

Remarks by Dr Maureen Gaffney, Chair, National Economic and Social Forum (and former Commissioner), at the launch of the Commission's *Consultation Paper on Professional Home Carers*, 28th July 2009

President of the Commission, ladies and gentlemen, I am delighted to be here today to launch the Law Reform Commission's *Consultation Paper on Professional Home Carers*. Of course I'm always glad to have any opportunity to connect again with the Commission since I spent one of the happiest and most fascinating phases of my career as a Commissioner. I am also particularly glad to be launching this Paper specifically as it dovetails very effectively with an NESF report that is closely related. We will shortly be publishing a report on the implementation of the home care package scheme and in fact the Commission and the NESF have been in close communication as we progressed both reports.

The Law Reform Commission's Paper is important on a number of levels. First and most obviously because legislation is so clearly needed in relation to the provision of home care to elderly people. Second, because it continues your already important work started in 2006 with the *Report on Vulnerable Adults and the Law*, thus ensuring that the law should provide all adults, including those who may be vulnerable for any reason, with the maximum degree of autonomy consistent with appropriate standards of protection. This is a vital and complex agenda and I salute the Law Reform Commission for its commitment to it. Thirdly, this Paper is important because, along with other initiatives, it is in the vanguard of one of the biggest social changes that face us in Ireland and indeed in every country - the changing status of older people.

The proportion of people living in Ireland who are aged over 65 - 11 % of the population - is increasing and is projected to increase at an even greater rate over the next few decades. By 2026 - just 15 years away - the number of people over 65 will almost double in every region of the state, with people aged 80 or over more than doubling. So in 15 years time, older people will constitute a quarter of the total projected population.

The majority of this new generation of older people will continue to enjoy good health well into their late 70s. This group has been called the "healthy old". For those over 80, the so-called "frail old", an increasing proportion will require health care provisions, whether in a hospital, nursing home or in their own home. The facts are strong on this: the vast majority of those requiring health care provision want to be cared for in their own home. At every stage of the life cycle, from infancy onwards when we feel tired, sick, stressed or in any other way vulnerable, our instinctual urge, our urgent desire is to go home. "Please take me home" is the oldest and last cry of the heart. Never more so than in old age, and most poignantly as we approach death.

We know then that the demand for home health care provision is going to grow and grow. Yet, there is no clear legislative scheme for regulating this home care sector, whether it is provided by the public sector or the private sector. Thus, service provision in this area is not regulated by the State. This is in contrast to the situation in the UK for example where the home care sector is tightly regulated. It is also in contrast to the clear legislative scheme and

standard-setting that applies to health care provided in the institutional setting of hospitals and nursing homes.

During our work for the NESF report, we found that most older people and their families appear to be very satisfied with the quality of care they receive from home care professionals. I am a strong admirer of the home help scheme and consider the work that they do to be a linchpin in ensuring that older people continue to live full and independent lives. However, when professional home care providers are not regulated there is the potential for abuse, including financial and physical abuse, as well as neglect. In 2008, HSE dealt with over 1,800 cases of alleged abuse of older people, of which 85% occurred in the home. As the report points out abuse that occurs in the home has a particularly private aspect to it which makes it difficult to detect and combat. Without regulation, there is also a very real possibility of at the very least inconsistencies in terms of service quality and delivery. This is the problem that this Consultation Paper sets out to address. The Consultation Paper makes 21 provisional recommendations for reform of the law in this area.

These include:

- That the remit of the Health Information and Quality Authority (HIQA) be extended to include the regulation and monitoring of professional home care providers.
- That the power of the Minister for Health and Children be extended to make regulations in respect of professional home care providers.
- That HIQA publish standards specifically typically tailored to the home care setting to ensure that home care is provided in a way that promotes the well-being and independence of the elderly person in their own home.
- That the terms and conditions for the provision of care be agreed and recorded in a care contract in order to offer the maximum protection to the elderly person.
- That the care contract should contain specific policies in relation to the home care provider entering and leaving the elderly person's home, the refusal of gifts and the handling of money and personal property owned by the elderly person. Like all good paranoid lawyers they've thought of all the angles.
- They provisionally recommend that any contract should include specific provisions that set out the financial arrangement between the contracting parties and also make specific reference to the responsibilities that arise under employment law.
- An individual who requires home care services should have the option to contract with an intermediary, whether a State or private sector body, who would fulfil the responsibilities of an employer towards the carer.
- They also recommend that there should be a public education campaign to highlight the fact that a service user could be regarded as an employer of a carer if they don't contract directly through an intermediary.
- The Commission provisionally recommends that consideration should be given to providing tax relief to an individual in meeting the cost of home care.
- The Commission endorses a proposal already in the Scheme of the *Mental Capacity Bill 2008* to create an offence of ill treatment or wilful neglect in the context of home care, and that the *Health Act 2004*, which deals with disclosure of abuse, be

amended to ensure that employees of home care providers will be covered by the protected disclosure safeguards and invites submission on the issue of mandatory and voluntarily reporting of abuse of vulnerable adults including by home care providers.

