity was not sufficiently protective of the right to liberty of a person who lacked the capacity to consent to admission. As a result the UK government had to

[23] H.L v United Kingdom 45508/99 (2004) ECHR 471

amend the Mental Capacity Act 2005 in order to protect the rights of those who were deprived of liberty in this manner. The European Court of Human Rights has discussed the deprivation of liberty in the context of nursing homes and hospitals on a number of occasions since 2005 and refined the concept of deprivation of liberty.

In Ireland the doctrine of necessity is invoked to admit and detain in residential care facilities those who need care. Usually no one is lawfully able to consent to admission on the person's behalf (see Wards and Attorneys, above), although next of kin are consulted and may well believe they have consented to admission. The person has no automatic right of appeal or challenge to their detention, and there is no automatic review of their situation, either with a view to release or altering the conditions of their detention. This lack of procedural safeguards, in the view of Age Action, amount to a failure to protect against arbitrary detention and amounts to a deprivation of liberty for some people.

(b) Remedy

A person so detained can turn to the High Court under Article 40.4.2 of the Constitution for release, but the person must have access to legal representation or someone must instruct solicitors on their behalf. Since those detained in nursing homes are not seen as being deprived of their liberty or unlawfully detained, there is no automatic access to legal advice in Ireland. There have been no actions against nursing homes or hospitals by those detained under the doctrine of necessity and no successful actions by those with dementia who are allege that they are unlawfully detained in mental hospitals after lapse or revocation of the order confining them.[24]

Summary

Those admitted under the doctrine of necessity are the very people who are most vulnerable to elder abuse: they suffer from dementia or strokes and may have physical disabilities. In addition they may have difficulties communicating, so they are much less likely to be able to complain about their treatment, or refuse treatment, or tell another person about it. This combination of disability and detention makes the violation of their security of person more likely to occur and less likely to be discovered.

(c) Assisted Decision Making (Capacity) Bill 2013

The Assisted Decision Making (Capacity) Bill 2013[25] has many features which are welcome and would seem to promote and protect the rights of older people. Although some references are made to the issue of restraint of persons who lack decision making capacity, there is no recognition of the distinction between restraint and deprivation of liberty.

The following features are of concern to Age Action:

[24] See, for example M.McN and Anor v H.S.E [2009] IEHC 236
[25] www.oireachtas.ie/bills/2013/8313/b8313d.pdf

(i) The Bill does not contain a commitment to respect the liberty of those who lack full decision making capacity.
(ii) The Bill contains no definition of deprivation of liberty.
(iii) The Bill allows informal decision makers, who have not been appointed by the person or by the courts, to restrain a person who lacks decision making capacity, but they are not accountable to the courts or any other body for their actions. The boundary between restraint and deprivation of liberty is often not clear to those working with older people. A piece of legislation which lacks a definition of deprivation of liberty does not offer clarity. The Public Guardian is mandated to issue guidelines on restraint and other matters for informal decision makers, but the Bill does not say how this can be done in the context of legislation which lacks a definition of deprivation of liberty.
(iv) The Bill allows others such as attorneys and decision making representatives who are appointed and accountable to restrain the person but not deprive them of liberty, although this is not meaningful if the legislation does not define deprivation of liberty.
(v) The Bill implies but does not explicitly state that the Circuit Court can authorise deprivation of liberty, but there is no guidance on the criteria that must be met, or the safeguards which should exist to protect those who are deprived of liberty.
(vi) The Bill only recognises that wards of court may be deprived of liberty and undertakes to review their situations if they are confined to a hospital or nursing home. There is no recognition that many older people in nursing homes, detained under the doctrine of necessity, are also deprived of liberty and that their conditions should be reviewed. As there is no recognition that those detained under the doctrine of necessity may be deprived of liberty, there can be no statutory regime for the review of their detention, or of the conditions of their detention.

If enacted in its present form this legislation will not promote or protect older adults' rights to liberty and security of person.

