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MISSOC INFO 1

LONG TERM CARE

For the European Commission
DG Employment, Social Affairs & Inclusion

Contract N° VC/2010/1131

May 2011

INTRODUCTION

This briefing note is based on responses to a short questionnaire sent to all MISSOC National Correspondents. The questionnaire sought information about the existing legal framework for Long Term Care, and in particular the existence (or otherwise) of a legally enforceable obligation on family members to provide support for those in need. Where such obligations were found to exist, questions were also asked about sanctions and penalties for default and the mechanisms (if any) for recovery of cost from a recipient's estate or assets. Focus was upon LTC for older people and not younger people with disability or other conditions that might require them needing LTC.[1]

The questionnaire did not seek information about the wider policy context, institutional arrangements at national, regional or local level or the distribution of LTC as between home based and institutional care. This note does not provide a wider description or discussion of Long Term Care policy, practice or prospects.

CONTEXT

The need for Long Term Care (defined as being a package of services made available to those with limited ability to live independently) has risen inevitably and inexorably up the European policy agenda in recent years. There is a demographic imperative of an ageing population (those aged over 65 will increase by over 75 per cent by 2050) and in particular there will be a significant increase in the number of over 80s. Life expectancy for females will have increased for EU25 from an average of 73 years in 1960 to 85 years by 2050; male life expectancy will have increased from 66 years to 80 years. At the same time and partly as a result of the decline in the birthrate, the dependency ratio is expected to double over the same period.

Long Term Care is a mixture of medical and social care and can be provided either in recipient's own homes or in institutional settings, residential or nursing homes. Most long term care is provided by family and friends, with between 60% and 80% of care provided by women, but as carers they too are ageing over time. The pool of family carers can be expected to diminish (not increase) over time because people are

[1] It is the convention in MISSOC Information Notes that there is no reference to individual countries; that convention is maintained in this note.

working longer and female labour market participation is increasing. Moreover, families have become more geographically dispersed and fragmented with implications for their ability to provide immediate support. These are trends that have been reinforced by a growth in childlessness, the development of smaller families and increased levels of female employment. Finally, medical and pharmaceutical innovations, coupled with more widespread use of new technologies enable more older people, including those with complex health conditions, to remain at home – providing they have support.

As a strand within the Open Method of Coordination, Member States are committed to three common objectives for health and long term care:

- promoting access
- improving quality
- ensuring sustainability

Great diversity is the dominant characteristic of LTC both within and between Member States. Proclaiming a right to LTC is not the same as providing access to LTC: the extent and nature of provision varies geographically with, for example, rural areas having lower levels of provision than urban localities; the high cost of care can inhibit access as can waiting times as a result of necessary administrative and assessment procedures.

Similarly, quality standards are highly variable: even in the most highly regulated systems there can be examples of poor nursing; evidence of patient or resident abuse; poor accommodation and nutrition; sometimes a lack of privacy and insensitivity to the need to maintain patient or recipient's personal dignity. Inspection regimes have been developed and inspection methodologies are being devised, refined and applied. Particular attention is being paid to infrastructural issues such as the fabric of buildings, the suitability of accommodation and facilities and staffing levels; to care in practice as evidenced by the availability of user-friendly information, assessment procedures, diet and staff training; above all, to measurable outcomes such as the prevalence of pressure sores, infection rates, drug use, resident falls and overall mortality rates in a residential unit.

The financial sustainability of LTC is a major challenge and a range and mixture of funding principles and schemes are currently in existence: some are rooted in models of public social insurance; some in universal public taxation; some are

means/asset tested and some are a complex amalgam. But financial sustainability is only part of the picture: the relationship between health, social care and social security is often problematic and in need of effective coordination; in some countries there are national frameworks and standards but delivery is configured and therefore varies at sub-national and local level; public health strategies and programmes to encourage healthy lifestyles (diet, smoking, alcohol and exercise), matched by greater emphasis on the development of appropriate life skills can reduce the (early) need for LTC; considerable attention will have to be paid to the need for more, better trained and better paid professional carers if rising expectations for (and about) LTC are to be met.

Growing old and becoming frail is an integral part of the human condition. To support and care for older relatives and friends is something that families and communities exist to provide but as the nature of families change (through fragmentation, re-composition and dispersal) and as personal expectations adapt to increased life expectancy so traditional roles and relationships are placed under strain. Personal financial resources may no-longer meet the cost of the ongoing need for care in residential or nursing accommodation and the wider cost to society of long term care is placed alongside demands for other forms of social protection. In such circumstances attention is focused on ways in which informal care arrangements can be supported. A question to be asked is whether 'traditional' or 'spontaneous' forms of care, rooted in family relationship and obligation, is a matter for social and public policy; that which is both private and personal, involving intimate tasks and activities including feeding, cleaning and personal hygiene, has become a matter for social research as well as public policy: the personal has become political.

But there is a further issue: recognizing the importance of familial obligation as a component of long term care is one thing; incorporating familial obligation into a constitution, civil code or specific legislation is something else entirely. Where such moves have been made (ie in countries that recognize familial obligation in law) it may be unclear whether the intention is simply to report or reflect a social (or anthropological) reality (in other words, that people care for one another when the need arises) or whether there is an additional intention to protect/assert the interests of either the recipient or the donor in the care relationship; indeed, it may be the further intention to use the law to actively shape both behaviour and policy by prescribing the nature, extent and duration of familial obligation. It is clear that countries have different traditions, expectations, legal frameworks and policy

contexts: there are those countries that have historically regarded the family as a private domain, insulated from state or public scrutiny and regulation; essentially *laissez-faire* in philosophy. Equally, however, there are those countries that would explicitly not regard themselves as *laissez-faire* in their approach to social policy and who have an entirely different interpretation of the concept of obligation, seeing a 'contract' existing between an individual citizen and the state rather than between family members. There is a group of other countries, many but not all with a Catholic ethos, that embrace the importance of the family (and the essential and inherent obligations that are thereby implied) as a life-long cornerstone of stability, social order and good practice: they may, or may not, provide public support, through social transfers or service, to underpin not just the values of familial solidarity but its substantive requirement for assistance.

