



LAW REFORM
COMMISSION/COIMISIÚN UM
ATHCHÓIRIÚ AN DLÍ

REPORT

LEGAL ASPECTS OF PROFESSIONAL HOME CARE

[LRC 105 – 2011]



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Law Reform Commission

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Full responsibility for this publication lies, however, with the Commission.

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INTRODUCTION

A Background to the Project

1. This Report forms part of the Commission's *Third Programme of Law Reform 2008-2014*¹ and follows the publication in 2009 of its *Consultation Paper on the Legal Aspects of Carers*,² which provisionally recommended that legislation be enacted to ensure that an appropriate regulatory framework and legal standards are in place for professional carers (as opposed to informal carers) engaged in the provision of care to people in their own home.

2. Since the Commission's Consultation Paper was published, the National Economic and Social Forum (NESF, now subsumed into the National Economic and Social Development Office, NESDO) published a *Review of the Home Care Package Scheme*,³ which describes a number of key policy issues concerning the initial development of the national home care package. The NESF Review has been of significant assistance to the Commission's analysis in this Report. Also of significance is the publication of the first results of the Irish Longitudinal Study on Ageing (TILDA),⁴ which sets out the initial findings of the most detailed study of ageing ever undertaken in Ireland. The Commission has also considered the *Report of the Expert Group on Resource Allocation and Financing in the Health Sector*⁵ and the implications of the findings in that Report for the funding of long-term care.

3. The Commission considers that these important developments should be seen against the general background of stated government health care policy of recent years, in particular as it applies to older persons and other adults who may require health care and other assistance in a home setting. The Commission notes in this Report that this policy involves the development of a fully-integrated health care service, including an approach that supports the stated wishes of older people and other adults who require care support to live

¹ Law Reform Commission *Third Programme of Law Reform 2008-2014* (LRC 83-2007), Project 27.

² LRC CP 53-2009.

³ National Economic and Social Forum *Implementation of the Home Care Package Scheme* Report 38 (September 2009).

⁴ *Fifty Plus in Ireland 2011: First Results from the Irish Longitudinal Study on Ageing (TILDA)*, available at www.tilda.ie.

⁵ *Report of the Expert Group on Resource Allocation and Financing in the Health Sector* (Department of Health and Children 2010).

in dignity and independence in their own homes and communities for as long as possible.

B Demographic changes

4. The 2006 census⁶ revealed that 11% of the population was over 65 years of age, and the preliminary data from the 2011 census indicated that, in 2011, 11.68% of the population was over 65 years of age.⁷ It was noted that the number of people over 65 had increased in every census from 1961. 95% of people over 65 live at home.⁸ According to CARDI, 9.1% of people in that age group are still in employment.⁹ The proportion of people in Ireland over 65 is predicted to continue to rise from its current level of 11.4% to 22.4% by 2041.¹⁰ In other words, it is anticipated that the proportion of people over this age in Ireland will double in the next 20 years. The number of those aged 80 and over is expected to rise from 2.8% of the population in 2011 to 3.5% of the population in 2021, a rise of 45%.¹¹ While there has been a recent upward trend in fertility rates, this is not likely to be maintained. It is expected that fertility rates will decline, albeit moderately.¹² It is predicted that the improvements in life expectancy will continue¹³ and that the life expectancy for males will increase from 76.7 years in 2005 to 86.5 years in 2041. For females it is expected that life expectancy will increase from 81.5 years in 2005 to 88.2 years in 2041.¹⁴

⁶ For full information on the 2006 census, see <http://cso.ie/en/census/>

⁷ See Department of Health *Health in Ireland: Key Trends 2011* at 6.

⁸ Department of Health *Comprehensive Review of Expenditure* (September 2011), at 131.

⁹ *The Role of Telecare in Supporting Carers of Older People* (Centre for Ageing Research and Development in Ireland, September 2011), available at www.cardi.ie/node/9524.

¹⁰ *Fifty Plus in Ireland 2011: First Results from the Irish Longitudinal Study on Ageing (TILDA)*, at 13, available at www.tilda.ie.

¹¹ *Fifty Plus in Ireland 2011: First Results from the Irish Longitudinal Study on Ageing (TILDA)*, at 14, available at www.tilda.ie.

¹² Central Statistics Office *Population and Labour Force Projections 2011-2041* at 11.

¹³ *Ibid* at 15.

¹⁴ *Ibid* at 16.

5. The growth in life expectancy will increase the participation of the older population in the cultural, social and political life of Irish society and such a development is to be welcomed, particularly due to the wealth of experience the older generation brings. While the majority of older people lead active lives, a minority require assistance to live independently and the increase in the older population is likely to result in a greater need for community-based health and social care services.¹⁵ The Department of Health has acknowledged that community-based service is expected to become more essential given the changing demographics and capacity limitations in the long-term care and acute hospital system and is a fundamental component in ensuring service delivery.¹⁶ In addition the majority of older people prefer to live at home and Government strategy has signified a clear preference to maintain older people in their own homes.¹⁷ Despite this commitment, there is an absence of a regulatory structure for the delivery of professional care in the home. The focus of this Report is to address this absence.

6. The Commission, however, notes that it is not just older people who may require home care. Any adult may require home care for a period of time, such as rehabilitation in the home after a car accident, an adult may develop a chronic illness which may require home care, or an adult may require home care due to age-related issues. In line with its previous work on vulnerable adults,¹⁸ the Commission's focus is on maximising the individual's independence, autonomy and choice and ensuring that their constitutional rights and international human rights standards are adhered to in the delivery of professional home care.

¹⁵ *Fifty Plus in Ireland 2011: First Results from the Irish Longitudinal Study on Ageing (TILDA)*, at 217, available at www.tilda.ie

¹⁶ Department of Health *Comprehensive Review of Expenditure* (September 2011) at 131

¹⁷ Currently just under 5% of older people over the age of 65 years live in one of the 607 nursing homes in Ireland. 120 of these nursing homes are public and the remaining 487 are private. See Pillinger *National Advocacy Programme for Older People in Residential Care: An Evaluation* (Commissioned by the HSE, 2011) at 7.

¹⁸ The Commission's *Report on Vulnerable Adults and the Law* (LRC 74-2006) recommended the enactment of mental capacity and adult guardianship legislation that would apply to all persons over 18, though the Commission acknowledged that such legislation would be of particular relevance to older persons. The Government Legislation Programme Autumn Session 2011 (September 2011), available at www.taoiseach.ie, proposes to publish a *Mental Capacity Bill* in early 2012.

C Outline of this Report

7. The Commission now proceeds to provide an overview of the Report.

8. Chapter 1 begins by tracing the evolution of long-term care for older people, which has moved from an emphasis on residential care to home care. An analysis of the history of long-term care for older people is appropriate in any discussion on the regulation of home care services in Ireland, as much of the work that has been carried out on the regulation of services for older people may be applicable by way of extension to all adults in need of home care.

9. The Commission then proceeds to consider the general outline of its proposed regulatory scheme for the provision of professional home care in Ireland. In the Consultation Paper, the Commission provisionally recommended that the Health Information and Quality Authority (HIQA), which was established under the *Health Act 2007* as the regulatory authority for institutional care provision, should also be empowered to regulate professional home care providers. The Commission notes that, since 2009, it has not received any submissions that have taken a contrary view on this general recommendation, and that indeed the developments discussed above indicate that policy initiatives since then have gradually moved towards further (albeit non-statutory) regulation of this area.

10. The Commission also notes that these moves that have been supported by general government policy and by the representative bodies of professional home care providers. Moreover, the Commission also notes that debate in this area has, in general, focused on whether the State is in a position from a financial perspective to extend the statutory regulatory role of HIQA under the 2007 Act and the extent to which the detailed standards and requirements of such a statutory regime could be met by all home care providers. Chapter 1 therefore proceeds to affirm the general approach taken in the Consultation Paper and the Commission also details the general principles which it considers should underpin the proposed legislative scheme.

11. Chapter 2 discusses the need for national standards which, in the Commission's opinion, should underpin the proposed contract for care. The purpose of the proposed legislation, standards and contract for care must be to ensure that there are protective procedures in place to protect the people receiving professional care services in their home and to ensure that relevant sanctions are available in cases of non-compliance.

12. Chapter 3 involves a consideration of funding long-term care in Ireland. This involves an examination of potential funding models which may be followed. While the Commission does not make any specific recommendations on future funding models, as this involves significant policy decisions, it is

important to note such issues which must be considered in line with the reform of the regulatory structures for delivering home care.

13. Chapter 4 contains a summary of the Commission's recommendations.

14. The Appendix contains a draft *Health (Professional Home Care) Bill 2011* to implement the Commission's recommendations.

CHAPTER 1 REGULATION OF HOME CARE IN IRELAND

A Introduction

1.01 In this chapter the Commission traces the changes that have occurred in long-term care for older people. In Part B the Commission examines the evolution of long-term care, moving from an emphasis on residential care to home care. The Commission also discusses the various international conventions in respect of older people. In Part C the Commission affirms the general thrust of the analysis taken in the Consultation Paper (in respect of which there has been general approval) and proposes a regulatory scheme for home care in Ireland, which involves an extension to the current regulatory remit of HIQA.. In Part D the Commission examines the general scope of the term “home care”. Finally, Part E details the general principles which the Commission considers should underpin the proposed legislative scheme.

B Development of care for older people

(1) *Care of the Aged Report*

1.02 The 1968 *Care of the Aged Report* was the first report to examine caring for an aging population in Ireland.¹ It acknowledged that old age is not always a time of ill-health and disability, because most older people live independent lives.² However the Report recognised that many older people need some assistance, often from their family, as they age. It was felt that better services should be provided to older people to help them to remain living in their homes. The Report considered that Ireland must improve the standard of domiciliary and institutional services for older people, which it noted had improved in other countries by the late 1960s.³ The report also recommended the establishment of the National Council for the Aged to promote the general welfare of older people.⁴

¹ Inter-departmental Committee on the Care of the Aged *Care of the Aged Report* (1968).

² *Ibid* at 13.

³ *Ibid* at 49.

⁴ *Ibid* at 112.

1.03 The *Care of the Aged Report* resulted in increased voluntary involvement in caring for older people and also brought about an increase in voluntary Care of the Aged Committees and Social Welfare Councils throughout Ireland.⁵ Despite the improvements resulting from this report, there continued to be shortcomings in the home care services for older people with many older people having no choice but be admitted to institutional care.⁶

(2) Health Act 1970

1.04 The health board system was established in Ireland in 1970 by section 4 of the *Health Act 1970*. Section 38(1) and section 56(1) of the 1970 Act detailed the care which the health boards were required to provide. However the *Health Act 1970* did not legally require the health boards to provide home help services. The provision of such services was left to the discretion of the health boards. It is thus unsurprising that the National Council for the Elderly have argued that the absence of a legal obligation to provide home care services has left the provision of such services susceptible to underfunding.⁷ To put in perspective the extent to which this service is currently made available, according to TILDA, only 3.5% of people over 50 years of age receive state-provided home help service in Ireland⁸ while 1% had the help of a state-provided personal care attendant.⁹

(3) The 1988 Years Ahead Report

1.05 Residential care for the elderly began to become the norm for Ireland with nursing home beds increased by 50% in the late 1980s.¹⁰ This was largely due to a growth in private sector nursing homes and occurred independently of any national plan.¹¹ In 1986, the Working Party on Services for the Elderly was

⁵ National Council on Ageing and Older People "The *Years Ahead* Report: A Review of the Implementation of its Recommendations" Report no. 38 (1997) at 38.

⁶ *Ibid* at 38-39.

⁷ National Council for the Elderly *Home Help Services for the Elderly People in Ireland*, Report no. 36 (1994) at 13.

⁸ *Fifty Plus in Ireland 2011: First Results from the Irish Longitudinal Study on Ageing (TILDA)*, at 6, available at www.tilda.ie.

⁹ *Fifty Plus in Ireland 2011: First Results from the Irish Longitudinal Study on Ageing (TILDA)*, at 215, available at www.tilda.ie.

¹⁰ National Council for the Elderly *The Role and Future Development of Nursing Homes in Ireland* (1991) at 7.

¹¹ *Ibid*.

established to review, among other things, community services for the elderly.¹² The *Years Ahead* report acknowledged the impact an aging population would have on the future planning of long-term care in Ireland.¹³ The report considered maintaining older people in their homes for as long as possible to maximise their independence and dignity as among its objectives.¹⁴

1.06 The *Years Ahead* report identified that policy in the 1980s placed the primary focus of care on hospital care, with community care playing a supporting role.¹⁵ As a result, Ireland had a high level of hospital admissions. The report also found that the high level of long stay beds for the elderly “made it too easy to admit elderly people to institutions when they could no longer cope with daily activities at home.”¹⁶

1.07 The report recommended the expansion of the home help nursing service as one method of alleviating hospital expenditure.¹⁷ The report also found that due to the largely voluntary nature of home help services, it was a cost effective method of delivering help in the home.¹⁸ However due to the lack of a legal obligation to provide home help services, the *Years Ahead Report* noted that such services were vulnerable to financial cutbacks. The report thus repeated the familiar demand that the health boards should be legally obliged to provide home help services.¹⁹

(4) 1997 Impact of the Years Ahead Report

1.08 In 1997 the National Council on Ageing and Older People reported on the implementation of the *Years Ahead Report*. While acknowledging that nine years on the report was not an adequate template for the development of policy on care for older people, the Council expressed disappointment that

¹² See Working Party on Services for the Elderly *The Years Ahead-A Policy for the Elderly* (1988) at ix.

¹³ It must be noted that at the time of the writing of the report in 1988, Ireland had a high level of immigration.

¹⁴ See Working Party on Services for the Elderly *The Years Ahead-A Policy for the Elderly* (1988) at 38.

¹⁵ *Ibid* at 80.

¹⁶ *Ibid*.

¹⁷ *Ibid* at 91.

¹⁸ *Ibid* at 96.

¹⁹ *Ibid* at 97.

many of the recommendations in relation to home care were not implemented.²⁰ The Council found that despite the optimism expressed in the *Years Ahead* Report, home care was not necessarily a cheaper option to institutional care. The real benefit of home care was that it gives older people the option to remain in their home.²¹

1.09 The Council noted that some advancement had been made. With the exception of two health boards, all health boards achieved the target number of public health nurses. However, as many of the nurses employed as public health nurses were not qualified public health nurses, but general nurses, it was felt that the number of public health nurses needed to be increased.²²

1.10 The Council noted the home help service was well received by those in receipt of the service. It was also of the opinion that such a service was vital as it enabled older people to live independently in their own homes and avoid unnecessary hospitalisation or admission to long stay institutions. However, home help services remained a discretionary service to be provided by the health boards.²³

(5) Government Strategy since the 1990s

1.11 In the *Programme for Economic and Social Progress* in 1991 the Government committed itself to development of community services.²⁴ It sought to ensure that older people living in the community would continue to do so and that those living in long stay institutions have the opportunity to move back into the community. It was envisaged that a seven year programme would give effect to the improvements in community care.

1.12 Regarding the elderly, the Government committed itself to

- Expanding nursing homes and other support services for the elderly and their carers living at home;
- Extending respite facilities to relieve the families caring for dependant elderly at home;

²⁰ National Council on Ageing and Older People “The *Years Ahead* Report: A Review of the Implementation of its Recommendations” Report no. 38 (1997) at 1.

²¹ *Ibid* at 155.

²² *Ibid* at 162.

²³ *Ibid* at 179.

²⁴ *Programme for Economic and Social Progress* (January 1991) at 25.

- Providing specialist assessment and rehabilitation units associated with the main acute general hospitals.²⁵

1.13 In 1994, the Government's health strategy *Shaping a Healthier Future - A Strategy for Effective Health Care in the 1990s* noted that failure to provide adequate community care would lead to an increase in unnecessary admissions to hospitals of people who could otherwise be treated in the community.²⁶ The strategy noted that the poor coordination of services for older people has led to unnecessary hospital admission.

1.14 Among the aims of the strategy was a home care service for those who are terminally ill and the encouragement of GPs to care for older people who would otherwise be admitted to hospital. The strategy also aimed to give priority to strengthening home and community services for older people and to provide support to older people who are ill or dependent and also to support those caring for them.²⁷ The strategy was concerned that services must be responsive to changes in the population and the expected rise in the number of older people living in Ireland. It was noted that services for older people had improved since the publication of the *Years Ahead* Report. Day care and respite services had increased along with the number of hospitals providing specialised departments for the care of older people. Long stay institutions had improved along with the coordination of services for older people within the health boards. Despite the noted improvements, the strategy was of the opinion that certain aspects of the care of older people was in need of improvement such as in promoting healthcare ageing and increasing the number of specialised departments of medicine of old age.²⁸

1.15 Despite the emphasis placed on home care, institutional care remained the norm for many people. This was due to a lack of resources and the lack of incentives to discriminate positively in favour of home care.²⁹ The lack of coordination of services also served to reinforce the bias towards institutional care. Thus while the *Care of the Aged Report* and the *Years Ahead Report* began the process of modernising the delivery of health care services

²⁵ *Ibid* at 25-26.

²⁶ *Shaping a Healthier Future-A Strategy for Effective Health Care in the 1990s* (1994) at 26.

²⁷ *Ibid* at 66.

²⁸ *Ibid* at 67.

²⁹ National Council for the Elderly *The Role and Future Development of Nursing Homes in Ireland* (1991) at 45.

for older people and began the process of focusing care for the elderly in community care settings, the reports did not achieve their aims.

1.16 In December 1997, section 268(1) of the *Taxes Consolidation Act 1997* introduced a scheme of capital allowances in respect of the construction or refurbishment of private nursing homes. This scheme was extended under section 33 of the *Finance Act 2002* for the construction or refurbishment of housing units associated with a registered nursing home. This tax incentive ensured that the bias towards residential care was underpinned further.

1.17 Not only do home care services remain outside the remit of a legislative framework, but it was not until 2001 that older people were asked for their perspectives on long-term care. The *Health and Social Care for Older People Report* (HeSSOP Report) was prepared by the National Council on Aging and Older People, the Western Health Board and the Eastern Regional Health Authority Area.³⁰ 937 older people who live in the community were randomly selected to be surveyed. The aim was to give older people a voice to express what they want from services and evaluate the extent to which their preferences are met.³¹ The study examined the perspectives of older people on health and social services. It provided an opportunity for older people to express their lifelong care preferences.

1.18 The older people surveyed clearly expressed that they wanted to remain living in their own homes. They expressed the wish that family and friends be the principal caregivers and the role of the health and social services should be to provide the support to help them and their families. It was clear from the study that options such as residential care and boarding out were unacceptable to significant numbers of older people.³²

1.19 The study highlighted that the range of health and social services in caring for older people in the community was limited. 37% of people who were severely impaired in carrying out their daily activities had not received any home service in the past year. It was also noted that one in ten people who had experienced severe disruption in their lives due to illness had not received any of the home or community based services studied. As a result of the findings, the Council noted that “at present health and social services are only meeting the needs of some older people with many more reporting need for services

³⁰ National Council on Aging and Older People *Health and Social Care for Older People Report (HeSSOP Report)* (2001) Report No. 64.

³¹ *Ibid* at 30.

³² *Ibid* at 29.

than are in receipt of them.”³³ The findings led the Council to recommend that home and community care should be legally provided.

1.20 According to the 2001 Health Strategy *Quality and Fairness: A Health System for You*, key actions for ageing and older people included:

- Inter departmental coordination of services for older people;
- Funding voluntary services which assist older people;
- Increased support for older people;
- Introduction of home subvention scheme for the care of older people;
- Introduction of a respite care grant for dependant older people;
- Introduction of legislation with a clear framework for financing care for older people.

1.21 In 2005, the National Economic and Social Forum (NESF) found that the bias towards residential care continued to exist. This is due in part to the financial supports and incentives which favour long-stay care.³⁴ In particular the NESF pointed out the following as such examples:

- An older person may qualify for a private nursing home subvention but not be able to convert that into a care subvention to live at home;
- Tax relief is available to the person who pays the nursing home fees but is not available for contracted nursing care at home.³⁵

1.22 The National Development Plan 2007-2013 allocated €4.7 billion to help older people live independently for as long as possible in their own homes and communities.³⁶ This allocation was to help fund home care packages, meals on wheels services, community intervention teams and respite day care services.³⁷ In the Programme for Government 2011, the Government pledged

³³ *Ibid.*

³⁴ National Economic and Social Forum *Care for Older People* Report 32 (2005) at 26-27.

³⁵ *Ibid* at 53.

³⁶ Due to the reduced level of resources available, the Department of Finance attached terms and conditions to the National Development Plan 2007 – 2013. However, according to the *Infrastructure and Capital Investment 2012 - 2016* Report, close to €2 billion will be invested in the period 2012-2016. *Infrastructure and Capital Investment 2012 – 2016: Medium Term Exchequer Framework* (Department of Public Expenditure and Reform, November 2011) at 29.

³⁷ National Development Plan 2007-2013 at 255-257.

their support for older people continuing to live in their own homes and communities for as long as they wish and promised to facilitate this by ensuring that the eligibility criteria for the home help and the Home Care Package Scheme are applied consistently.

1.23 Under the Government's *Infrastructure and Capital Investment* programme for 2012-2016, published in November 2011, it is envisaged that funding will be allocated across a number of sub-programmes – primary care, mental health, older people, disability and acute hospitals – in accordance with the commitment in the Programme for Government to prioritise primary care centres, long-term facilities and community care facilities such as day centres for older people.³⁸

(6) Home Care Supports

1.24 As public policy evolved and the benefits of home care were acknowledged, home care supports became available. Financial support is available not only to purchase home care but also to support informal carers. Currently supports are available for both the carers and the person to whom the care is being provided. However, currently tax relief is not available for the costs incurred for meeting home care.³⁹

(a) HSE Home Help Services

1.25 The Health Service Executive (HSE), established under the *Health Act 2004* as successor to the health boards, may make arrangements through its home help service to help maintain people in their homes who would otherwise need institutional care. There is, however, no legal obligation on the HSE to provide such a service. The home help usually provides a set number of hours assistance each day or week, depending on individual needs. According to TILDA, people with impairments in their ability to go about the various activities of daily living receive on average 118 hours of help per month – the most common helper for this group is the recipient's spouse. Only 3.5% of people over 50 years of age receive state provided home help services.⁴⁰ For the limited number of those who are in receipt of this service, the home help can assist or provide them with a number of household tasks such as cooking, light

³⁸ *Infrastructure and Capital Investment 2012 – 2016: Medium Term Exchequer Framework* (Department of Public Expenditure and Reform, November 2011, at 30.

³⁹ See Chapter 3, below.

⁴⁰ *Fifty Plus in Ireland 2011: First Results from the Irish Longitudinal Study on Ageing (TILDA)*, at 204, available at www.tilda.ie.

cleaning, laundry and some shopping. The home help may also provide some personal care but they are not expected to provide nursing or medical care.

1.26 The service is generally free to medical card holders but people may be asked to contribute towards the service even if in possession of a medical card. If the person can pay for the service themselves they must do so. The HSE can however assume the responsibilities of the employer on behalf of the person who pays the costs.

(b) Home Care Packages

1.27 The Home Care Support Scheme (also known as a *Home Care Support Package*) is a non-statutory scheme introduced in 2006 and operated by the HSE. At the time of writing (December 2011), the Scheme is currently free of charge and it forms part of €4.7 billion allocated under the National Development Plan 2007-2013 to assist people to live independently. The home care packages are provided under a grants-based system⁴¹ and the services provided can include assistance from public health nurses, home care attendants, home helps, physiotherapists and occupational therapists. There is no set home care package and the package will vary according to need. In 2010, in an attempt to bring greater consistency to the scheme, the HSE introduced *National Guidelines and Procedures for the Standardised Implementation of the Home Care Package Scheme*.⁴² These Guidelines incorporated recommendations from the National Economic Social Forum (NESF), who, in a 2009 Report, had highlighted the lack of uniformity in the manner in which the Home Care Package Scheme had been implemented.⁴³

1.28 A 2011 Department of Health evaluation indicated that the majority (77%) of home care package recipients are over age 75, and around 40% are

⁴¹ The cash grants awarded pursuant to the scheme are to be approached in accordance with HSE policy as set down in the *National Guidelines and Procedures for the Standardised Implementation of the Home Care Packages Scheme* (2010). According to these Guidelines, no charges will be levied on applicants in respect of services provided through the Scheme. However, the home care envisioned by the Commission involves a system whereby those who can afford professional care in their own homes have the option of paying for that service, if necessary through the HSE. This is one of the principal distinctions between the home care system recommended in this Report and the home care packages operated at present by the HSE.

⁴² *National Guidelines and Procedures for the Standardised Implementation of the Home Care Packages Scheme* (2010).

⁴³ National Economic and Social Forum *Implementation of the Home Care Package Scheme* Report 38 (September 2009).

over age 85. Most are female (63%) and 89% of all recipients have a medical card. The service is expected to become more essential given the changing demographics.⁴⁴ In terms of the growing need for professional home care services and the extent to which the services are provided to those in need at present, the TILDA study concluded that 12% of older people who suffer from impairments in the activities of daily living, some of whom are severely impaired, do not receive any formal or informal help. The study highlighted the potential vulnerability of this group of people and made known the extent to which many people who require home care are left without any support – formal or otherwise.⁴⁵

1.29 The priority of the Home Care Support Scheme is for people who are 65 years of age and older and who are living in the community or inpatients in acute hospitals who are at risk of admission to long-term care. However, the Scheme is not limited to those over 65. Home care packages are also available to people who are in long-term care but wish to return to the community. The Scheme is designed to enhance rather than replace home support services already in place. In terms of the ability of the scheme to meet the needs of people who require assistance with the activities of daily living, it is emphasised in the 2010 *National Guidelines and Procedures for the Standardised Implementation of the Home Care Packages Scheme* that the extent of the support available through the Home Care Package Scheme is subject to the limit of the resources allocated each year to the HSE for the running of the scheme. The limited resources available may be one of the reasons for the TILDA finding that only 1% of the older population in Ireland had the help of a state-provided personal care attendant.⁴⁶

1.30 Once a person has been admitted to the scheme, the Home Care Package may consist of a direct cash grant to enable a person's family to purchase a range of services or supports privately. The decision to allocate a home care package is based on an assessment of need, identification of any needs not being met by mainstream community services and the appropriateness of care in the community in the individual case. If family or a friend can provide the care, they are encouraged to do so with HSE help. Home care packages can be delivered in 4 principal ways:

⁴⁴ Department of Health *Comprehensive Review of Expenditure* (September 2011), at 131.

⁴⁵ *Fifty Plus in Ireland 2011: First Results from the Irish Longitudinal Study on Ageing (TILDA)*, at 204, available at www.tilda.ie.

⁴⁶ *Ibid*, at 215.

