

## Nursing Homes Support Scheme, *A Fair Deal*Summary of Submissions Received to Inform the Review of the Scheme

December 2012

#### Please Note -

The Views, Comments and Opinions and Recommendations contained in this Report are derived from written submissions received following a call for submissions to inform the Review of the Nursing Homes Support Scheme. They do not necessarily concur with those of the Minister for Health, the Minister of State for Disability, Equality, Mental Health and Older People, nor officials of the Office for Older People at the Department of Health.

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### FOREWORD BY KATHLEEN LYNCH, T.D. MINISTER FOR DISABILITY, EQUALITY, MENTAL HEALTH AND OLDER PEOPLE

When the Nursing Homes Support Scheme, *A Fair Deal*, was introduced in October 2009, a commitment was made that it would be reviewed after three years. The reason for allowing this period to elapse was to ensure that the Scheme had bedded in and that established and validated trends and statistics would be available in order to inform the work.

Public consultation is a key component of effective policy development. It was considered essential that those availing of financial support under the Scheme, along with their families and friends, medical professionals, statutory bodies, representative groups and other stakeholders would be given an opportunity to express their views and inform the review. These are the people with the on the ground knowledge of what works well and what could be improved.

On foot of the call for submissions which issued on the 14<sup>th</sup> June, the Department received submissions from a broad range of individuals, statutory bodies, professionals, groups representing the interests of older people and organisations in the community and voluntary sector. On behalf of myself and the Office for Older People, I would like to express my thanks to everyone who took the time to share their experience and knowledge in the area of long-term nursing home care.

I am very pleased to present this report which reflects the views submitted during the consultation process. Given the nature of this summary report, it was not possible to reflect every issue raised. However, I can assure those that contributed that every submission made will inform the final review process.

Kathleen Lynch, T.D. Minister of State with responsibility for Disability, Equality, Mental Health and Older People

#### **BACKGROUND**

The Nursing Homes Support Scheme commenced on the 27<sup>th</sup> October 2009. It replaced the scheme of Nursing Home Subvention which had been in existence since 1993, the system of contract beds and Long-Stay Charges in public nursing homes.

The Scheme aims to ensure that long-term nursing home care is accessible and affordable for everyone and that people are cared for the in most appropriate settings.

#### Brief Overview of the Scheme

The first step in the application process is a care needs assessment which is carried out by healthcare professionals. This identifies whether the person can be supported to continue living at home or whether long-term nursing home care is more appropriate. Once it has been determined that long-term nursing home care is the most appropriate option, a financial assessment is carried out to determine the person's contribution towards the cost of their care.

The financial assessment takes account of both income and assets. Individuals contribute 80% of their assessable income and 5% of the value of any assets per annum. Where one member of a couple requires long-term nursing home care, the assessment is based on half of the couple's combined income and assets.

Where an individual's assets include land and property in the State, the 5% contribution based on such assets may be deferred and collected from their estate. This is the optional Nursing Home Loan element of the scheme.

There are several important safeguards built into the scheme which ensure that both the person entering long-term nursing home care and their spouse/partner are adequately provided for:

- i. Nobody will pay more than the actual cost of care.
- ii. The first €36,000 for a person's assets, or €72,000 for a couple, is not taken into account during the financial assessment.
- iii. The principal residence (and farms/businesses in certain circumstances) is only included in the financial assessment for the first three years of a person's time in care.
- iv. Individuals keep a personal allowance of 20% of their income, or 20% of the maximum rate of the State Pension (Non-Contributory), whichever is the greater.
- v. If there is a spouse/partner remaining at home, he/she will retain 50% of the couple's income, or the maximum rate of the State Pension (Non-Contributory), whichever is the greater.
- vi. There is a financial review mechanism which takes account of the fluctuating value of assets and the fact that cash assets will naturally deplete over time as payments are made to the nursing home etc.

The scheme also provides for certain items of expenditure, 'allowable deductions', to be taken into account during the financial assessment. These include health expenses, rent payments and borrowings in respect of a person's principal residence.

