

Ombudsman's speeches

Rights and Entitlements of Older People (22.10.2009)

**Address by Emily O'Reilly, Ombudsman and Information Commissioner at Nursing Homes
Ireland Conference**

Thank you for that introduction and could I say how pleased I am to have been asked to contribute to what I consider to be one of the most important social, moral and ethical issues that we face as a people - the care of our oldest, and at times, most vulnerable members.

You, in Nursing Homes Ireland, and charged with part of that care have major responsibilities, but also major influence and I would hope that you will bring that influence to bear for the good of the people who live in your homes and for their families.

Some weeks ago, former President Mary Robinson spoke of the need for the creation of a vision for this country. I would hope that that vision would encompass the quality of life for people as they begin to lose the capacities of their youth and grow ever more dependent on the State and on the people who live in the State to look after them.

The title of my address here this afternoon is Rights and Entitlements and when it comes to the issue of institutional care for the elderly that is an enormously complex and opaque space. Almost since its inception in 1984, my Office has wrestled with the problems that arise when people simply do not know what their rights and entitlements are and when the State, for whatever reason, has failed to relieve that burden of pain and frustration by spelling out precisely what people in need of nursing home care can expect as their right. There has been in the past much dancing around the heads of two particular pins, one called entitlement, the other eligibility with as yet no clear understanding of what the State itself understand either to mean.

I am conscious that in less than a week the Fair Deal scheme will kick in, a scheme that will undoubtedly relieve many of the financial burdens of families supporting their relatives in private nursing homes and that is to be welcomed. I hope that many families will find comfort and solace through this scheme, but I would also urge its administrators to be mindful of the problems and stresses caused by the lack of clarity surrounding past schemes and to ensure that people are made absolutely clear of what the scheme entails for them, what it doesn't encompass, and the consequences for those who may end up on waiting lists if the budget for the year runs out before everyone's needs are accommodated.

I will talk some more about the Fair Deal scheme a little later, but I first want to share with you the lived reality of what happens when Rights and Entitlements are unclear, when people are forced to make choices the consequences of which are also unclear. Let me read to you extracts from letters that are typical of the dozens I have received from people over the years in relation to the panic, frustration and bewilderment they have experienced as they attempt to secure decent and secure nursing home care for a relative. I am sure many of you in this room will be very familiar with them, but it is worth highlighting exactly why there is such a need for clarity when it comes to nursing home entitlement and eligibility.

This from the adult daughter of a woman suffering from dementia and placed in a Private Nursing Home.

"My mum has no property and no other income but her social welfare so she qualified for the full subvention of 340 euros a week and I've to make up the difference. I appealed it straight away to be told six months later when I was growing concerned about the lack of finances at home how I was going to pay for my Mum's care and I applied for an enhanced payment of which I haven't heard anything back since.

At present I'm finding things very difficult keeping up my jobs and bills and our mortgage with my husband who doesn't have regular employment. I don't know how much more of this I can take emotionally or physically."

This from another young woman in broadly similar circumstances who had to place her mother in a private care home.

"Could you please find out why my mother was not offered a contract bed in X. as my mother gets subvention but this is not enough to cover her cost of care. Her pension plus money from the family have to make up the cost of her care.

We applied for the clothes allowance and have been refused on the grounds that she is in full time care, but care does not include the supply of clothes, toiletries or having her laundry done."

Yet another woman wrote and told me how her hospitalised mother had been assessed as in need of nursing home care but that the waiting list could be anything from eight weeks plus. In the meantime, a private nursing home, contacted by the hospital, contacted the family directly to say that they had a spare bed.

Expecting that they would get full subvention, the family accepted the place and were shocked to discover a short time later that this was not the case. Even worse however, was the manner in which the 84-year-old woman had been discharged from the hospital.

"The manner of her discharge was a source of particular upset to me," wrote her daughter . "As I was phoned within a few hours of making the decision to put her in the private home and told to come and get her or else she would be put in a taxi and sent to the nursing home."

Some months later, this woman contacted the HSE to see when her mother could access a public bed. "I was informed that because she was already in a nursing home, her care needs were deemed to be fulfilled and that basically she would never move up the waiting list because there would always be someone else whose need was greater."

