

# CASE NOTES AND RECENT DEVELOPMENTS

## REGULATING HOME CARE OF OLDER PEOPLE: THE INEVITABLE POOR RELATION?

### Introduction

When it comes to care for our older population, the thrust of recent policy documents in Ireland has been to strongly promote home care over institutional care whenever possible. While care provided by family and other informal carers in a domestic setting makes up a large proportion of home care, formal home care is growing in importance in Irish society. The care of older persons in their own home by paid (formal) carers is referred to as “domiciliary care.” However, despite the clear policy objective of promoting home care, the political and legislative agenda remains trained on issues concerning the institutional care of older people. Of late considerable energies have been invested in reform of the regulation of institutional care culminating in the recent enactment of the Health Act 2007 which provides for the establishment of new institutional structures to facilitate the registration and inspection of public and private nursing homes.<sup>1</sup>

While these reforms are commendable, the Health Act 2007 ignores the regulatory gap surrounding the domiciliary care of older persons. A blinkered focus on institutional care, which contrasts starkly with the corresponding lack of consideration regarding the regulation of the domiciliary care of older people, evidences a lack of joined-up thinking in regulating the care of older people. This is perhaps not surprising when one considers that recent initiatives in this area have been reactive in nature, responding to media<sup>2</sup> and public pressure which has built up in the aftermath of media and judicial<sup>3</sup> attention to abuses of older people in institutional care settings in Ireland. Consequently, while

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1. The Act was signed onto law on 21 April 2007 but has not yet been commenced.
  2. The Prime Time documentary *Home Truths* in relation to the Leas Cross nursing home broadcast on 30 May 2005 was particularly influential as was the resulting independent report by Prof D O’Neill *A Review of the Deaths at Leas Cross Nursing Home 2002-2005* (Department of Health, 2006).
  3. See *In re Article 26 and the Health (Amendment) (No 2) Bill 2004* [2005] IESC 7; [2005] 1 IR 105 leading to the enactment of the *Health (Repayment Scheme) Act*

the current focus on standards in institutional care is overdue and welcome, in this article the authors contend that in the light of the strong policy emphasis on home care at a policy level it is both surprising and alarming that no initiatives to regulate domiciliary care in Ireland are underway. This article raises and seeks answers to a number of questions as to why this is the case. Is home care too sensitive, or simply too difficult an area to regulate? Has it successfully been regulated in other countries? What form does or could such regulation of home care take? Based on the authors' backgrounds in law and social policy this article offers answers to these questions from an inter-disciplinary perspective, engaging in an analysis of the Health Act 2007 and existing regulatory frameworks in four different contexts, namely, England, the United States, Denmark and Germany.

### **Background: Irish Policy and Legislation Concerning Older People**

The State has long placed a heavy rhetorical emphasis on the importance of community care over institutional care. Among the reasons forwarded for this is that community care is a cheaper alternative to institutional care and it is the preference of the majority of older people.<sup>4</sup> In practice, however, as Pierce points out, government policy (and investment) has favoured the growth of institutional-based as opposed to community-based services.<sup>5</sup> Indeed the nursing home subvention scheme is considered to have resulted in attracting people into residential care who are not aware of viable alternatives.<sup>6</sup>

One of the public policy objectives of the State has explicitly been "to maintain elderly people in dignity and independence in their own home."<sup>7</sup> In itself this is a commendable recognition of autonomy and freedom of choice in relation to care of older people with echoes of constitutional protection for privacy, autonomy and dignity under Article 40.3.1<sup>08</sup> and of the respect for

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2006 providing for the repayment of charges unlawfully imposed on public nursing home residents. See further N Howlin, MJ Shariff and A Del Rio, "The Health Bill Fiasco: Thirty Years of Doublethink?" in E O'Dell ed, *Older People in Modern Ireland: Essays on Law and Social Policy* (FirstLaw, 2006).

4. See eg Inter-Departmental Committee on the Care of the Aged, *The Care of the Aged* (Stationery Press, 1968); Report of the Working Group on Services for the Elderly, *The Years Ahead: A Policy for the Elderly* (Stationery Office, 1988); Department of Health and Children, *Adding Years to Life and Life to Years: A Health Promotion Strategy for Older People* (Stationery Office, 1998).
5. M Pierce, "Older People and Social Care" in B Fanning and M Rush eds, *Care and Social Change in the Irish Welfare Economy* (University College Dublin Press, 2006).
6. See further E O' Shea, *Review of the Nursing Home Subvention Scheme* (Department of Health Stationery Office, 2002).
7. Report of the Working Party on Services for the Elderly, note 4, at 38.
8. See *Norris v Attorney General* [1984] IR 36; *Kennedy v Ireland* [1987] IR 587; *Re*

private and family life guaranteed by Article 8 of the European Convention on Human Rights.<sup>9</sup> The translation of this laudable objective into reality is, however, far from complete. The 2001 Quality and Fairness Health Strategy report<sup>10</sup> which also emphasises the importance of community care acknowledges that “current funding arrangements do not effectively support home care”<sup>11</sup> and that proactive changes need to be made to improve provision of community care services (albeit that a very strong emphasis on the development and promotion of informal care is reiterated throughout the same report). It is interesting to note that this report also lists the development of “national standards for *community* (authors’ emphasis) and long-term residential care of older people” as “priority areas for quality /safety standards.”<sup>12</sup>

The Report of the Working Group on Elder Abuse<sup>13</sup> recommended that in developing and implementing policy the rights of the individual to lead an independent life based on self-determination and personal choice should be supported and that adequate protection be given to adults who are unable to protect themselves, their assets and their bodily integrity.<sup>14</sup> Most fundamentally, the Working Group recognised that policy had to be based on the principle that “the right to self-determination can involve risk” and therefore such risk must be recognised, understood and minimised.<sup>15</sup> It was also recommended that consideration should be urgently given to establishing a formal framework to ensure quality of care for older people in both institutional and community settings.<sup>16</sup> This report’s recommendations were adopted as official policy in 2002 and led to the establishment of the Elder Abuse National Implementation

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*a Ward of Court (withholding medical treatment)* [1996] 2 IR 79; *Bailey v Flood* 14 April 2000 (SC); *Foy v An t-Ard Chlaraitheoir* 9 July 2002 (HC) (under appeal); *Bailey v Flood* 14 April 2000 (SC).