Anyone who is assessed as requiring long-term nursing home care can avail of the scheme, regardless of age. However, nursing home care must be appropriate to meet the individual's care needs.

A fundamental principle enshrined in the legislation underpinning the Scheme is that of patient choice. Once a person receives approval for financial support, they can choose to enter any nursing home that is participating in the scheme in any part of the country, subject to the nursing home having an available bed and being able to cater for the person's particular needs. This applies to public, private and voluntary nursing homes alike.

#### REVIEW OF THE NURSING HOMES SUPPORT SCHEME

When the Scheme was introduced in October 2009, a commitment was made that it would be reviewed after three years.

The reason for allowing this period to elapse was to ensure that the Scheme had bedded in and that established and validated trends and statistics would be available in order to inform the work.

The Terms of Reference for the review are:

Taking account of Government policy, demographic trends and the fiscal situation -

- 1. To examine the on-going sustainability of the Nursing Homes Support Scheme.
- 2. To examine the overall cost of long-term residential care in public and private nursing homes and the effectiveness of the current methods of negotiating/setting prices,
- 3. Having regard to 1. and 2. above, to consider the balance of funding between long-term residential care and community based services,
- 4. To consider the extension of the scheme to community based services and to other sectors (Disability and Mental Health), and
- 5. To make recommendations for the future operation and management of the scheme.

The Department of Health will be seeking tenders through the public procurement process for the carrying out of the review. The review should be completed in 2013.

It should be noted that, as the Scheme is statutory based, the implementation of any recommendations arising from the review may require significant amendments to the Nursing Homes Support Scheme Act, 2009.

#### THE PUBLIC CONSULTATION PROCESS

A call for written submissions was made on the 14<sup>th</sup> June 2012. This was done by means of an advertisement placed in the national media and a notice on the Department of Health website (see Appendix 1). Various representative groups and other stakeholders were also emailed directly to draw their attention to the call for submissions.

In total, 61 submissions were received (see Appendix 2) from a broad range of individuals, nursing homes, statutory bodies, groups representing the interests of older people, private/commercial bodies and organisations in the community and voluntary sector. Table 1 below sets out the breakdown of submissions by sector.

Table 1 - Breakdown of Submissions by Sector

Sector	Submissions	%
Individual	15	25%
Nursing Home	6	10%
Private/Commercial	3	5%
Statutory Body	11	18%
Representative/Professional Organisation	25	41%
Political Party	1	2%
Total	61	101%*

<sup>\*</sup>Due to rounding, percentages do not add up to 100%

### ANALYSIS OF SUBMISSIONS REVEIVED DURING THE PUBLIC CONSULTATION PROCESS

A thematic analysis of the submissions received was conducted. These themes were not pre-determined, the analysis was open to the emergence of all themes. However, given the volume of material received (submissions ranged in length from a few sentences to 27 pages), it was necessary to have a structured approach. The Terms of Reference for the review were, therefore, used as the framework, with relevant themes associated to each element as follows:

#### **⇔** General Comments about the Scheme

#### **⇔** On-going Sustainability of the Scheme

- Eligibility for Financial Support
- Application Process
- Funding
- Care Needs Assessment
- Financial Assessment
- Ancillary State Support (Nursing Home Loan)
- Capacity Issues
- Scope of 'Long-term Residential Care Services'
- Uncooperative Applicants
- Under 65s / Complex Care Needs

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- Cost of Care
- Method of Determining Cost of Care
- Additional Costs in Nursing Homes

### **□** Balance of Funding Between Long-term Residential Care and Community Based Services

- Alternatives to Nursing Home Care
- Funding for Community Services
- Access to Community Services

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- Community-Based Services
- Disability and Mental Health Sectors

#### **⇔** Miscellaneous

- Nursing Home Capacity
- Care & Welfare Related Issues
- Miscellaneous

### Recommendations for the Future Operation and Management of the Scheme

#### GENERAL COMMENTS ABOUT THE SCHEME

Views about the Scheme were mixed. Some considered the Scheme to be very fair, resulting in great assistance and professional care being provided for many. It was noted that the Scheme ensures equal access to long-term care for all and provides older people a real choice regarding the nursing home that they wish to reside in.