I am aware that Fair Deal has as its aim the elimination of some of that confusion and economic stress; I am equally aware that even before it begins there are question marks around possible rationing, around the provision of therapies, even, around the provision of incontinence pads. I will return to those issues later but I want first to go back to my earlier reflection on former President Robinson's call for a national vision.

It strikes me that what she was saying was that very often in this country we trundle forward, introducing new schemes, new regulations, new laws, without really stopping to think about what sort of ultimate landscape we are trying to create. What is the model of elder care we are trying to achieve? What constitutes good quality of life for older people be that an older person suffering from debilitating Alzheimer's or an older person, who is physically fit but lonely and isolated. Is the national aim to ensure that people can stay in their homes for as long as possible and if so, are the resources of the State really directed towards that end, or do we want to create a nursing home culture and if that is deemed to be the best fit, then what are we doing to ensure that if that is our vision, we are doing our best to realise it at its optimum. Or do we have no clear vision, but rather bits of visions, no one scheme that screams excellence or best practice but simply the creation of a dull -coloured patchwork landscape that somehow, in our heart of hearts, we know that none of us would want to inhabit when the time comes.

We should ask ourselves whether there are ways of thinking outside the box; question whether it should be the natural order of things for older people, particularly those of low dependency, to be shunted into places where there are no young people to interact with, where strangers come together in a pale semblance of an actual home, where a regime dictates the order of your day, of your activities, of your bedtime and mealtimes. Are there community solutions engaged in by other countries that we could usefully transplant? This recession is proving already to be a time of fresh engagement with issues, of creativity, forced yes by necessity but recessions historically have given rise to great new ideas and inventions. Why should the creation of essentially artificial homes for our elderly, isolated from a vibrant community outside, be increasingly the model of choice for so many?

It is often said that death and talk of death is the ultimate taboo, I would suggest that the ultimate taboo is actually old age, that a great many of us fear it, are repelled by it, and it is that fear, that failure of the imagination to allow us into that space while we are still young, that actually informs our less than excellent thinking around the care of our older people.

Some months ago, the English journalist AA Gill painted a particularly bleak picture of old age as lived out in the UK. Even allowing for Gill's polemicist pretensions, and that nothing anodyne is ever allowed to litter the pages of the Sunday Times newspaper, I knew that as I was reading it, growing more depressed with every sentence, that Gill was illuminating some small part of the truth at least. He asked us to recall conversations we have heard about old people, and listed some of things he had heard when older people are being talked about.

“They list the deficiencies, the problems, the conditions, the failings, the diminutions, usually with a tired fondness and a growing hum of exasperation. A woman I sat beside once at dinner recently told me how wonderful her father was because he’d died so well, so quietly and quickly, ne’er a fuss. And then with a sigh, now my mother, she’s always complaining, miserable, I think she’s scared of letting go. It wasn’t said carelessly, but mostly it was said with annoyance.” Gill wrote about how older people are described by professionals and in the media:- “The old are slow and cold, brittle and cancerous, breathless, toothless, sexless, forgetful. And, most news worthily, they’re victims — of bugs, of councillors and chancellors, or welfare and weather. They’re also the victims of grief and pity and comedians. To be old is to vanish behind the sum of incurable, piteous conditions.” Gill suggested that:- “If you ever leave a care home, it will be in an ambulance or a hearse. Every inmate is on a life sentence. These bright, wipe-down, neon-lit rooms, smelling of fish, urine and disinfectant are death row for the blameless.”

Even allowing for the hyperbole, many of Gill's readers could discern a central, often horrible truth. His article attracted a huge response. Older people, families, friends, all wrote of how he had spoken the unspeakable, but he had spoken the truth as it exists for too many older people. Older people, especially those who dare to be sick, disabled or require care, become a burden on society. Their rights and entitlements as human beings disappear exponentially as they slide further down the scale of age related incapacity.