9. Personal autonomy and dignity were regarded by the European Court of Human Rights as aspects of the right to respect for private life in *Pretty v United Kingdom* [2002] 2 FLR 45.

10. Department of Health and Children, *Quality and Fairness: A Health System for You – Health Strategy* (Pn 10537 Government Publications, 2002).

11. *Ibid*, at 150.

12. *Ibid*, at 87.

13. Report of the Working Group on Elder Abuse, *Protecting Our Future* (The Stationery Office, 2002).

14. Working Group on Elder Abuse, note 13, [4.3]. For an overview of relevant constitutional and human rights protections see Law Reform Commission, *Consultation Paper on Vulnerable Adults and the Law: Capacity* (LRC 37-2005), at 29-39 and *Report on Vulnerable Adults and the Law* (LRC 83-2006), at 37-40.

15. Working Group on Elder Abuse, note 13, at [4.3].

16. *Ibid*, at [2.2].

Group whose work in setting up structures to combat elder abuse based on the report's recommendations is ongoing.<sup>17</sup>

Despite this emphasis in policy documents on community and domiciliary care, public debate on the long-term care of older persons, particularly in the area of standards of care, tends to be very focused on institutional care. While such attention on the quality of long-term care is welcome, to date it has been almost exclusively focused on quality and standards in institutional care as opposed to domiciliary care. As Mangan succinctly attests:

There is a clear and widely accepted policy on the care of older people. That policy favours community or domestic care over care in a long stay institution and it recognises the need for quality long stay institutional care when care at home is no longer possible. The legislation on care for older people does not back the stated policy.<sup>18</sup>

The most recent notable example of this focus on institutional care is the Health Act 2007 examined below.

### **The Rationale for Regulating Domiciliary Care**

Trinity College's Social Policy and Ageing Research Centre has concluded that "despite their secondary position (after informal care), formal home care services constitute an increasingly important part of any strategy to enable continued residence at home when care needs emerge."<sup>19</sup> As already noted, this is enshrined in policy but is not reflected in legislation. The failure to regulate may in part be attributable to a policy bias in favour of family carers and the previously largely voluntary (*ie* unpaid or nominally paid) "home helps" leading to a blind spot concerning the burgeoning role of the private sector in the delivery of domiciliary care to older persons. The effect of this in policy terms is a centralised failure to consider the risks associated with a continuing dearth of regulation of the provision of formal paid home care by professional service providers.

What are the risks of not regulating? In this regard it is instructive to refer to the experience in England (examined more fully below) where regulation was preceded by the identification of risks to users of domiciliary care agencies should the sector not be regulated.<sup>20</sup> These were identified as both qualitative

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17. See the O'Neill Report, note 2, at 53.

18. I Mangan, "Deficiencies of the Law Relating to the Care of Older People" in E O' Dell ed, note 3.

19. See V Timonen and M Doyle, "The Historical and Systemic Context" in V Timonen, M Doyle and D Prendergast, *No Place Like Home: Domiciliary Care Services for Older People in Ireland* (The Liffey Press, 2006).

20. Department of Health, *Partial Regulatory Impact Analysis Domiciliary Care Standards* (2001) available on [www.dh.gov.uk](http://www.dh.gov.uk), at [5].

and safety issues. In relation to quality, there was a risk of inconsistency between agencies in terms of the quality and the reliability of the service and a lack of training and supervision. From a safety perspective, concerns were raised as to the inconsistency of checks made on the suitability of management and staff seeking employment in the domiciliary care sector. Additional concerns centred around inadequate arrangements being made to ensure safety, security, wellbeing and confidentiality for service users receiving personal care domiciliary services.

These risks can be readily transposed to the unregulated Irish domiciliary care sector. In the UK, anecdotal evidence from Action on Elder Abuse suggests that there is “a significant risk of abuse of vulnerable people receiving care in their own homes, and in particular from care staff.”<sup>21</sup> The issue of elder abuse remains a live one in Ireland. The Working Group on Elder Abuse recommended that elder abuse be defined as:

A single or repeated act or lack of appropriate action occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person or violates their human and civil rights.<sup>22</sup>

The range of conduct which may fall within the ambit of elder abuse includes physical abuse, sexual abuse, psychological abuse, financial abuse and neglect.<sup>23</sup> As Rickard-Clarke notes, “[i]t is generally accepted that abuse in domiciliary settings is the commonest type of abuse but the most difficult to combat.”<sup>24</sup> Accordingly there is a real concern about dependant vulnerable older people in receipt of domiciliary care services being the subject of such abuse and feeling unable to speak out.<sup>25</sup>

It is clear that legislative initiatives do exist which reflect the current broader policy focus on quality assurance. Apart from the Health Act 2007 examined below, the Health and Social Care Professionals Act 2005 provides for the establishment of a system of statutory registration for certain designated health and social care professionals. A system of statutory registration facilitates a system whereby each individual member of a designated profession<sup>26</sup> will be

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21. *Ibid.*

22. Working Group on Elder Abuse, note 13, at 25.

23. See further PT Rickard-Clarke, “Elder Abuse – Legal Solutions” in E O’ Dell ed, note 3; Law Reform Commission *Consultation Paper on Law and the Elderly* (CP 23-2003) Chapter 5.

24. PT Rickard-Clarke, note 23, at 265.

25. The Law Reform Commission has recently recommended the establishment of an Office of the Public Guardian charged with ensuring the protection of vulnerable adults who lack legal decision-making capacity: Law Reform Commission, *Report on Vulnerable Adults and the Law* (LRC 83-2006). For proposed implementation of this see Part 5 of the Mental Capacity and Guardianship Bill 2007.

26. The health and social care professions designated by section 4 of the Health and

recognised by the recently established Health and Social Care Professionals Council as competent to practice within that profession. The role of the Council in promoting high standards of professional conduct and education shows that the seeds are being sown for the development of quality assurance in the provision of professional social care.

The Law Reform Commission in its recent *Report on Vulnerable Adults and the Law*<sup>27</sup> recommended the establishment of an Office of the Public Guardian with a remit to protect vulnerable adults. The Law Reform Commission envisaged that the Public Guardian would have a role to play in ensuring that codes of practice are formulated in respect of health and social care providers dealing with vulnerable adults. This has resulted in the publication of the Mental Capacity and Guardianship Bill 2007 as a Private Member's Bill.