- Direct provision by the HSE, usually through staff directly employed by the Local Health Office;
- Services provided through private commercial agencies, but paid for by the HSE;
- Services provided through community and voluntary groups, and paid for by the HSE;
- Cash grants, which allow people to use the funding to organise their own care. However, this arrangement is no longer available in many areas.⁴⁷

1.31 As previously mentioned, in September 2009, the National Economic and Social Forum (NESF) published a report on the implementation of home care packages.⁴⁸ In general terms, the submissions received by the NESF praised the introduction of the packages and the positive impact they had on people's lives. This was also highlighted in the PA Consulting Group's *Evaluation of Home Care Packages* which noted that the packages resulted in older people remaining in their home who otherwise would have been admitted to residential care.⁴⁹ The NESF Report did, however, highlight a number of problems with the operation of the scheme. Regional variations in eligibility criteria for home care packages were noted. Not only did this result in inconsistency but it also lead to confusion as to the eligibility criteria.⁵⁰ It was noted that the maximum amounts payable per week under a health care package varied according to the local health office and also variations in how the home care packages are delivered.⁵¹ The Report pointed out the regional variation in the provision of information regarding home care packages, with different local health offices providing differing levels of information.⁵²

⁴⁷ National Economic and Social Forum *Implementation of the Home Care Package Scheme* Report 38 (2009) at 34. The NESF's review of the Home Care Package Scheme also found that it was being implemented in different ways in different HSE local health offices around the country and that applicants to the Scheme faced different eligibility criteria, means tests and funding, depending on where they lived.

⁴⁸ National Economic and Social Forum *Implementation of the Home Care Package Scheme* Report 38 (2009).

⁴⁹ PA Consulting Group *Evaluation of Home Care Packages* (November 2009) at 9.

⁵⁰ *Ibid* at 54.

⁵¹ *Ibid* at 56-57.

⁵² *Ibid* at 60-61.

1.32 A number of health care providers noted that the variations in the implementation of the scheme led to a duplication of their administrative work. It was also found that double or triple assessment of the care needs and of the means test of an older person occurs.⁵³ Significantly it was pointed out in submissions that the inconsistencies between the funding and means tests for health care packages and nursing home care favoured nursing home care.⁵⁴ The NESF thus recommended that greater coordination of services was required⁵⁵ to reduce the duplication of work and improve the service provided to people in need of professional home care.

(7) Regulatory Developments since the 2009 Consultation Paper

1.33 The Commission welcomes the introduction in 2010 of the *National Guidelines and Procedures for the Standardised Implementation of the Home Care Packages Scheme* which aims to reflect the recommendations of the NESF review of the Home Care Package Scheme. The Commission also welcomes the Government's commitment to make professional home care services subject to inspection by the Health Information and Quality Authority (HIQA).⁵⁶ This was one of the provisional recommendations in the *Consultation Paper on the Legal Aspects of Carers*.⁵⁷

1.34 In 2011, in response to the various reviews of the Home Care Packages Scheme, the Health Service Executive (HSE) initiated a new Procurement Framework for Home Care services. The purpose of these measures is to promote quality and safety and also promote a more standardised and cost effective approach to provision nationally, whether directly by the HSE, or those providing services on its behalf. It is anticipated that any savings generated would be used to fill unmet need in view of increasing demographic pressures.⁵⁸

1.35 The Commission also welcomes the proposed adoption by the Health Service Executive (HSE) of the interRAI suite of tools (previously known as the MDS and MDS-HC [Home care]) for the assessment of the care needs of older people.⁵⁹ This particular assessment tool is currently the subject of a pilot study

⁵³ *Ibid* at 69.

⁵⁴ *Ibid* at 70.

⁵⁵ *Ibid* at 95.

⁵⁶ Programme for Government 2011-2016, available at www.taoiseach.gov.ie.

⁵⁷ LRC CP 53-2009.

⁵⁸ Department of Health *Comprehensive Review of Expenditure* (September 2011), at 132.

⁵⁹ <http://www.interrai.org/section/view>

conducted by the HSE in order to determine how usable, practical and acceptable these tools are to service users, their carers and to staff involved in the delivery of healthcare services in Ireland.

(8) International Law

1.36 Protecting the rights of older people is part of various action plans and conventions from the United Nations and the Council of Europe.

(a) United Nations

1.37 In 1991, the *United Nations Principles for Older Persons* saw the principles of independence, participation, care, self-fulfilment and dignity as core to older people. Principle 14 states as follows:

“Older persons should be able to enjoy human rights and fundamental freedoms when residing in a shelter, care or treatment facility, including full respect for their dignity, beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives.”

1.38 The UN Principles were followed up in 2002 by the *Madrid Plan of Action on Ageing*.⁶⁰ It called for changes in attitudes, policies and practices so that the enormous potential of ageing in the twenty-first century may be fulfilled. This will ensure that people can age with dignity and security while continuing to participate in their community.

1.39 Despite the intentions of the principles and the action plan, both these instruments fall into the category of “soft law” in that neither are legally binding and States are under a moral as opposed to a legal obligation to follow their recommendations regarding the treatment of older people. Both the International Covenant on Social and Political Rights and the International Covenant on Economic, Social and Cultural Rights are examples of “hard law” or legally binding conventions which apply to people of all ages. Currently, there is no legally binding international convention which obliges governments to realise the rights of older people specifically, but at the time of writing (December 2011), this is under consideration.⁶¹

(b) Council of Europe

1.40 The European Social Charter, adopted in 1961 and revised in 1996, was the first human rights treaty to specifically protect the general rights of older

⁶⁰ Second World Assembly on Ageing *International Plan of Action on Ageing* (April 2002)

⁶¹ Help Age International *Strengthening Older People's Rights: Towards a UN Convention* (January 2010) at 3.

people. Article 23 concerns the right of elderly people to social protection and seeks to ensure that older people remain full members of society for as long as possible by means of adequate resources to help them play an active part in public, social and cultural life. It also seeks to ensure that older people can choose their life-style freely and lead independent lives in an environment with which they are familiar for as long as they wish and are able to do so.

1.41 The general principles of the European Convention on Human Rights are also relevant to the rights of care recipients and have been considered by the courts in the context of home care services. In the English case *R (A and B) v East Sussex County Council*,⁶² Munby J held that a “no lift” ban would be in breach of the service user rights under the European Convention on Human Rights. In this case, two sisters A and B, who were profoundly disabled, and suffered from learning difficulties, successfully applied (with the support of the British Disability Rights Commission) for a declaration that East Sussex County Council’s (ESCC) virtual blanket “no manual lifting policy” was illegal. The sisters lived with their parents in a house which had been especially adapted. Under British legislation, they were entitled to care from the local authority. As a result of some incidents, A and B and their parents challenged the ESCC’s policy of not permitting care staff to lift A and B manually.

1.42 Munby J held that it was not “reasonably practicable” within the meaning of section 2 of the British *Health and Safety at Work Act 1974* for the ESCC to avoid the need for their employees to undertake manual handling of A and B altogether. The Commission notes that section 2 of the British 1974 Act broadly corresponds to section 8 of the *Safety, Health and Welfare at Work Act 2005*, which also uses the legal standard of “reasonably practicable.” Munby J accepted that the ESCC’s revised manual handling policy, which was presented to the Court after the case had begun and which made clear that it did not have a blanket no manual lifting policy, was lawful and “representative of good practice.” It was therefore compatible with the British *Manual Handling Operations Regulations 1992*, made under the 1974 Act,⁶³ and with the ECHR, which had been implemented in the UK by the *Human Rights Act 1998*.

⁶² [2003] EWHC 167 (Admin) (High Court of England and Wales, 18 February 2003).

⁶³ This is the equivalent of Part 4, Chapter 4 of the *Safety, Health and Welfare at Work (General Application) Regulations 2007* (SI No.299 of 2007), made under the *Safety, Health and Welfare at Work Act 2005*. The Commission also notes here that these Regulations (like their British 1992 counterparts discussed in the 2003 *A and B* case) implemented in the State a 1990 EU Directive on Manual Handling at Work, 90/269/EEC. See generally, Byrne, *Safety, Health and Welfare at Work Law in Ireland*, 2nd ed (Nifast, 2008), Chapter 26.

1.43 Thus, the new policy of the ESCC shifted the dispute from being an issue about the lawfulness of the ESCC's alleged blanket no manual lifting policy, to being an issue about whether A and B were entitled to be manually lifted by their carers. Munby J held they were. He held that the British 1992 Regulations established a clear hierarchy of safety measures but were a risk reduction/minimisation regime and not "a no risk regime." There was, he noted, no "absolute prohibition on hazardous lifting." Rather, the employer's duty was to avoid or minimise the risk in so far as is reasonably practicable. In the case of A and B, and when considering the needs of those with a disability, the term reasonably practicable must, he said, take account of the rights of disabled persons in the ECHR. The reasonably practicable test must now, where the disabled are concerned "be informed" by the ECHR.

1.44 Without suggesting that the decision in the *A and B* case would necessarily be followed if the same issue arose in Ireland, it is worth noting that Irish courts are also required to take account of the ECHR because it too has been implemented in Ireland by the *European Convention on Human Rights Act 2003*, which is modelled on the UK *Human Rights Act 1998*. The Commission returns to this specific issue in Chapter 2 of this Report, below.

1.45 The rights of older people are also mentioned in the European Reference Framework, an annex of a recommendation of the European Parliament which sets out policy objectives for education and training and specifically refers to the need to ensure access to education for older people.⁶⁴ The Framework recommends that the differing needs of learners should be met by ensuring equality and access for people who, due to educational disadvantages caused by personal, social, cultural or economic circumstances, need particular support to fulfil their educational potential. Examples of such people include those with low basic skills, early school-leavers, the long-term unemployed and those returning to work after a period of extended leave, older people, migrants, and people with disabilities.⁶⁵

1.46 Also of relevance is the European Reference Framework Online for the Prevention of Elder Abuse and Neglect.⁶⁶ This is a Pilot Project on preventing elder abuse and is being carried out under the European

⁶⁴ European Reference Framework: Key Competencies for Lifelong Learning, available at http://ec.europa.eu/dgs/education_culture/publ/pdf/ll-learning/keycomp_en.pdf.

⁶⁵ *Ibid* at 3.

⁶⁶ The European Reference Framework Online for the Prevention of Elder abuse and Neglect: Background, Good Practices and Recommendations, available at www.preventelderabuse.eu.

Commission. Age Action Ireland is involved in the pilot and one of the specific objectives of the project is to develop a European Reference Framework, by way of establishing good practices and policies, for the prevention of elder abuse. Nine European countries are participating in the project and of all the countries involved, none has specific legislation concerning elder abuse.⁶⁷ The Framework document also notes that more than legislation is needed to combat this form of abuse. There is a need for infrastructure, agreements, measures, protocols, standards, networking, regulation and monitoring. The Framework document also specifically notes that Ireland has a national policy for dealing with elder abuse and a national definition, whereas many other European countries do not.⁶⁸ The definition of elder abuse adopted by Ireland, as set out in the report of the Working Group on Elder Abuse, *Protecting Our Future*, is:

“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.”⁶⁹

C Proposed Regulatory Scheme for Professional Home Care Provision

1.47 In the Consultation Paper, the Commission provisionally recommended that the Health Information and Quality Authority (HIQA), which was established under the *Health Act 2007* as the regulatory authority for institutional care provision (whether in the public and private sector), should also be empowered to regulate professional home care providers.⁷⁰ This recommendation would involve amending section 8(1)(b) of the *Health Act 2007* to extend the authority of HIQA to include the regulating and monitoring of professional domiciliary care, home care, providers.

⁶⁷ The European Reference Framework Online for the Prevention of Elder abuse and Neglect: Background, Good Practices and Recommendations, available at www.preventelderabuse.eu, at 11.

⁶⁸ *Ibid* at 5 and 11. At 5, the Framework document notes the *Protecting Our Future* report of 2002 which represents the Irish national policy on elder abuse and also notes the Irish definition of this form of abuse.

⁶⁹ Report of the Working Group on Elder Abuse *Protecting our Future* (2002) at paragraph 3.3.

⁷⁰ Law Reform Commission *Consultation Paper on Legal Aspects of Carers* (LRC CP 53-2009) at paragraph 1.42.

1.48 The Commission notes that, since 2009, it has not received any submissions that have taken a contrary view on this general recommendation, and that indeed the developments discussed above indicate that policy initiatives since then have gradually moved towards further (albeit non-statutory) regulation of this area. The Commission also notes that these moves that have been supported by general government policy and by the representative bodies of professional home care providers. Moreover, the Commission also notes that debate in this area has, in general, focused on whether the State is in a position from a financial perspective to extend the statutory regulatory role of HIQA under the 2007 Act and the extent to which the detailed standards and requirements of such a statutory regime could be met by all home care providers.

1.49 The Commission acknowledges that these policy issues, as with all such matters which may arise on the decision to implement recommendations for reform, remain ultimately a matter for the Government and the Oireachtas. Nonetheless, given the broad consensus in favour of eventual regulation of professional home carers, the Commission has concluded that it should confirm the main recommendations made in the Consultation Paper.

1.50 Before turning to set out its final recommendations on the proposed statutory regulation of professional home care providers, the Commission notes that the current HIQA registration and inspection system is based on three key elements:

- (a) the general statutory framework in the *Health Act 2007* which sets out the powers of HIQA;
- (b) the Regulation-making powers of the Minister for Health in section 101 of the 2007 Act, under which detailed statutory duties are imposed on designated centres such as nursing homes. These are currently set out in the *Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2009 and 2010*,⁷¹ and
- (c) National Standards published by HIQA, which provide further detail as to how registered centres are to comply with the requirements of the ministerial Regulations made under section 101 of the 2007 Act. These

⁷¹ *Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2009* (SI No.236 of 2009), as amended by the *Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) (Amendment) Regulations 2010* (SI No.36 of 2010), made under section 101 of the 2007 Act.

include HIQA's 2009 *National Quality Standards for Residential Care Settings for Older People in Ireland*.⁷²

1.51 The Commission considers that these three key elements provide a suitable template for the proposed regulatory framework for professional home care providers, to which it now turns.

(1) Role of HIQA

1.52 As already mentioned, the Health Information and Quality Authority (HIQA), which was established under the *Health Act 2007*, is responsible, under Part 8 of the 2007 Act, for the registration and inspection of designated centres. A designated centre notably includes institutions providing residential care, such as nursing homes, whether private sector or public sector. The HIQA registration and inspection system for designated centres came into force in 2009.⁷³

1.53 Since the introduction of this system in 2009, there have been repeated calls for the regulation of professional care in the home and for the extension of HIQA's remit. Indeed, the Commission notes that section 8(1)(b) of the *Health Act 2007* provides that one of the functions of HIQA is to set standards for certain services provided by the HSE or a service provider who provides health and personal social services on behalf of the HSE. A "service provider" is someone who "enters into an arrangement...to provide a health or personal social service on behalf of the [HSE]." While this general oversight function in the 2007 Act could, arguably, be taken to include professional home care provision, in reality it would not be possible for HIQA to exercise a suitable regulatory role unless it was also empowered to register and inspect home care provision in a manner that mirrors the current regulatory arrangements under Part 8 of the 2007 Act for residential care centres, such as nursing homes.

1.54 In the Consultation Paper the Commission noted that, while HIQA has the authority to regulate certain institutional care providers under the *Health Act 2007*, it does not have the authority to regulate professional home care providers.⁷⁴ The Commission provisionally recommended that Section 8(1)(b) of the *Health Act 2007* be amended to extend the functions of HIQA to include the setting of standards in relation to services provided by professional home care providers.⁷⁵ Submissions received by the Commission welcomed the

⁷² Available at www.hiqa.ie.

⁷³ See *Health Act 2007 (Commencement) (No.2) Order 2009* (SI No.237 of 2009).

⁷⁴ Law Reform Commission *Consultation Paper on Legal Aspects of Cares* (LRC CP 53-2009) at paragraph 1.36.

⁷⁵ *Ibid* at paragraph 1.42.

recommendation. It was thought that such a move would go towards ensuring that people in receipt of care in the home receive the same level of care and protection as people in residential care. Having regard to the general comments made above, the Commission has concluded, and recommends, that section 8(1)(b) of the *Health Act 2007* be amended to extend the functions of HIQA to include the setting of standards in relation to services provided by professional home care providers.

1.55 *The Commission recommends that section 8(1)(b) of the Health Act 2007 be amended to extend the functions of the Health Information and Quality Authority (HIQA) to include the setting of standards in relation to services provided by professional home care providers.*

(2) Registration of home care providers

1.56 In the Consultation Paper the Commission noted that section 40 of the *Health Act 2007* established the Office of the Chief Inspector of Social Services (the Social Services Inspectorate “SSI”).⁷⁶ The SSI must register and inspect the residential care services provided by all designated centres. A designated centre is an institution at which residential services are provided for children, older people and/or people with a disability, whether in the public or private sectors, or a nursing home.⁷⁷

1.57 The SSI must establish a list of all registered designated centres. Under section 50 of the *Health Act 2007*, registration is only granted once it is established that the care provider is a fit person and that the centre is operated in a manner that complies with relevant standards and regulations. In the Consultation Paper the Commission provisionally recommended the amendment of the definition of designated centre to include institutions involved in the delivery or provision of home care services. This would extend the power of the SSI to register and monitor home care providers.

1.58 In the Consultation Paper the Commission was of the view that there is a need to establish a register of all independent professional home carers. The Commission was of the opinion that this would ensure that all professional home carers are properly regulated by a particular body which would inspect each provider to ensure compliance with standards and regulations.⁷⁸ The Commission is of the view that the SSI should have overall responsibility for

⁷⁶ Law Reform Commission *Consultation Paper on Legal Aspects of Carers* (LRC CP 53-2009) at paragraph 1.43.

⁷⁷ Section 2 of the *Health Act 2007*.

⁷⁸ Law Reform Commission *Consultation Paper Legal Aspects of Carers* [LRC CP 53-2009] at paragraph 5.6.4.

monitoring all registered professional home carers. Any home carer convicted of an offence under section 51(2) of the *Health Act 2007* would have their registration cancelled. The Commission thus recommends the amendment of the definition of designated centres in section 2(1) of the *Health Act 2007* to include undertakings (both unincorporated and incorporated, and whether established for gain or not established for gain) who are involved in the provision of professional home care services. This would extend the power of the SSI under section 41 of the 2007 Act to register and monitor all home care providers. The Commission also recommends that the SSI establish a registry of all professional home carers.

1.59 *The Commission recommends the amendment of the definition of designated centres in section 2(1) of the Health Act 2007 to include undertakings (both unincorporated and incorporated, and whether established for gain or not established for gain) who are involved in the provision of professional home care services. The Commission also recommends that the Social Services Inspectorate (SSI) establish a registry of all professional home carers.*

(3) Ministerial regulation-making power

1.60 In the Consultation Paper the Commission provisionally recommended that section 101 of the *Health Act 2007* be extended to confer the power to make regulations in respect of professional home care providers on the Minister for Health and Children.⁷⁹ The Consultation Paper noted that under section 101 of the *Health Act 2007* the Minister may currently make regulations to ensure the proper maintenance, care, welfare and well-being of persons resident in a designated centre. This recommendation was met with wide approval during the consultative process. It was thought that the extension of the regulation-making power would ensure that standards were set and met. The Commission is of the opinion that the extension of section 101 of the 2007 Act would ensure that home care is delivered in a professional manner and ensure that people in receipt of professional care services in the home are protected. The Commission thus recommends that the Ministerial regulation-making power conferred on the Minister for Health by section 101 of the *Health Act 2007* be extended to include the authority to make regulations in respect of professional home care providers.

1.61 *The Commission recommends that the Ministerial regulation-making power conferred on the Minister for Health by section 101 of the Health Act 2007 be extended to include the authority to make regulations in respect of undertakings involved in the provision of professional home care services.*

⁷⁹ Law Reform Commission *Consultation Paper Legal Aspects of Carers* (LRC CP 53-2009) at paragraph 1.48.

D Scope of Professional Home Care

1.62 The Commission now turns to the scope of what is involved in professional home care. As previously discussed, the Commission is of the opinion that the delivery of professional home care must be regulated and that this will involve an extension of HIQA's powers under the *Health Act 2007*. The World Health Organization (WHO) has described home care as care which satisfies:

“people’s health and social needs while in their home by providing appropriate and high-quality home-based health care and social services, by formal and informal caregivers, with the use of technology when appropriate, within a balanced and affordable continuum of care.”⁸⁰

1.63 Section 4(3) of the English *Care Standards Act 2000* defines a “domiciliary care agency” as a body which arranges for the provision of personal care in a person’s home where they would not ordinarily be able to care for themselves due to illness, infirmity or disability. While the 2000 Act provides no definition of “personal care”, the English and Welsh *National Minimum Standards on Domiciliary Care*, made under the 2000 Act, provide some guidance and describes such care as follows:

- 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 physiological support, including the promotion of social functioning, behaviour management, and assistance with cognitive functions.⁸¹

1.64 Only the first two points will give rise to the registration of a domiciliary care agency and the National Standards also note that the courts are likely to continue to shape the interpretation of “personal care” over time.⁸²

⁸⁰ World Health Organisation *Home Care in Europe: The Solid Facts* (2008) at 1.

⁸¹ Department of Health “Domiciliary Care National Minimum Standards” (2003). See also Welsh Assembly Government “National Minimum Standards for Domiciliary Care Agencies in Wales” (2004).

⁸² *Ibid* at 6.

The issue of advocacy services is specifically raised and the standards provide that service users and their relatives or other representatives are to be informed about independent advocates who will act on their behalf and they are also to be informed about self-advocacy.⁸³ This is comparable to the non-statutory guidance in Ireland, discussed below.

1.65 In Australia, care provided at home is defined as “community care.”⁸⁴ Such care is described as “care consisting of a package of personal care services and other personal assistance provided to a person who is not being provided with residential care.”⁸⁵ Care for older people who wish to remain at home is funded through the Community Aged Care Packages (CACP) and the Home and Community Care services (HACC).

1.66 CACPs are tailored to meet an individual’s personal needs. They are provided to older people who require low level care in order to remain living in their own home. On the other hand, the Extended Aged Care at Home (EACH) and the Extended Aged Care at Home Dementia (EACHD) provide care for older people who require high level care in order to remain living in their own home. The HACC service provides the basic needs required to maintain a person’s independence at home and in the community. The types of services include community nursing, domestic assistance, personal care, meals on wheels, home modification and maintenance, transport and community-based respite care.

1.67 As the Commission has already noted, Ireland has a non-statutory system of home care packages. In order to avoid any confusion, this Report defines such care as home care and not domiciliary care. In its 2009 Report, the National Economic and Social Forum (NESF) stated that home care packages may include “the services of nurses, home care attendants, home helps and various therapies including physiotherapy services and occupational therapy services.”⁸⁶ The Commission concurs with this definition. The Commission is of the opinion that personal care which is provided under the HSE home help service must come under the definition of home care. This is to ensure that any person employed to provide a service to a person in their home to enable them to remain living independently is subject to the proposed regulations and standards. The Commission thus recommends a definition of professional home care as services which are required to ensure that a person can continue to live

⁸³ *Ibid* at Standard 9.9.

⁸⁴ *Aged Care Act 1997*.

⁸⁵ Section 45(3) of *Aged Care Act 1997*.

⁸⁶ National Economic and Social Forum *Implementation of Home Care Packages in Ireland*, Report 38, 2009.

independently in their own home. This may include, but is not limited to, the services of nurses, home care attendants, home helps, various therapies and personal care.

1.68 An ageing population is likely to lead to increased health services demands and also increased needs for palliative care services.⁸⁷ Palliative care is defined by the World Health Organisation (WHO) as:

“...an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illnesses, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

1.69 In 2001, 95% of people in receipt of palliative care are suffering from cancer.⁸⁸ However, since 2001, there has been a gradual increase in people suffering from renal, cardiac and neurological diseases availing of palliative care. If this trend continues demand for palliative care could increase by 80%.⁸⁹ GPs and public health nurses are the main providers of palliative care in the home. However, there is no formal framework to support the delivery of palliative care by primary care teams in Ireland.⁹⁰ The palliative care team, also known as the home care team, provides specialist support to patients, families and to community based health care professionals. Since 2006, the Irish Hospice Foundation (IHF) has provided a night nursing service whereby people suffering from a non-malignant condition wishing to die at home have access to a night nurse. The aim of the scheme is to respond to the unmet palliative care needs of people suffering from a malignant condition and to highlight awareness of this group’s needs. The service is funded by the IHF but is provided by the Irish Cancer Society’s pool of nurses. However, the IHF wishes to identify long-term funding options for the service. For people suffering from a malignant condition, the Irish Cancer Society provides a similar service.

⁸⁷ TILDA found that the most pressing effects of ageing are likely to be on demands for a range of community-based health and social care services. *Fifty Plus in Ireland 2011: First Results from the Irish Longitudinal Study on Ageing (TILDA)*, at 217, available at www.tilda.ie.

⁸⁸ Department of Health and Children *Report of the National Advisory Committee on Palliative Care* (2001) at paragraph 1.8.

⁸⁹ *Ibid.*

⁹⁰ *Primary Palliative Care in Ireland: Identifying Improvements in Primary Care to Support the Care of Those in Their Last Year of Life* (November 2011), available at www.hospice-foundation.ie

1.70 The Commission is of the opinion that palliative care is an important aspect of end-of-life care. The Commission also notes that many people wish to die at home.⁹¹ To ensure that this wish can be met, the Commission is of the opinion that palliative care must come within the definition of professional home care. The Commission thus recommends that palliative care be included in the definition of professional home care.

1.71 *The Commission recommends that professional home care should be defined as services which are required to ensure that an adult person can continue to live independently in their own home. This may include, but is not limited to the services of nurses, home care attendants, home helps, various therapies and personal care. The Commission also recommends that palliative care be included in the definition of professional home care.*

(1) Informal Care

1.72 Informal carers play an important role in the provision of care in Ireland and around the world. Informal care may be provided by a voluntary organisation or, more likely, a family member. Indeed in British Columbia it has been estimated that 80% of care comes from informal carers. It is thought that if this informal care were to be provided on a professional basis, the cost would amount to €2.5 billion each year.⁹² Due to this high level of informal care, the Department of Health has stated that professional home care services must be seen to complement, rather than take over, the provision of care in the home.⁹³ The provision of informal care must thus remain part of any development of the provision of care in Ireland. In recent years, the Department of Social Protection has provided support for informal carers through the provision of the carer's allowance, carer's benefit and the respite care grant.

1.73 Despite the importance of informal care both to the people receiving care and the savings to the Exchequer, the Commission notes that the regulation of informal care is outside the scope of this project. The Commission notes that no financial exchange occurs between a care recipient and an informal carer. Thus the relationship and the arrangements involved in the

⁹¹ Dr. Paul Gregan, Chairperson of the Primary Palliative Care National Steering Group, stated that “[r]esearch has found that 80% of people with end-stage disease in Ireland want to die at home”, *Primary Palliative Care in Ireland: Identifying Improvements in Primary Care to Support the Care of Those in Their Last Year of Life* (November 2011), available at www.hospice-foundation.ie

⁹² “Carers group claims its members save state €2.5 billion”. *The Irish Times*, Health Supplement, 10 February 2009.