Just some weeks ago, another columnist, this time in the New York Times wrote on a broadly similar theme. Responding to the debate about Obama's healthcare initiative, this writer wrote about what he called the elephant in the room, the fact that, according to some official statistic he quoted, a high percentage of the national health budget goes on the last two years of people's lives as more and more elaborate and expensive procedures are required to keep them alive. To my surprise, and this betrays

of course a cultural difference, but one that may not be as big as we imagine it to be, he won wide praise for his comments with many people writing to commend an aged parent or relative who had decided to save the State and indeed the relatives a great deal of money by opting to refuse care and hastening their death in a most cost efficient manner.

So maybe now, as we head into this great new adventure called the Fair Deal Scheme, it's time for a national debate or just perhaps mass individual sessions of consciousness raising about our collective responsibilities towards people who are essentially us but us just a few years further along the road.

Let me give you another practical example of what happens when rights are blurred, when access to services becomes dependent on the lottery of where you end up as an older person. This concerns a complaint received on a general issue from Nursing Homes Ireland.

Some of you will be aware that the HSE is not providing therapies, such as chiropody and physiotherapy, on a domiciliary basis, to medical card holders who are in private nursing homes. It is my understanding that this is due to limited resources. The HSE has told me that residents of private nursing homes who have been referred by their GP may access "clinic-based, outpatient physiotherapy services" but that "priority is given to the home-based population" for domiciliary services, where they exist, because older people living at home are seen as most vulnerable. Residents of private nursing homes who are simply too unwell or too disabled to travel to a local health centre must do without.

I very much appreciate that when resources are finite, we must use them very wisely. But I would be concerned if decisions about the provision of domiciliary therapy services were made solely on the basis of place of residence, rather than on an assessment of a person's need. Many people find themselves in private nursing homes purely because a place in a public nursing home is not available or indeed because there was insufficient support in the community. They do not necessarily have the means to fund therapeutic services that they need, and which might be provided to them by the HSE if they were still living in their own homes.

I believe that people should be supported to live in their own homes for as long as possible, and I fully support the HSE initiatives that are designed to facilitate this. However, I also believe that access to public services should not be decided based on where someone lives, irrespective of other factors. There should be a transparent and evidence based method of determining how scarce resources should be used, that achieves the right balance and addresses both need and potential outcome. I recently notified the HSE of my intention to carry out an investigation of this matter under section 4 of the Ombudsman Act, 1980 and I understand NHI are collating details of individual complaints and will revert to me by the end of this month. These complaints will inform my approach to the investigation by providing practical examples of the extent to which individuals may have been adversely affected by the

practises of the HSE in relation to the provision of therapy services. The purpose of my investigation will be to determine whether the HSE is discharging its statutory responsibilities in a proper manner.

So going back to the stark picture that Gill portrayed in his column, if you were shocked, as I was, then let's assert that it is different here. Let's assert that older people are valued, cherished, their needs responded to swiftly and without question . Is this correct?

There have been a number of very positive developments in respecting the rights and entitlements of older people in the last couple of years. There are the new HIQA Standards and the Department of Health and Children's recent Care and Welfare Regulations. We have better regulation than ever before; HIQA, the new Medical Council, the new Health and Social Care Professionals' Council, to name but a few. (In mentioning HIQA, I might add that an Amendment Bill at final stages before the Oireachtas at the moment proposes to extend my remit to cover bodies such as HIQA and the National Treatment Purchase Fund.)

Other very positive developments for older people include the substantially increased support for older people in the community. The Department and the HSE have developed home care packages designed to maintain people in the community. Those that have benefited from these packages sing their praises, but many have not been so lucky and still await assistance to "keep their heads above water" in their caring role. The development of Primary Care Teams, Health and Social Care Networks, key workers and inter-agency collaboration has to be welcomed. The Older and Bolder Campaign has championed the contribution of older people to society and demanded that they achieve what is their just reward and expectation. Active retirement groups provide a fantastic intellectual, social and recreational resource for their members. However, older people who are not so active, not so able, with little family support, require advocates representing them, to articulate their needs and wishes. I very much welcome developments by the Citizens Information Board, the Consumer Affairs directorate within the HSE, and many of you as proprietors of Private and Voluntary Nursing Homes, to develop advocacy services, patient charters, residents' councils and other similar initiatives. That is what valuing the rights and entitlements of older people is all about.