If minimum standards were required to be observed in the provision of domiciliary care by all providers, it would ensure that reasonable quality standards would have to be met by all service providers as a prerequisite to competing in the market for domiciliary care. Registration requirements would constitute a legal barrier to market entry and the requirement to observe best practice-based quality standards would also enshrine a legal route to market exit in appropriate cases to the benefit of the older population availing of such services.

### **The Health Act 2007: A Missed Opportunity**

The immediate impetus for the publication of the Health Bill 2006 was the O'Neill report which followed in the wake of the Leas Cross documentary.<sup>28</sup> It revealed serious concerns regarding the care of residents in the privately run long stay care facility resulting from insufficient numbers of adequately trained staff and poor care practices culminating in a finding of institutional abuse. In the aftermath of the Leas Cross documentary it became starkly apparent that appropriate quality assurance for long stay care was not in place. Apart from a lack of care standards, public nursing homes were not inspected and although the Health Service Executive (HSE) was charged with inspecting private nursing homes twice a year, a lack of resources meant that this was often not complied with. The Government responded to the public outcry following the screening of the Leas Cross documentary with an announcement that legislation would follow to create an inspectorate for public and private nursing homes. Following consultation with both the public and stakeholders, the Health Bill 2006 was published on 14 December 2006 and following its passage through the Houses

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Social Care Professionals Act 2005 include professional social workers and social care workers.

27. Note 14.

28. Note 2.

of the Oireachtas was enacted as the Health Act 2007.

Part 2 of the Act provides for the formal establishment of the independent Health Information and Quality Authority (HIQA) on a statutory basis.<sup>29</sup> It is envisaged that HIQA will be a key driver in setting and implementing quality standards based on best practice. The current Social Services Inspectorate; the Irish Health Services Accreditation Board and the National Cancer Registry will be incorporated into HIQA. It would appear that draft standards for long stay care facilities drawn up by the Department of Health<sup>30</sup> will be finalised by HIQA.<sup>31</sup> Section 10(2) refers to a requirement that HIQA will take into consideration any representations made to it in relation to draft standards; in effect it is expected that HIQA will liaise with the healthcare community including service users, carers, healthcare professionals and the voluntary sector as well as the academic community.

Under section 8(1)(b), HIQA will set standards on safety and quality in relation to, *inter alia*, services provided for or on behalf of the HSE and services provided by private nursing homes.<sup>32</sup> It also has a role in monitoring compliance with standards. The Health Act 2007 undoubtedly represents a significant step forward in raising quality standards and its application to public and private nursing homes is to be welcomed. To begin with, until this legislation there was no framework for monitoring standards in public nursing homes and the regulation of private nursing homes under the Health (Nursing Homes) Act 1990 was inadequate in that rather than establishing an independent regulator it gave the Health Service Executive the role of registering and monitoring the private sector.

Some aspects are unclear from the wording of the Health Act 2007. “Services” is not a defined term but “service provider” used in the context of the provision of services on behalf of the HSE is defined in section 2(1) as “a person who enters into an arrangement under section 38 of the Health Act 2004 to provide a health or personal social service on behalf of the Executive.” Although concerned with both setting and monitoring safety and quality standards, the Health Act 2007 is limited in its application simply to health and personal social services provided by the HSE or on behalf of the HSE.<sup>33</sup>

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29. The establishment of HIQA was recommended as part of the Health Service Reform Programme announced in June 2004 and HIQA was established on an interim basis in March 2005.

30. Department of Health, *Draft National Standards for Residential Care Settings for Older People* (2007).

31. It was unsuccessfully advocated that such standards should be legally binding: National Disability Authority, *Submission to the Department of Health and Children – Health Bill 2006* (2006), at 2.

32. As defined by section 2 of the Health (Nursing Homes) Act 1990.

33. There is an exclusion in respect of services within the remit of the Mental Health Commission.



Despite its role in assuring the safety of those in receipt of health and personal social services, with the notable exception of private nursing homes, HIQA's remit does not generally extend to the private sector other than where the private sector provides services on behalf of the HSE. Therefore the Act does not extend HIQA's remit to the independent delivery of domiciliary care to older persons in their own home by the private sector. It is notable that an amendment sought to be introduced by Emmet Stagg TD at Committee Stage which would have broadened HIQA's standard-setting role to include private service providers received scant consideration and was not passed.

Section 8(1) of the Health Act 2007 sets out the functions of HIQA to set standards for services provided by the HSE and service providers providing health and personal social services on behalf of the HSE and to monitor compliance with those standards. The standards formulated by HIQA will require the approval of the Minister for Health and Children.<sup>34</sup> In tandem with this, the section provides for HIQA to operate accreditation programmes in respect of the relevant services.<sup>35</sup> Although the Act does not expressly mention home care, it is possible that section 8(1)(b) could be interpreted as permitting HIQA to lay down quality standards in respect of domiciliary care if it can be interpreted as "personal care" or a "personal social service" being provided by a service provider on behalf of the HSE. Home care packages may be provided directly by the HSE or the HSE may provide the money to the person needing care in order to buy in that care which may lead to a direct contractual relationship between the care worker or care agency and the individual receiving care. In the latter circumstance the question of whether the services would be regarded as being provided on behalf of the HSE is far from clear.

It is interesting that section 8(4)(b) admits of the possibility of operating accreditation programmes "for and at the request of health providers" other than those providing services on behalf of the HSE. Clearly this envisages that it would be possible for private service providers to seek voluntary accreditation. However, the language used in this sub-section is troublingly narrow: the reference to "health providers" is not consistent with the definition of "service provider" in the Act in terms of a provider of health and personal social services. A wider definitional term would broaden the remit to include a wider range of service provision since domiciliary care will not necessarily qualify as a health service. This lack of clarity surrounding fundamental terms is not helpful. Drafting ambiguities aside, this type of provision does not go far enough. There is no provision for mandatory accreditation nor are there sanctions for non-compliance. Rather, the initiative for accreditation programmes must come from service providers. This is surely no recipe for robust standard setting. Clearly a system of voluntary accreditation is no substitute for a compulsory

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34. Section 10(2) of the Health Act 2007.