⁹³ Department of Health and Children *Long-term Care Report* (2008 at paragraph 1.41).

provision of informal care are substantially different from those that apply in the provision of professional services. For this reason the Commission reiterates that informal carers do not come within the scope of the recommendations contained in this Report.

(2) Older People, Vulnerable Adults and the Scope of the Report

1.74 The Commission notes that, while older people may well be the dominant users of professional home care services, the need for such care is not confined to older people and it also applies, for example, to people with disabilities and those with chronic illnesses. The following are examples of the types of situations in which professional home care may be required by an adult person:

- An adult may require professional home care for a period of time, such as rehabilitation services in the home after a car crash;
- An adult may develop a chronic illness during their life, such as MS, in which they may need professional home care services to continue to live independently in their home;
- An adult may have been born with a physical or mental disability and may require home care services; and
- An adult may require professional home care services due to age related issues.

1.75 The purpose of this Report is to recommend a regulatory scheme by which all adults may continue to live independently in their homes should they wish to do so and in so far as they are able. It is for this reason that the Commission recommends that the proposed legislative scheme should not be limited to a specific age cohort of adults, and that it should apply to professional home carers who provide professional care services to adults aged 18 years and over in the home.

1.76 *The Commission recommends that the proposed legislative framework should apply to undertakings who provide professional home care to persons aged 18 years and over.*

E General Principles

1.77 In this Part the Commission outlines the principles which it considers should inform the proposed legislative framework on professional home care in Ireland. In its 2003 Report *Older People in Long Stay Care* the Irish Human Rights Commission noted that the “enumeration, clarification and implementation of rights of vulnerable people ought to be a priority in a civilised

society.”⁹⁴ The relevant principles are: the promotion of independent living, privacy, dignity, quality of care and the protection of vulnerable adults.

(1) Independent living

1.78 In a 2001 study by the National Council on Aging and Older People (NCAOP), it was found that a large majority of older people wish to continue to live in their own homes.⁹⁵ Government policy supports older people to live in dignity and independence in their own homes and communities for as long as possible.⁹⁶ Indeed, older people have expressed a higher satisfaction rate when cared for at home in comparison to older people cared for in institutional residences.⁹⁷ As many people get older however, the likelihood of a person suffering from an age related disability increases, thus requiring the need for home care. The home care provided should not hinder but promote the independence of the care recipient and enable them to live independently.”

1.79 The Department of Health in England noted that the care provider provides assistance to the care recipient and encourages the care recipient to maximise their independence.⁹⁸ The care recipient must thus be assisted in the performance of duties to ensure they may remain in their homes. The care provider must not take over duties which the care recipient does not require assistance with as this will increase independence on the care provider.

1.80 The concept of “assisted living” is an integral part of Canadian policy on long-term care. Assisted living is a housing and care alternative for those who are no longer able to continue living in their own homes, but who do not need the level of care offered in residential care facilities. An assisted living residence provides hospitality services such as meals, social and recreational opportunities, and personal care in the form of assistance with activities of daily living or medications.⁹⁹ Such residences enable a person to retain a degree of independence in their daily lives.

⁹⁴ Irish Human Rights Commission *Older People in Long Stay Care* (2003) at 11.

⁹⁵ Health and Social Services for Older People *The Years Ahead Report: A Review of the Implementation of its Recommendations* (National Council on Aging and Older People, June 2001) at 23.

⁹⁶ *Towards a Restraint Free Environment in Nursing Homes* (Department of Health, 2011) at 2.

⁹⁷ OECD *Long-term Care for Older People* (2005) at 70.

⁹⁸ Department of Health “Domiciliary Care National Minimum Standards Regulations,” at 3.

⁹⁹ Report of the Premier’s Council on Aging and Seniors’ Issues *Aging Well in British Columbia* at 53.

1.81 What independent living is will depend upon the person.¹⁰⁰ It may mean deciding where one lives or choosing which care and support services a person receives. Research has shown that if there is intervention at the correct time, the need for intensive care later in life is lessened. While early assistance will help ensure that a person will remain in their home, care must not be forced upon a person.¹⁰¹ Care must only be provided to a person who has agreed to be the care recipient. It is thus of importance that the care provider and care recipient discuss what type of care the care recipient would like to receive. This will ensure that the care will be individualised to suit a person's needs and that a person exercises choice and control over the type of care they receive.

1.82 The promotion of independent living may influence the mechanism through which professional home care services are offered. Many people seeking professional home care may opt for a cash grant known as a direct payment, as this enables the older person to choose who provides their care. This independence in choosing their care provider may be considered very important by some older people as the care provider will often assist a person in toileting, bathing, dressing and other essential daily activities which up to this point will have been conducted by the person themselves in private.

1.83 The Commission is of the opinion that the promotion of independent living must underpin any legislation concerning home care. While no one definition of independent living is possible due to the diverse needs of care recipients, the philosophy of independent living will ensure that a person is consulted on all aspects of their care. The Commission is of the opinion that a person must have control over the type of care they receive which will increase a person's independence rather than their dependence on their carer. The Commission thus recommends that the principle of independent living should form part of the legislative framework for professional home care.

1.84 *The Commission recommends that a guiding principle of the proposed legislative framework should be the principle of independent living.*

(2) Privacy and dignity

1.85 The type of care which a person may receive in their home can vary from medical care to personal care. In their review of home care packages in Ireland, the National, Economic and Social Forum (NESF) stated that home care packages may include "the services of nurses, home care attendants, home helps and various therapies including physiotherapy services and

¹⁰⁰ HM Government *The Case for Change – Why England Needs a New Care and Support System* (2008) at 34.

¹⁰¹ *Ibid.*

occupational therapy services.”¹⁰² The care provided may also cover assistance in eating and the preparation of meals dressing and undressing, bathing, washing and oral hygiene and assistance using the toilet. Despite the level of care required, the privacy and dignity of the care recipient must always be respected. Care providers may respect the privacy and dignity of the care recipient:

- Through their general demeanour;
- Through the manner in which they address and communicate with the resident;
- Through their appearance and dress;
- By avoiding inappropriate comments or jokes;
- Through discretion when discussing the resident's medical condition or treatment needs.¹⁰³

1.86 As home care is provided in the recipient's private home, the care provider must respect the care recipient's personal belongings and the privacy of their home. The care provider and care recipient must agree policies on when the care provider can enter the house and on knocking before entering a room.¹⁰⁴ A balance, however, must be struck with the need of easy access to the home in cases of emergency and situations where the care recipient is not in a position to answer the door.

1.87 The care provider must also be able to respond to the varying domestic situations. For example, the care recipient may be living with a spouse, family member or friend. The provision of home care must not prevent the care recipient from maintaining their social network outside the home, nor prevent them from spending time alone.¹⁰⁵ Providing home care must not erode the environment of the home or make family or friends residing there

¹⁰² National Economic and Social Forum *Implementation of Home Care Packages in Ireland*, Report 38, 2009.

¹⁰³ Health Information and Quality Authority *National Quality Standards for Residential Care Settings for Older People in Ireland* (2009), Standard 4.

¹⁰⁴ The Health Information and Quality Authority's Standards for Residential Care state that the "resident's permission must be sought before any person enters his/her room." Standard 4.8 of Health Information and Quality Authority *National Quality Standards for Residential Care Settings for Older People in Ireland* (2009).

¹⁰⁵ See Standard 4 of Health Information and Quality Authority *National Quality Standards for Residential Care Settings for Older People in Ireland* (2009).

uncomfortable.¹⁰⁶ Such relationships may also have an impact on providing care in the home. While the carer must respect the close relationships in the home, they must not divulge information to the family or friends without the express agreement of the care recipient and the confidentiality of the arrangements between the carer and the care recipient must be maintained. Thus while respecting the privacy of the other residents of the home, the primary duty of the care provider is to respect the privacy and the dignity of the care recipient. The Commission recommends that the principle of privacy and dignity should form part of the legislative framework for professional home care.

1.88 *The Commission recommends that guiding principles of the proposed legislative framework should be the principles of privacy and dignity.*

(3) Quality of care

1.89 The Commission acknowledges that care provided within the private home of the care recipient is more difficult to supervise than institutional care.¹⁰⁷ With more and more older people wishing to remain in their homes and thus opt for home care, the relatively unsupervised nature of this type of care must not result in a poor quality service. In 2001, the National Health Strategy *Quality and Fairness: A Health System for You* identified quality as a key principle and argued that it should be embedded in the health system.

1.90 In the context of the review of care plans, the National Quality Standards for Residential Care Settings for Older People in Ireland provide that a resident's care plan must be updated as indicated by the resident's changing needs, circumstances, current health objectives and personal and social care and no less frequently than at three-monthly intervals.¹⁰⁸ The Commission notes the provisions made in the 2008 draft National Quality Guidelines for Home Care Support Services regarding the review of the quality of care, which provide for a six monthly visit to care recipients by a supervisor whereby the home care support plan may be reviewed and the performance of the care provider monitored. Regular supervision meetings between the line manager and the care provider and an annual survey of all clients and/or their representatives were also encouraged by the draft Guidelines.¹⁰⁹ The

¹⁰⁶ See *Ethical Issues in Home Care*, Summary and Overview of Presentations and Discussions at the Annual Meeting of the Canadian Society (2004).

¹⁰⁷ Ahern, Doyle and Timonen "Regulating Home Care of Older People: The Inevitable Poor Relation" (2007) 29 *Dublin University Law Journal* 374 at 385.

¹⁰⁸ *National Quality Standards for Residential Care Settings for Older People in Ireland* (Health Information and Quality Authority, 2009) at Standard 11.9.

¹⁰⁹ Services for Older People Expert Advisory Group and Governance Group *Draft National Quality Guidelines for Home Care Support Services* (October 2008).

Commission considers that a review of the quality of care is an integral part of home care services and recommends that National Standards be introduced and implemented to address this issue along the lines of the review of care plans provided for by the National Quality Standards for Residential Care Settings for Older People in Ireland.

1.91 In its report on the implementation of home care packages, the NESF recommended that professional carers should receive appropriate training where they are caring for people with specific needs, such as palliative care. Similarly Part 4.1 of the Australian *Aged Care Act 1997* states that it is the responsibility of the approved providers “to maintain an adequate number of appropriately skilled staff to ensure that the needs of the care recipients are met.” Ensuring that appropriately trained staff are employed will assist in ensuring the quality of care delivered to each care recipient. The Commission is of the opinion that the quality of care delivered must be of particular importance and thus recommends that quality of care forms part of the guiding principles of the legislative framework for home care.

1.92 *The Commission recommends that a guiding principle of the proposed legislative framework should be the principle of quality of care.*

(4) Protection of at risk or vulnerable adults

1.93 The draft Scheme of the *Criminal Justice (Withholding of Information on Crimes against Children and Vulnerable Adults) Bill 2011*, published by the Department of Justice and Equality in 2011, defines a “vulnerable adult” as a person of 18 years and older who does not have mental capacity or who is suffering from a physical, intellectual or mental impairment, whether through disability, injury, illness or age, which is of such a nature or degree as to render that person unable to guard against neglect, abuse or exploitation or to require assistance with the activities of daily living such as washing, dressing, toileting or feeding. Protection of vulnerable adults must be to the fore when considering professional home care.

1.94 As to protection of at risk or vulnerable adults, two areas of law have particular relevance in the context of the regulation of professional home care. These are the law and policies on elder abuse and changes to the criminal law which are expected to be introduced in the proposed mental capacity legislation in the near future concerning the introduction of new offences of ill-treatment and wilful neglect.

1.95 As regards elder abuse, the 2010 NCPOP Report *Abuse and Neglect of Older People in Ireland*¹¹⁰ indicates that over 10,000 people in Ireland over

¹¹⁰ *Abuse and Neglect of Older People in Ireland* National Centre for the Protection of Older People (November 2010) at 65.

the age of 65 years experienced mistreatment in the one year period the subject of the review. It is well established that the majority of elder abuse occurs in the home.¹¹¹ It is therefore of great importance to ensure that the increasing demand for home care services will not lead to an increase in cases of elder abuse and it is acknowledged that the protection of older people in receipt of home care is more difficult to safeguard than older people in institutional residences. There is therefore a real need for appropriate and robust standards to be put in place to guard against such abuse in the home care setting.¹¹²

1.96 The Commission is of the opinion that safeguards must be in place to ensure that at risk or vulnerable people in receipt of professional home care are protected from all types of abuse, including, but not limited to “physical, financial, psychological, sexual abuse, neglect, discriminatory abuse or self-harm or inhuman or degrading treatment through deliberate intent, negligence or ignorance in accordance with written policies and procedures.”¹¹³ The *Report of the Working Group on Elder Abuse* has defined such abuse 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.”¹¹⁴

1.97 In the document *No Secrets*, the English Department of Health provided the following extensive definition of abuse:

“(1) Physical abuse, including hitting, slapping, pushing, kicking, misuse of medication, restraint, or inappropriate sanctions;

(2) Sexual abuse, including rape and sexual assault or sexual acts to which the vulnerable adult has not consented, or could not consent or was pressured into consenting;

(3) Psychological abuse, including emotional abuse, threats of harm or abandonment, deprivation of contact, humiliation, blaming,

¹¹¹ The *Open Your Eyes* report noted that 82% of reported cases of alleged abuse of older people occurred in the home, HSE *Elder Abuse Service Developments 2008 ‘Open Your Eyes’* (February 2009) at 31.

¹¹² Ahern, Doyle and Timonen “Regulating Home Care of Older People: The Inevitable Poor Relation” (2007) 29 *Dublin University Law Journal* 374 at 385.

¹¹³ See Standard 14.1 of the English Department of Health “Domiciliary Care National Minimum Standard Regulations” (2003).

¹¹⁴ Report of the Working Group on Elder Abuse *Protecting our Future* (2002) at paragraph 3.3.

controlling, intimidation, coercion, harassment, verbal abuse, isolation or withdrawal from serious or supportive networks;

(4) Financial or material abuse, including theft, fraud, exploitation, pressure in connection with wills, property or inheritance or financial transactions, or the misuse or misappropriation of property, possessions or benefits;

(5) Neglect and acts of omission, including ignoring medical or physical care needs, failure to provide access to appropriate health, social care or educational services, the withholding of the necessities of life, such as medication, adequate nutrition and heating; and

(6) Discriminatory abuse, including racist, sexist, that based on a person's disability, and other forms of harassment, slurs or similar treatment."¹¹⁵

1.98 The HSE *Draft Quality Guidelines on Home Care Support Services* define elder abuse as "verbal, physical, financial, psychological, sexual abuse, neglect, discriminatory abuse or inhuman or degrading treatment or restraint through deliberate intent, negligence or ignorance in accordance with written policies and procedures. This also includes acts of omission. It is the responsibility of all Home Care Support Workers and service providers to safeguard clients from this abuse."¹¹⁶

1.99 The Commission now turns to the question of the introduction of offences of ill-treatment and wilful neglect. It appears that the proposed mental capacity legislation will make it an offence to ill-treat or wilfully neglect a person whose capacity is absent or limited.¹¹⁷ In terms of those who could be

¹¹⁵ Department of Health "No Secrets": *Guidance on Developing and Implementing Multi-Agency Policies and Procedures to Protect Vulnerable Adults from Abuse* at paragraph 2.7. This definition has also been endorsed by the Health Service Executive (HSE) see http://www.hse.ie/eng/services/Find_a_Service/Older_People_Services/Elder_Abuse/#what

¹¹⁶ Guideline 9.1 of the *Draft National Quality Guidelines for Home Care Support Services*.

¹¹⁷ In the proposed mental capacity legislation (as set out in the *Scheme of the Mental Capacity Bill 2008*), the offences of ill-treatment and wilful neglect are punishable on summary conviction by imprisonment for a term not exceeding 12 months or a fine not exceeding €3,000 or both, or on conviction on indictment, by imprisonment for a term not exceeding 5 years or a fine not exceeding €50,000 or both.

prosecuted for the offence of ill-treatment or wilful neglect, it is anticipated that the proposed mental capacity legislation will apply to anyone caring for a person who lacks capacity – this includes family carers, healthcare and social care staff in hospitals or care homes and those providing care in a person’s own home. This aspect of the proposed legislation is modelled on section 44 of the *Mental Capacity Act 2005*, which has been in force in England and Wales since 2007. According to the Code of Practice accompanying the 2005 Act, the type of ill-treatment which may result in prosecution can be either deliberate or reckless. Also, it does not matter for the purposes of prosecution whether the ill-treatment actually caused harm to the person being cared for. In other words, if the treatment in question was likely to cause harm, that in itself may be sufficient to ground a prosecution. As regards the offence of wilful neglect, the Code of Practice accompanying the 2005 Act makes it clear that this offence consists of a deliberate failure to carry out an act the defendant knew they had a duty to perform.

1.100 The Commission is of the opinion that the protection of adults in receipt of home care must be of the utmost importance through all aspects of the delivery of the service. Care providers must thus be sufficiently vetted to ensure that appropriate people only are employed to work in the homes of vulnerable adults. In addition to wilful neglect and ill-treatment of adults receiving home care services, the Commission is also of the opinion that abuse may be attributable to inadequate care due to insufficient training. Care providers must thus be sufficiently trained and receive ongoing training to ensure that they understand what is meant by abuse in this context and that they can meet the needs of care recipients through the implementation and use of appropriate policies on the prevention, detection and response to abuse. Policies and Standards which may be in place for home care must ensure the protection of people in their homes.¹¹⁸ It is for this reason that the Commission recommends that the protection of adults in receipt of home care be a guiding principle of the legislative framework for the provision of this type of care.

1.101 *The Commission recommends that a guiding principle of the proposed legislative framework should be the protection of adults in receipt of professional home care.*

¹¹⁸ See also Standard 8 of the Health Information and Quality Authority *National Quality Standards for Residential Care Settings for Older People in Ireland* (2009) and Health Information and Quality Authority *Your Guide to the National Quality Standards for Residential Care Settings for Older People in Ireland*.

CHAPTER 2 NATIONAL STANDARDS FOR PROFESSIONAL HOME CARE AND THE CONTRACT FOR CARE

A Introduction

2.01 In this chapter the Commission considers the type of national care standards which should underpin the contract for care between the professional carer and recipient, the contracting arrangements and the proposed protective measures. In Part B the Commission discusses the existing guidelines of relevance to home care packages in Ireland at present and the need for standards to govern the delivery of professional home care. In Part C the Commission examines the contract for care and the composition of the care contract. Part D focuses on the various contracting arrangements which may arise under a home care agreement. Finally, in Part E the Commission discusses the various protective measures to protect older people in receipt of care in their home.

B National Standards for Professional Home Care

2.02 In 2008 the Health Service Executive (HSE) published draft *National Quality Guidelines for Home Care Support Services*.¹ These draft guidelines were compiled by the HSE Expert Advisory Group on Services for Older People with the aim of minimising risk to older people in a home care setting. The 2008 draft guidelines are grouped into five sections: rights, protection, staffing, home care support needs (which include needs assessments and guidance in respect of medication management) and finally, governance and management.

2.03 The draft guidelines are comprehensive and deal with a diverse range of matters² pertaining to the care of older people. The Commission again

¹ Services for Older People Expert Advisory Group and Governance Group *Draft National Quality Guidelines for Home Care Support Services* (October 2008).

² The draft Guidelines provide that professional home care providers must give each client a service guide which sets out the various obligations on each party involved in the home care service, including a duty on the client to disclose any infection control issues such as MRSA and obligations arising out of the fees payable for the service, if applicable. *Draft National Quality Guidelines for Home Care Support Services* (October 2008), Guideline 1.2.

reiterates its position that the regulation of professional home care should cater for all adults requiring this service and not be limited to older people. However, the Commission is of the view that the draft guidelines could form the basis for national standards for professional home care, although additional provision would have to be made to ensure the protections afforded by the draft guidelines were extended to all adults in need of professional home care.

2.04 The Commission considers the 2008 draft guidelines should form the basis for national standards on the provision of professional care in the home. The development of such national standards for home care are integral to the Commission's recommendation that the statutory remit of the Health Information and Quality Authority (HIQA) be extended to include the regulation of professional home care providers. The Commission therefore recommends that the HSE's 2008 draft *National Quality Guidelines for Home Care Support Services* should form the basis for national standards on the provision of professional care in the home to be prepared by HIQA under the *Health Act 2007*. The Commission also recommends that the proposed national standards should provide guidance on all aspects of professional care in the home, including the detailed requirements derived from the necessary ministerial Regulations on professional home care to be made under section 101 of the *Health Act 2007* (as amended in accordance with the recommendations made in this Report), any protective measures necessary and, importantly, the sanctions that will apply in the event of a breach of the standards. The Commission also recommends that the National Standards form the basis for the individual contract of care between the professional care provider and the care recipient..

2.05 *The Commission recommends that the Health Service Executive's 2008 draft National Quality Guidelines for Home Care Support Services should form the basis for National Standards for Professional Home Care to be prepared by HIQA under the Health Act 2007. The Commission also recommends that the proposed National Standards should provide guidance on all aspects of professional home care, including the detailed requirements derived from the necessary ministerial Regulations on professional home care to be made under section 101 of the Health Act 2007 (as amended in accordance with the recommendations made in this Report), any protective measures necessary, and the sanctions that will apply in the event of a breach of the National Standards. The Commission also recommends that the National Standards form the basis for the individual contract of care between the professional care provider and the care recipient.*

C Contract for Care

2.06 In this section the Commission explores the content of the contract for care between the professional carer and recipient. In the Consultation Paper the Commission noted that, in order to ensure a high standard of care for people receiving professional care in their home, a contract for care should be in place. The Consultation Paper envisaged that this contract for care would set out the various terms and conditions for the provision of care.³ The contract for care would be a guide for both professional home care providers and care recipients as it would identify the services to be provided, who is to provide them and how they are to be provided. As already noted, the Commission considers that each stage of drawing up the contract for care must be informed by the proposed National Standards.

(1) Assessment of needs

2.07 In the Commission's view, before drawing up the care contract, an assessment of need should be carried out. An assessment of needs ensures that care recipients are provided with care appropriate to their needs. It may also have the benefit of preventing unnecessary admission to hospitals and residential care. It is thus important that the assessment of needs is conducted by people who are sufficiently trained to do so before home care begins.⁴ The Commission notes that the 2008 draft Guidelines provide for a home care support needs assessment but does not address the issue as to who should carry out the assessment. The Commission is of the view that this is an important issue.

2.08 In Australia, the *Aged Care Assessment and Approval Guidelines*, made under the *Aged Care Act 1997*, provide information and guidance to an Aged Care Assessment Team (ACAT) who approve residential, community or flexible care under the 1997 Act. The ACAT assesses the needs of older people and takes account of the restorative, physical, medical, psychological, cultural and social dimensions of their care needs. In assessing their needs, the ACATs can involve the older person, their carers, GP, family and their service

³ Law Reform Commission *Consultation Paper on Legal Aspect of Carers* (LRC CP 55-2009) at paragraph 3.02.

⁴ Standard 10.3 of the HIQA *National Quality Standards for Residential Care for Older People* provides that a comprehensive assessment of each resident's or prospective resident's health, personal and social care needs is undertaken before admission. This needs assessment must be undertaken by appropriate professionals trained to do so.

providers.⁵ Under section 22(4) of the 1997 Act, care cannot be provided unless a person has been assessed.

2.09 During the assessment process the ACAT must determine all of the person's needs and the type of services which would be best suited to meet those needs. The ACAT must also consider the person's usual accommodation arrangement, financial circumstances, access to transport and community support systems. Once this assessment is complete and a person's care needs are determined, a care plan is drawn up.⁶

2.10 The Australian *Aged Care Assessment and Approval Guidelines* make it clear that there must be ongoing assessment to ensure that the care is provided in response to the needs of the older person. This includes:

- The person's medical condition (this must be assessed by a health care professional);⁷
- The physical capability of the person to perform everyday tasks. This includes mobility, ability to maintain personal hygiene, eating and drinking, their level of independence and their ability to manage health conditions;⁸
- The mental capacity of the person;⁹
- The support the person has, including family, carers, neighbours and friends;¹⁰
- The person's living environment and its suitability;¹¹
- The care preferences of the older person.¹²

2.11 In 2002, the Mercer Report on the future financing of long-term care in Ireland noted that the assessment of needs for older people and people with disabilities is carried out by a number of different State organisations who use

⁵ *Aged Care Assessment and Approval Guidelines* (2006) at 1.

⁶ *Ibid* at paragraph 1.4.

⁷ *Ibid* at paragraph 1.6.1.

⁸ *Ibid* at paragraph 1.6.2.

⁹ *Ibid* at paragraph 1.6.3.

¹⁰ *Ibid* at paragraph 1.6.4.

¹¹ *Ibid* at paragraph 1.6.5.

¹² *Ibid* at paragraph 1.6.6.

differing assessment procedures.¹³ The 2002 Report recommended that national guidelines be established to measure dependency and entitlement to benefits and services. These guidelines should:

- develop appropriate standardised assessment tools;
- provide a comprehensive and quantified scale of assessment for disability as well as housing and social circumstances;
- designate the appropriate care settings for the various categories of assessed need.¹⁴

2.11 The 2009 PA Consulting Group's *Evaluation of Home Care Packages* has noted that the absence of a standard needs assessment for home care packages has led to inconsistency and duplication.¹⁵ As referred to in Chapter 1, the Commission welcomes the proposed adoption by the Health Service Executive (HSE) of the interRAI suite of tools for the assessment of the care needs of individuals requiring professional care. Were the interRAI tools to be adopted, this would provide a standardised assessment tool to be applied in ascertaining the care needs of individuals requiring health and social care services in Ireland and such a move would remedy some of the deficiencies and duplications of effort identified in the Mercer Report.

2.12 In 2009, the Health Information and Quality Authority (HIQA), in accordance with the *Health Act 2007*, published the *National Quality Standards for Residential Care Settings for Older People in Ireland*, which conform to the model recommended in the 2002 Mercer Report in terms of assessment of needs. The 2009 Standards require that each resident must have their needs assessed before they move into residential care. The resident's health, personal and social care needs must be assessed and the resident must participate in the assessment. The assessment must be carried out by a person who is appropriately trained to do so.¹⁶

2.13 The Commission notes that that the *Common Summary Assessment Report* Guidance Document¹⁷ for assessment for residential care highlights the

¹³ Department of Social and Family Affairs *Study to Examine the Future Financing of Long-Term Care in Ireland* (2002) (the Mercer Report) at 8.

¹⁴ *Ibid* at 8-9.

¹⁵ PA Consulting Group *Evaluation of Home Care Packages* (November 2009) at 43.

¹⁶ Standard 10 of the *National Quality Standards for Residential Care Settings for Older People in Ireland*. See also paragraph 2.23 in relation to the importance of the risk assessments.