There is so much good happening, but there is still a long journey ahead of us. At present, over 468,000 people in Ireland are aged 65 years or older. Of these, approximately 22,000 or 5% are in long-stay residential care. Financial provision in 2008 for care of the elderly was €2.14 billion. However, with increasing life expectancy, the proportion of the elderly population requiring long-stay care is set to rise significantly over the coming years and with this will come greater costs to deliver health and social care for older people generally.

The current system of long-stay care, comprising a combination of public and voluntary beds, along with contract, subvented and private beds in private nursing homes, is not only lacking in transparency, but is, in many cases, simply unfair. In nursing homes throughout the country, an elderly patient and their family may have suffered great distress and hardship to sell assets and pay nursing home costs, while in the next bed, a patient with similar assets may be paying only a fraction of the costs.

This arbitrariness, real or otherwise, is in stark contrast to the social welfare system whose schemes are nationwide, widely understood and, for the most part, firmly based in legislation. For example, to qualify for a contributory pension, regardless of whether you live in Dublin or Donegal, you must satisfy the same clear conditions, such as having a certain number of paid PRSI contributions. If you are unhappy with a decision of the Department, there is an appeals mechanism in place in the form of the Social Welfare Appeals Office and if you are still unhappy, you have recourse to my Office. But to whom do you appeal your place on the public long-stay care waiting list, or the refusal of a contract bed? Where is the clarity that older people and their families require about what they are entitled to when they set about making possibly the biggest decision of their lives? These are just some of the issues that my Office has wrestled with over the years on behalf of older people who have complained to my Office.

My predecessors and I have continually promoted the view that long-stay care for the elderly ("in-patient services" under section 52 of the Health Act 1970) is an enforceable entitlement; that is, an entitlement which must be met by the Health Service Executive on a national basis and which, where necessary, will be upheld by the courts. The Department of Health and Children and the Health Service Executive (and the health boards previously) do not share this view. Instead, the Department of Health and Children promised, as far back as November 2001, to promote new legislation that would clarify entitlement and put these services on a clear and unambiguous footing. In 5 days time new legislation - popularly known as "Fair Deal" - will be commenced. However, during the intervening years, thousands of elderly patients and their families have endured denial of entitlement, monetary loss, worry and distress.

Some of these patients and their families have sought to vindicate their entitlement to long-stay care by taking court proceedings against the HSE and the State. To date, no such case has (at least to my knowledge) been decided upon in court. Others have contacted my Office for assistance. In the period since 2001 alone, my Office has received at least 150 complaints relating to this area.

Prompted by this persistent stream of complaints, I have recently commenced an investigation, under section 4 of the Ombudsman Act 1980, into the provision of in-patient services under section 52 of the Health Act 1970. Although I have chosen nine specific complaints for illustrative purposes, this will be a wide-ranging investigation that looks at the actions of the Department of Health and Children, of the

Health Service Executive, and of some of the public voluntary hospitals, in providing for patients who are found to require in-patient services on a long-term basis. It will cover the period since 2001 when my predecessor, Kevin Murphy, produced a related report on Nursing Home Subventions.

You may well ask why I should at this stage proceed with an investigation of an issue where, on the face of it, the problem has now been solved by the " Fair Deal " initiative. Indeed, the Department of Health and Children has asked this question. I am very happy to explain why this investigation should proceed.

Even if it is the case that the problem has been solved - and I'm not at all sure that it has - all of those people, and their families, who complained to me surely deserve some formal investigation into the reasons why they endured such confusion and hardship over many years. Ideally, my Office would have begun this investigation several years ago; but we were influenced by the fact that the issue of an enforceable entitlement to long-stay care had become the subject of legal action against the HSE and the Department. I'm told that more than 300 such actions are currently outstanding. It seemed sensible that my Office should not investigate complaints where the central issue - whether or not the complainants had an entitlement to long-stay care - was likely to be adjudicated upon definitively by the High Court. But as the years went by, while some of these cases were settled, none of them was dealt with and decided by the High Court. It remains to be seen whether any of these cases will be decided by the High Court. In any event, in July of this year I decided that it was no longer reasonable to continue to postpone my own investigation pending what might, or might not, emerge from these court actions.