It is very difficult to assess the true numbers of older people who are deprived of their liberty under the doctrine of necessity. Significant numbers of people have not or cannot consent to admission to residential care, but not all are deprived of their liberty in that they can leave to visit their families and friends, or go shopping or to church or attend important events, they can receive visitors at any time and can use the telephone or internet when they want to. Some older persons are completely and effectively controlled by the staff of the care institution and do not enjoy even these basic freedoms, and their docility and compliance is ensured by the administration of medication such as antipsychotics: these are the people who can truly be said to be deprived of liberty. Their true numbers are unknown, but may amount to thousands of people.

(d) The use of antipsychotics

Antipsychotic drugs were originally developed to treat mental illness such as schizophrenia and bipolar disorder. They are also administered to older people with dementia who exhibit challenging behaviour such as shouting and wandering. Critics of their use sometimes refer to them as a "chemical cosh". Antipsychotics may be divided into two main categories: conventional antipsychotics such as haloperidol and chlorpromazine, and atypical antipsychotics such as risperidone, quetiapine and olanzapine. Both categories are known to cause serious health problems for older people with dementia including increased risk of stroke and heart attacks, increased risk of falls and infections, and increased risk of death.[26] Their efficacy in treating dementia is very limited and clinicians are asked to consider the risks and benefits before prescribing, and to prescribe as small a dose as possible for as short a time as possible.[27] Both the Irish Medicines Board[28] and the US Federal Drug Administration[29] have issued warnings about the dangers of antipsychotics for older people with dementia. Only risperidone is licensed to use in the treatment of older people with dementia, but many conventional and atypical antipsychotics are prescribed off label. A recent study in Northern Ireland showed that when older people entered care homes there was a sharp increase in the administration of antipsychotics from 8.8% to 18.6%.[30]

Many people in nursing homes with dementia are incapable of giving informed consent to medical treatment and it is unlikely that anyone would consent to the use of drugs with such severe and possibly lethal side effects. The lack of efficacy combined with the adverse effects would confer very little benefit on the patient, yet they continue to be used. Their misuse and overuse in nursing homes have been documented in a number of countries, including Ireland. The use of antipsychotics in elderly patients with dementia who are unable to give informed consent to their use; experience no therapeutic benefit; and are likely to suffer adverse effects, including stroke, heart attacks and death amounts to degrading and inhuman treatment.

5. Protection of the family

(i) Older people in nursing homes who are married/ have partners

Many older people are effectively separated from their partners when one or both of them enters a nursing home, despite Ireland's avowed Constitutional protection of the institution of marriage. It is not unusual for spouses to be in different homes, or in different parts of the same home, which may make it difficult for them to enjoy each other's company except when it is convenient for the nursing staff.

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[26] Gil SS et al. Antipsychotic drug use and mortality in older adults with dementia. *Annals of Internal Medicine*. 2007 Jun 5th ; 146(11) : 775-86

[27] National Health Information and Quality Authority. National quality standards for residential care settings for older people in Ireland. February 2009. P37-38. Standard 21

[28] Irish Medicines Board. Update on the safety of Antipsychotic Medicines. (July 2009)

[29] United States Federal Drug Administration Public Health Advisory. Deaths with Antipsychotics in Elderly Patients with Behavioural Disturbances (April 2005). www.fda.gov/Drugs/DrugSafety/PublichealthAdvisories/UCM053171

[30] Maguire A et al. Psychotropic Medications and the Transition into Care: A National Data Linkage Study. *Journal of the American Geriatrics Society*. 2013 ;61(2):215-21

(ii)Marriage and the Lunacy Regulations (Ireland)

At present the Marriage of Lunatics Act prevents those who are wards of court from marrying. This Act will be repealed by the enactment of the Assisted Decision Making (Capacity) Bill 2013 and will allow those who have the capacity to marry to do so.