¹⁷ CSAR-Guidelines (NHSS 2009).

need for a CSAR to combine assessment information from various sources, thereby creating a single, permanent and transferable record of the information relevant to a decision on an individual's care needs at a given point in time. A completed CSAR must also clearly show why long term residential care is, or is not, required.

2.14 The 2008 draft HSE Guidelines mirror the 2009 HIQA Standards and require that the care recipient and their personal or family carers be assessed before a person is offered a home care support service. The Commission has already recommended in this Report that the 2008 draft HSE Guidelines should form the basis for the proposed national standards. The Commission supports the view in the 2008 draft HSE Guidelines that the person's ability to carry out the activities of daily living, personal care and physical well-being, family involvement and mental health must be assessed. The Commission considers that a thorough assessment of needs must be conducted, using a standardised assessment tool so as to avoid duplication of assessments, in order to ensure that the actual needs of the person to receive the care are met.¹⁸ The personal contribution of the proposed care recipient during the assessment of needs is essential to ensure that all aspects of a person's care needs are assessed and not simply those needs which a professional person may consider ought to be assessed. This will ensure there is a holistic approach to the assessment of needs. The Commission is aware that the HSE Integrated Services Directorate (ISD) Older People Care Group Team established a Single Assessment Tool (SAT) Working Group in 2010 to "select, pilot and recommend a single assessment tool or suite of tools to be utilised for the assessment of older people nationally." The aim of the initiative includes the requirement to have the needs of older people met in the most appropriate setting, to provide care that is properly co-ordinated to support quality and efficiency and to support current national policy on enabling older people to remain at home in independence for as long as possible.

2.15 The Commission notes the observations of the Law Commission for England and Wales that focusing exclusively on the needs of a person may result in neglecting the care outcomes that a person may wish to achieve.¹⁹ The English Law Commission was concerned that examining the needs of a person

¹⁸ See comment in *Report of the Expert Group on Resource Allocation and Financing in the Health Sector* (Department of Health and Children 2010) at 199 which states that in the absence of *operational* standardised needs assessment guidelines and criteria, the allocation of resources may serve to perpetuate existing inequities in the delivery of home care support services.

¹⁹ Law Commission of England and Wales *Consultation Paper Adult Social Care* (February 2010) No. 192 at paragraph 4.31.

exclusively may fail to identify the manner in which the person wishes to have their care delivered. This Commission concurs that it is important that the person be involved in their needs assessment – not simply in discussing their needs but also in terms of identifying the person’s individual characteristics in terms of physical ability, mental health, cognitive status and any other relevant information relevant to their individual needs. This will also assist in identifying how the person wishes to have their needs met. Their involvement will ensure that the care they need is understood as well as the manner in which they wish to have this care delivered. For this reason, the needs assessment proposed by the Commission considers both the required needs and the outcomes desired by the person. The Commission thus recommends that an assessment of needs of the care recipient must be carried out prior to the provision of care.

2.16 *The Commission recommends that an assessment of needs of the care recipient must be carried out prior to the provision of care and that the assessment considers both the needs of and the outcomes desired by the care recipient.*

2.17 The Commission acknowledges that the care required may range from basic assistance with household tasks through to high level care that could include assistance with medication. The Commission thus considers that care needs should be assessed under the following headings: companionship, home care and advanced home care.²⁰ Companionship needs may include preparing snacks or light meals, monitoring diet and eating, arranging appointments, reminders for medication, overseeing home deliveries and organising visits to neighbours and friends. Home care may include meal preparation, light housekeeping, providing transport, assisting with walking and exercise, assisting with personal hygiene and dressing. Advanced home care involves the highest level of care and may involve some health care. It may include personal care, respite care, dementia care, early Alzheimer’s care, assistance with toileting and palliative care.

²⁰ In the nursing home context, care needs are assessed under health, personal and social care needs. See Standard 10, *National Quality Standards for Residential Care for Older People* in relation to health and social care needs. Standard 10 provides for assessment of needs at the pre-admission stage and again upon admission and at regular intervals thereafter, including an assessment of needs prior to the discharge of a resident. A comprehensive assessment of the resident’s health, personal and social care needs, using a Minimum Data Set tool, is completed within seven days of his/her admission or sooner if the risk assessment indicates that an earlier assessment may be necessary. This assessment is reviewed as indicated by the resident’s changing needs or circumstances and no less frequently than at three-monthly intervals.

2.18 The Commission considers that examining a person's needs under companionship needs, home care needs and advanced home care needs will ensure that their needs are adequately assessed and the appropriate level of care is provided. It is important that the level of care should be appropriately attuned to the actual needs of the person and that special care is taken to ensure that the level of care provided is not too high because to do so may negatively impact on a person's independence and cause him or her to become overly dependent on the carer. Analysing a person's needs in this way will also identify those most suitable to provide the required care. Such a process will ensure that care is focused on the needs of the person which will help promote their independence.

2.19 *The Commission recommends that care needs should be assessed under the following headings: companionship needs, care needs and the advanced home care needs of the care recipient. Companionship needs may include preparing snacks, monitoring diet and eating, arranging appointments, reminders for medication, overseeing home deliveries and organising visits to neighbours and friends. Home care may include meal preparation, light housekeeping, providing transport, assisting with walking and exercise, assisting with personal hygiene and dressing. Advanced home care involves the highest level of care and may involve some health care. It may include personal care, respite care, dementia care, early Alzheimer's care, assistance with continence and toileting and palliative care. The Commission also recommends that the level of care should be appropriately attuned to the actual needs of the person and that especial care is taken to ensure that the level of care provided is not too high, thereby promoting the autonomy and independence of the care recipient to the fullest degree.*

(2) Assessment of funding

2.20 Once the care needs of a person are determined, their financial situation must be assessed. This will determine the amount the person will be expected to pay and will also determine what type of care will be available to them. Under the current system of entitlements, the Home Help Service provided through the Health Service Executive (HSE) is generally free to medical card holders. However, people may be asked to contribute towards the cost of the service. When an application for the service is received, the HSE may take income, the degree of family support available, remoteness from services and the availability of suitable people to provide the service into account. If the care recipient requires palliative care in the home, the Irish Hospice Foundation and the Irish Cancer Society provides this service.

Palliative care is provided free of charge by both organisations as care is provided based on need and not on ability to pay.²¹

2.21 Home Care packages, on the other hand, may prove problematic as regards funding. While guidelines were drafted in 2008 regarding means testing and the value of the home care package a person could receive, these guidelines did not become operational. Thus, each local health office (LHO) devised differing guidelines to address this deficit. This led to policies differing depending on the part of the country the person resides.²² Depending on the LHO a person may reside in, income, savings and family support may be taken into consideration when accessing eligibility.²³ Hence, due to the varying approaches to means testing, there was no uniformity across the country as to how the home care service was provided or as to whom was eligible to receive the service and at what cost to themselves, if any. While the 2008 draft Guidelines were not implemented, as previously mentioned, in 2010 the Health Service Executive (HSE) introduced *National Guidelines and Procedures for Standardised Implementation of the Home Care Packages Scheme*.

2.22 Pursuant to the 2010 HSE Guidelines, the care delivered will depend on the funding available. As regards the funding of home care services generally, the Commission notes that if the person who is seeking the service is capable of paying for the care themselves, then they should have access to care for which they are willing to pay and if they require help from the HSE in obtaining those services, this help should be available to them by the HSE acting as an intermediary. However if the care is fully or part funded by the State, the care available to an intended care recipient will depend on the funding available. While the needs assessment will determine what care a person requires, the assessment of funding will indicate what funds can be provided. This will then determine what care can actually be provided. The Commission thus recommends that an assessment of funding be conducted to

²¹ See *Primary Palliative Care in Ireland* (November 2011), available at www.hospice-foundation.ie. According to this report, primary care teams are now gradually being established around the country and they work with specialist palliative care services that are already in place. The report also highlighted the need to establish a formal framework to support the delivery of palliative care by community-based health care professionals. One of the recommendations made in the report is the introduction of a formal mechanism for GPs to communicate to their local out of hours service providers with regard to the palliative care needs of their patient.

²² See National Economic and Social Forum *Implementation of the Home Care Package Scheme* Report 38 (2009) at 40.

²³ *Ibid* at 54.

determine who is paying for the care and what care can be provided. The Commission returns in Chapter 4, below, to the wider policy issues concerning future funding of professional home care.

2.23 *The Commission recommends that an assessment of funding be conducted to determine who is paying for the professional home care and what care can be provided.*

(3) Risk assessment

2.24 Before professional home care begins, a risk assessment should be carried out in order to anticipate how to prevent and manage the potential risks to both the care recipients and care provider. Under the 2009 HIQA *National Quality Standards for Residential Care Settings for Older People in Ireland*, a risk assessment is carried out on admission to the residential care setting. This must be reviewed every three months or as the resident's needs change.²⁴ The approach to risk assessment advocated by the *National Quality Standards for Residential Care Settings for Older People* and the provisions set out in that document regarding risk may also be applicable in the provision of professional home care, particularly the provisions pertaining to the risks associated with the self-administration of medication.²⁵

2.25 The Northern Ireland *Domiciliary Care Agencies Minimum Standards*, made under the *Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003*, require that the domiciliary care agency and the professional home care provider have procedures in place to ensure that its staff are aware of their health and safety obligations.²⁶ Staff must be provided with training to cover, amongst other matters, accident prevention, fire safety awareness, food hygiene and manual handling.

²⁴ Standard 10. 4 provides that a general risk assessment is to be carried out and recorded upon admission to the nursing home and as indicated by the resident's changing needs or circumstances and no less frequently than at three-monthly intervals. The *National Quality Standards for Residential Care Settings for Older People* refer to risks and the need for frequent risk assessments throughout the document. The risk of falls must be assessed and documented as well as any risks posed to the resident by the self-administration of medication.

²⁵ Standard 14.9 provides that residents in a nursing home may self-administer medications where the risks have been assessed and his/her competence to self-administer is confirmed. Any change to the initial risk assessment must be recorded and arrangements for self-administering medicines are to be kept under review.

²⁶ Standard 16.2 of *Domiciliary Care Agencies Minimum Standards* (2008).

2.26 The Commission considers that the detection of risk should not be a once-off process but must be ongoing. Any problems identified by the home care provider or the home care recipient must be logged. This log will then ensure that problems are not ignored but remedied and avoided in the future.

2.27 The 2008 HSE Draft Guidelines require the service provider to ensure that a risk assessment is conducted which must be carried out by “a trained person”.²⁷ The Commission has already recommended in this Report that the draft Guidelines should form the basis of the proposed national standards. The proposed standards would detail the process which must be followed when carrying out the risk assessment. The Commission thus recommends that the proposed National Standards should provide that, prior to the commencement of professional home care, a risk assessment must be carried out and that the risk assessment must be reviewed on an ongoing basis.

2.28 *The Commission recommends that the proposed National Standards should provide that, prior to the commencement of professional home care, a risk assessment must be carried out and that the risk assessment must be reviewed on an ongoing basis.*

(4) Care plan

2.29 Following the assessment of needs, funding and potential risks, the Commission considers that a care plan should be drawn up. This care plan will detail what care is to be provided, who will provide the care and the hours of care to be provided. It will also detail any responsibilities the person themselves and, where relevant, their family may have in the provision of care. This care plan should be kept under review and altered to meet the changing needs of the care recipient.

2.30 The Commission is aware that in the in-patient setting, Irish hospitals follow the Roper-Logan-Tierney model of nursing.²⁸ This model forms a type of check list in which the admitting nurse assesses a patient, thus leading to the drawing up of the care plan.

²⁷ Guideline 8 of the HSE Draft *National Quality Guidelines for Home Care Support Services*.

²⁸ Roper, Logan and Tierney (1980) *The Elements of Nursing* (Edinburgh: Churchill Livingstone). The Roper-Logan-Tierney model of nursing was originally published in 1980, with the most recent edition published in 1998. It is a model of nursing care based on the activities of daily living. The original purpose of the model was to be an assessment used throughout the patient’s care, but it has become the norm to use it only as a checklist on admission.

2.31 Under the English *Domiciliary Care Agencies Regulations 2002*, made under the *Care Standards Act 2000* and the Northern Ireland *Domiciliary Care Agencies Regulations (Northern Ireland) 2007*, made under the *Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003*, a written plan known as the “service user plan” must be prepared after consultation with the service user. This plan must specify the needs of the service user and how those needs will be met by the provision of personal care.²⁹ It is the duty of the domiciliary care agency to ensure that the personal care provided meets the needs of the person in the care plan.³⁰ The service user plan must be made available to the service user and it must be kept under review.

2.32 The 2009 *HIQA National Quality Standards for Residential Care Settings for Older People in Ireland* require that each resident have an individual care plan which is developed and agreed with the resident or their representative. The care plan must reflect the assessment of need and ensure that all aspects of the health, personal and social care needs of the resident are met. Each resident or their representative must have access to the care plan which is updated every three months or as the care needs of the resident changes.³¹

2.33 The Commission considers that a template of a care plan is necessary. It may be similar to the template suggested when completing the assessment of need. Thus the care to be provided under the care plan may be completed under the headings of companionship care, home care and advanced home care. Such a template should be part of national standards on home care and provide guidance when the care plan is drawn up. The care plan should document the care needs and how they are to be met. It should also document the amount of hours in which the care will be provided each week. The amount of care needed should be measured against the hours available. This will identify any gaps in the service which should also be documented. The care plan should be drawn up by the service provider in conjunction with the care recipient. The care plan must be agreed by both parties and should outline the tasks which will be undertaken by the care recipient and their family. The Commission considers that detailing the tasks to be carried out by the care recipient is important in order to maintain their independence, mobility, activity and mental stimulation. Such processes will be detailed in the proposed national standards.

²⁹ Reg. 14(1) of the 2002 Regulations; Reg. 15(2) of the 2007 Regulations.

³⁰ Reg. 14(4) of the 2002 Regulations; Reg. 15(4) of the 2007 Regulations.

³¹ Standard 11 of the *National Quality Standards for Residential Care Settings for Older People in Ireland*.

2.34 It is also important to note that a report examining the organisation of home help services in Ireland noted that the majority of older people surveyed stated that they would want one person to provide their care.³² The report noted that many older people saw their home help as a friend, confidant and companion and not just someone who provided meals or helped them with their personal hygiene.³³ While additional training may ensure that one carer may meet all the care requirements in some cases, it may not be possible to have only one carer providing the service in many cases because of the complex care needs of people receiving professional home care and because of the hours of work involved in providing the care. The Commission considers that, where possible, a team of people should be involved in the care of the person. This will ensure the continuity of care where one carer may be ill or on holidays. It also ensures that the care recipient is familiar with their carers if one carer is not available.

2.35 The Commission is also concerned in this context that if the care recipient has made an advance care directive,³⁴ this should be discussed in the completion of the care plan. An advance care directive is an advance expression of the wishes of a person in the health care or wider setting. The advance care directive should be outlined in the care plan to ensure that the directive is both understood and followed. In its 2008 Consultation Paper, the Commission recommended that “an appropriate legislative framework should be enacted for advance care directives, as part of the reform of the law on mental capacity.”³⁵ In its 2009 Report, the Commission made a number of recommendations concerning Advance Directives and included a draft *Mental Capacity (Advance Care Directives) Bill* which makes provisions for definitions of advance care directives, appointment of health care proxies in assisting with such decisions, and provision for the publication of Codes of practice and the power of the Court to determine the existence, validity and applicability of such directives. The Commission looks forward to the introduction of this legislation.

2.36 The Commission recommends that a care plan be drawn up on completion of the needs assessment, the assessment of funding and risk assessment. The care plan should detail the companionship plan, the home

³² National Council on Ageing and Older People *The Future of the Home Help Service in Ireland*, Report No 53 (1998).

³³ *Ibid.*

³⁴ Law Reform Commission *Report on Bioethics: Advance Care Directives* (LRC 94-2009) at paragraph 7.

³⁵ Law Reform Commission *Consultation Paper on Bioethics: Advance Care Directives* (LRC CP 51-2008) at 29.

care plan and advance home care plan. The content of the care plan and the review process should be informed by the proposed national standards.

2.37 *The Commission recommends that a care plan be drawn up on completion of the needs assessment, the assessment of funding and risk assessment. The care plan should detail the companionship plan, the home care plan and advance home care plan. The Commission also recommends that the detailed content of the care plan and the review process should be set out in the proposed national standards for professional home care.*

(5) Complaint procedure

2.38 The Commission considers that every professional home care provider must have in place a clear complaints procedure. This procedure must be communicated to and understood by the person in receipt of care. The Commission concurs with the requirement in the English *Domiciliary Care-National Minimum Standards* which states that there should be:

“an easily understood, well publicised and accessible procedure to enable service users, their relatives or representative to make a complaint and for complaints to be investigated.”³⁶

2.39 Part 12 of the *Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2009*³⁷ sets out an internal complaints procedure for persons seeking, receiving or having received services in a designated centre. Under the previously existing legislation, a mechanism for the making of complaints existed but it provided only for the making of a complaint to the relevant health board or the Health Service Executive (HSE) rather than to a member of staff at the nursing home. The 2009 Regulations superseded the *Nursing Homes (Care and Welfare) Regulations 1993* which had provided that the complaints procedure provided for did not encompass any mechanism for the making of an internal complaint.³⁸ Part 12 of the 2009 Regulations represents an improvement in quality of care

³⁶ Standard 26 of the *Domiciliary Care-National Minimum Standards*.

³⁷ SI 236 of 2009

³⁸ Regulation 26(1) of the *Nursing Homes (Care and Welfare) Regulations 1993* provided: “A dependent person being maintained in a nursing home or a person acting on his or her behalf may make a complaint to the chief executive officer or a designated officer of the health board.” Under Regulation 26(2), a complaint had to be in writing, except where a written complaint was not possible, in which circumstances, as provided for by Regulation 26(3), a chief executive officer could cause a verbal complaint to be considered and investigated, once he or she was satisfied that the complainant was acting in good faith.

for people receiving nursing home care in that it affords them the benefit of a statutory procedure for the airing of grievances internally in circumstances where no such formal mechanism existed under the preceding laws and it imposes a duty on registered providers of nursing homes to investigate all complaints, not simply written complaints.

2.40 The Commission notes that the draft 2008 HSE guidelines require a service provider to ensure that there is an easily understood, well publicised and accessible complaints procedure.³⁹ In addition, the HSE have in place a complaints policy manual entitled “Your Service, Your Say”⁴⁰. The manual outlines a complaints procedure available to all people who have used HSE services or sought such services, close relatives or carers of any such person who have consent to act on their behalf or the close relatives or carers of a deceased person who had used or sought services. This complaints procedure was put in place as a statutory obligation under the *Health Act 2004*.⁴¹

2.41 The Commission considers it essential that a complaints procedure be put in place by each professional home care service provider, and that the complaints procedure should be informed by the proposed national standards for professional home care. The Commission thus recommends that all home care service providers make available an easily understood, well publicised and accessible complaints procedure, informed by the proposed national standards.

2.42 *The Commission recommends that all professional home care service providers make available an easily understood, well publicised and accessible complaints procedure, informed by the proposed national standards for professional home care.*

³⁹ Guideline 7 of the HSE Draft *National Quality Guidelines for Home Care Support Services*.

⁴⁰ HSE Complaints Policy and Procedures Manual ‘*Your Service Your Say*’ 2009 HSE Consumer Affairs.

⁴¹ Part 9 of the *Health Act 2004* makes provision for a statutory complaints system within the HSE. Section 49 of the 2004 Act provides that a complaint may be made against the HSE or a service provider. Section 53 of the Act confers a power on the Minister for Health to make regulations pertaining to the statutory complaints process. Pursuant to section 53, the *Health Act 2004 (Complaints) Regulations 2006* were introduced and became operational on 1 January 2007. The 2006 Regulations provide that any person who is dissatisfied with any outcome of the complaints procedure may refer the matter to the Ombudsman or the Ombudsman for Children as the case may be.

(6) Protective measures

2.43 As the Commission has previously noted, 85% of cases of reported elder abuse in 2008 occurred within the home. Similarly, the 2008 draft HSE *National Quality Guidelines for Home Care Support Services* note that elder abuse does not have to be extreme or obvious but can be unintentional, insidious and the cumulative result of ongoing bad practice.⁴² The Commission is thus concerned that a number of protective measures must be in place to guard the person in receipt of care from abuse. Such measures will not only protect the person receiving care from abuse but also the care provider from allegations of abuse.

2.44 Under the English *Domiciliary Care Agencies Regulations 2002*, the domiciliary care agency must have in place procedures in which a domiciliary care worker may administer medication and circumstances under which the domiciliary care worker may handle money on behalf of the service user.⁴³

2.45 In line with the general principle recommended as part of the proposed legislative scheme, the Commission is of the opinion that protection of adults in need of professional home care from all forms of abuse and exploitation must be to the fore in the care contract. In terms of what is meant by “abuse” in this context, the Commission reiterates that the user of professional home care services will not always be an older person (i.e. a person over 65 years of age) but recognises that a high proportion of the people in receipt of such services will fall into that category. Hence, definitions of elder abuse may be helpful in terms of providing a description of the types of abusive behaviour and acts that people in receipt of home care services need to be protected against. According to the 2010 *Open Your Eyes Report*, a HSE report on the workings of the HSE elder abuse services for that year, financial abuse is one of the most common abuse types referred to HSE Senior Case Workers.⁴⁴ In this regard, the Commission considers that the protective measures adopted in the professional home care sphere must also address financial protection as well as any relevant health and safety work practices that it may be necessary or prudent to adopt.

⁴² *Ibid* at 14.

⁴³ Regulation 14(6) of the *Domiciliary Care Agencies Regulations 2002*.

⁴⁴ The Commission notes the establishment of the National Financial Abuse of Older Persons Working Group in 2010, a multi-agency forum which aims to ensure that the financial abuse of older people is responded to effectively.

(a) Abuse in a home care setting

2.46 While the vast majority of people who provide professional home care do so in a caring, competent and professional manner, the Commission considers that the protection of adults receiving professional home care must be a foremost consideration. The Commission considers it important that a home care provider must have procedures in place to prevent abuse, ill treatment or neglect from occurring. Every staff member should be trained not only in the prevention of abuse but also trained to identify the signs or indicators of abuse.⁴⁵ Again, the 2009 HIQA *National Quality Guidelines for Residential Care Settings for Older People* may be relevant to the approach to abuse to be adopted in the home care setting.⁴⁶

2.47 Also, the 2002 Report of the Working Group on Elder Abuse considered that every service organisation's employee, agent, contractor and service user must be able to identify elder abuse and report their concerns. The Working Group was of the opinion that procedures and policies should be in place on elder abuse. The Working Group recommended that procedures should include:

- A statement of specific roles and responsibilities, authority and accountability (to ensure that all staff understand their role and their limitations);
- A statement of the procedures for dealing with allegations of abuse, including those for dealing with emergencies;
- Contact details of those to whom an allegation should be referred, inside and outside normal working hours;
- Details of inter-service communication channels and procedures for decision-making;
- A statement indicating what to do in the event of a failure to take necessary action;
- A list of sources of expert advice;

⁴⁵ HSE *Elder Abuse Policy – Responding to Allegations of Elder Abuse* (2008). The HSE Elder Abuse Policy is not underpinned by legislation.

⁴⁶ Standard 8.4 of the HIQA *National Quality Guidelines for Residential Care Settings for Older People in Ireland* provides that all nursing home staff must receive induction and on-going training on the prevention of and protection from abuse, indicators of abuse, responding to suspected, alleged or actual abuse, reporting such cases and the procedures for protecting residents with particular vulnerabilities.

- A list of services that might offer advice and support to older people.⁴⁷

2.48 The 2009 HIQA Standards require a policy for the prevention, detection and response to abuse to be drawn up within each residential care setting.⁴⁸ The policy must outline procedures for the prevention of abuse, responding to suspected cases of abuse, allegations or evidence of abuse and procedures for reporting concerns or allegations to the HSE, the Garda Síochána and the Chief Inspector of Social Services. The policy must be reviewed annually.⁴⁹ The Commission considers that similar standards should be in place to ensure that people in receipt of professional care in their home are protected from all forms of abuse.

2.49 The Commission agrees with the approach of the Working Group on Elder Abuse and considers that all allegations of abuse must be taken seriously. The procedure for dealing with allegations of abuse in the home must also be clear to all services users. The Commission also endorses the HSE 2008 draft guidelines which state that procedures must be in place for the prevention of abuse, responding to suspicions, allegations or evidence of abuse or neglect and reporting concerns or allegations to the HSE or the Gardaí.⁵⁰ The Commission considers that the detection of abuse must be to the fore. While such policies are important, the Commission is of the view that the policies must be informed by the proposed national standards. This will ensure that policies are standardised and that older people receive the highest protection from abuse irrespective of the care provider. The Commission thus recommends that the professional home care service provider have policies in place to ensure that care recipients are protected from all forms of abuse and that those policies are informed by the proposed national standards.

2.50 *The Commission recommends that a professional home care service provider must have policies in place to ensure that professional home care recipients are protected from all forms of abuse and also recommends that those policies are informed by the proposed national standards.*

⁴⁷ *Ibid* at paragraph 6.7.

⁴⁸ Standard 8 of the *National Quality Standards for Residential Care Settings for Older People in Ireland*.

⁴⁹ Standard 8 of the *National Quality Standards for Residential Care Settings for Older People in Ireland*.

⁵⁰ Guideline 9.2 of the HSE *Draft National Quality Guidelines for Home Care Support Services*.

(i) Medication Management

2.51 According to the TILDA study, the vast majority of older adults in Ireland use medications regularly and rates of polypharmacy are high.⁵¹ One in five adults over 50 years of age takes 5 or more medications.⁵² This proportion rises to almost one in two for those aged 75 years and older.⁵³ Appropriate medication can be an important and crucial part of ensuring that individuals continue to enjoy a full, and extended, high-quality life at home.⁵⁴ Medication use in older adults is a particularly significant issue, both because of increasing numbers of medications and age-related physiological changes which predispose older people to side effects.⁵⁵ As regards the misuse of medication in the home care setting, the Commission notes that abuse can occur when medication is overused or underused. Misuse of medication also includes the use of medication for the wrong reason or for a different purpose to its indication.⁵⁶ Over-prescription of medication can be used as a tool for managing

⁵¹ *Fifty Plus in Ireland 2011: First Results from the Irish Longitudinal Study on Ageing (TILDA)*, at 94, available at www.tilda.ie.

⁵² The use of multiple medications, whether prescription or non-prescription, is generally described as 'polypharmacy'. According to the TILDA Report, polypharmacy is associated with an increased risk of falls and fall-related injuries, delirium, decline in activities of daily living and increased mortality. The risk of falls increases with increasing numbers of medications, from 15% in older adults not taking medications, up to 27% in those taking five or more medications. *Fifty Plus in Ireland 2011: First Results from the Irish Longitudinal Study on Ageing (TILDA)*, at 90, available at www.tilda.ie.

⁵³ *Fifty Plus in Ireland 2011: First Results from the Irish Longitudinal Study on Ageing (TILDA)*, at 74, available at www.tilda.ie.