This investigation will also provide an opportunity to probe the extent of the solution provided in the Fair Deal legislation. I understand it is the position of the Department that the new legislation establishes beyond any doubt that older people do not, as a matter of entitlement, have a right to be provided with long-stay care. While the Department in recent years has contested the view that older people had an enforceable right to be provided with long-stay care, I understand it now takes the view that this is no longer a matter of contention. As I understand it, Fair Deal provides a scheme of financial support to older people under which they can choose nursing home care - whether public or private - provided they are assessed as in need of care and following an assessment of means. However, and again as I understand it, there is no question of older people having an absolute entitlement to this support - even where they meet the care and financial assessments. Getting support under Fair Deal, because it is not a demand-led scheme, will depend on the availability of finances; there will be a fixed allocation each year and it will not necessarily help all of those who need support.

Above all, though, I hope this investigation will tell us something about how we, collectively, have dealt or failed to deal with the needs of older people. On the face of it, the investigation has to do with the actions of the HSE and of the Department of Health and Children; but of course these public bodies act

on our behalf and if there are shortcomings in how these bodies have acted - on our behalf - we cannot absolve ourselves from some share in the responsibility for any such shortcomings. Ultimately, I suppose, this investigation is about how we govern ourselves and whether our present governmental practices are up to the mark. I hope to be able to publish my report on this investigation in about six months time.

As for Fair Deal, my Office is already taking numerous calls about the legislation and I imagine that the number of calls will increase as it is introduced. However, two issues of potential confusion and concern have already been flagged. One is that the Department already acknowledges that there may not be enough money to support everyone who qualifies for the fair Deal scheme, put crudely, rationing will have to take place. And if that happens, then on what basis will the rationing take place?

The second concerns the extent of the care package that people will get under Fair Deal. In a recent issue of Nursing Homes Ireland, Eamon Timmons of Age Action, raised the possibility that some residents will have to pay extra for therapies or even for such essential items as incontinence pads. Again, clarity is needed on these matters before further stress is caused to people in already very highly stressful situations.

There are further concerns that some people in some public homes will have a better overall care package than those in private homes, yet because of the lack of public nursing home places, some people may have no option but to go into private care.

But perhaps, it is not what older people are entitled to, but what they should be entitled to that we should be considering here today. What is our vision for Older People in this country? Are they a burden or a bounty as Dr O Shea from NUIG has asked in the past? I wonder if Maeve Binchy's recent description of older people represents truly what we think of old age?

"Age is not a problem, a worrying situation, or an absence of glorious youth. It's just another time of our life, a time to laugh, a time to sing. A time to dance." Just as Gill's description unsettled me, so too does Binchy's. Whose description more accurately reflects the truth for the most vulnerable older people in Irish society?

I welcome the Minister for Older People's commitment to developing a strategy for older people. I am, however, more than a touch concerned with the health warning it carries with it "the strategy is not to involve any new programmes or services and it must be developed within the constraints of the present fiscal situation". I am a keen supporter of doing much more with what we have; greater efficiencies are definitely possible; better focus on the most important outcomes will deliver better results, but if we do not aim for the sky, we may make do with what we can easily reach without any strain.

Don't we all have a duty, personally and professionally, to be enthusiastic, to stretch the limits, to seek to achieve what seems beyond our reach. There is a chance that if AA Gill were to walk into one of your nursing homes tomorrow, despite his disparaging view of residential care in the UK, he would be happy to retire there although I'm not necessarily convinced that you'd be happy to have him as a resident. I like to think that when the time came I would be happy to leave my home, my beloved possessions that mark all the milestones of my life, my neighbours and community and retire to a nursing home that will operate, genuinely, as a home from home. And that in that nursing home, despite any physical or mental disability I might have, I would be happy to put my trust, fully, in you and those that will continue in your shoes after you. I would like to think that all my physical, psychological, emotional, spiritual and vocational needs will be met and that my legal and moral rights will be respected without question. Shouldn't that be the standard we all aspire to?

Wouldn't that be proof that we have arrived?

[Back to contents](#)



[Print this Page](#)

Your browser does not support JavaScript!

[Home](#) |
[FOI](#) |
[Privacy Statement](#) |
[Contacts](#) |