35. The Irish Health Services Accreditation Board will be subsumed into HIQA.



national regulatory framework enshrined in statute. The National Disability Authority sensibly advocated that HIQA be given a statutory remit to require all health and personal social service providers to comply with mandatory standards.<sup>36</sup> It also called for HIQA to identify accreditation or quality improvement programmes and activities which service providers may participate in on a voluntary basis.<sup>37</sup>

The other aspect of the Health Act 2007 which goes hand in hand with standard setting is provision for an independent inspectorate. Part 7 of the Act provides for the establishment within HIQA of the Office of the Chief Inspector of Social Services. This will subsume the Social Services Inspectorate which has been operating on a non-statutory basis since 1999 focusing on child welfare and protection services including inspecting homes for children. The legislation places it on a statutory footing as the Office of the Chief Inspector and also gives it responsibility for registering and inspecting public and private nursing homes, as well as residential centres for people with disabilities to determine whether they meet the standards set by HIQA. The independent statutory social services inspectorate will cover both public and private nursing homes. Section 98 of the Act empowers the Minister to make regulations covering matters such as the numbers, qualifications and availability of persons employed in residential care facilities and the provision of an appropriate complaints procedure.

Under section 50, in order to register a residential care facility, the chief inspector must be satisfied that the person who is the registered provider and the management are fit persons and will comply with relevant standards set by HIQA. To obtain a renewal of registration, the chief inspector must also be satisfied that such standards have been adhered to in the past. The chief inspector is entitled to attach conditions to registration.

Under section 79(1), it will be an offence to operate a nursing home without the appropriate registration, to knowingly make a material false or misleading statement in connection with an application for registration, or to obstruct an investigation or inspection. Such offences attract a fine not exceeding €5,000 and/or 12 months imprisonment. Under section 79(2) it is also an offence to, *inter alia*, fail to comply with a duty imposed under the regulations or a condition of registration. In this instance, the penalty on summary conviction is a fine of up to €5,000 and/or 12 months imprisonment and on indictment, a fine of up to €70,000 and/or 2 years imprisonment. By contrast no provision is made in the Health Act 2007 for the registration or inspection of non-residential services including the provision of domiciliary care.

Section 103 of the Health Act 2007 provides for the insertion of a new Part 9A into the Health Act 2004 which is headed “Protected Disclosures of Information.” It provides whistleblower protection for employees of

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36. National Disability Authority, note 31, at 2.

37. *Ibid.*

organisations providing a service similar to that provided by the HSE who employ persons registered with a professional regulatory body. This does not appear to have any application in the context of private agencies providing home care services to older people in their own home where the domiciliary care agencies do not employ health care professionals. This means that non-professional domiciliary care agency staff will receive no protection on reporting suspected abuse. This is regrettable since it means that non-provision of standards to the private sector is coupled with a disincentive to report foul play.

Where does this leave older people in Ireland who need to avail of private home care? State-backed statements of home care as the preferred policy remain policy rather than practice. At present there is no requirement that pre-employment checks be sought from the Central Garda Vetting Unit on potential employees of a private domiciliary care service. Rather, it is necessary for a private home care service to approach the Unit with a view to securing an arrangement to carry out such checks.<sup>38</sup> Clearly this voluntary arrangement is an inadequate safeguard against abuse of our older population. Furthermore there are currently no minimum standards to be complied with or designated regulatory bodies with tailor-made powers of inspection.

It may be speculated that the exclusion of service providers independently providing domiciliary care from the standards, registration and inspection framework proposed in the Health Act 2007 is a regrettable oversight born, not necessarily of a principled rejection of the desirability of regulation of the paid home care sector but, of political expediency. Although many of the concepts underpinning the Act have been on the table for some time, it is nevertheless difficult not to regard the eventual publication of the Health Bill 2006 as evidence of a timely determination to plug the gaping legislative hole exposed in the wake of public horror at the revelations of institutional abuse of older people revealed by the overcharging scandal and the outcry following the Leas Cross documentary. Against this background, it is not surprising that a broader, more considered, legislative focus is not in evidence, namely one which would provide a more inclusive regulatory framework in respect of all providers of health and personal care services based on a unifying quality imperative founded on registration. A comparative analysis of regulation in other jurisdictions reveals that a more coherent, joined-up regulatory approach is indeed possible.

The adoption of a blinkered (or, at least, piecemeal) State vision in relation to care of older people is also underlined in two recent regulatory developments. The first of these concerns section 11 of the Health (Nursing Homes) (Amendment) Act 2007 which inserts a new section 61A into the Health Act

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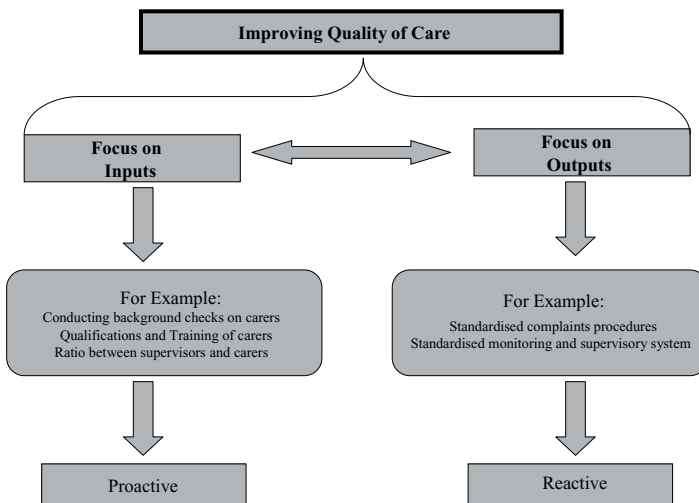
38. On the need for legislation and additional resources in this area see *Report of the Working Group on Garda Vetting* (Department of Justice, Equality and Law Reform, 2004).

1970 requiring home care providers to give written details to the HSE of the provider's name and address, the nature of services provided and of persons to whom the services are provided. Rather than being motivated by a need to regulate the area through the establishment of registration controls, the primary motivation behind the section was a desire to facilitate the provision of a VAT exemption on privately provided home care. The second development concerns the recent publication by the Department of Health of draft national standards for long stay care facilities for older people.<sup>39</sup> This is the logical next step in establishing a regulatory regime but again it is disappointing that parallel efforts to pursue a corresponding system of standards for home care are not in motion.

This article will not dwell on the complex reasons for the exclusion of home care from the remit of standard-setting and monitoring in the Health Act 2007. Rather, against the backdrop of a consideration of the approach taken in a number of other jurisdictions, we seek to explore (both at the conceptual level and in the light of case studies) what forms regulation can take. Secondly, the article offers some reflections regarding the desirability and possible consequences (positive and negative) of regulation.