(iii) Access to home care packages vs admission to nursing homes

Home care packages are designed to keep those with care needs living in their homes rather than in institutions. Care services include things like home helps, nursing, physiotherapy and occupational therapy. Respite care may also be provided. Access to care packages is not enshrined in law, and the number of packages and the type of care provided varies from place to place in Ireland, with large urban centres being better provided than rural areas. This means that many older people living in rural areas have no choice but to enter residential care. There have been cuts in funding for home helps, with reductions in the amount of hours allocated, often to the detriment of older people trying to live in the community. The lack of uniformity of this service across the country and the erosion of services mean that more and more older people cannot be safely cared for at home and must enter the residential care system, a situation which discriminates against those living in rural areas. Those living in residential care settings may face their own set of problems including separation from spouses/partners and loved ones and deprivation of liberty.

6. Employment and pensions

Section 34 (4) of the Employment Equality Acts 1998-2011 allows employees to fix a retirement age for their employees. Some contracts of employment will therefore have a clause giving a mandatory retirement age, while others will not. There are many older people in Ireland who do not have a written contract of employment and who do not know whether their employer operates a mandatory retirement age or not. While some people may welcome the opportunity to retire, others are willing and able to continue to work. The Social Welfare and Pensions Act 2011 proposes to gradually increase the age at which a person is entitled to receive a State pension from 65 years old to 68 years old in 2028. Some people may be forced to retire before they are entitled to receive a state pension. The present age for obtaining a state pension is 66, but many people retire at the age of 65.

There appears to be a lack of connection between age of retirement and pensionable age which will have most impact on workers who will be dependent on state pensions when they retire. Many of them work in lower paid, physically demanding occupations where conditions such as arthritis, failing eyesight and decreasing physical strength may mean that they are unable to work beyond the age of 65.

If no action is taken on the part of government to correct the imbalance between retirement age and pensionable age some retired workers will be forced to register as unemployed and claim jobseekers' allowance until they become eligible for a pension. A jobseekers' allowance or jobseekers' benefit is a

maximum of €188 a week and ends at age 66, while the maximum state pension is €230.30. One solution may be to amend the Employment Equality Acts 1998-2011 so that employers cannot set a mandatory retirement age for their employees below the age at which state retirement pensions are available.

At present those who have been dismissed on the grounds of age can seek redress at the Equality Tribunal. Many cases are brought on the grounds of age discrimination in the area of employment and many are unsuccessful because of mandatory retirement clauses in the contract of employment combined with some justification for the action on the part of the employer, for example that the person has become physically incapable of performing their duties safely due to their age. In Nolan v Quality Hotel, Oranmore[31] a 68 year old hotel worker was forced to retire when her employer discovered she was 68 years old although no justification was given for her dismissal apart from her age. The Equality Tribunal accepted her claim and awarded compensation. By contrast in A Worker v A Meat Processing Company[32] the Equality Tribunal rejected claims of discrimination on the grounds of age because the 67 year old could no longer safely perform his duties at the abattoir where he worked.

7. Social security and the right to an adequate standard of living

(i) Bereavement grant

Prior to January 1st 2014 if an insured person or their spouse or child died, they could obtain €850 Bereavement Grant if they had sufficient PRSI contributions. This grant was discontinued in at the end of December 2013. Older persons are most likely to experience the death of a spouse or partner, and the grant helped with funeral expenses.

(ii) Household benefits package

Those over 70 and living alone or receiving a fulltime carers allowance are entitled to help with gas or electricity of €35 per month for eligible people. The package formerly included an allowance of €9.50 but this was discontinued in January 2014.

(iii) Travel

People aged 66 and over are entitled to a free travel pass for buses, trains and some ferries. There are fears that this will be removed in the next budget.

(iv) Fuel poverty

The inability to adequately heat a home in cold weather has a number of adverse health outcomes, particularly for people with respiratory and cardiovascular conditions.[33] This inability arises from low

[31] DEC- E2012-110
[32] DEC-E2013-127
[33] Fuel poverty and doe it contribute to health inequalities.
www.publichealth.ie/healthinequalities/Fuelpovertyandhow

incomes, poorly insulated houses and high energy costs. There is a considerable amount of excess mortality in winter in Ireland: some older people on fixed incomes may have to decide between eating and heating, and may only be able to afford to heat one room in very cold weather.

Comments on withdrawal of subsidies for telephones and the bereavement grant are in the next section on health. The introduction of means testing for the medical card may reduce some people's available income and have a serious impact on their standards of living, as those who are not in good health would have to pay for GP visits that were formerly free. (See Health section).