⁵⁴ Studies have shown that correct adherence to medication can dramatically improve quality of care and prevent disability, resource-intensive complications of chronic conditions. *Transforming primary care in Ireland: information, incentives, and provider capabilities* Padhraig Ryan, Centre for Health Policy and Management Trinity College Dublin Working Paper 01/2011 at page 23

⁵⁵ *Fifty Plus in Ireland 2011: First Results from the Irish Longitudinal Study on Ageing (TILDA)*, at 90, available at www.tilda.ie.

⁵⁶ Kurrle "Treatment or Mistreatment? Medication as an Agent of Abuse of Older People" World Elder Abuse Awareness Day, 15 June 2007, available at www.agedrightsasn.au/events.

patients in receipt of care. It is often thought that over prescribing of anti-psychotic drugs makes the management of patients easier.⁵⁷

2.52 In the UK, the years between 1999 and 2002 saw a 6.2% increase in community prescriptions of anti-psychotic drugs.⁵⁸ Over-prescribing drugs is thus clearly a form of physical abuse.⁵⁹ Anti-psychotic medicines are used to manage the behavioural and psychological difficulties experienced by many dementia patients such as agitation, aggression, wandering, shouting, repeated questioning and sleep disturbance.

2.53 This form of chemical restraint may be in breach of both the *National Quality Standards for Residential Care Settings for Older People* and the *Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2009*, as amended. It may also be incompatible with Government policy on restraint. Both the 2009 Regulations and the Standards require that residents are protected from all forms of abuse, including misuse of restraint. Furthermore, a 2011 report produced by the Department of Health, *Towards a Restraint Free Environment in Nursing Homes*, noted that while the use of anti-psychotic medication may in certain cases be appropriate for the treatment of a condition or a reduction of the symptoms, this does not constitute restraint and that the use of “chemical restraint is always unacceptable”.⁶⁰ That report set out the Government’s policy on restraint as being:

“To eliminate the use of restraint or where this is not possible, to restrict the use of all forms of restraint to those exceptional emergency situations where it is absolutely necessary. Where restraint is necessary it should only be applied in accordance with the law and best professional practice.”⁶¹

2.54 In England, the 2009 Banerjee Report noted that drugs are too often used as a first-line response to behavioural difficulty in dementia rather than as a considered second-line treatment when other non-pharmacological

⁵⁷ House of Commons Health Committee *Elder Abuse* Second Report of Sessions 2003-04 at 18.

⁵⁸ *Ibid.*

⁵⁹ *Ibid* at 19.

⁶⁰ *Towards a Restraint Free Environment in Nursing Homes* (Department of Health, 2011)

⁶¹ *Towards a Restraint Free Environment in Nursing Homes* (Department of Health, 2011) at 2/

approaches have failed.⁶² The Commission is thus of the view that strong guidelines must be put in place which promote a restraint free environment in the home care setting and also regarding the use of medication in the delivery of these services and that the issue of the appropriate use of prescribed medication is to be dealt with in the contract for care.

2.55 Submissions received by the Commission after the publication of the Consultation Paper noted that the strict control of medication in in-patient care does not exist in professional home care. The potential for the over-administration of opiates as well as the potential for unauthorised people to take opiates from the home was highlighted. The Commission is also concerned that the over-prescribing of drugs may limit a person's ability to inform their care plan. Historically, controlled drugs were administered intravenously by a trained professional, but it is now possible for opiates to be taken orally, thus further increasing the potential for medication mismanagement. The Commission considers that suitable procedures must be in place on the administration of medication in the home. The Commission also notes the recommendation of the Expert Group on Resource Allocation and Financing in the Health Sector to the effect that the control of drugs is best approached by implementing guidelines and protocols and by increasing consumer awareness about drug prescribing.⁶³

2.56 In the Consultation Paper the Commission noted that the administration of drugs often rests with the care staff and that such staff may lack sufficient experience or knowledge for the management of medicines.⁶⁴ It should also be noted that many people self administer drugs in the home. The care plan should thus set out who is to administer any medication. While the regulation of the administration of drugs and the question of who is authorised to administer drugs is outside the scope of this Report, the Commission recommends that a review of the administration of drugs in the home be carried out. This review could include, but not be limited to, representatives of the Department of Health, HIQA, the Medical Council, An Bord Altranais and carer groups.

2.57 *The Commission recommends that a review of the administration of medicines in the home be carried out, involving representatives of the*

⁶² Banerjee "The use of anti-psychotic medication for people with dementia: Time for action" A Report for the Minister of State for Care Services, October 2009.

⁶³ *Report of the Expert Group on Resource Allocation and Financing in the Health Sector* (Department of Health and Children 2010) at 122.

⁶⁴ Law Reform Commission *Consultation Paper on Legal Aspects of Carers* (LRC CP 53-2009) at paragraph 3.33.

Department of Health, HIQA, the Medical Council, An Bord Altranais and carer groups.

2.58 During the consultation period the importance of a log on what drugs were administered and by whom was highlighted. It was expressed that best practice required that a log would be kept in the home and be accessible to all. This is particularly important where carers and family members may be administering medication. It was also expressed that in drawing up the care plan, it must be agreed on what medication the carer may administer. The Commission thus recommends that policies and procedures on the administration of medication in the home must be agreed between the care recipient or their guardian and the care provider as informed by the proposed national standards. This must be included in the care plan.

2.59 The Commission recommends that policies and procedures on the administration of medication in the home, informed by the proposed national standards, must be agreed between the professional home care provider and the care recipient and must be included in the care plan. The Commission further recommends that it should be a requirement that a log be kept of all medication administered in the home and be accessible to all.

(ii) Financial abuse

2.60 The Working Group on Elder Abuse was of the opinion that financial abuse was a widespread concern which could be difficult to identify. It was noted that it can be difficult to differentiate between “acceptable exchange and exploitative conduct, between misconduct and mismanagement.”⁶⁵ To prevent financial abuse from occurring, the Scottish *National Care Standards*, made under the Regulation of Care (Scotland) Act 2001, require that all care recipients are informed whenever staff are involved in any financial transaction.⁶⁶

2.61 The Commission notes the provisions in the 2008 HSE *Draft National Quality Guidelines for Home Care Support Services* regarding financial protection. Guideline 10 imposes an obligation on the service provider to ensure that there is a policy in place for home care support workers on the safe handling of clients’ money and property. This policy must cover a wide range of issues including the duty not to accept gifts or cash beyond a very minimal value and the procedures to be followed in relation to the collection of pensions on behalf of clients and the payment for the service, if applicable.

⁶⁵ *Ibid* at paragraph 2.22.

⁶⁶ Standard 4 (4) of the National Care Standards (2005).

2.62 In addition to the draft HSE guidelines, the Commission also notes the HSE *National Financial Regulations on Voluntary Donations, Gifts and Bequests*.⁶⁷ These regulations impose stringent obligations on all HSE employees not to receive benefits of any kind from a third party which might reasonably be seen to compromise their personal judgement or integrity. Any benefits received should be of nominal value. All such benefits received in connection with a person's employment or office must be disclosed in writing to the employee's line manager. The Commission endorses the 2008 HSE draft guidelines and is of the view that such guidelines are necessary to ensure that the money and property of the care recipient are protected at all times. Thus the Commission considers it important that policy and procedures on the handling of money on behalf of the care recipient in the context of professional home care are introduced on the basis of those set out in the 2008 draft HSE guidelines.⁶⁸ The Commission recommends that these procedures regarding financial affairs be included in the contract for care.

2.63 *The Commission recommends that policies and procedures on the handling of money and property by the professional care provider on behalf of the care recipient be included in the proposed National Standards. The Commission also recommends that the policies and procedures be included in the contract for care.*

(7) Safety and Health

2.64 As noted in the Consultation Paper, the provision of home care gives rise to specific safety and health concerns. The relevant legislative provisions on this matter are contained in the *Safety, Health and Welfare at Work Act 2005* and the *Safety, Health and Welfare at Work (General Application) Regulations 2007*. In particular, a particular issue concerns the extent to which professional home carers might be regarded as inhibited from engaging in manual handling in the home. This can include the issue of reaching high shelves to take down

⁶⁷ NFR – 17.

⁶⁸ See also HSE *National Financial Regulation: Patient Private Property* (NFR – 22). This provides that the HSE must not allow any client's funds in its safekeeping to be utilised for any purpose without the clear permission of the client other than where the client is unable to give that permission due to a lack of capacity. It also contains detailed provisions regarding the approach to be taken to clients' funds in the event of incapacity. Also of relevance is Standard 9 of HIQA *National Quality Standards for Residential Care Settings for Older People in Ireland* which sets out provisions in respect of the resident's finances. Standard 9.3 provides that where any money belonging to the resident is handled by staff within the residential care setting, signed records and receipts are kept. Where possible, the records and receipts are signed by the resident or his/her representative.

items for the care recipient, assisting the care recipient to move and patient lifting where the care recipient might have a significant movement disability. The question has arisen as to whether, under the comparable statutory provisions in the UK, a professional home care provider could impose a “no lift” ban so that a professional home carer would be prohibited from assisting clients from getting out of bed or from getting materials which are stored in high cupboards. As already noted, in the English High Court case *R (A and B) v East Sussex County Council*, Munby J concluded that a blanket or absolute “no lift” ban would be in breach of the rights of the service user under the European Convention of Human Rights.⁶⁹

2.65 The Commission is concerned that safety and health policies and procedures put in place by a professional home care provider must not infringe the human rights of a home care recipient, while of course accepting that the safety and health of the professional home carer must, as required by section 8 of the 2005 Act, be protected so far as is reasonably practicable. In the Consultation Paper the Commission provisionally recommended that any contract for home care must make specific reference to responsibilities which may arise under safety and health legislation.⁷⁰ The Commission considers that clear guidance on safety and health obligations, particularly in relation to manual handling, is essential in the home care setting. A careful balance must be struck between ensuring that the relevant safety and health legislation, including the 2007 Regulations made under the 2005 Act, are followed while also ensuring that the human rights of the home care recipient are not diminished. This will ensure that a suitable level of care is provided safely. The Commission therefore recommends that the proposed National Standards include specific guidance on safety and health requirements in the delivery of professional care in the home, including suitable guidance on manual handling (and which should be developed in liaison with the Health and Safety Authority).

2.66 *The Commission recommends that the proposed National Standards include specific guidance on safety and health requirements in the delivery of professional care in the home, including suitable guidance on manual handling (and which should be developed in liaison with the Health and Safety Authority).*

⁶⁹ [2003] EWHC 167 (Admin) (High Court of England and Wales, 18 February 2003). The case is discussed in Chapter 1 in the context of the discussion of the impact of the European Convention on Human Rights in professional home care.

⁷⁰ Law Reform Commission *Consultation Paper Legal Aspects of Carers* (LRC CP 53-2009) at paragraph 4.52.

(8) Service provider

2.67 The Commission emphasises that professional home carers must have a rigorous recruitment policy. Only competent, qualified staff must be selected. The Northern Ireland *Domiciliary Care Agencies Minimum Standards* require that, before an offer of employment is made, the home care agency must be provided with at least two written references and professional and vocational qualifications must be confirmed.⁷¹ Similarly the 2009 HIQA *National Quality Standards for Residential Care Settings for Older People in Ireland* require that before new staff are confirmed in a post they must have had satisfactory Garda vetting, have provided their employer with two references, confirmed their identity, confirmed their registration where appropriate, verified their qualifications and explained any gaps in their employment history. All new staff must also be able to communicate effectively with the residents, including residents with communication difficulties.⁷²

(a) Training

2.68 All carers must be sufficiently trained to perform their duties. Professional home carer agencies must ensure that only suitable carers will provide care in the home. The Working Group on Elder Abuse recommended that appropriate and ongoing training should be provided to all working with older people. This will help ensure that staff are adequately trained in the prevention, detection and reporting of elder abuse.⁷³

2.69 Those employed to provide professional home care should have the necessary training to ensure that they have the requisite skills to provide both domestic and home care services. The Commission considers that this training needs to be accredited by the Further Education and Training Assessment Council (FETAC). All professional home carers should receive initial safety and health training, core domestic care training and training in personal care issues. Training should then be provided on an incremental basis to meet the changing needs of the older person as they become more dependent.⁷⁴ The Commission

⁷¹ Standard 11.2 of the *Domiciliary Care Agencies National Minimum Standards*. The standards also contain guidance on criminal history disclosure and vetting procedures. The Commission will consider such issues in Section D below.

⁷² Standard 22 of HIQA *National Quality Standards for Residential Care Settings for Older People in Ireland*.

⁷³ Report of the Working Group on Elder Abuse *Protecting Our Future* (2002) at paragraph 2.3.

⁷⁴ HSE *Implementation of 'National Quality Home Care Support Guidelines'* (2008) at 6.

considers that this proactive approach to training will help minimise the need for multiple people becoming involved with the care of the older person.

2.70 The Commission also considers that ongoing training must be provided to ensure that carers are kept informed of any changes in care practices or, indeed, the law. Ongoing training is currently required under Standard 24 of the *National Quality Standards for Residential Care Settings for Older People in Ireland*. The Commission also notes the Draft *National Quality Guidelines for Home Care Support Services* which will require all newly recruited home care workers endeavour to undertake appropriate training to FETAC Level 5 or equivalent within two years of taking up employment. For existing home care support workers it will be necessary to have their capability and skills assessed as being appropriate to their work in the home care support service and they are also obliged to endeavour to undertake appropriate training to FETAC level 5 or equivalent. There will be an obligation on service providers to ensure that there is a home care support workers development and training programme, which is reviewed and updated annually. The training and development programme should ensure that home care support workers meet the changing needs of clients, fulfil the aims of the service provider, understand and adhere to the policies and procedures of the service provider and are suitably capable to carry out their role.⁷⁵

2.71 The Commission recognises that abuse of adults in receipt of professional home care may be caused by poor or inadequate training. It is thus of the utmost importance that staff are suitably trained to perform their duties. It is also important that staff have the opportunity to receive further training as the needs of the care recipient change. The Commission thus recommends that only suitably trained personnel may provide professional care and that the proposed national standards should set out relevant and detailed training requirements for those providing professional home care services.

2.72 *The Commission recommends that only suitably trained personnel may provide professional home care, and that the proposed national standards should set out relevant and detailed training requirements for those providing professional home care services.*

(b) Supervision

2.73 In the Consultation Paper the Commission provisionally recommended that all professional home carers must be adequately monitored

⁷⁵ Guideline 18 of HSE *Draft National Quality Home Care Support Guidelines* (2008) at 30.

and supervised in the performance of their duties.⁷⁶ It was noted that while staff may have the required skills and experience, further supervision and monitoring is required to ensure protection of all care recipients. Thus, once appointed and delivering care in the home, the home care provider must adequately supervise their staff. This may include observing the home carer in the home. It has been noted that if the care provider does not regularly see the carer and the person being cared for, the “opportunistic identification” of abuse is unlikely.⁷⁷ Thus, through appropriate supervision, management can help to ensure that abuse does not take place within the home.

2.74 In order to ensure quality of care, the Commission considers it imperative that professional home carers are supervised and have their performance appraised regularly. Direct supervision by the carer’s employer (whether the HSE or a private employer) is essential if care standards are to be assured. Where the Health Service Executive (HSE) contracts with a private service provider, the HSE will also monitor the standard of care provided. Where the care recipient contracts directly with the care provider there is, however, no monitoring obligation on the HSE. In both situations, the regulation of professional home care recommended by the Commission foresees an additional layer of oversight provided by HIQA, with HIQA acting in the role of an inspectorate, providing external assurance on the maintenance of care standards.

2.75 The Commission therefore recommends that the professional home care service provider must adequately supervise the individual carer to ensure the maintenance of care standards. The Commission also recommends that, where the Health Service Executive (HSE) contracts with a private service provider, the HSE must then also monitor the service standards used by that provider. The Commission also recommends that the professional home care service provider be monitored and inspected by HIQA in accordance with the proposed national standards.

2.76 *The Commission recommends that the professional home care service provider must adequately supervise the individual home care providers to ensure the maintenance of care standards. The Commission also recommends that, where the Health Service Executive (HSE) contracts with a private service provider, the HSE must then also monitor the service standards provided by the service provider. The Commission also recommends that the*

⁷⁶ Law Reform Commission *Consultation Paper on Legal Aspects of Carers* (LRC CP 53-2009) at paragraph 3.11.

⁷⁷ House of Commons Health Committee *Elder Abuse* Second Report of Sessions 2003-2004 at 14.

professional home care service provider be monitored and inspected by HIQA in accordance with the proposed national standards.

D Contracting Arrangements

2.77 In the Consultation Paper the Commission discussed the distinction between a contract of service and a contract for services.⁷⁸ A contract of service typically arises where one person, the employer, pays a wage or salary to another person, the employee, with the employer being entitled to supervise and give directions to the employee about “what to do and how to do it.” In other words, in a contract of service the person paying the wages, the employer, can instruct the other person, the employee, to do certain things and can decide how these things are to be carried out. This also usually requires the employer to provide suitable training and supervision for the employee. By contrast, a contract for services typically arises where one person pays a fee to another person to carry out a particular job. In this case, the person paying the fee gives instructions about “what to do *but not how to do it.*”

2.78 The crucial distinction is that, under a contract for services, the person paying the fee is not an employer and is not entitled to tell the person engaged to do the work how that work is to be carried out, and is therefore not responsible for providing him or her with suitable training or for supervising them. Again, typically a contract for services is entered into when the fee payer wishes to have a specialist job carried out but does not have the know-how to do it themselves or to understand how it should be done. This can range from engaging a plumber, an accountant, a lawyer, or, in the context of this Report, a professional home carer. The distinction between a contract of service (in which the person paying is an employer) and a contract for services (in which the person paying is not an employer) is particularly important: if there is a contract of service between the care recipient and the professional care provider, the carer is an employee of the care recipient. If there is a contract for service between the two parties, the professional home carer is an independent contractor and the care recipient is not an employer.

2.79 The Commission has noted that, in most arrangements involving the provision of professional home care, the care recipient is not an employer. Where the professional home care is provided by the HSE pursuant to the Home Care Package Scheme, the HSE is the employer of the carer. Equally, where the HSE provides this service by engaging a private sector provider, that private sector provider is the employer of the carer. Also, where the care recipient pays for the professional home care service either directly to a private

⁷⁸ Law Reform Commission *Consultation Paper Legal Aspects of Carers* (LRC CP 53-2009) at paragraph 4.02-4.09

sector provider or, as the Commission recommends, by using the HSE as an intermediary, the private sector provider is the employer of the professional carer, not the care recipient. The Commission notes that there has been a significant growth in private sector home care providers in Ireland, which clearly reflects the wish of individuals to maintain an independent life within their own home to the greatest extent practicable. It is important to ensure that the contractual arrangements in place in such situations ensure that the HSE or, as the case may be, the relevant private sector home care provider is clearly the employer. The Commission reiterates that, in the vast majority of cases, the home care recipient is not, and should not be, described as the employer of the professional home care provider.

(1) Contracting with the HSE

2.80 There may be situations in which a person who requires home care may wish to purchase such services directly through the HSE given the HSE's long experience in providing care. Thus in the Consultation Paper the Commission provisionally recommended that an individual who wishes to pay for the provision of home care services should have the option to contract directly with the HSE for such services.⁷⁹ It was noted in the Consultation Paper that, where the HSE completely funds and provides home care, the care recipient will not be involved in the financial arrangements concerning the care contract. The HSE will either directly provide the care themselves or will contract with a private sector home care provider to provide the care on behalf of the HSE.⁸⁰ A public health nurse would then assess the person's needs to determine the type of care they may need to receive. In such circumstances the HSE would have, as already recommended, a monitoring role, which would complement the role of HIQA under the proposed national standards.

2.81 During the consultative period that followed the publication of the Consultation Paper, concern was expressed that this provisional recommendation would change the nature of the HSE home care service from one of service provider to a revenue generating unit. Questions were also raised regarding the role of the public health nurse changing from a position where a person would be assessed according to their needs to a position where it was perceived that the public could be "sold" home help services provided by the HSE. The Commission also notes the findings of the Expert Group on Resource Allocation and Financing in the Health Sector regarding the need for full transparency in the contractual relationships between the HSE and all

⁷⁹ *Ibid* at paragraph 4.22.

⁸⁰ *Ibid* at paragraph 4.12.

providers, including HSE hospitals and nursing homes.⁸¹ In the Report of the Expert Group, reference was made to the HSE's obligation, pursuant to the *Health Act 2004*, to enter into legal arrangements with health care providers whenever it seeks to contract services. The Group noted that this legal obligation has begun to be implemented by the HSE in several areas but not in every case. The Commission endorses the Expert Group's recommendation that this legal obligation to enter into contracts on the part of the HSE be extended to apply to a wider range of areas so that each time the HSE contracts for the provision of a particular health care service, full transparency can be accounted for. The Expert Group also noted that the Comptroller and Auditor General in this regard had made similar recommendations in its review of the HSE.⁸²

2.82 The Commission has no role in determining the level of service which has been, or will be, provided directly to care recipients through the HSE under the Home Care Package Scheme. Any individual in need of care and who cannot afford to pay for a service will continue to be provided with the level of support that is available under the State funding provided to the HSE.⁸³ This is a separate matter from the question as to whether a person who wishes to pay for care should have the choice to contract directly with a private sector care provider or through the HSE. The Commission considers that a care recipient *should* have the choice or option of paying the HSE or a private sector provider for professional home care services if they so wish. The Commission therefore recommends that a person who wishes to pay for professional home care services should have the choice to contract directly with a private sector care provider or to do so through the Health Service Executive.

2.83 *The Commission recommends that a person who wishes to pay for professional home care services should have the choice to contract directly with a private sector care provider or to do so through the Health Service Executive.*

(2) Contracting with a private sector home care provider

2.84 As explained above, where a person is financing the cost of care themselves, they may wish to enter into an arrangement with the HSE to

⁸¹ *Report of the Expert Group on Resource Allocation and Financing in the Health Sector* (Department of Health and Children 2010) at 114.

⁸² *Report of the Expert Group on Resource Allocation and Financing in the Health Sector* (Department of Health and Children 2010) at 114.

⁸³ The HSE *National Guidelines and Procedures for the Standardised Implementation of the Home Care Packages Scheme* (2010) specifically state that the extent of the support available pursuant to the Scheme is subject to the resources allocated each year to the HSE for its operation.

provide care. However, a person may also wish to enter into a private contractual relationship with a private home care agency. An ageing population has seen a growth in the private sector home care market in Ireland which is expected to continue. Often the HSE will provide some home care needs while the older person may also contract with a private sector home care provider to meet those needs which are not being met by the HSE. When a person opts to contract with a private sector home care provider, that provider will assume the responsibilities of the employer.

(3) Private contractual arrangements

2.85 In a very small minority of cases, a person may wish to contract directly, as employer, with an individual to provide professional home care. In such situations, the care recipient may be deemed to be the employer. The Commission notes that, while this arrangement may suit some care recipients, others may not be aware of the obligations such a contractual relationship will bring. However, the Commission notes that a person has the freedom to enter into such a contract. To ensure that all persons are aware of obligations which may arise under such a contract, the Commission provisionally recommended in the Consultation Paper that there should be a public awareness campaign to indicate the limited circumstances in which a home care recipient could be regarded as an employer of a professional home carer.⁸⁴ The Commission reiterates this recommendation. The Commission also recommends that any national standards governing professional home care must also apply to any independent contractors providing such services in a person's own home.

2.86 *The Commission recommends that there should be a public awareness campaign to indicate the limited circumstances in which a professional home care recipient could be regarded as an employer. The Commission also recommends that any national standards governing professional home care must also apply to any independent contractors providing such services in a person's own home.*

(4) Intermediary

2.87 In the Consultation Paper the Commission provisionally recommended that an individual who wishes to enter into an arrangement for the provision of home care should have the option to contract with an intermediary, whether a State body or a private sector body, who would arrange for the provision of care.⁸⁵ This was supported by a number of organisations representing the interests of vulnerable people who made submissions to the

⁸⁴ *Ibid* at paragraph 4.32.

⁸⁵ Law Reform Commission *Consultation Paper* (LRC CP 53-2009) at paragraph 4.09.

Commission. It was felt that the majority of people would not wish to enter into a private contractual arrangement but would prefer to contract with an intermediary who would be the employer of the professional home carer. The Commission concurs with this view and reiterates the view it took in the Consultation Paper. The Commission also reiterates that the use of an intermediary would assist in ensuring that some care recipients who may be vulnerable are protected from any potential abuse which may arise when drawing up a contract.

2.88 Concern was expressed in some submissions that an intermediary body could potentially make decisions as to who provides the care and thus take away the independent decision-making power of a care recipient (particularly an older care recipient). The Commission acknowledges these concerns and the potential for this to occur. However, the Commission notes that it is the legal duty of the HSE to obtain informed consent from those it treats or provides services to. In this regard, it would be incumbent on the HSE to respect the care recipient's right to autonomy and self-determination in terms of their choice of carer. Also, as set out in Chapter 1, the Commission recommends that maintaining the independence of all care recipients should be a guiding principle of the proposed legislative scheme. The Commission is thus of the opinion that the proposed intermediary body must not be in a position to take away from the care recipient such fundamental choices as deciding who provides the care.

2.89 In the Consultation Paper the Commission considered that a State body, such as the HSE, or a private sector provider could act as the intermediary. During the consultative process, it was suggested that a voluntary organisation could also act as the intermediary.

2.90 The Commission reiterates its approach that the proposed intermediary will not make decisions regarding who is to provide care. They ensure that potentially vulnerable adults do not assume responsibilities they do not wish to have or that they may be unable to deal with due to age or infirmity. The care recipients will be paying for the care themselves and thus have full choice regarding who is to provide the care. As the HSE is a service provider which has experience in contracting with individuals and agencies to provide care, the Commission is of the opinion that the HSE is an example of one body which may act as an intermediary.

2.91 The Commission thus recommends that the intermediary body be responsible for contracting on behalf of the care recipient with an agency, organisation or individual to provide care and that the HSE is an example of one body which is suitable to act as an intermediary.

2.92 *The Commission recommends that a care recipient who wishes to enter into an arrangement for the provision of professional home care should*

have the option to contract with an intermediary, whether a State body (such as the Health Service Executive) or a private sector body (including a voluntary or not-for-profit undertaking), who would arrange for the provision of care. The Commission recommends that the intermediary be responsible for contracting on behalf of the care recipient with an agency, organisation or individual to provide care. The Commission also recommends that the relevant national standards introduced in conjunction with the proposed legislation for the regulation of home care should address arrangements with intermediaries.