### How can home care be regulated?

Home care can be regulated in a number of different ways. The following diagram illustrates the two main approaches that can be taken:



39. Department of Health, *Draft National Standards for Residential Care Settings for Older People* (2007).

“Input” focus can take the form of regulations concerning the characteristics and qualifications of care staff, and the ratio between supervisors and care workers. Broadly speaking, the focus on inputs is “pro-active” as the intention is to put in place procedures that will serve to *prevent* the occurrence of abuses and malpractices. For instance, background checks are intended to ensure that people with (certain types of) criminal records are not allowed to enter care work.

“Output” focus relates to the attempts to monitor and measure the care that is delivered; it can take the form of supervisory visits to the care recipients’ homes, or the establishment of complaints procedures. Broadly speaking, the focus on outputs is more “reactive” as it seeks to identify problems and issues and to react to these.

It is sometimes argued that home care is inherently more difficult to regulate and supervise than institutional care: home care is carried out behind the closed doors of a private dwelling, in most cases by a single care worker. There is, therefore, less scope for mutual observation by care workers than in institutional settings and the ongoing monitoring of care work by supervisors is also more difficult since a care worker typically moves between several clients. Despite these practical difficulties, in the light of the intended shift of emphasis (and therefore people) from institutional towards home care, the greatest possible effort must go into ensuring that home care is safe and of good quality, lest the State be exposed to the accusation that it is more concerned about the safety and quality of care for institutional, than the community-dwelling, older population.

We will now turn to an exposition of home care regulation in four different social care regimes: England, the State of California, Germany and Denmark. These were chosen because they represent different ways of organising and financing the home care of older persons: these differences are also reflected in the kind of regulatory framework that has been opted for. They all form a contrast to Ireland where home care of older people is at present not regulated in any meaningful way.

### *England*

The domiciliary care sector in England is highly regulated, and unsurprisingly the bulk of this regulation applies to the “input” variables as these tend to be easier than “outputs” to control and monitor. The Care Standards Act 2000 was a major piece of reforming legislation concerned with the regulatory system for care services in England and Wales. This Act introduced improved regulation of residential nursing homes and domiciliary care services, placing responsibility for this regulation on the National Care Standards Commission, an independent, non-governmental public body charged with the regulation of social and health services including, for the first time, services provided by domiciliary care

agencies. Section 23 of the Care Standards Act gives the Secretary of State for Health the power to publish National Minimum Standards. These were adopted following widespread consultation; the aim is that the National Standards are “realistic, proportionate, fair and transparent.”<sup>40</sup>

The Domiciliary Care Agencies Regulations 2002<sup>41</sup> further contributed to the regulation of the domiciliary care sector in England. The Regulations detail in considerable depth the procedures and processes with which public, private and voluntary/non-profit domiciliary care agencies must comply.<sup>42</sup> Prior to their adoption, the Partial Regulatory Impact Assessment conducted indicated that there was “substantial variation in the quality of care services, and it is believed that the absence of any registration and inspection system for domiciliary care is a major contributory factor.”<sup>43</sup>

The regulatory regime applies to domiciliary care agencies that deliver personal care services. Unfortunately, the Care Standards Act 2000 did not define the term “personal care” but rather provided that regulations could be made excluding certain activities from the term. The Department of Health policy document setting out the relevant standards states that “personal care” can be ordinarily understood to include four main types of care:

- assistance with bodily functions such as feeding, bathing and toileting;
- care falling just short of assistance with bodily functions, but still involving physical and intimate touching, including activities such as helping a person get out of a bath and helping them to get dressed;
- non-physical care, such as advice, encouragement and supervision relating to the foregoing, such as prompting a person to take a bath and supervising them during this;
- emotional and psychological support, including the promotion of social functioning, behaviour management, and assistance with cognitive functions.<sup>44</sup>

Although no refinement of the term “personal care” was included in the *Domiciliary Care Agencies Regulations*, pending judicial guidance, the current

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40. See UK Department of Health, *Domiciliary Care: National Minimum Standards Regulations* (2003) (“National Minimum Standards”), at 8. The separate but parallel regime for Wales is outside the scope of this review.

41. SI 3214/2002. These Regulations came into force on 1 April 2003. See also the Care Standards Act 2000 (Establishment and Agencies) (Miscellaneous Amendments) Regulations 2004 (SI 1770/2004),

42. However, many of these stipulations do not apply to employment agencies that only place carers i.e. act as intermediaries rather than direct employers.

43. *Partial Regulatory Impact Analysis Domiciliary Care Standards*, note 20, at [2.1].

44. *National Minimum Standards*, note 40, at 5-6.

view taken by the Department of Health is that it is only where a domiciliary care agency is involved in personal care within the first two bullet points that registration with the NSC is required.<sup>45</sup> In other words, non-physical care, emotional care and assistance with household tasks are not covered.

Implementation of the standards is undertaken by the National Care Standards Commission and it is an offence to provide a relevant service without the required registration. It is notable that there is an exclusion where the domiciliary care provider delivering personal care services is a sole individual working alone.<sup>46</sup> The rationale behind this is the Government's desire to avoid unnecessary intervention in "personal, informal or low-key personal care arrangements between neighbours, friends or relatives."<sup>47</sup>

By clarifying and specifying minimum standards of care the UK government has strengthened the rights of the service users and home care worker. At a basic level each domiciliary agency is obliged to provide a guide to prospective service users which outlines the services they offer, the aims and objectives of the organisation, the terms and conditions of contracts, quality assurance processes, details of insurance cover and a copy of the organisation's most recent inspection report.

The National Minimum Standards require that agencies must ensure that the care worker has received adequate training including training on lifting, and, where appropriate, specialist training in areas such as dementia care, mental health problems and sensory impairment. Agencies are also obliged to ensure that there is a clear written policy which outlines when a care worker can assist with medication and health-related tasks. Care workers must undergo an induction programme prior to commencing work. A structured induction process is outlined in the Department of Health's National Minimum Standards Report. This induction programme includes communication skills, confidentiality, quality assurance and monitoring, dealing with gifts and bequests and prevention of abuse or exploitation. Staff development and training programmes must be reviewed and updated annually. Care workers who do not hold a relevant care qualification are required to register for a NVQ award within the first 6 months of employment and to complete this training within three years. Staff support and monitoring procedures are recognised as important: the National Minimum Standards report specifies that all staff should meet formally on a one-to-one basis with their managers at least once every 3 months, and that all staff have an annual appraisal of their performance.<sup>48</sup>

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45. *National Minimum Standards*, note 40, at 6.