8. Health

(i) Medical cards

A medical holder was formerly entitled to free visits to a GP; free prescription medicines, and the use of aids like crutches and wheelchairs; free hospital inpatient and outpatient care, dental care, aural services and eye testing. Many older people gave up their private healthcare insurance when they reached the age of 70, believing that they would now be able to get free medical care for the rest of their lives. The Health Act 2008 abolished automatic entitlement to a medical card at 70 years old. It came into force in January 2009 and introduced a means test for eligibility for a medical card. Initially those with an income below €600 a week for a single person and €1200 a week for couples were able to retain their medical cards. The threshold has now been reduced to €500 a week for a single person and €900 a week for couples. In addition there is now a €2.50 charge per item for prescription medicines.

(ii) Cost of prescription drugs

Many older people suffer from conditions such as heart disease, arthritis and lung disease and require several drugs each month on a regular basis as well as needing prescriptions for drugs like antibiotics from time to time. Those with full medical cards pay €2.50 per item for their medicines. Those who lost their medical cards under the new rules may have been able to get a "doctor visit card" allowing them free GP visits, but they are no longer able to get free or subsidised prescription medicines. Medicines in Ireland are the most expensive in Europe and the need to pay for medicines may represent significant expenditure each month. Patients can apply for a subsidy under the drugs payment scheme[34] such that an individual or their family's payments for drugs is capped at €144 a month: still a significant expenditure.

(iii) Access to services: breast screening, cervical check

Ireland operates health screening in the form of free cervical smears for registered patients aged 25 to 60[35] and free mammography for patients aged 50-64.

[34] Your guide to the drugs payment scheme. HSE. www.hse.ie/eng/services/list/1/schemes/drugs
[35] www.cervicalcheck.ie

Many women want to continue cervical smear screening after the age of 60 but must pay for a cervical smear after that age. In England, Wales and Northern Ireland cervical cancer screening programs extend to age 64.[36] Cervical cancer is rare in women over 60 who have had negative cervical smears in the past, but it does happen. Almost ¾ of deaths from cervical cancer occur in women aged 50 and over.[37]

Breast screening is offered to women aged 50-64 in the breastcheck service.[38] It is a screening service offering mammograms every 2 years. Those who have had breast cancer should get mammograms every year. This was formerly done at their local hospital, but since centralisation of breast cancer services their breast care centre, located at larger hospitals must arrange mammograms. Some women, for example those who have a family history of breast cancer, may want to have regular mammograms after the age of 64 but must arrange mammography through their GPs after this age. In England breast screening is available until the age of 70 and is being extended to age 73.[39]

(iv) Access to services: GP services

General practitioners fees from the GMS system have been cut progressively since 2009 when the Financial Emergency Measures in the Public Interest Act 2009 permitted government to reduce payments to a number of institutions as part of its austerity program. In 2010 there were cuts to the fees paid for medical card holders, to subsidies for practice nurses and secretaries, to payments for maternal and infant care and the heartwatch scheme.[40] Further cuts were imposed in 2013 with more cuts to subsidies for practice staff and rural practices together with a reduction in the fee paid for over people over 70 who had a medical card: When the scheme was introduced a single patient over 70 attracted three times the fee for a medical card holder aged 69 in recognition of the increasing ill health of people over the age of 70. That proportion was cut to double the fee in 2013.[41]

(v) Access to services: waiting lists

Older people are more likely to suffer chronic illness and disability than younger people and tend to be high users of healthcare services: Ill health increases with age and 25% of older people over 65 report long term illness, health problems or disability. There are long waiting times for first appointments in outpatients in Irish public hospitals. Some progress has been made in decreasing waiting lists, but in January 2014 169 people had been on waiting lists for 4 years or more, 249 people had been waiting for 3-4years, 852 people were waiting 2-3 years and 8334 were waiting 1-2 years. Of those waiting

[36] www.cancerresearchuk.org
[37] www.cancerresearchuk.org
[38] www.breastcheck.ie
[39] Public Health England. www.cancerscreening.nhs.uk
[40] Statutory Instrument no: 638 of 2010. Health Professionals (Reduction of Payments to General Practitioners) Regulations 2010
[41] Statutory Instrument no 277 of 2013. Health Professionals (Reduction of Payments to General Practitioners) Regulations 2013

less than a year 87,806 people waited 6-12 months. These waiting times represent a reduction in waiting times but are still unacceptably long.