The following discussion explores some of the issues involved in classifying familial obligation and engaging with legal frameworks in national contexts. A set of questions where sent to National Correspondents, asking for information about familial obligation and whether it was recognized in law, and if so how the obligation was described, prescribed, sanctioned or penalized in the event of failure to comply. Responses to the questionnaire varied considerably: for some countries, the questions were considered to be irrelevant and therefore without answer; others appeared to recognize the relevance of the questions but failed to address the specifics of LTC for older people, rather focusing on the circumstances of, for example, younger adult with learning difficulties or physical disability; in other cases, the responses were couched in general (vague) terms and therefore lacked necessary precision and applicability.

Some countries (>10) have no legal framework to regulate familial obligation for the provision of long term care. This may reflect historic patterns of policy, treating the family as a private sphere where the bright light of public concern should not be shone; indeed, it may be more than 'just' a reluctance or failure to intervene but a formal and considered position, explicitly removing from family members any obligation to provide long term care (directly or by financial subvention) to older family members. This does not imply, however, that it is entirely the state's responsibility to provide and/or meet the cost of such care. There may very well be explicit legislation, some of it may take the form of a national framework which is interpreted and applied locally, that requires individual care recipient's to meet or contribute to the cost of care. An assessment of income and/or assets (including the

individual's residence) may well be the initial determinant of financial liability and contribution. In some instances, for example when continuing to live at home, the individual will be 'advised' to meet care needs through the private market, paying directly for services provided. In other instances, a local authority may assess the need for care (cleaning, meals-on-wheels, personal care etc), coordinate its provision, and either provide from its own in-house staff or commission the care from third party providers (private companies, social enterprises or voluntary organisations). The cost of such care may be met wholly by the state (national or local), by the care recipient or by a mixture of the two (sometimes involving social security payments).

Where an individual lives with a partner, who may also be elderly, it is usual for their joint income and assets to be assessed. In circumstances where one individual moves into a residential setting and the other remains at home, the remaining individual continues to receive support as before. If an individual requires nursing and/or residential care it may be required that the care recipient disposes of capital assets (including their home, providing there is no remaining resident such as a surviving partner) and contributes to the cost of care from the capital sum until such times as it is depleted to a pre-defined level.

In some jurisdictions, a distinction is made between the need for residential care and nursing care with the latter being regarded as a charge upon the state (the health service) and the former (essentially treated as board and lodging) regarded as an individual's responsibility. Although there is no obligation on family members to provide or meet the cost of long term care (either at home or in a residential setting) there are implications for family members because what is often regarded as a prospective inheritance (house and other capital assets following death) are depleted before death to meet the costs of care. This is a live political issue in several jurisdictions and will continue to be a matter of controversial public debate.

Only a minority of countries (c 7) have explicit and specific legislation relating to long term care. More usual, is for there to a be several separate acts each dealing with for example, health, social assistance, social insurance, social care or regulation. Coordination of legislation and the associated services, some of which may be responsible to different tiers of government or agencies presents a common challenge.

In the absence of explicit and focused legislation concerning long term care, the specification of a familial obligation is unlikely to be found coherently presented and linked to LTC. More often in such circumstances the concept of familial obligation is to be found in 'higher level' legal frameworks such as inclusive statements of Family Law, General Civil Codes or other forms of constitutional document. In such countries (c. 12) it is not unusual to encounter reference to a generalized familial obligation: at its heart will be a requirement that parents will look after their children but often the obligation is deemed to be both reciprocal (that is, children will be expected to look after parents) and extended (that is, and to varying degrees, to include in-laws, step-children and in some instances un-married partners and former partners who have separated and/or divorced). A further important distinction may be drawn between the obligation to support (implying direct provision of care) as opposed to maintain (provide financial resource to meet the cost of care provided by a third party). In one jurisdiction spouses are required to maintain but not necessarily to care for each other.

In all countries for which data is available, excepting one, the obligation to support and/or maintain is applied until the death of the recipient or the proven inability of the donor to meet the financial cost. In one country the obligation is limited to a specified 96 days.

The applicability of these generalized familial obligations to the specific context of long term care is sometimes a matter of legal interpretation, case law and judgement from the courts. Several countries are actively seeking to review, revise and consolidate legal frameworks to meet the emerging demands for long term care.

Most countries with either an explicit or attributable familial obligation to provide or maintain long term care also apply sanctions and penalties in the event of default: this may take the form of either a fine or imprisonment of between six months and five years.

CONCLUSION

One of the great achievements of the past 50 years has been the significant improvement in life expectancy but while welcome it has brought many great challenges in addition to raised expectations. The process of population ageing shows no sign of halting and this is matched by important changes in the composition, distribution and role of families and family members. There is a generalized public debate about prospects for long term care: the appropriate balance between home and residential care; how to reconcile the different but complementary contributions from formal and informal, professional and familial support as elements of increasingly complex, high quality and cost-effective packages of care for older people. This is partly about 'soft issues' to do with human dignity and quality of life but also about 'hard issues' such as financial sustainability, monitoring and inspection, staff recruitment, training and remuneration. An important strand in this developing debate is to recognise, clarify and legitimate the boundaries and practice of familial obligation as part of long term care: no easy task.

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