46. *Domiciliary Care Agencies Regulations 2002*, regulation 3 (SI 3214/2002).

47. *Partial Regulatory Impact Analysis Domiciliary Care Standards*, note 20, at [2.3].

48. Doyle found that within the Irish context private sector home care workers in most instances did not meet with their employer after the initial placement. Furthermore, the majority of workers intimated that they received little or no support from their employer in the normal course of their employment: M Doyle, note 19.

Regarding occupational risks and safety, UK legislation requires agencies to ensure that an inspection of the home residence is conducted which considers the risks associated with each new home, including any risks associated with travelling to and from the home of the service user, particularly late at night; a separate assessment must be undertaken of the risks associated with manual handling. All responsibility, however, is not transferred to the care agency in this regard and it is acknowledged that the service user also has a duty to ensure an adequate safe environment for the care worker.

When brought into force, the Safeguarding Vulnerable Groups Act 2006 will replace the existing protection of vulnerable adult provisions of the Care Standards Act 2000. A list will be maintained of adults who are barred from working with vulnerable adults. The new regime will involve the establishment of an Independent Barring Board which will be empowered to decide whether a care worker should be prevented from working with vulnerable adults in cases other than those of automatic exclusion based on conviction for certain serious offences.<sup>49</sup> Employers will commit an offence and will face penalties if they employ people to work with children and vulnerable adults that they know are barred or fail to make the required pre-employment background check.

On the “outputs” side, the National Minimum Standards recognise the importance of maintaining a paper trail and specifies that written contracts must be issued from the care agency within 7 days, containing, *inter alia*, processes for assuring the quality of the services and the monitoring and supervision methods which shall be employed. The service users’ care plan must be reviewed at least once a year. The importance of record keeping is acknowledged within the National Minimum Standards which specify that care workers must record the time, and dosage of medication administered and key events that occurred during the working day. These files are kept in the service user’s home for one month and then transferred to the agency or Health Authority. The agency must have comprehensive health and safety policy procedures in place, and specifies that procedures and protocols in relation to financial transactions, abuse, entering the house and recruitment procedures must be enforced. Service users are encouraged and entitled to give feedback on the service they receive and agencies are instructed to implement a formal quality assurance system, the results of which must be published on an annual basis.

From the above overview of the regulatory framework in England, it is clear that, in contrast to the position in this jurisdiction, the legislative scheme

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49. On the difficulties of achieving the appropriate balance between protection and human rights see *R (Wright) v Secretary of State for Health* [2006] EWHC 2886 (Admin) which impugned the current system of lengthy periods of provisional exclusion pending a determination.



and standards formulated are consistent with the implementation of the Government's policy objective of supporting older people living in their own home.

*The United States (California)*

Commenting on the monitoring of quality assessments in the United States by the Federal government, the OECD states:

In the United States, states have been required to certify to the Federal government that they had methods for assuring quality of home and community-based services. Actual monitoring of quality of home care is variable across states and across Medicaid benefits. There is generally an emphasis on "inputs" standards in the form of "provider qualification." Use of outcome standards and corresponding measurement is rare and its adequateness controversial.<sup>50</sup>

The major source of public funding for home care services in the United States is the Medicaid programme, which was established in 1965 to provide medical care and long term care to low income Americans.<sup>51</sup> There are three types of Medicaid community care programmes. Allocation of finances to these respective programmes is largely at the discretion of the individual states. The first and only mandated (in 1970) domiciliary care programme under Medicaid is *home health*. The second community care programme was created in 1981 and is provided under the *waiver* programme. Section 1915(c) of the Social Security Act enables states to request a waiver of certain federal Medicaid requirements and to establish community-based "waiver" programmes. The third community care programme is the *state plan personal care programme*. This has been available since the mid-1970s. Currently 32 states run this personal care programme. Unlike waivers, where a personal care programme is offered as a state plan benefit, it must be made available state-wide, to all categorically eligible persons. While some states still place a heavy emphasis on institutional care, a growing number of states are expanding and developing their community care programmes, so much so that a number of states in an effort to promote the use of community services now administer pre-admission institutional screening to assess whether all possible services have been exhausted in the community.

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50. Organisation for Economic Co-operation and Development, *The OECD Health Project: Long Term Care for Older People* (2005), at 76.

51. See further US Department of Health and Human Services (Office of the Assistant Secretary for Planning and Evaluation), *Understanding Medicaid Home and Community Services: A Primer*, (2000).

The Social Security Act mandates the establishment of minimum health and safety standards that must be met by providers and suppliers participating in the Medicaid programme. These standards are outlined in the Code of Federal Regulation (CFR) Title 42. Part 484 of the CFR relates specifically to the regulation of the Home Health Agencies, delivering care via the home health programme: it outlines that home health aides must complete a specific training program which addresses a provided list of topics<sup>52</sup> through classroom and supervised practical training totalling at least 75 hours, with at least 16 hours devoted to supervised practical training. The individual being trained must complete at least 16 hours of classroom training before beginning the supervised practical training. Home health provides services to an individual who has acute care needs for a short period of time. While it does include domiciliary care this is only available if skilled nursing services are required and typically lasts for a period of four to six weeks.