These provisional recommendations seem to me on the face of it to be long overdue, and well thought out. Undoubtedly they will provoke concern and perhaps disagreement in some sectors.

For example there may be an objection that making a contract between a carer and an older person too formal will create a psychological distance between them, and may discourage well-intentioned and helpful carers from providing services that the older person may want occasionally. It might in other words introduce a kind of restrictive practice. I believe however that such concerns can be dealt with by providing intelligent and sensible training to carers enabling them to make appropriate decisions in a flexible way. The solution to such problems is not to dilute protections offered to older people.

The issue of mandatory reporting will provoke controversy as it always does.

But I want to return again to why this Paper is important outside of the narrow legal sense. This cohort of the Irish people coming into late adulthood are very different from previous generations: better educated, more prosperous, with higher expectations of equal treatment and choice and a strong desire to control the process of ageing for themselves. They will increasingly want to see their lives as 'lives in progress' and will resist any attempts to segregate them away from the mainstream of Irish life. They will above all want to be independent and autonomous.

All societies structure themselves to meet the basic human needs of survival, connection, achievement, learning and meaning in a plethora of institutions, association and initiatives. Just as we reshaped virtually all of these to be gender integrated, once thought inconceivable, we need to reshape them to be age integrated. Age integration should be an ethic, a principle, an obligation informing how we do all our business.

This Paper goes part of the way toward addressing the scale of the transformation required to turn the boom in older people from a crisis into an opportunity for personal and social renewal. How can we meet this new generation of individual halfway? We need a "New Deal" - a new social contract that offers continued income, identity, social connection and the promise of purpose and significance in late adulthood. Realising that vision will require, as it were, the soft tissue of innovative policies but will also require a vital bone structure of legal reform. The magnitude of what is occurring is so great, the consequences so vast, and the obstacles sufficiently significant that only big thinking and bold action will do the trick.

Many people of the same chronological age are in very different life phases in relation to work, family, social responsibilities, health status and economic status. Compare a 65 year old highly educated, recently retired well-pensioned man, with a range of options as non-executive director, social entrepreneur open to him, and plans to travel extensively with his

wife and friends with a 65 year old woman in poor health, with chronic diabetes and limited mobility, who never held a fulltime job, recently widowed, still living with an adult son with mental health difficulties.

Age is a poor indicator of the individual's condition or behaviour and a poor basis for policy-making. Even more than that, age stages themselves are becoming more blurred.

Surveys used to point to age 60 as the beginning of late adulthood. Now I'm glad to see that a recent review stated that it is no longer uncommon to consider middle age to extend to 75. In a study conducted by the National Council on Aging in 2000, nearly half of those aged 65-69 considered themselves to be middle aged, nearly a third of those in their 70s think of themselves as middle aged. As we live longer and remain healthier for a greater proportion of the lifespan, the upper end of middle may be stretched further.

Moreover, the older you are, the more you stretch it upwards: middle aged adults typically report feeling about 10 years younger than they are and that in turn is associated with greater health and well being.

Increasingly, the upper end of the life span is defined as when old age sets in: many will associate that with a decline in physical health.

Social class also determines how life stages are defined, with earlier entrances and accelerated movement through life stages for those from lower socioeconomic status (SES).

The implication? As the great Bernice Neugarten said "Age (chronological age) is increasingly becoming an empty variable."

Yet we can't ignore life stages altogether. People share the view that there are different life stages, These stages carry a distinctive set of roles, opportunities, responsibilities, declines and growth, but increasingly they are characterised by a psychological flavour.

We need a deeper understanding of those lives and what shapes them socially and psychologically. I will offer a few insights from psychology:

- Change is continuous, multiple and multidirectional
- Behaviour remains flexible throughout lifespan
- People continue to learn if motivated and facilitated
- People seek to exercise their competencies throughout their lives.

This brings me to my second point. The big breakthrough we need is to develop policies to manage transitions at all stages of the life cycle. We are in a new era. At every stage of the life cycle, we are experiencing a much more fluid structure, characterised by multiple transitions, multiple entrances and exits from family, occupational and social roles. Just look at young adulthood - a vastly extended sequence of moving back and forth between education and work, home and own residence, living with someone and singledom.

Ulrich Beck the eminent German sociologist writes most persuasively about people's intense desire to take control of their own lives: the choosing, deciding, shaping human being who

aspires to be the author of his own life, do-it-yourself biographies, the creator of an individual identity is the central character of our time – the modern Everyman.

Beck says that to meet these expectations will call for a radicalised democracy for which many of the concepts, formulas, and institutions of current society have become inadequate. This is as true for late adulthood as it is for every other stage of adolescent and adult life. To paraphrase Neugarten again: we are all in this living business together.