(vii) Access to services: Inpatient admission for procedures and operations

After being seen in outpatients there is a further wait for operations and procedures. In January 2014 185 people had been waiting for more than a year; 1708 were waiting 8-12 months and 5660 waiting 6-8 months. The overall national target for waiting times set by the HSE is 8 months, but to an older person with decreasing mobility waiting for a joint replacement, suffering pain, this represents a significant proportion of the rest of their life. 19% of the total number of people waiting for procedures have to wait for more than 8 months. A higher proportion (21%) in the Dublin east area wait more than 8 months.[42]

In contrast, those with private healthcare insurance or the ability to pay for private medical care wait a matter of days or weeks for outpatient consultations and admission for procedures.

(vi) Access to services: Accident and Emergency (A&E) services

Closure and downgrading of A&E departments, shortage of staff and shortage of inpatient beds lead to growing waiting times in A&E departments. National targets of 95% of patients in Emergency Departments (ED) being seen and discharged or admitted within 6 hours, and 100% of patients being seen and discharged or admitted within 9 hours are not being met. Low performing hospitals such as Tallaght hospital and Connolly hospital in Dublin are only achieving these targets 65-67% of the time. Patients spend long periods of time waiting on trolleys in severely overcrowded EDs.[43] Dr James Grey, consultant in Accident and Emergency medicine at Tallaght Hospital in Dublin warned that "These patients have no privacy, no confidentiality, no dignity and poor infection control protection…" after the death of an elderly patient in a cubicle in his department.[44]

(vii) Access to services: Nursing homes and the Fair Deal

People who are in hospital but who do not need acute care may be charged for their care. This disproportionately affects older adults who have been admitted to hospital and must then wait for a place in a nursing home because they cannot be safely returned to their own homes. Staff may refer to them derisively as "bed blockers" although most older people are not in hospital by choice but because beds in nursing homes or other wards or rehabilitation units are unavailable.[45]

Nursing homes in Ireland may be run by the HSE, by the charity or voluntary sector or the private sector. Nursing home fees are negotiated by the National Treatment Purchase Fund. The HSE

[42] Information from the National Treatment Purchase Fund: National waiting list data at www.ntpf.ie/home/nwld/html

[43] Special Delivery Unit, National Treatment Purchase Fund: Unscheduled care Jan 2014 at www.ntpf.ie/home/PDF/SDU_Access

[44] Eilish O'Regan. Inquiry as patient dies after cardiac arrest in "severely overcrowded" A and E. Irish Independent. February 11th 2014

[45] Gallagher P et al. Do relatives of elderly patients block the discharge process? Irish Med J. 2008 Mar;101(3):70-72

assesses eligibility for the scheme and determines financial co payment arrangements between nursing homes and residents, and disburses state payments to private nursing homes. Long term care covers bed and board, nursing and appropriate personal care, laundry service, basic aids and appliances such as wheelchairs and crutches and GP services and medicines under the medical card scheme. The care does not cover things like physiotherapy, and chiropody. There is a set level of funding available for nursing home places each year, so unless an older person can afford to fund their care privately they may have to wait until funding becomes available. The scheme for funding nursing home is known as the Fair Deal and is administered under the Nursing Home Support Scheme Act 2009. It was originally presented as a means to ensure that older people were able to gain access to nursing home care without fear of anxiety, but the scheme generates considerable anxiety and many people must wait until a bed is available (when the present incumbent dies) or for funding to become available if they lack the funds to pay for their own nursing home care.

The scheme was suspended in 2011 due to lack of funding. There is growing disillusionment with the Fair Deal among nursing home owners and some will not now accept Fair Deal patients.