As such the Federal government places more emphasis on the “inputs” of the home health programme than in either the waiver or state plan programme. Moreover, the states are given a large element of discretion to develop and design both their state plan programme and waiver programmes. Section 1929 (§1396t) of the Code of Federal Regulation outlines the boundaries within which the states must comply in order to receive grants for home community care programmes for functionally disabled elderly individuals. These boundaries are quite broad and enable the states to enforce and develop their own unique regulations and quality standards. The national code specifies, however, that the states must develop a standardized assessment instrument to determine eligibility and that each individual identified as being functionally disabled shall be reassessed periodically and not less frequently than once every 12 months. It outlines that community care case managers in a non-profit or public agency must visit the home care recipient not less than once every 90 days. In addition, it specifies a number of minimum requirements which while quite broad afford some form of protection to the home care recipient. Among these are “the right to be fully informed in advance, orally and in writing of the care to be provided ... and to participate in planning care

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52. These include, communications skills, observation, reporting and documentation of patient status and the care or service furnished, reading and recording temperature, pulse, and respiration, basic infection control procedures, basic elements of body functioning and changes in body function that must be reported to an aide’s supervisor, maintenance of a clean, safe, and healthy environment, recognizing emergencies and knowledge of emergency procedures, the physical, emotional, and developmental needs of and ways to work with the populations served by the Home Health Agency, including the need for respect for the patient, his or her privacy and his or her property and appropriate and safe techniques in personal hygiene and grooming.

or changes in care;” “that individuals providing care are competent to provide such care;” “the right [of the home care recipient] to voice grievances with respect to services that are (or fail to be) furnished without discrimination or reprisal;” and “the right to education or training for oneself and for members of one’s family or household on the management of care.” Each state is also responsible for certifying the compliance of providers of home and community care and must periodically review these providers performance. In order to do this, each state is obliged to maintain procedures and adequate staff to investigate complaints of violations. If the state discovers substandard care practices the state “shall make a reasonable effort to notify promptly an immediate family member of each such individual.” Furthermore in such eventualities the state “may terminate the provider’s participation under the state plan programme and may provide in addition for a civil money penalty.”

The problems that arise from the emphasis on service users’ rights (“consumer power” in social care) are briefly alluded to below.

### *Germany*

Since the introduction of long-term care insurance in Germany in 1994, local governments (or *Länder*) have lost much of their regulatory authority in the area of long-term care. Equity and parity of the long-term care insurance programme was emphasized from the outset of the scheme, with legal guidelines and universal eligibility criteria established at national level. Responsibility for monitoring and supervising the domiciliary care financed through this system lies with the insurance funds. The use of a national universal assessment tool ensures parity in the eligibility assessment. The eligibility criteria for each category of “care dependency” are the same for institutional and domiciliary care and apply to those insured through both the public and private LTCI schemes. Supervision of the delivery of home care services varies according to whether a recipient has availed of the in-kind benefit or the cash option (*Pflegegeld*) that is used to reward an informal family carer or other persons chosen by the care recipient such as a neighbour or friend. Where the care recipient has elected to use the insurance payment to reward an informal carer (typically a family member), a doctor or a nurse from the Medical Office of the insurance fund visits the home three or four times per annum, depending on the level of care needs (more frequent visits for individuals with higher levels of care need). Uniformity of the evaluation process is also viewed as essential. The LTCI law requires that the insurance funds administer a universal questionnaire and that all supervisors adopt the same approach to ensure that parity and objectivity are guaranteed.

Separate legislation applies to the supervision of the formal domiciliary care providers. They are required to adhere to a range of “input” criteria concerning for instance staff qualifications and ratios (staff on the ground per

supervisory staff). Aside from these criteria, the owners of domiciliary care agencies have since the Care Quality Improvement Act 2000 held responsibility for monitoring the quality of care. Any provider who fulfils certain pre-requisites is entitled to obtain a service contract with the insurance funds. In 2002, it was ruled that only providers who introduce internal quality management practices would get a contract with the insurance funds. If complaints arise, the responsibility for investigating these reverts to the medical officers of the insurance funds.

### *Denmark*

In Denmark, the financing and provision of domiciliary care services has traditionally been the responsibility of municipalities. Municipalities are required, by law, to ensure that adequate domiciliary care is available flexibly (where necessary, at night-time and at weekends) to all who require such care. A formal requirement on the municipalities to establish quality standards was issued as late as 1998 by the Ministry of Social Affairs, but individual municipalities had defined their standards prior to this. The emphasis in this requirement lay heavily on the working conditions of formal carers.

In 2003 a new law entitled “greater choice for the provider” was introduced. With this the provider and supervisory functions within municipalities were separated: municipalities retained responsibility in each sphere, but via different offices. With the so-called freedom of choice initiative, home care recipients were enabled to choose from a list of approved public and private sector providers. These changes were intended to improve efficiency and enable the municipality to focus less attention on direct service provision and instead to take overall responsibility for regulation and supervision of service delivery. Elected representatives at the municipality level determine the qualifying criteria for including agencies on this list, and set guidelines for the price that agencies can charge (the municipality, not the service users, is billed for such charges as all home care is free to the care recipients). Each municipality decides what education and qualifications are necessary for domiciliary care staff. Service level agreements with the providers are reviewed on an annual basis.

In addition to detailed regulation of “input” variables, the procedures for taking action on problems relating to “output” have also been legislated for. A large number of channels for processing complaints exists, from the local to the Ministerial level.<sup>53</sup>

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53. M Doyle and V Timonen, *Home Care for Ageing Populations: Comparison of Domiciliary Care Policies for Older People in the US, Germany and Denmark* (Edward Elgar, 2007).

### Home Care *Can* be Regulated – but *Should* it be Regulated?

As can be seen from the above sketch of the four regulatory regimes, home care patently can be regulated. A separate, but related, question is: is regulation of home care beneficial?

The costs and benefits of regulation can be considered from a number of different angles. For the State, regulation holds both the promise of guarding itself against the accusation of neglect but also implies the cost of additional resources that are required to do so. From the worker's perspective, regulation of the care sector can improve the safety, social security rights and pay of care workers. However, care workers could be negatively affected by cumbersome requirements and restrictions such as not being allowed to carry out certain tasks that both they and their clients would find beneficial, e.g. going for a walk. Timonen and Doyle found that a large proportion of the care workers viewed companionship as a very important part of their job since many of their clients were isolated or depressed and greatly anticipated the visit.<sup>54</sup> If regulation leads to less scope and time for such companionship, the end result from the point of view of both workers and care recipients could be a loss of welfare and quality of life rather than a gain. However, it must be also recognized that regulation can yield gains in this area. For instance, the British legislation cited above states that unless specified by the service user or the care worker, care workers should be placed with the same person on a continuous basis as this helps to ensure a deeper, more nurturing and informed relationship. Commenting on the regulation of the nursing home sector in the United States, Kane argues that instead of focusing on staff ratios, policy should seek to enable care workers to facilitate the needs of their clients.<sup>55</sup> This in turn necessitates better opportunities to progress in their job and more support in their role.