(5) Contractual issues

(a) Mental Capacity

2.93 In the Consultation Paper the Commission noted that the proposed mental capacity legislation⁸⁶ implements the key recommendations of the Commission's 2006 *Report on Vulnerable Adults and the Law*.⁸⁷ The Commission noted that the draft legislation proposes a functional approach to capacity in that a person is deemed to have capacity if he or she has cognitive understanding of a particular decision at the time the decision is to be made. The proposed legislation also proposes to establish an Office of Public Guardian (OPG). The functions of the OPG would include a supervisory role in respect of personal guardians and persons appointed under enduring powers of attorneys.⁸⁸ The OPG would also deal with representations including complaints about the way in which personal guardians exercise their power.⁸⁹

(b) General authority to act and supported decision-making

2.94 In the Consultation Paper the Commission noted three possible options under the proposed mental capacity legislation for contracting on behalf of a person who does not have the capacity to contract. Under Head 16 of the *Scheme of the Mental Capacity Bill 2008*, a person would have a general authority to act on another's behalf when making relatively minor decisions about their personal care, healthcare or treatment decisions if their capacity is in doubt. The Scheme of the Bill also proposes that where such a decision involves money and is carried out in the interest of an adult who is reasonably

⁸⁶ The Government Legislative Programme indicates that publication of the Mental Capacity Bill is expected in early 2012. The Legislative Programme is available at www.taoiseach.ie/eng/Taoiseach_and_Government/Government_Legislation_Programme/SECTION_B1.html.

⁸⁷ Law Reform Commission *Report on Vulnerable Adults and the Law* (LRC 83-2006).

⁸⁸ Head 32(2) of the *Scheme of Mental Capacity Bill 2008*.

⁸⁹ Head 32(2)(i) of the *Scheme of Mental Capacity Bill 2008*.

believed to lack capacity to consent, the person taking the action could lawfully apply the money in the possession of the person concerned for meeting his or her expenditure.⁹⁰ Thus a person with a general authority to act would be able to enter into a contract for the provision of home care and not incur any liability.

2.95 In the Consultation Paper the Commission considered that such decisions should be referred to the proposed Office of Public Guardian (OPG). However it was noted that even with the additional safeguard of the OPG, this general authority to act may be open to abuse.⁹¹ The Commission thus considered that a personal guardian (as proposed under Head 6(2)(b) of the 2008 Scheme of the Bill) should be appointed to enter into a contract for the provision of home care on behalf of the person who lacks capacity. The Commission noted that the proposed OPG would have a supervisory role over all personal guardians appointed by a guardianship order, which would provide additional protection.⁹²

2.96 Finally the Consultation Paper considered the possibility of an attorney appointed under an enduring power of attorney (EPA) entering into a contract for home care where a person lacks mental capacity and where an EPA has been executed.⁹³

2.97 Submissions received highlighted the important role of the OPG in this process. It was noted that the onset of dementia or other illness affecting a person's capacity must not impact on their home care. Thus, to ensure that there is no delay in entering into a contractual arrangement for the provision of care or to avoid the collapse of current contracting arrangements, it was urged during the consultative process that entering into a contract should be covered by the proposed general authority to act in the proposed mental capacity legislation.

2.98 Nonetheless, the potential danger of abuse of such a power and the risks involved were also highlighted during the consultative process. The Commission is of the view that too wide a power should not be given to those with a general authority to act. In general, no one has the authority or any legal right to make decisions or enter into contracts on behalf of another adult. The exceptions to this general principle, such as where there exists an enduring power of attorney or where a person has been made a ward of court, are limited

⁹⁰ Head 16(4) of the *Scheme of Mental Capacity Bill 2008*.

⁹¹ Law Reform Commission *Consultation Paper Legal Aspects of Carers* (LRC CP 53-2009) at paragraph 4.56.

⁹² *Ibid.*

⁹³ *Ibid* at paragraph 4.57.

and controlled by legislation. The introduction of a new legislative means of making decisions on behalf of another person by way of a general authority to act may be beneficial in a host of ways, particularly regarding minor decisions that are part of everyday life, but is not an absolute authority to act in all situations concerning the individual on whose behalf the authority is used. The introduction of this general authority was intended to end the requirement to refer minor decisions regarding a person whose capacity was in doubt to a court but was not intended to apply in respect of more serious decision. Hence, the more serious the decision to be made, the greater the need for more formal mechanisms to be in place to ensure the vulnerable adult in question is protected.

2.99 The Commission has concluded that a personal guardian or an attorney appointed under an enduring power of attorney may enter into a contract for the provision of home care on behalf of another person. The Commission reached this conclusion based on the need for safeguards when a decision to enter into a contract for care is made on behalf of another individual. In circumstances where a guardian or an attorney enter the contract, certain statutory oversights will exist to ensure that those decision-makers may be held to account, such as the proposed Office of the Public Guardian. In respect of those who enter a contract pursuant to a general authority to act, no such oversights or regulatory mechanisms exist. There is no forum for complaints to be made against such individuals and it would therefore be more difficult to hold such persons legally accountable in the event of an abuse of their powers. Hence, the more serious the decision to be made, the greater the need for statutory safeguards and the less likely it becomes that a general authority to act will be sufficient.

2.100 *The Commission recommends that, assuming the enactment of mental capacity legislation, a personal guardian or an attorney appointed under an enduring power of attorney may enter into a contract for the provision of home care on behalf of another person.*

(c) Fee arrangements

2.101 In the Consultation Paper the Commission provisionally recommended that any contract for the provision of home care services should include specific provisions that set out the financial arrangement between the contracting parties for the agreed services.⁹⁴ The Commission also noted that under HIQA's 2009 *Standards for Residential Care Settings for Older People*, service providers must provide each resident with a written contract setting out

⁹⁴ Law Reform Commission *Consultation Paper Legal Aspects of Carers* (LRC CP 53-2009) at paragraph 4.39.

the fees payable and identifying who is to pay the fees.⁹⁵ This provisional recommendation was strongly endorsed during the consultative process. It was thought that such a recommendation would serve to protect older people in particular from cases of financial abuse. The Commission is of the opinion that the proposed national standards on home care services should provide guidance in relation to any financial arrangements. Thus the Commission recommends that the proposed national standards should set out that a contract for the provision of home care should include specific provisions setting out, in plain and easily understood language, the fee arrangements between the contracting parties for the agreed services.

2.102 *The Commission recommends that the proposed national standards should set out that a contract for the provision of home care should include specific provisions setting out, in plain and easily understood language, the fee arrangements between the contracting parties for the agreed services.*

E Protective Measures

2.103 In this Part the Commission examines the protective measures which can be put in place to protect professional home care recipients. The Commission has already discussed protective measures from the perspective of the need for policies and procedures to be put in place regarding elder abuse. This Part discusses the steps which may be taken by service providers, care staff and any other concerned party in order to ensure elder abuse does not occur or, where such abuse has occurred, to ensure that it is reported. These mechanisms include personal advocacy, pre-employment checks such as vetting and a safe screening process and processes such as whistle-blowing and mandatory reporting of abuse.

(1) Personal Advocacy

2.104 Under the *Health Act 2007*, all designated centres, including nursing homes, must be inspected and registered. The provision of independent advocacy, though not itself specifically required by the legislation, has been included in the Inspection framework.⁹⁶ The *HIQA National Quality Standards for Residential Care Settings for Older People in Ireland* includes advocacy and

⁹⁵ Standard 7 of *HIQA National Quality Standards for Residential Care Settings for Older People in Ireland* (2008) and Standard 13.11 of *HIQA National Quality Standards for Residential Care for People with Disabilities* (2009).

⁹⁶ *Pillinger National Advocacy Programme for Older People in Residential Care: An Evaluation* (Commissioned by the HSE, 2011) at 7.

information as national quality standards, but these standards on advocacy and information do not have a regulatory base to them.⁹⁷

2.105 In the realm of disability legislation, the role of a personal advocate is to assist people with disabilities in making applications for services to which they may be entitled and in submitting formal complaints if such services are not provided.⁹⁸ Advocates can also provide support and training to the person and their family while applications or complaints are being made.⁹⁹ The personal advocacy service is governed by section 5 of the *Citizens Information Act 2007* but that section has not yet come into force.

2.106 Under the 2007 Act, “disability”, in relation to a person, means a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment. The emphasis in this statutory definition on the enduring quality of the disability means that many people currently in need of professional home care may not come within the ambit of the 2007 Act and may not, when in force, avail of the advocacy service envisaged by that Act.

2.107 In 2011, the National Advocacy Service, as distinct from the Personal Advocacy Service envisaged by the 2007 Act, was set up to provide professional, independent advocacy services to people with disabilities. As part of this service, a number of Advocacy Support Workers (ASWs) have been recruited to work with the Citizens Information Service (CIS) at different locations across Ireland. Each Advocacy Support Worker will be based in a CIS location but will work with staff in all CIS locations within a specific region. The role of these ASWs will involve building on the work of the Advocacy Resource Officer (ARO) project, and working mainly on training, providing specialised advice on cases, and conducting case reviews. It is expected to have these new ASWs in place in the summer of 2012. The new National Advocacy Service is being provided within the same annual budget as the pilot Community and Voluntary Advocacy Programme.

2.108 In relation to advocacy services specifically for older people, the Advocacy Programme for Older People in Residential Care was launched in 2007, commenced in 2008 and is funded by the HSE. The programme was

⁹⁷ *Ibid* at 7.

⁹⁸ Section 7A(1) of the *Comhairle Act 2000*, as amended by section 5 of the *Citizens Information Act 2007*.

⁹⁹ Flynn “Ireland’s Compliance with the Convention on the Rights of Persons with Disabilities: Towards a Rights-based Approach for Legal Reform?” (2009) 16(1) DULJ 357.

launched following the revelations of the abuse that had taken place and the poor quality of care in Leas Cross Nursing Home in North Dublin.¹⁰⁰ The people who serve as advocates are volunteers who are trained in advocacy for older people and in order to become an advocate, they must complete a recognised and accredited training programme. Under this programme, volunteer advocates provide a weekly advocacy service for between two and four hours a week. These advocates deal with a broad range of issues, however the more serious issues are dealt with by the Development Officer assigned to support the volunteer.¹⁰¹ At present, the programme is only available to older people resident in nursing homes¹⁰² but it is intended that in time the programme will broaden its remit to include advocacy services for older people in receipt of hospital care and care in the community.

2.109 An evaluation of the National Advocacy Programme for Older People in Residential Care was concluded in 2011. In the evaluation report, it was stated that advocacy for older people should be located in an independent organisation that is independent from the service provider.¹⁰³ A key recommendation of the report was this need to develop an independent Advocacy Programme for Older People outside of the HSE.¹⁰⁴ The evaluation report also noted that in spite of the low budget available to it, the advocacy programme had achieved significant outcomes such as the putting in place of policies and procedures on advocacy, including a National Advocacy

¹⁰⁰ Pillinger *National Advocacy Programme for Older People in Residential Care: An Evaluation* (Commissioned by the HSE, 2011) at 5.

¹⁰¹ Pillinger *National Advocacy Programme for Older People in Residential Care: An Evaluation* (Commissioned by the HSE, 2011) at 7. At page 8 of the evaluation report, the importance of the role of Development Officers was referred to and the need to ensure that paid professional Development Officers continue to carry out this important support function in the future.

¹⁰² It is noted on page 5 of the evaluation report that €385,000 was provided for the Advocacy Programme between 2008 and 2010 and that this amount was insufficient to establish a robust and professional support structure for the advocacy programme in residential homes.

¹⁰³ Pillinger *National Advocacy Programme for Older People in Residential Care: An Evaluation* (Commissioned by the HSE, 2011) at 6.

¹⁰⁴ *Ibid* at 11. At page 12, the report notes that the HSE would need to continue to play a key role both as a funder and as a partner in any new, independent Advocacy Programme for Older People, particularly under the remit of the HSE Director of Advocacy (Quality and Clinical Care Directorate).

Programme Handbook and a Volunteer Advocate Policy.¹⁰⁵ Crucially, the report recommended that the advocacy programme be broadened out from residential care to hospital care and to care in the community. In other words, the report recommended the extension of advocacy services to all areas where professional care is delivered.¹⁰⁶ The report also recommended the development of a specialist Dementia Advocacy Programme in the future¹⁰⁷ and that the advocacy programme needed to be put on a statutory footing through the introduction of legislation on the rights of older people to independent advocacy and information on public bodies.¹⁰⁸ The Commission has concluded in this respect, and so recommends, that a volunteer advocacy service for professional home care recipients be developed and that the voluntary advocates be trained to the same FETAC Level 6 as applies to comparable care advocates in institutional settings.

2.110 *The Commission recommends that a volunteer advocacy service for professional home care recipients be developed and that the voluntary advocates be trained to the same FETAC Level 6 as applies to comparable care advocates in institutional settings.*

(2) Offence of ill treatment or wilful neglect

2.111 In the Consultation Paper the Commission noted the proposed offences of ill treatment and wilful neglect.¹⁰⁹ The Consultation Paper noted that three categories of people would be covered by these proposed offences:

- a person who has the care of another who lacks, or whom the [carer] reasonably believes to lack capacity;
- a person appointed as an attorney under an enduring power of attorney; and
- a person appointed under the Scheme of the Bill as a personal guardian.

2.112 In the Consultation Paper the Commission endorsed the proposed creation of the offences of ill treatment and wilful neglect.¹¹⁰ As a professional

¹⁰⁵ *Ibid* at 6.

¹⁰⁶ *Ibid* at 11.

¹⁰⁷ *Ibid* at 12.

¹⁰⁸ *Ibid* at 13.

¹⁰⁹ Law Reform Commission *Consultation Paper on Legal Aspects of Carers* (LRC CP 53-2009) at paragraph 5.14.

¹¹⁰ *Ibid* at paragraph 5.15.

home carer would come within the category of people dealt with in the proposed mental capacity legislation, due to their responsibility for the care of another who lacks capacity, the Commission considers that the prohibition of ill-treatment and wilful neglect will serve as an important protective measure for home care recipients.

(3) Vetting

2.113 In its *Consultation Paper on Sexual Offences and Capacity to Consent*,¹¹¹ the Commission noted the Draft Heads of the *National Vetting Bureau Bill*, which had been published in 2011. This Bill will provide for a vetting process that will include the use of both 'hard' and 'soft/relevant' information, in particular information relating to the endangerment, sexual exploitation or sexual abuse, or risk thereof, of children and vulnerable adults. The Commission noted that the Bill will allow the use of information where individuals are under investigation for alleged abuse and also if an organisation is concerned that an individual could place a child or vulnerable adult at serious risk, the agency will be obliged to provide that information to the vetting bureau.

(4) Disclosures of information

(a) Whistle-blowing

2.114 During the consultative process, the Commission invited submissions on the issue of protecting people who report concerns about incidents of possible abuse of adults by professional carers.¹¹²

2.115 A "whistleblower" is someone who discloses information to authorities about serious concerns they have about a health or social care service which either they or someone they are in contact with receive. A whistleblower may also be someone who is employed by a health or social care provider, and who discloses information to the relevant authority about the care provider.

2.116 Protection for whistleblowers was also dealt with by the Commission in its *Consultation Paper on Sexual Offences and Capacity to Consent*.¹¹³ The Commission noted its awareness of the Government's intention to propose the enactment of generally applicable legislation to prevent employers from taking action against whistleblowers.¹¹⁴ The Commission also noted the protection

¹¹¹ Law Reform Commission *Consultation Paper on Sexual Offences and Capacity to Consent* (LRC CP 63 – 2011) at paragraph 4.73.

¹¹² Law Reform Commission *Consultation Paper on Legal Aspects of Carers* (LRC CP 53-2009), at paragraph 5.19.

¹¹³ Law Reform Commission *Consultation Paper on Sexual Offences and Capacity to Consent* (LRC CP 63 – 2011), at paragraph 4.75.

¹¹⁴ "New whistleblower laws outlined" *The Irish Times* 11 April 2011.

afforded to whistleblowers by the Health Act 2004, as amended by the Health Act 2007. That Act affords protection to the employees of relevant bodies who make disclosures of information.¹¹⁵ Where such an employee makes a disclosure of information to an authorised person in good faith, the disclosure shall be deemed to be a “protected disclosure”.¹¹⁶ Hence, where a professional carer employed by the HSE, or another organisation that has entered into a contractual arrangement with the HSE, makes a disclosure of information on reasonable grounds and in good faith, the disclosure will be deemed to be protected.¹¹⁷ Furthermore, section 103 of the *Health Act 2007* provides some protection for whistle-blowers in the health sector who bring their concerns to the Health Information and Quality Authority or the Mental Health Commission. As noted in the Commission’s *Consultation Paper on Sexual Offences and Capacity to Consent*, the Irish Human Rights Commission has queried whether this mechanism for the making of protected disclosures is commonly known to healthcare workers and whether the type of whistleblowing provided for in the legislation actually works in practice.¹¹⁸

(b) Mandatory and Voluntary Reporting

2.117 As noted by the Commission in its *Consultation Paper on Sexual Offences and Capacity to Consent*, some services are obliged by the Health Service Executive to report any abuse or allegation of abuse committed against

¹¹⁵ Relevant bodies, within the meaning of the *Health Act 2004*, includes (a) the Health Service Executive, (b) a service provider, (c) any other person who has received or is receiving assistance in accordance with section 39 of the *Health Act 2004* or section 10 of the *Child Care Act 1991* and (d) a body established under the *Health (Corporate Bodies) Act 1961*. Under section 2 of the *Health Act 2004*, a “service provider” is a person who enters into an arrangement with the HSE to provide a health or personal social service on behalf of the HSE.

¹¹⁶ Section 55A of the *Health Act 2004*. Also, in any action for damages for defamation, section 18 of the *Defamation Act 2009* affords the defence of qualified privilege to a defendant who can prove that the statement was published to a person who had a duty to receive or had an interest in receiving the information. The defence is also open to a defendant who believed on reasonable grounds that the person had such a duty or interest in receiving the information and the defendant had a corresponding duty to communicate the information to that person.

¹¹⁷ Section 55B of the *Health Act 2004*.

¹¹⁸ Law Reform Commission *Consultation Paper on Sexual Offences and Capacity to Consent* (LRC CP 64-2011), at paragraph 4.83.

children and adults on a monthly basis.¹¹⁹ While this is not a statutory obligation, the duty stems from service agreements with the HSE which are legally binding on those that enter them. In addition to the well established existence of this type of duty, legislation is being prepared which will make it a criminal offence to withhold information relating to sexual abuse or other serious offences against a child or vulnerable adult.¹²⁰ As noted in its *Consultation Paper on Sexual Offences and Capacity to Consent*, the Commission is aware that, in general, voluntary reporting systems tend to be more common than mandatory reporting ones and the voluntary reporting practices are usually set out in inter-agency protocols.¹²¹ England, Scotland and Wales share this voluntary reporting system, whereas Northern Ireland has enacted mandatory reporting legislation in its child protection laws. The Commission also noted that there is no empirical research that clearly shows that introducing a legal obligation to report decreases the incidence of abuse.¹²² Given the Government's commitment to introduce legislation providing for mandatory reporting of certain types of abuse, the Commission restates its view on the importance of clarifying to what extent the abuse needs to be reported. The Commission also reiterates its view that multidisciplinary training should be introduced alongside imposing a legal duty on those with concerns regarding possible abuse to report their concerns.¹²³

¹¹⁹ LRC CP 63-2011, at paragraph 4.64.

¹²⁰ The *Draft Scheme of the Criminal Justice (Withholding Information on Crimes against Children and Vulnerable Adults) Bill 2011* was published by the Department of Justice and Equality in 2011, available at www.justice.ie.

¹²¹ *An examination of local, national and international arrangements for the mandatory reporting of child abuse: the implications for Northern Ireland* (National Society for the Prevention of Cruelty to Children 2007) at 9.

¹²² LRC CP 63-2011, at paragraph 4.69.

¹²³ LRC CP 63-2011, at paragraph 4.72.

CHAPTER 3 FUNDING LONG-TERM CARE

A Introduction

3.01 In this chapter the Commission considers possible models for the future funding of long-term home care provided by professional carers. The Commission notes that the law reform issue of regulation of home care is distinct from the issue of funding. However, due to the impact an ageing population may have on budgetary demands, the Commission is of the opinion that a discussion of the funding of long-term care is necessary.¹ The Commission does not make any specific recommendations on this matter but gives an outline of the possible models that could be used to underpin certain necessary amendments to the *Health Act 2007* to allow HIQA to regulate professional home carers.

3.02 In Part B the Commission discusses the demographic changes which are relevant in this context. In Part C the Commission outlines the various mechanisms which can be adopted to fund long-term care, taking into account comparative funding models from other States.

B Demographic Changes in Irish Society

3.03 It is well documented that the proportion of older people living in Ireland has increased in recent years; a trend which is set to continue. It is expected that the Irish population will increase from 4.24 million in 2006 to 5.1 million in 2021.² It is projected that this population increase will also lead to increased ageing. It is estimated that people aged 65+ will increase from 11% of the population in 2006 to 15.4% of the population in 2021. Furthermore it is anticipated that those aged 85+ will increase by 42,900 from 1.1% to 2.1%.³

¹ According to the Economic and Social Research Institute (ESRI), basing its estimates on population trends and disability projections, there will be a need for an additional 13,324 long-term care places from 2006 to 2021, or 888 each year from 2007 to 2021, for people of 65 years of age and over.

² Economic and Social Research Institute Projecting the Impact of Demographic Change on the Demand for and Delivery of Health Care in Ireland (2009) at xv.

³ *Ibid* at xvi.

The number of people over the age of 65 is projected to increase from over 500,000 now to almost 1,200,000 in the next 30 years.⁴ By 2050, one quarter of the Irish population will be over 65.⁵

3.04 Not only will the population of older people increase, but it is also expected that the number of older people living alone will increase from 114,000 in 2002 to 210,000 in 2021. Indeed it is projected that the number of people aged over 70 living alone will almost double from 88,400 to 161,900.⁶

3.05 An aging population is not a phenomenon exclusive to Ireland. In 2008, people aged 65+ accounted for 17.1% of the total population of the European Union. This is expected to rise to 30% by 2060.⁷ It is also expected that by 2060 the working age population within the European Union will decrease by 50 million people, with the population of people 65+ expected to rise by 67 million people. Thus the old age dependency ratio for the European Union is expected to double by 2060.

3.06 The type of health care services to be provided needs to be addressed in the context of population change in the future. The traditional approach that treated acute episodes cannot provide effective care for a population with increased longevity.⁸ As TILDA points out '[o]ne of the great success stories of modern times is the increasing number of people living into old age. This triumph is also one of the greatest challenges'.⁹ It is expected that GP consultations will increase by 33% in 2021¹⁰ and outpatient consultations for older people is expected to increase by 22% by 2021.¹¹ Indeed

⁴ Department of Health *Health in Ireland: Key Trends* (2011) at 8. This document states that Ireland Population projections are based on; decreasing mortality rates, immigration returning to moderate levels and fertility rate to decrease gradually from present level of 2.07 to 2.02.

⁵ National Economic and Social Forum *Care for Older People* (2005) Report 32 at paragraph 1.38.

⁶ *Ibid* at 1.37.

⁷ Eurostat *Ageing Characterises the Demographic Perspectives of the European Societies* 72/2008 at 1.

⁸ *Report of the Expert Group on Resource Allocation and Financing in the Health Sector* (Department of Health and Children 2010) at 104.

⁹ *Fifty Plus in Ireland 2011: First Results from the Irish Longitudinal Study on Ageing (TILDA)*, available at www.tilda.ie.

¹⁰ Economic and Social Research Institute *Projecting the Impact of Demographic Change on the Demand for and Delivery of Health Care in Ireland* (2009) at xviii.

¹¹ *Ibid* at xxi.

if the target of only 4% of older people in long-term care is met, this will cost the state €4.6 billion by 2051.¹² To achieve the aim of 4%, considerable investment in community care facilities will be necessary. As TILDA points out despite the widely held belief that ageing will lead to large increases in the demands for hospital care which will be hard to accommodate, the evidence from TILDA suggests that increased demands will be modest, and will be driven primarily by the health of the population as opposed to the age structure. The most pressing effects of ageing are likely to be on demands for a range of community-based health and social care services.¹³

3.07 Traditionally the family, in particular the female members of the family, provided the majority of long-term care. However, TILDA noted that while the role of the family is often emphasised in Ireland, there was little actual evidence on what families provide by way of care to older adults.¹⁴ One of the aims of the study was to gather information on such matters. The study ultimately found that for older adults who required assistance with the activities of daily living, the principal source of help is the family and the most common primary helper is the care recipient's spouse.¹⁵ Worryingly, TILDA also found that 12% of people over 50 with significant disability receive no formal or informal care and are therefore potentially at risk.¹⁶

3.08 As the Irish family unit is getting smaller, with increased levels of women entering the work force, it can no longer be assumed that home care will be provided by family members. It is thus unsurprising that many people are worried about the costs associated with paying for care for older relatives. The Comptroller and Auditor General's Report for 2010, *Accounts of the Public Services*, highlighted the unsustainable costs of public nursing home care in Ireland. The Report noted that the average cost of care in a public nursing home is €1,245 a week, compared with €865 in private homes.¹⁷ Submissions

¹² *Long-term Care Report* (2002) at paragraph 8.22.

¹³ *Fifty Plus in Ireland 2011: First Results from the Irish Longitudinal Study on Ageing (TILDA)*, at 217, available at www.tilda.ie.

¹⁴ *Fifty Plus in Ireland 2011: First Results from the Irish Longitudinal Study on Ageing (TILDA)*, at 2, available at www.tilda.ie.

¹⁵ *Fifty Plus in Ireland 2011: First Results from the Irish Longitudinal Study on Ageing (TILDA)*, at 18 and 19, available at www.tilda.ie.

¹⁶ *Fifty Plus in Ireland 2011: First Results from the Irish Longitudinal Study on Ageing (TILDA)*, at 19, available at www.tilda.ie.

¹⁷ Report of the Comptroller and Auditor General *Accounts of the Public Services* September 2011.

received by the NESF in their Report *Care for Older People*, highlighted the concerns which many people have surrounding the costs of hospital care, primary care and nursing home care. Many people who made submissions considered that routine health examinations were already quite expensive, especially for older people living on a low pension and those who do not qualify for a medical card. This has led some older people to neglect their health due to the costs attached to GP visits and medication.¹⁸

3.09 The European Commission has noted that the working age population (15-64 years) will decrease by 48 million between now and 2050. This will result in a change from the EU having four to only two people of working age for each citizen 65 and older.¹⁹ The European Commission has thus urged that reforms on public spending on pensions and health should not be delayed until such spending has risen. To do so would be a missed opportunity to ensure that every generation contributes to the necessary adjustment process.²⁰ The Commission notes the findings of a recent study undertaken on behalf of the ESRI that, in spite of the increases in expenditure on healthcare in recent years, Ireland still spends less per capita on health than many other OECD countries and performs poorly in terms of aggregate health outcomes such as life expectancy and mortality rates.²¹ The Commission is thus of the opinion that planning for care is a major policy issue and it is necessary to decide on the future financing of long-term care.

C Funding Long-term Care

3.10 An increase in people living longer must be welcomed. This increase indicates improvements in medical science, improved hospital practices as well as improvements in the health and well being of Irish people. Older people can also contribute to both their own families and society as a whole. However as older people may have more health concerns, there may be future budgetary implications for long-term care funding to address.

¹⁸ National Economic and Social Forum *Care for Older People* (2005) Report 32 at 116.

¹⁹ European Commission *The Demographic Future of Ireland-from Challenge to Opportunity* (October 2009) at 5.

²⁰ *Ibid* at 7.

²¹ Nolan "Health: Funding, Access and Efficiency", in O'Hagan and Newman (eds) *The Economy of Ireland* 11th ed (Gill & Macmillan 2011) Chapter 12.

3.11 In 2004, care services for older people cost almost €1 billion.²² Despite this spend, only Spain and Portugal spent proportionally less on care for older people.²³ When examined further, almost half of the €1 billion euro spent was spent on residential care, despite residential care only covering 5% of older people. It is thus unsurprising that in 2005 NESF recommended increased spending on care services for older people to attain, at least, the OECD average of 1% of GDP.²⁴

3.12 Since 2005, however, a number of notable developments have occurred, namely the introduction of the *Social Care and Professionals Act 2005* and the establishment of HIQA under the *Health Act 2007*. Also, the introduction of health care packages increased expenditure on community care services for older people. These developments have sought to improve the quality of care for people receiving health care services in Ireland. However, the onset of a recession in the latter half of 2008, together with the lack of national standards for home care packaged,²⁵ made the provision of services for older people more susceptible to a lack of resources and serve to perpetuate existing inequities in the delivery of services.

3.13 The Expert Group on Resource Allocation and Financing in the Health Sector, established in April 2009, was asked to examine how the existing system of resource allocation within the Irish public health service could be improved to better support the aims of the health reform programme. In its Report, published in July 2010, the Group described the poorly developed system of community health services as the greatest deficiency in the current provision of public health services in Ireland.²⁶ The Group noted that the

²² National Economic and Social Forum *Care for Older People* Report No. 32 (2005) at Table 1.2.

²³ *Ibid* at paragraph 1.11.

²⁴ *Ibid* at paragraph 1.14.

²⁵ As mentioned earlier, the HSE introduced Draft National Quality Guidelines for Home Care Support Services in 2008 but these guidelines have yet to be formally implemented. According to the HSE's *National Service Plan 2011*, the National Quality Guidelines for Home Care Services were to be implemented in the second quarter of 2011. The HSE's *National Service Plan* also noted that its strategic priority for 2011 and beyond would be to maintain older people in their own home for as long as possible. HSE *National Service Plan 2011*, at 44.

²⁶ *Report of the Expert Group on Resource Allocation and Financing in the Health Sector* (Department of Health and Children 2010) at 48.

community health sector in Ireland remains small and weak when compared to provisions in other European countries.²⁷

3.14 Due to the mix of public, private and family care involved in the care of older people, it is difficult to determine the precise cost of providing long-term care in the future. Differing approaches have been taken by European Union countries to cope with the specific budgetary demands of this type of care:

- Some countries, such as the Netherlands and Germany, have created a single funding stream;
- The scope of public funding has been reduced, such as in the Netherlands, where the social insurance-based system has dramatically reduced the scope of services;
- England, among other countries, has invested heavily in disease prevention services;
- Some countries, such as Germany, have frozen benefit levels while costs continue to rise, thus increasing the amount of individual contributions;
- Means-testing has been tightened in other countries.²⁸

3.15 In most OECD countries, there is a mix of private and public funding for long-term care. While long-term care is funded out of public funds, this is supplemented by informal care, “substantial co-payments and/or out-of-pocket spending for care provided under public programmes.”²⁹ Thus, generally older people contribute towards their long-term care regardless of the funding model in operation.

3.16 An OECD Report on *Long-term Care for Older People* notes that the level of public spending on long-term care is not dictated by a rise in the population of older people. Rather, the funding model, the level of cost sharing and the quality of care play important roles in determining the level of public funding for such long-term care.³⁰ Despite increasing public funds for long-term care, informal care continues to have an important role in the providing this

²⁷ *Ibid* at 48.

²⁸ World Health Organisation *Home Care in Europe: The Solid Facts* (2008) at 19-20.

²⁹ OECD *Long-term Care for Older People* (2005) at 29.

³⁰ *Ibid* at 30.

service. In Sweden, which has a comparatively high level of expenditure on public services, two-thirds of all long-term care is provided by informal carers.³¹

3.17 Currently in Ireland, long-term care is provided on a means tested basis, with those who can afford to do so paying for their own care. However due to the increased budgetary demands an aging population will bring, the Commission is of the opinion that it is necessary to formulate a long-term plan to fund long-term care. Until such a plan is in place it is likely that the current system will remain. The Commission, however, is concerned that the current system cannot continue indefinitely if the Government's policy to encourage older people to remain living in the community is to come to fruition. For example, while the introduction of home care packages is welcomed, budgetary constraints have led to waiting lists in many local health offices. In the summer of 2008, it was discovered that in some Dublin local health offices, new clients could only access a health care package when another client stopped availing of it.³² In a 2010 report by SIGA, reference was made to the effect of the current economic climate on the HSE's ability to provide home care packages, noting that further cutbacks had been made in relation to the home care packages scheme, home helps and other community based services for older people.³³

3.18 The Commission welcomes the proposed review of the balance of funding between residential and community care that is to take place as part of the commitment of the Department of Health to review the sustainability of the Nursing Home Support Scheme in 2012 and the relative costs of public versus private provision.³⁴ The Commission notes that if people do not receive the care services they require early, their health concerns can become acute. Such a system costs more in the long term due to the increased need for hospital admissions. Thus in recognition of the budgetary benefits that preventative medicine brings, the Commission is of the opinion that this position should change.

³¹ *Ibid* at 50.

³² National Economic and Social Forum *Implementation of the Home Care Packages Scheme* Report No. 38 at paragraph 4.64.

³³ Special Interest Group on Ageing (SIGA) *Annual Report 2010 – 2011*, available on the Irish Association of Social Workers website, www.iasw.ie

³⁴ Department of Health *Comprehensive Review of Expenditure* September 2011.

3.19 In 2002 a report was commissioned by the Department of Social and Family Affairs to examine specifically the financing of long-term care in Ireland (the Mercer Report).³⁵ The Report considered three broad areas:

- The potential of the private sector or a combined public/private approach to assist in financing/funding long-term care;
- The potential of the PRSI system to finance/fund long-term care;
- Whether the current system of long-term care financing (through taxation) should remain the status quo.³⁶

3.20 Long-term care was broadly defined as “care provided to those who are unable to look after themselves without support due to long-term physical disability or cognitive impairment disability.”³⁷ This was said to include practical help, personal care, paramedical services and medical services. The Report pointed out that there was no blueprint solution which Ireland could adopt. However, it was noted that there is a consensus within the European Union that long-term care should be publically financed. Despite this, due to the projected demographic changes, individuals should be required to make some provision for their future care.³⁸

3.21 Finally, it was noted that not only will demographic changes have an impact on the financing of long-term care but future generations requiring long-term care will come from the “consumer society” and thus are likely to have higher expectations as to their care.³⁹ However, the Commission notes that this “consumer society” was partly brought about by an increase in income and disposable income for many people living in Ireland. The Commission thus considers that it is possible for many people to contribute towards their future long-term care. However, what is important is that a planned policy for the funding of long term care is essential.

3.22 In 2008, a number of consultative events were held in England to determine the public’s opinion with regard to reforming the system of long-term care.⁴⁰ It was generally agreed that the system was in need of reform. The

³⁵ Department of Social and Family Affairs *Study to Examine the Future Financing of Long-Term Care in Ireland* (2002).

³⁶ *Ibid* at paragraph 1.3.

³⁷ *Ibid* at paragraph 2.2.

³⁸ *Ibid* at paragraph 3.35.

³⁹ *Ibid* at paragraph 2.18.

⁴⁰ See COI *The Case for Change-Why England needs a New Care and Support System: Engagement Findings*.

public were in agreement that any reform of the system should protect people who are unable to fund their own care, but should also encourage and reward people who plan for their future care.⁴¹ There was a strong consensus that people should pay more in the future, but there was little agreement on how this should be implemented.⁴² There was however, broad agreement that any reform of the current system must be transparent and sustainable with wide support for ring-fenced budgets.⁴³ While this consultative process took place in England, a similar case could be made for the reform of financing long-term care in Ireland. In the Irish context, in 2009, the McCarthy Report proposed charges for Home Care Packages. The question of charges is being examined by the Department of Health in the wider context of eligibility for community based services for older people and it is possible that such charges may be introduced in the future.⁴⁴

(1) Taxation

3.23 In Ireland at present, funding from taxation pays around 80% of the costs of health care.⁴⁵ The Mercer Report noted that 44% of the Irish population favoured financing long-term care through taxation.⁴⁶ However, the Report also noted that countries which have adopted tax based models to fund the health care system have experienced difficulties in reaching agreement on how long-term care should be financed in the future. This led the Group to conclude that there may be difficulties in financing long-term care in Ireland through taxation.⁴⁷

3.24 Nevertheless public taxation currently funds long-term care in Ireland through the Fair Deal Scheme, Home Care Packages and public health nurses to name but a few. The Mercer Report noted a few advantages with taxation funding long-term care:

- Public financing can provide both risk pooling and income redistribution;

⁴¹ *Ibid* at 49.

⁴² *Ibid* at 53.

⁴³ *Ibid*.

⁴⁴ Department of Health *Comprehensive Review of Expenditure* (September 2011), at 133.

⁴⁵ *Fifty Plus in Ireland 2011: First Results from the Irish Longitudinal Study on Ageing (TILDA)*, at 5, available at www.tilda.ie.

⁴⁶ *Ibid* at paragraph 2.73.

⁴⁷ *Ibid* at paragraph 3.20.

- The cost of care is redistributed over the population, however an aging population will increase this cost;
- Structures are currently in place to finance long-term care through taxation;
- In theory, benefits and services can be provided on a universal basis.⁴⁸

3.25 Despite the benefits such a scheme would bring, the Report was conscious of the numerous pitfalls:

- Significant additional resources are required to enhance current long-term care provision. The possibility of improving resources through additional taxation may not be possible;
- Currently funds for the provision of long-term care are not ear marked, thus the budget for long-term care is subject to considerable variation;
- In practice it is very difficult to provide universal coverage and services will be most likely subject to means testing;
- It would not be possible to pre-fund any of the expected increase in long-term care costs due to the aging population.⁴⁹

3.26 The Report noted that if the State opted to develop a public/private financing option, it would be necessary to develop and implement a clearly defined and lasting policy on the benefits and services to be provided. The Mercer Group also considered that the provision of home care services should be placed on a statutory footing, thus giving people an entitlement to home care services. It is for this reason that the Group considered that long-term care should not be funded through general taxation. The Report concluded that an entitlement-based system is much more suited to being funded through social insurance.

3.27 In 1993, Austria introduced a tax funded system to provide long-term care. Allowances are payable in cash only and payment will depend upon an assessment of the needs of the person. The system was introduced to prevent inequity and to support home care. While new allowances are funded through general taxation, contributions to health insurance in Austria have risen by 0.8% for the self-employed and farmers and 0.5% for retired people.⁵⁰

⁴⁸ *Ibid* at paragraph 6.98.

⁴⁹ *Ibid* at paragraph 6.99.

⁵⁰ OECD *Long-term Care for Older People* (2005) at 81.

(a) Tax relief

3.28 In the Consultation Paper the Commission provisionally recommended extending section 469 of the *Taxes Consolidation Act 1997* to provide tax relief for fees incurred by an individual in meeting the cost of home care. Currently under section 469 of the 1997 Act, tax relief is available to individuals who have incurred health care expenses, which includes nursing home fees. This Scheme, however, is not extended to a taxpayer who incurs expenditure for home care services. The Commission's view as expressed in the Consultation Paper was that this was inequitable and inconsistent with the Government's policy to encourage community based care.⁵¹

3.29 An alternative solution to extending the tax relief system to the taxpayer who incurs home care expenses can be found under section 467 of the 1997 Act. Under this section, a person may claim tax relief up to €50,000 if they employ a carer to assist an incapacitated relative. A relative in this context is a relative of the individual tax payer, a civil partner, a spouse or a relative of a civil partner or spouse. While a person may claim tax relief under section 467 if they employ a carer to assist an incapacitated relative, for the purposes of equity and consistency, section 469 of the 1997 Act could also be extended to provide tax relief for fees incurred in meeting the cost of home care.

(2) Social insurance

3.30 The benefits of funding long-term care through social insurance are quite similar to the benefits of taxation: it can combine risk pooling with income redistribution, structures are currently in place to fund long-term care through social insurance and people already receive benefits under the social insurance scheme. However the Mercer Report noted some distinguishing features: entitlement to benefits is dependent on contributions paid, social insurance contributions are ring-fenced and provide social insurance benefits only and benefits are automatic once a person contributes and thus not subject to means testing.⁵² The Report noted the considerable benefits of a social insurance scheme for funding long-term care:

- A public social insurance scheme would provide a stable and lasting framework in which to fund long-term care while also raising the public's awareness of long-term care issues;

⁵¹ Law Reform Commission *Consultation Paper Legal Aspects of Carers* (LRC CP 53-2009) at paragraph 4.26.

⁵² Department of Social and Family Affairs *Study to Examine the Future Financing of Long-Term Care in Ireland* (2002) at paragraph 6.101.

- A national entitlements structure would provide equity and would also be structured to favour home care over residential care;
- The social insurance scheme is transparent as there is a clear linkage between contributions and benefits;
- As a social insurance scheme would be based on entitlement and, importantly, it would remove the welfare stigma associated with a means-tested system;
- A social insurance scheme can potentially be pre-funded;
- The public may be more willing to pay additional social insurance contributions than higher taxes to fund long-term care.⁵³

3.31 Despite the perceived benefits of a social insurance scheme, the Mercer Report noted a number of potential difficulties:

- Benefits would be required for those who are not working and thus not contributing to the scheme;
- Those with assets are not required to make use of those assets to contribute towards their long-term care;⁵⁴
- A social insurance scheme would give rise to a higher level of inter-generational transfers than broader tax-based financing, although this could potentially be addressed by requiring that pensioners continue to pay contributions in respect of long-term care benefits;
- Funding long-term care through social insurance may reduce the ability of the government to control expenditure;
- Funding long-term care through social insurance will be affected by changes in economic growth, thus it will be necessary to supplement the scheme in times of recession.⁵⁵

⁵³ *Ibid* at paragraph 6.102.

⁵⁴ While the Mercer Report noted that a potential difficulty with social insurance schemes would be that people who could afford to make a contribution towards the costs of their long-term care would not be required to do so, matters have progressed since then and in 2007 the Fair Deal Scheme saw the introduction of a model of funding nursing home care whereby those who were in a position to make a contribution towards the costs of their nursing home care would make such a contribution. See *Nursing Home Support Scheme Information Booklet* available at www.hse.ie.

⁵⁵ *Ibid*.

3.32 The Mercer Report noted that health care in Ireland is financed through taxation, the health levy⁵⁶ and voluntary health insurance. While health care is not funded through social insurance, people are accustomed to contributing directly to health care costs. The Report thus recommended that financing long-term care in Ireland could be achieved through a social insurance scheme.⁵⁷ The Group did discuss the potential difficulty in funding long-term care for those who were not in a position to contribute. The Group raised the possibility of designating income from a social insurance scheme to fund long-term care for older people, while long-term care for younger people with a disability could be funded through general taxation. However, it was noted that such a policy could create a two tier system with many older people not qualifying for benefits.⁵⁸

3.33 It was noted, however, that the majority of people who would not qualify for social insurance benefits would qualify for benefits under a means tested basis. Thus it was recommended that the level of long-term care provided under a social insurance scheme and through social assistance beneficiaries should be equal.⁵⁹

3.34 In 1999, Luxembourg reformed its social insurance system to cover long-term care. 45% is funded from general taxation; the individual pays a 1% contribution based on their salary or pension, with the remainder funded through a special tax on electricity bills. The benefits provided under the scheme provide both home and institutional care and benefits are provided

⁵⁶ The *Report of the Expert Group on Resource Allocation and Financing in the Health Sector* (July 2010), at 63, noted that the health levy, or the amount of money earmarked each year for health care, is too small to affect decisions on the overall level of public health expenditure in Ireland.

⁵⁷ Support for the funding of long-term care by way of a social insurance scheme is strong. This approach to funding was also advocated by Comhairle in its submissions to the Department of Social and Family Affairs at the time of the writing of the *Consultation Document on the Study to Examine the Future Financing of Long-term Care in Ireland*. In its submissions, Comhairle expressed its agreement with the proposal that “long-term care services should be funded by Social Insurance. We would, however, point out that general taxation must continue to play a significant role in health and service provision for people requiring long-term care and that the levying of social insurance contributions on investment income (as is the practice in some countries) should also be considered.”

⁵⁸ *Ibid* at paragraph 6.108.

⁵⁹ *Ibid* at paragraph 6.110.

based on the extent of a person's need.⁶⁰ While projections on the future financial sustainability of the plan are currently not available, from 1999-2003, the Luxembourg long-term care insurance had an annual budget surplus.⁶¹

3.35 Since 2000, Japan also has a public long-term insurance scheme in operation. 50% is funded from general taxation, 32% from employee contributions with pensioners contributing the remaining 18%. There is no single rate of contribution. It is dependent on income up to a maximum with social assistance funds subsidising the contributions of those on the lowest incomes. Only people over 40 years of age currently contribute to the scheme.⁶²

3.36 The transition to the new scheme appears to have improved the system with an increase in the choice of home care services and a reduction in levels of inappropriate hospitalisations. However, an ageing population in Japan has led many to be concerned about the future of the scheme. It is thought that average contributions may have to grow by 80% within the next ten years to ensure that the scheme can be sustained.⁶³

(3) Universal benefit

3.37 The Mercer Report considered the possibility of funding long-term care through an earmarked, ring-fenced tax. Such a statutory scheme would give universal benefit and would not be means tested. While a person would not need to have contributed to the scheme in order to benefit, there would be a clear link between payment of the tax and long-term care. The Report noted that a similar system is currently in place: each employee pays a health levy. This levy could be earmarked for long-term care.⁶⁴ A universal benefit scheme shares many of the benefits with that of a social insurance scheme. Such an earmarked tax would ensure that long-term care services would not compete with other health care services for funding. However, a universal benefit scheme would also share many of the problems associated with a social insurance scheme, for example, a universal benefit scheme would result in a rise in taxation which could be met with much resistance. However, a Report setting out the findings of the 2011 Pfizer Health Index showed that the majority of Irish people want a fairer health system based on need, even if it means

⁶⁰ OECD *Long-term Care for Older People* (2005) at 83.

⁶¹ *Ibid* at 84.

⁶² *Ibid*.

⁶³ *Ibid*.

⁶⁴ Department of Social and Family Affairs *Study to Examine the Future Financing of Long-Term Care in Ireland* (2002) at paragraph 6.113.

having to pay more tax.⁶⁵ The Report cautioned that the apparent enthusiasm for universal healthcare access might be limited by a more rigorous debate on the costs and principles underlying any such scheme.⁶⁶

(4) Universal Health Insurance

3.38 A Universal Health Insurance (UHI) scheme, which at the time of writing (December 2011) is under active consideration by the Government, every citizen would be insured for their health care needs. Under a UHI system, insurers would be obliged to offer the same package of services to all people. In October 2011, the Government gave approval for an Implementation Group on Universal Health Insurance to lay the necessary foundations for the introduction of the scheme.

(5) Private insurance

3.39 In Ireland, nearly half of the population has supplementary private health insurance and most people face full cost fees for using primary care services.⁶⁷ As regards payment for primary care, the position for older adults is somewhat different. For example, TILDA found that 97% of those aged 80 or over have medical cards that exempt them from paying fees for primary care and hospital care. Furthermore, 91% of people in their 70s have medical cards and 30% of those in their 50s. Despite the high level of medical card holders in the older population in Ireland, nearly 60% of people between 50 and 69 have

⁶⁵ “Majority back universal healthcare, survey finds” *The Irish Times*, 25 October 2011; “Most Back Universal Healthcare” *Belfast Telegraph*, 24 October 2011.

⁶⁶ The 2011 Pfizer Health Index, available at www.pfizer.ie.

⁶⁷ *Fifty Plus in Ireland 2011: First Results from the Irish Longitudinal Study on Ageing (TILDA)*, at 5, available at www.tilda.ie. See also the *Report of the Expert Group on Resource Allocation and Financing in the Health Sector* (July 2010), which noted, at 44, that notwithstanding the eligibility for heavily subsidised public hospital care, in Ireland in 2009, close to 50% of the population held supplementary private health insurance, which mainly covers hospital care. The Report attributed the high percentage of people bearing private health insurance in Ireland to, in part, the unusual role of the VHI in the Irish health-care sector and the late arrival of free hospital cover in Ireland. According to the Report, the high level of uptake on this type of insurance also reflects the fact that private health insurance in Ireland has been available at low prices in comparison with other countries, which in turn has been linked to the limited scope of services covered, subsidy of services in public hospitals and the availability of tax relief on premiums.

private medical insurance. This drops to 46% for those in their 70s and 32% for those over 80.⁶⁸

3.40 While long-term health insurance policies are not yet available in Ireland, such insurance policies are available in other countries. However, such a method to finance long-term care is viewed as inadequate as insurance companies may refuse cover to people who may have a high risk of illness e.g., a person with a family history of Alzheimer's disease.⁶⁹ Such insurance is also not suitable for people who need long-term care from an early age. It has also been noted that experiences in other countries has shown that premiums are not spread out over a person's lifetime as people generally do not purchase such insurance until they are in their sixties.⁷⁰ The Mercer Report noted that the take-up of long-term care insurance, were this to be an option, would be affected by:

- The unwillingness of people to focus on the probability that they may need long-term care;
- Perceptions as to the probability of needing care and the likely duration of that need (research has shown that Irish people underestimate their life expectancy);
- The level of understanding of what the State will and will not provide and uncertainty as to the future role of the State.⁷¹

3.41 The Mercer Report thus concluded that while there is a role for long-term care insurance in Ireland, this is a very limited role. The Group was of the opinion that long-term care insurance was likely to be taken up by people who wished to protect their assets and people wishing to provide for the cost of more expensive care.⁷²

3.42 The Mercer Report raised the option of a compulsory private insurance scheme. A number of advantages of such an approach were noted:

- Younger people who may not consider their future long-term care needs would have insurance to cover these needs;

⁶⁸ *Fifty Plus in Ireland 2011: First Results from the Irish Longitudinal Study on Ageing (TILDA)*, at 204, available at www.tilda.ie.

⁶⁹ Department of Social and Family Affairs *Study to Examine the Future Financing of Long-Term Care in Ireland* (2002) at paragraph 6.39.

⁷⁰ *Ibid* at paragraph 6.41.

⁷¹ *Ibid* at paragraph 6.47.

⁷² *Ibid* at paragraph 6.53.

- A compulsory scheme would have a large number of subscribers thus lower the risk and the cost of insurance;
- A compulsory scheme would ensure that even those considered a high risk would be covered;
- Administrative savings would come from an economy of scale.⁷³

3.43 Despite the benefits of such a scheme, the Report considered that a compulsory private insurance scheme is not an appropriate solution to financing long-term care in Ireland:

- It may not be rational to expect young people to insure the risk of long-term care, which is most likely to be required at the end of their life, while they have mortgages to pay;
- Such a scheme may increase the cost. As private insurance will cover the cost of formal care, people will be more likely to avail of formal care over informal care;
- A compulsory scheme will be seen as a further tax on income and have an impact on the economy's competitiveness;
- Such a scheme provides for long-term care for older people and not for people who require long-term care from birth;
- Problems also arise for people who are unable to pay the premiums as they will be left outside the scheme and have no coverage.⁷⁴

3.44 Germany currently has a public and private scheme of long-term care insurance. The mandatory public scheme covers over 70 million people, while the private insurance scheme covers 8.5 million.⁷⁵ Both retired and working people contribute 1.7% of their gross income, up to a maximum contribution to the public scheme. Employers usually pay 50% with the employee paying the other 50%. Contributions to private long-term care insurance depend upon the age of the recipient and federal regulation. However, private insurance must provide the same cover as that provided under the public scheme.⁷⁶ If the recipient is receiving care in an institution, the service part of the nursing home

⁷³ *Ibid* at paragraph 6.63.

⁷⁴ *Ibid* at paragraph 6.64-6.65.

⁷⁵ These figures are based on 2005 data. See OECD *Long-term Care for Older People* (2005) at 81.

⁷⁶ *Ibid* at 83.

costs are covered (except for accommodation), up to a maximum for three care levels.⁷⁷

(6) Individual contributions

3.45 It has been argued that people should save towards the cost of their potential long-term care. However, as pointed out by the Mercer Report, this is not always feasible as many people on low incomes will not be in a position to do so.⁷⁸ Indeed people who have required long-term care from birth will not be in a position to save for future long-term care. The Report also noted that such an approach does not take into account the uncertainty of long-term care. In other words, a person is unlikely to know in advance the type of care they will need and the length of time such care will be necessary which may leave quite a shortfall to pay for the necessary care. Conversely, many who may never need long-term care will have tied up a substantial resource unnecessarily.⁷⁹ Such factors led the Group to conclude that it is unreasonable to expect people to pay for their long-term care through their savings.⁸⁰

3.46 The majority of countries favour a scheme whereby those who can afford to pay do pay with the state providing full cover only for those who are unable to support themselves.⁸¹ Very often most people are expected to make a contribution to the cost of their long-term care with some financial assistance from the state. The level of contribution each person is expected to make will depend upon their individual financial circumstances.

(7) Nursing Homes Support Scheme

3.47 To The Nursing Homes Support Scheme, known as the Fair Deal Scheme, was introduced under the *Nursing Homes Support Scheme Act 2009*. It is a single funded means of accessing long-term nursing home care. The aim of the Scheme is to equalise State support for public and private long-term care recipients and introduce one transparent system of support towards the cost of care that is fair to all. It replaced the Nursing Home Subvention Scheme which had been in operation under the *Health (Nursing Homes) Act 1990* since 1993. In the Government's 2010 Budget, it was announced that €97 million would be provided in 2010 to support the Scheme in addition to the €55 million provided

⁷⁷ *Ibid.*

⁷⁸ Department of Social and Family Affairs *Study to Examine the Future Financing of Long-Term Care in Ireland* (2002) at paragraph 6.10.

⁷⁹ *Ibid* at paragraph 6.11.

⁸⁰ *Ibid* at paragraph 6.13.