While regulation can seek to “marry” the interests of care recipients and care workers, it has to be acknowledged that certain types of regulatory policies can tip the balance in the relationship in favour of the care recipient. In recent years there has been a push across Europe and the US to increase consumer power and autonomy in respect to the home care services older people receive. Under this school of thought, care is viewed as a commodity similar to other services, which the person has the right to criticise, change and control. However, empowerment of the service user does not necessarily have to equate with a lack of oversight by the funding body or by the service provider(s). In the US for example in some state plan community care programmes, *eg* in

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54. V Timonen and M Doyle, “Worlds Apart? Public, Private and Non-Profit Sector Providers of Domiciliary Care for Older Persons in Ireland” (2007) 21(3) *Journal of Ageing Studies* (forthcoming).

55. R Kane, “Long-term care and a good quality of life: bringing them closer together” (2001) 41(3) *The Gerontologist* 293.

Home Supportive Services in California, consumer control has been interpreted as extensive powers invested in the service user to hire and fire care workers: it is debatable whether such a price in terms of employment security and stability of care workers is worthwhile. In Germany the LTCI law states that senior personnel within the formal home care organisation must have appropriate qualifications, usually nursing qualifications. However, there are no minimum training qualifications for a domiciliary care worker, although their work is supervised by a qualified nurse. This can have negative repercussions for the social security rights of the low skilled workers. For example, Theobald notes how the introduction of the LTCI programme coincided with an increase in employment rates for qualified staff, but that less skilled carers were “over-represented within marginal, part-time employment, which very often leaves them without any type of basic social security cover.”<sup>56</sup>

Ironically, regulation (or implementation of specific prerequisites) of formal service providers (if not done correctly) does not necessarily always lead to improved quality of home care from the perspective of the home care recipient. Glendinning, commenting on the annual negotiations between the LTCI funds and the service providers in Germany points out that these negotiations in most instances are inadequate and focus on *price* rather than *quality*.<sup>57</sup> Similarly we have noted that in the Danish context price rather than quality can dictate the delivery of domiciliary care services.<sup>58</sup> Since the price that the municipality is prepared to pay tends to be fairly inflexible, agencies largely compete on the basis of their productivity. Care workers can have up to 10 clients in one day and as a result, their working day becomes highly structured with strict time-keeping being of paramount importance. It is debatable whether such structuring of the working days of care workers is conducive to high-quality care from the point of view of the care recipients, but it must also be acknowledged that this practice takes place in the context of a social care regime that is determined to, and arguably succeeds in, delivering home care to all who need it, free of charge: none of our other case study countries come close to such universalism in their approach to care provision.

While no existing regulatory system is perfect, Ireland now has the opportunity to learn from these and adopt a system that tries to cover both “input” and “output” variables. Some areas, in particular, could be covered at

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56. H Theobald, *Evaluation of Results of Care Arrangement Study under Consideration of a Comparative Perspective on the Impact of Welfare States on Marginalisation of the Aged: Care for the Ages at Risk of Marginalisation (CARMA) Project* (2003), at 167.

57. C Glendinning and G Igl, “Social Policy for an Ageing Society – Britain and Germany Compared” in G Naegele and A Walker A eds, *Social Policies for in Ageing Societies: Britain and Germany compared* (Palgrave Macmillan, forthcoming).

58. M Doyle and V Timonen, note 53.

a relatively low cost, *eg* Garda checks and the daily recording of key events relating to the delivery of care. It must be accepted, however, that regulation will not be free of costs. A number of key questions which may have considerable ramifications on the cost of domiciliary care provision need to be asked. Among these are: is the State prepared to subsidise training of home care workers (private and non-profit); what is adequate training; and what will be the respective roles of the State and home care providers in monitoring the work of the home carer?<sup>59</sup> Whatever the answer to these questions, regulation is arguably necessary from an ethical point of view, especially where the stated intention is to increase the community-dwellers' share in the population of older people who need formal care services.

In any event, putting in place a regulatory system for institutional care while ignoring the domiciliary care system is absurd and counter-productive and contradicts with the Government's stated intentions in the Quality and Fairness Health Strategy (2001)<sup>60</sup> to regulate both sectors: if one of the sectors is regulated, it follows logically that the other must also be regulated. The Government's lack of initiative to regulate the domiciliary care sector can only be construed as reflecting the ambivalent stance taken on the provision of home care services. With the heavy emphasis placed by the Government on the provision of informal (family) care, it is conceivable that the Government does not want to acknowledge the importance of the expanding formal home care sector (both non-profit and private). Such complacency, however, will eventually jeopardise the health and safety of some of the most vulnerable people within our society.

## Conclusions

The Health Act 2007 reveals a failure to take an integrated approach to quality assurance in respect of services provided to our older population. Public and private institutional care is to be subject to a strict registration and inspection regime. Other health and personal social services provided by or on behalf of the HSE are also to be subject to a quality and safety standards regime. It is worrying that where domiciliary care services are provided privately there is no certain prospect of anything other than a voluntary accreditation regime and then only where this is sought at the behest of relevant service providers. This policy differential is not justified on risk assessment principles and is disappointing in draft legislation with such normative potential. Furthermore, while it has been noted that the standards provision in section 8(1) of the Act may potentially be stretched to apply to the provision of home care in certain

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59. M Doyle, "The Market: Role in the Provision of Home Care" in V Timonen, M Doyle and D Prendergast eds, note 19.

60. Note 10.



circumstances, this reading would lead to an anomalous position whereby regulation is based on a characterisation of care as public or private rather than on the basis of the need for regulation to protect the vulnerable. It is contended that this is inadequate and unjustified.

As the examples from four very different social care systems outlined above indicate, regulation of home care is eminently possible in very diverse and complex care regimes. The fact that home care is monitored in countries as diverse as Denmark and the US clearly indicates that different kinds of systems are amenable to regulation, and that even very complex systems, with an elaborate “care mix,” can be successfully regulated. While it is not our intention to portray any of these systems as ideal, they nonetheless stand in stark contrast to the situation that pertains in Ireland at present, namely the complete lack of regulation and the apparent lack of initiative to regulate the sector in any way.

In the Irish context, it appears that the Health Act 2007 constitutes a missed opportunity to devise, for the first time, a comprehensive regulatory framework for home care, and to integrate the regulation of community and institutional care. It is to be hoped that regulation and inspection of home care will be incorporated into legislation in the near future. Such legislation ought to cover both “input” and “output” aspects of regulation, and adopt an approach that is both preventative and reactive.

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