⁸¹ National Council for the Elderly *The Role and Future Developments of Nursing Homes in Ireland* (1991) at 145.

in 2009. In the 2011 Budget, additional funding of €8 million was said to be provided for Home Care Packages. An additional €6 million for the Nursing Homes Support Scheme was also announced. However, the Scheme was suspended in May 2011 because of funding issues. It became operational again in June but there is now a waiting list comprised of people who have had their applications for admission to the Scheme approved but who are waiting to receive their placements until such time as the funding is available.⁸²

3.48 To determine the amount the individual is expected to contribute under the Fair Deal Scheme, a financial assessment of the person's income and assets is carried out. Income includes any earnings, pension income, social welfare benefits or allowance, rental income, income from holding an office or directorship, income from fees, commissions, dividends or interest. Under the *Nursing Homes Support Scheme Act 2009*, an asset includes cash assets such as savings, stocks, shares and securities, or a relevant asset which covers all forms of property other than cash assets. For couples, the assessment is based on half of their combined income and assets.

3.49 Applicants to the NHSS agree to pay up to 80% of their assessable income and 5% of their assets towards the cost of nursing home care each year with the Scheme paying for the remaining cost of care. The first €36,000 (or €72,000 for a couple) worth of assets will not be counted in the financial assessment. The principal residence is only included in the financial assessment for the first three years of a person's time in nursing home care. Thereafter, the principal residence is excluded from the financial assessment. Where a person's assets include land and property in the State, the 5% contribution may be deferred and collected from their estate. This is known as the Nursing Home Loan (the legal term is Ancillary State Support). Thus only 15% of the value of the nursing home resident's family home will go towards the cost of their care. This can also be extended to cover farms and businesses in circumstances where:

- The person has suffered a sudden illness or disability which causes them to need long-term nursing care;
- The person or their partner was actively engaged in the daily management of the farm or business up until the time of the sudden illness or disability;

⁸² Department of Health *Comprehensive Review of Expenditure* (September 2011). The Department has also stated that there is a commitment to formally review the scheme in 2012. The review will look at the ongoing sustainability of the scheme, the relative costs of public versus private provision, and the balance of funding between residential and community care.

- A family successor certifies that he or she will continue the management of the farm or business.

3.50 The purpose of the nursing home loan is to ensure that a person does not have to sell their assets during their lifetime. The loan must be repaid to the Revenue within twelve months of the person's death otherwise interest will accrue. If, however, the loan is based on the principal residence only, repayment can be further deferred even when the person has died. The people who can apply for this further deferral are:

- A spouse or partner;
- A child (or a spouse/partner's child) if they are under the age of 21 years or if their assets do not exceed the asset disregard;
- A sibling if their assets do not exceed the asset disregard;
- A relative in receipt of a disability or similar allowance, blind person's pension, or the State pension (non-contributory), or whose income doesn't exceed the State pension (contributory);
- A relative who is in receipt of a foreign pension or allowance similar to those outlined above;
- A relative who owns a building to which the principal residence is attached;
- Any person who cared for an applicant prior to the latter entering the nursing home (this is defined by reference to relevant social welfare payments).

3.51 Any person who applies for a further deferral, except for a spouse or partner, must have lived in the residence for three years or more prior to the original application to the Nursing Home Loan Scheme, the residence must be their only residence and they must not have an interest in any other property.

3.52 Regardless of income and assets, no one will pay more than the actual cost of their care. A person will also keep 20% of their income or 20% of the maximum rate of the State pension (non-contributory), whichever is greater. If a person's financial contribution does not cover the cost of care, the State will pay the balance.⁸³

3.53 The Commission notes the *Report of the Expert Group on Resource Allocation and Financing in the Health Sector* and its finding that the Fair Deal Scheme had accelerated improved access to community nursing home capacity

⁸³ *Nursing Home Support Scheme Information Booklet* available at www.hse.ie.

and allowed service user greater choice of facility.⁸⁴ The Commission also notes the findings of the *Review of Expenditure* which showed that during May 2011, a total of 21,960 people were in receipt of support from the State for long-term residential care and that of these, over 12,777 were in receipt of financial support under the Nursing Homes Support Scheme.⁸⁵

(8) Conclusion

3.54 The methods of financing health care should be as effective and equitable as possible.⁸⁶ As noted by the Mercer Report, all public financing options (general taxation, social insurance and universal benefit scheme) are suitable to fund long-term care in the medium to long-term. However, financing long-term care through taxation will be subject to budgetary constraints, while contributions towards a social insurance scheme will vary according to the rate of unemployment.

3.55 The Mercer Report, however, favoured a social insurance scheme. The Group was of the opinion that an increase in social insurance contributions would be more favourable than an increase in taxation. A social insurance scheme would also confer an entitlement to services. It was felt that entitlement to home care was important. Such an approach would conform to the Government policy of supporting older people to remain living in the community.

3.56 Internationally, while there are significant differences in the schemes adopted to fund long-term care, many schemes are supported by additional contributions.⁸⁷ Thus individual contributions to long-term care will likely continue however the financing of long-term care may be reformed in Ireland. It is likely that the rise in demand for long-term care will be financed through a rise in general taxation or an increase in social insurance contributions. Increases in taxation or social insurance are often justified as there will be an immediate benefit to the public and this is the most efficient way to insure against the risk.⁸⁸ Whichever scheme Ireland adopts to fund long-term care must be financially sustainable in the long-term.

⁸⁴ *Report of the Expert Group on Resource Allocation and Financing in the Health Sector* (Department of Health and Children 2010) at 50.

⁸⁵ Department of Health *Comprehensive Review of Expenditure* (September 2011) at 128.

⁸⁶ *Report of the Expert Group on Resource Allocation and Financing in the Health Sector* (Department of Health and Children 2010) at 118.

⁸⁷ OECD *Long-term Care for Older People* (2005) at 85.

⁸⁸ *Ibid* at 88.

CHAPTER 4 SUMMARY OF RECOMMENDATIONS

The recommendations made by the Commission in this Report are:

4.01 The Commission recommends that section 8(1)(b) of the *Health Act 2007* be amended to extend the functions of the Health Information and Quality Authority (HIQA) to include the setting of standards in relation to services provided by professional home care providers. [Paragraph 1.55]

4.02 The Commission recommends the amendment of the definition of designated centres in section 2(1) of the *Health Act 2007* to include undertakings (both unincorporated and incorporated, and whether established for gain or not established for gain) who are involved in the provision of professional home care services. The Commission also recommends that the Social Services Inspectorate (SSI) establish a registry of all professional home carers. [paragraph 1.59]

4.03 The Commission recommends that the Ministerial regulation-making power conferred on the Minister for Health by section 101 of the *Health Act 2007* be extended to include the authority to make regulations in respect of undertakings involved in the provision of professional home care services. [Paragraph 1.61]

4.04 The Commission recommends that professional home care should be defined as services which are required to ensure that an adult person can continue to live independently in their own home. This may include, but is not limited to the services of nurses, home care attendants, home helps, various therapies and personal care. The Commission also recommends that palliative care be included in the definition of professional home care. [Paragraph 1.71]

4.05 The Commission recommends that the proposed legislative framework should apply to undertakings who provide professional home care to persons aged 18 years and over. [paragraph 1.76]

4.06 The Commission recommends that a guiding principle of the proposed legislative framework should be the principle of independent living. [Paragraph 1.84]

4.07 The Commission recommends that guiding principles of the proposed legislative framework should be the principles of privacy and dignity. [Paragraph 1.88]

4.08 The Commission recommends that a guiding principle of the proposed legislative framework should be the principle of quality of care. [Paragraph 1.92]

4.09 The Commission recommends that a guiding principle of the proposed legislative framework should be the protection of adults in receipt of professional home care. [Paragraph 1.101]

4.10 The Commission recommends that the Health Service Executive's 2008 draft National Quality Guidelines for Home Care Support Services should form the basis for National Standards for Professional Home Care to be prepared by HIQA under the *Health Act 2007*. The Commission also recommends that the proposed National Standards should provide guidance on all aspects of professional home care, including the detailed requirements derived from the necessary ministerial Regulations on professional home care to be made under section 101 of the *Health Act 2007* (as amended in accordance with the recommendations made in this Report), any protective measures necessary, and the sanctions that will apply in the event of a breach of the National Standards. The Commission also recommends that the National Standards form the basis for the individual contract of care between the professional care provider and the care recipient. [Paragraph 2.05]

4.11 The Commission recommends that an assessment of needs of the care recipient must be carried out prior to the provision of care and that the assessment considers both the needs of and the outcomes desired by the care recipient. [Paragraph 2.16]

4.12 The Commission recommends that care needs should be assessed under the following headings: companionship needs, care needs and the advanced home care needs of the care recipient. Companionship needs may include preparing snacks, monitoring diet and eating, arranging appointments, reminders for medication, overseeing home deliveries and organising visits to neighbours and friends. Home care may include meal preparation, light housekeeping, providing transport, assisting with walking and exercise, assisting with personal hygiene and dressing. Advanced home care involves the highest level of care and may involve some health care. It may include personal care, respite care, dementia care, early Alzheimer's care, assistance with continence and toileting and palliative care. The Commission also recommends that the level of care should be appropriately attuned to the actual needs of the person and that especial care is taken to ensure that the level of care provided is not too high, thereby promoting the autonomy and independence of the care recipient to the fullest degree. [Paragraph 2.19]

4.13 The Commission recommends that an assessment of funding be conducted to determine who is paying for the professional home care and what care can be provided. The Commission recommends that an assessment of

funding be conducted to determine who is paying for the care and what care can be provided. [Paragraph 2.23]

4.14 The Commission recommends that the proposed National Standards should provide that, prior to the commencement of professional home care, a risk assessment must be carried out and that the risk assessment must be reviewed on an ongoing basis. [Paragraph 2.28]

4.15 The Commission recommends that a care plan be drawn up on completion of the needs assessment, the assessment of funding and risk assessment. The care plan should detail the companionship plan, the home care plan and advance home care plan. The Commission also recommends that the detailed content of the care plan and the review process should be set out in the proposed national standards for professional home care. [Paragraph 2.37]

4.16 The Commission recommends that all professional home care service providers make available an easily understood, well publicised and accessible complaints procedure, informed by the proposed national standards for professional home care. [Paragraph 2.42]

4.17 The Commission recommends that a professional home care service provider must have policies in place to ensure that professional home care recipients are protected from all forms of abuse and also recommends that those policies are informed by the proposed national standards. [Paragraph 2.50]

4.18 The Commission recommends that a review of the administration of medicines in the home be carried out, involving representatives of the Department of Health, HIQA, the Medical Council, An Bord Altranais and carer groups. [Paragraph 2.57]

4.19 The Commission recommends that policies and procedures on the administration of medication in the home, informed by the proposed national standards, must be agreed between the professional home care provider and the care recipient and must be included in the care plan. The Commission further recommends that it should be a requirement that a log be kept of all medication administered in the home and be accessible to all. [paragraph 2.59]

4.20 The Commission recommends that policies and procedures on the handling of money and property by the professional care provider on behalf of the care recipient be included in the proposed National Standards. The Commission also recommends that the policies and procedures be included in the contract for care. [Paragraph 2.63]

4.21 The Commission recommends that the proposed National Standards include specific guidance on safety and health requirements in the delivery of

professional care in the home, including suitable guidance on manual handling (and which should be developed in liaison with the Health and Safety Authority). [Paragraph 2.66]

4.22 The Commission recommends that only suitably trained personnel may provide professional home care, and that the proposed national standards should set out relevant and detailed training requirements for those providing professional home care services. [Paragraph 2.72]

4.23 The Commission recommends that the professional home care service provider must adequately supervise the individual home care providers to ensure the maintenance of care standards. The Commission also recommends that, where the Health Service Executive (HSE) contracts with a private service provider, the HSE must then also monitor the service standards provided by the service provider. The Commission also recommends that the professional home care service provider be monitored and inspected by HIQA in accordance with the proposed national standards. [Paragraph 2.76]

4.24 The Commission recommends that a person who wishes to pay for professional home care services should have the choice to contract directly with a private sector care provider or to do so through the Health Service Executive. [paragraph 2.83]

4.25 The Commission recommends that there should be a public awareness campaign to indicate the limited circumstances in which a professional home care recipient could be regarded as an employer. The Commission also recommends that any national standards governing professional home care must also apply to any independent contractors providing such services in a person's own home. [paragraph 2.86]

4.26 The Commission recommends that a care recipient who wishes to enter into an arrangement for the provision of professional home care should have the option to contract with an intermediary, whether a State body (such as the Health Service Executive) or a private sector body (including a voluntary or not-for-profit undertaking), who would arrange for the provision of care. The Commission recommends that the intermediary be responsible for contracting on behalf of the care recipient with an agency, organisation or individual to provide care. The Commission also recommends that the relevant national standards introduced in conjunction with the proposed legislation for the regulation of home care should address arrangements with intermediaries. [paragraph 2.92]

4.27 The Commission recommends that, assuming the enactment of mental capacity legislation, a personal guardian or an attorney appointed under an enduring power of attorney may enter into a contract for the provision of home care on behalf of another person. [paragraph 2.100]

4.28 The Commission recommends that the proposed national standards should set out that a contract for the provision of home care should include specific provisions setting out, in plain and easily understood language, the fee arrangements between the contracting parties for the agreed services. [paragraph 2.102]

4.29 The Commission recommends that a volunteer advocacy service for professional home care recipients be developed and that the voluntary advocates be trained to the same FETAC Level 6 as applies to comparable care advocates in institutional settings. [paragraph 2.110]

DRAFT HEALTH (PROFESSIONAL HOME CARE) BILL 2011

ARRANGEMENT OF SECTIONS

Section

1. Short title and commencement
2. Interpretation
3. Amendment of section 2 of the Act of 2007 (definitions)
4. Amendment of section 5 of the Act of 2007 (general principles)
5. Amendment of section 8 of the Act of 2007 (standards for professional home care)
6. Amendment of section 41 of the Act of 2007 (register of professional home care services)
7. Amendment of section 101 of the Act of 2007 (regulations for professional home care services)
8. Insertion of section 106 into the Act of 2007 (general duties concerning professional home care services)

ACT REFERRED TO

Health Act 2007

2007, No. 23

DRAFT HEALTH (PROFESSIONAL HOME CARE) BILL 2011

BILL

entitled

AN ACT TO PROVIDE FOR THE REGULATION OF PROFESSIONAL HOME CARE, FOR THAT PURPOSE TO AMEND THE HEALTH ACT 2007; AND TO PROVIDE FOR RELATED MATTERS

BE IT ENACTED BY THE OIREACHTAS AS FOLLOWS:

Short title and commencement

1.—(1) This Act may be cited as the Health (Professional Home Care) Act 2011.

(2) This Act comes into operation on such day or days as the Minister for Health may appoint by order or orders either generally or with reference to any particular purpose or provision, and different days may be so appointed for different purposes or provisions.

Explanatory Note

This is a standard section setting out the short title and commencement arrangements.

Interpretation

2.—(1) In this Act, unless the context otherwise requires—

“Act of 2007” means the Health Act 2007;

“Minister” means the Minister for Health.

Explanatory Note

This is a standard section setting out necessary definitions.

Amendment of section 2 of the Act of 2007 (definitions)

3. — (1) Section 2 of the Act of 2007 is amended by the insertion after the definition of “designated centre” of the following —

“ ‘designated centre’ also includes (without prejudice to the above definition) an undertaking (whether unincorporated and incorporated, and whether established for gain or not established for gain) that is involved in the provision of professional home care services;”.

(2) Section 2 of the Act of 2007 is amended by the insertion after the definition of “prescribed” of the following —

“ ‘professional home care’ means services which are required to ensure that an adult person, that is, a person aged 18 years and over, can continue to live independently in their own home, and includes, but is not limited to the services of nurses, home care attendants, home helps, various therapies and personal care, and palliative care;”.

Explanatory Note

Subsection (1) implements the recommendation in paragraph 1.59 to amend the definition of designated centres in section 2(1) of the *Health Act 2007* to include undertakings (both unincorporated and incorporated, and whether established for gain or not established for gain) who are involved in the provision of professional home care services.

Subsection (2) implements the recommendation in paragraph 1.71 that professional home care should be defined as services which are required to ensure that an adult person can continue to live independently in their own home. This may include, but is not limited to the services of nurses, home care attendants, home helps, various therapies and personal care. It also implements the recommendation in paragraph 1.71 that palliative care be included in the definition of professional home care. It also implements the recommendation in paragraph 1.76 that the proposed legislative framework should apply to undertakings who provide professional home care to persons aged 18 years and over.

Amendment of section 5 of the Act of 2007 (general principles)

4. — Section 5 of the Act of 2007 is amended by the insertion of the following subsection after subsection (4) —

“(5) In carrying out its functions concerning professional home care the Authority shall have regard to the following general principles as they apply to the adults to whom such care is provided—

(a) the principle of independent living,

(b) the principles of privacy and dignity,

(c) the principle of quality of care, and

(d) the protection of those adults.”

Explanatory Note

This section implements the recommendations in paragraphs 1.84, 1.88, 1.92 and 1.101 on the guiding principles to be applied in the legislative framework.

Amendment of section 8 of the Act of 2007 (standards for professional home care)

5. — (1) Section 8 of the Act of 2007 is amended by the insertion in subsection (1)(b) after “1990,” of the following—

“and,

(iii) services provided by professional home care providers,”.

(2) Section 8 of the Act of 2007 is amended by the insertion of the following after subsection (4)—

“(5) Without limiting the generality of *subsection (1) to (4)*, standards set by the Authority under this section concerning the provision of professional home care services, within the meaning of

the additional designation of “designated centre” in section 2 (as inserted by section 2(1) of the *Health (Professional Home Care) Act 2011*)—

- (a) shall provide guidance on all aspects of professional home care, and shall—
 - (i) include all the requirements in the Health Service Executive’s 2008 draft *National Quality Guidelines for Home Care Support Services* (or any replacement equivalent document), and
 - (ii) include requirements derived from regulations on professional home care made under section 101 (as amended by section 7 of the *Health (Professional Home Care) Act 2011*), any protective measures necessary, and the sanctions that apply in the event of a breach of the standards, and
- (b) shall form the basis for the individual contract of care between the professional care provider and the care recipient, and
- (c) shall provide that, prior to the commencement of professional home care, a risk assessment shall be carried out and that the risk assessment be reviewed on an ongoing basis, and
- (d) shall include requirements concerning the care plan required under section 106 (inserted by section 8 of the *Health (Professional Home Care) Act 2011*), including the companionship plan, the home care plan and advance home care plan, and
- (e) shall include requirements concerning the handling of money and property by the professional care provider on behalf of the care recipient, and
- (f) shall include specific guidance on safety and health requirements in the delivery of professional care in the home, including suitable guidance on manual handling (which shall be developed in liaison with the Health and Safety Authority), and
- (g) shall include relevant and detailed training requirements for those providing professional home care services, and

- (h) shall provide that a contract for the provision of home care shall include specific provisions setting out, in plain and easily understood language, the fee arrangements between the contracting parties for the agreed services.”.

Explanatory Note

Subsection (1) implements the recommendation in paragraph 1.55 that section 8(1)(b) of the *Health Act 2007* be amended to extend the functions of the Health Information and Quality Authority (HIQA) to include the setting of standards in relation to services provided by professional home care providers.

Subsection (2)(a) and (b) implement the recommendations in paragraph 2.05 that: the Health Service Executive’s 2008 draft *National Quality Guidelines for Home Care Support Services* should form the basis for National Standards for Professional Home Care to be prepared by HIQA under the *Health Act 2007*; that the proposed National Standards should provide guidance on all aspects of professional home care, including the detailed requirements derived from the necessary ministerial Regulations on professional home care to be made under section 101 of the *Health Act 2007* (as amended in accordance with the recommendations made in this Report), any protective measures necessary, and the sanctions that will apply in the event of a breach of the standards; and that the standards form the basis for the individual contract of care between the professional care provider and the care recipient. *Subsection (2)(c)* implements the recommendations in paragraph 2.28 concerning risk assessments. *Subsection (2)(d)* implements the recommendations in paragraph 2.37 concerning the care plan (see section 8(2) of the Bill, below), including the companionship plan, the home care plan and advance home care plan. *Subsection (2)(e)* implements the recommendations in paragraph 2.63 that the standards include requirements concerning the handling of money and property by the professional care provider on behalf of the care recipient. *Subsection (2)(f)* implements the recommendations in paragraph 2.66 that the standards include specific guidance on safety and health requirements in the delivery of professional care in the home, including suitable guidance on manual handling (which are to be developed in liaison with the Health and Safety Authority). *Subsection (2)(g)* implements the recommendations in paragraph 2.72 that the standards include relevant and detailed training requirements for those providing professional home care services. *Subsection (2)(h)* implements the recommendations in paragraph 2.102 that the standards provide that a contract for the provision of home care must include specific provisions setting out, in plain and easily understood

language, the fee arrangements between the contracting parties for the agreed services.

Amendment of section 41 of the Act of 2007 (register of professional home care services)

6. — Section 41 of the Act of 2007 is amended by the insertion in subsection (1)(b) after “centres,” of the following—

“including, without prejudice to any other register or registers, a register of undertakings providing professional home care services within the meaning of the additional designation of “designated centre” in section 2 (as inserted by section 2(1) of the *Health (Professional Home Care) Act 2011*),”

Explanatory Note

This section implements the recommendation in paragraph 1.59 that the Social Services Inspectorate (SSI) establish a registry of all professional home carers.

Amendment of section 101 of the Act of 2007 (regulations for professional home care services)

7. — Section 101 of the Act of 2007 is amended by the insertion of the following after subsection (3)—

“(4) Without limiting the generality of *subsection (1) to (3)*, regulations under this section may apply to an undertaking involved in the provision of professional home care services within the meaning of the additional designation of “designated centre” in section 2 (as inserted by section 2(1) of the *Health (Professional Home Care) Act 2011*).”

Explanatory Note

This section implements the recommendation in paragraph 1.59 that the Ministerial regulation-making power conferred on the Minister for Health by section 101 of the *Health Act 2007* be extended to include the authority to make regulations that apply to an undertaking involved in the provision of professional home care services.

Insertion of section 106 into the Act of 2007 (general duties concerning professional home care services)

8. — The Act of 2007 is amended by the insertion of the following section after section 105—

“General duties concerning professional home care services

106. — (1) (a) An undertaking providing professional home care services shall carry out an assessment of needs of the care recipient prior to the provision of care, and the assessment shall consider both the needs of and the outcomes desired by the care recipient.

(b) The assessment shall include an assessment of companionship needs, care needs and the advanced home care needs of the care recipient, and,

(i) companionship needs may include preparing snacks, monitoring diet and eating, arranging appointments, reminders for medication, overseeing home deliveries and organising visits to neighbours and friends,

(ii) home care may include meal preparation, light housekeeping, providing transport, assisting with walking and exercise, assisting with personal hygiene and dressing,

(iii) advanced home care involves the highest level of care and may involve some health care and may include personal care, respite care, dementia care, early Alzheimer’s care, assistance with continence and toileting and palliative care.

(c) An undertaking providing professional home care services shall ensure that the level of care shall be appropriately attuned to the actual needs of the person and shall, in particular, ensure that the level of care provided is not too high and promotes the autonomy and independence of the care recipient to the fullest degree.

(2) On completion of the assessment of needs, an undertaking providing professional home care services shall draw up a care plan, which shall include the companionship plan, the home care plan and advance home care plan.

(3) An undertaking providing professional home care services shall make available an easily understood, well publicised and accessible complaints procedure.

(4) An undertaking providing professional home care services shall have policies in place to ensure that professional home care recipients are protected from all forms of abuse.

(5) An undertaking providing professional home care services shall

(a) agree with the care recipient policies and procedures on the administration of medication in the home, which shall be included in the care plan, and

(b) maintain a log in the home of all medication administered, which shall be accessible to all.

(6) An undertaking providing professional home care services shall include in the contract for care policies and procedures concerning the handling of money and property by the professional care provider on behalf of the care recipient.

(7) An undertaking providing professional home care services shall ensure that only suitably trained personnel may provide professional home care.

(8) An undertaking providing professional home care services shall adequately supervise the individual home care providers to ensure the maintenance of care standards.”

Explanatory Note

Subsection (1) implements the recommendation in paragraphs 2.16 and 2.19 that an assessment of needs of the care recipient must be carried out prior to the provision of care and that the assessment considers both the needs of and the outcomes desired by the care recipient. The assessment must include an assessment of companionship needs, care needs and the advanced home care needs of the care recipient. Companionship needs may include preparing snacks, monitoring diet and eating, arranging appointments, reminders for medication, overseeing home deliveries and

organising visits to neighbours and friends. Home care may include meal preparation, light housekeeping, providing transport, assisting with walking and exercise, assisting with personal hygiene and dressing. Advanced home care involves the highest level of care and may involve some health care and may include personal care, respite care, dementia care, early Alzheimer's care, assistance with continence and toileting and palliative care. An undertaking providing professional home care services must also ensure that the level of care is appropriately attuned to the actual needs of the person and must, in particular, ensure that the level of care provided is not too high and promotes the autonomy and independence of the care recipient to the fullest degree. *Subsection (2)* implements the recommendations in paragraph 2.37 concerning a care plan, which must include the companionship plan, the home care plan and advance home care plan. See also section 5(2)(d) of the Bill, above. *Subsection (3)* implements the recommendations in paragraph 2.42 that an undertaking providing professional home care services must make available an easily understood, well publicised and accessible complaints procedure. *Subsection (4)* implements the recommendations in paragraph 2.50 that an undertaking providing professional home care services must have policies in place to ensure that professional home care recipients are protected from all forms of abuse. *Subsection (5)* implements the recommendations in paragraph 2.59 that an undertaking providing professional home care services must agree with the care recipient policies and procedures on the administration of medication in the home, which must then be included in the care plan; and must maintain a log in the home of all medication administered, which must be accessible to all. *Subsection (6)* implements the recommendations in paragraph 2.63 that an undertaking providing professional home care services must include in the contract for care policies and procedures concerning the handling of money and property by the professional care provider on behalf of the care recipient. *Subsection (7)* implements the recommendation in paragraph 2.72 that only suitably trained personnel may provide professional home care. *Subsection (8)* implements the recommendation in paragraph 2.76 that an undertaking providing professional home care services must adequately supervise the individual home care providers to ensure the maintenance of care standards.



The Law Reform Commission is an independent statutory body established by the *Law Reform Commission Act 1975*. The Commission's principal role is to keep the law under review and to make proposals for reform, in particular by recommending the enactment of legislation to clarify, modernise and consolidate the law.

This role is carried out primarily under a Programme of Law Reform. The Commission's *Third Programme of Law Reform 2008-2014* was prepared and approved under the 1975 Act following broad consultation and discussion. The Commission also works on specific matters referred to it by the Attorney General under the 1975 Act. The Commission is also involved in making legislation more accessible through Statute Law Restatement, the Legislation Directory and the Classified List of Legislation in Ireland. Statute Law Restatement involves the administrative consolidation of all amendments to an Act into a single accessible text. The Legislation Directory is a searchable annotated guide to legislative changes. The Classified List of Legislation in Ireland comprises all Acts of the Oireachtas that are in force, organised under 36 major subject-matter headings.

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The Law Reform Commission is a statutory body established by the Law Reform Commission Act 1975