It was felt that the Scheme had successfully addressed the inequitable system which had existed prior to its introduction and that it has been well received by older people and their families, giving older people a greater degree of financial certainty.

The standardisation, transparency, certainty, partnership between provider and patient and supervision by HIQA were considered positive elements which should be retained.

However, there were also those who considered the Scheme inequitable. One submission stated that it penalises older people who worked hard in difficult times only to be faced with an unfair system when they require long-term nursing home care.

It was also considered that accessing and using the Scheme can be very challenging and that accessing appropriate care (whether in a nursing home or in the community) can be difficult.

There was concern that the review would lead to an undermining of the positive aspects of the Scheme, an increase in costs for applicants and that the burden of payment would fall to those people who had bought their own homes, made provision for pensions and provided for their old age by sacrifice and saving.

It was suggested that any new criteria introduced as a result of the review should only apply to new applicants and not to those already in receipt of State support, except in so far as it may benefit them. It was also highlighted that care should be taken to ensure that recipients of State support and their families are reassured of this as the review progresses.

What People Said...

"...the scheme is a "fair deal", resulting in great assistance and professional care for many."

"In general, the Nursing Homes Support Scheme has met its key objectives of providing security and certainty to members of society requiring long-term residential care...The scheme provides assurance regarding care costs to those in need of residential care. This guarantee of affordability means that individuals need not worry about being unable to meet the costs or being forces to sell off assets such as their home to fund their care. They need not worry about having to turn to relatives or friends for assistance in meeting care costs...It is recognised as a significant improvement upon the subvention scheme that preceded it and provides people with a single comprehensive system of support based on a co-payment framework that is easy to understand."

"The name 'Fair Deal' is a misnomer. It is factual that the only people being unfairly penalised due to their age is the older person; every other category of person is treated as their income dictates."

"It has been in the main, a very traumatic experience for me..."

#### ON-GOING SUSTAINABILITY OF THE SCHEME

#### **Eligibility for Financial Support**

The Nursing Homes Support Scheme Act 2009 provides that a person must be 'ordinarily resident' in the State in order to apply for the Scheme<sup>1</sup>. However, the term 'ordinarily resident' is not defined in the Act. The HSE's *National Guidelines for the Standardised Implementation of the Nursing Homes Support Scheme* state that "Ordinarily resident means that you have been living in Ireland for at least a year or that you intend to live in Ireland for at least a year".

It was suggested that either the Act or the HSE's Guidelines be amended to ensure that there is no potential for applications to be submitted by people who may decide to take advantage of the benefits of the Scheme, but who may never have had any connection with the State.

It was also proposed that there should be consistency across all state agencies regarding the definition of 'ordinarily resident'. It was pointed out that, for Revenue/tax purposes, if you come to Ireland for the first time and remain resident for three consecutive tax years, you become 'ordinarily resident' from the beginning of the fourth tax year.

#### **Application Process**

The application process was variously referred to as complex, lengthy, time-consuming, toilsome, frustrating, lacking transparency and daunting. There was general consensus that it needs to be more user-friendly.

#### Information

A number of submissions reported difficulty in accessing information, as well as a lack of information in the system about the operation of the Scheme. Concern was expressed about geographical variations in the time taken to process applications. It was considered vital that there is consistency in the assessment and processing of applications and it was stressed that there should be no undue delays in processing applications. This was regarded as being of particular importance following the amendment to backdating provision in the HSE's Guidelines<sup>2</sup>.

It was reported that the HSE letters relating to the Scheme are extremely difficult to understand, with insufficient information provided as to how the resident's weekly contribution was determined.

<sup>&</sup>lt;sup>1</sup> This is consistent with other health legislation in terms of general eligibility for health services.

<sup>&</sup>lt;sup>2</sup> According to the HSE's June 2012 Performance Report, in June, 100% of complete applications were processed within four weeks. An application is complete when the Nursing Home Support Office has received all of the necessary documentation and information required to make a determination. This includes documentary evidence of all income and assets as well as documentation regarding title of any properties owned.

However, it was also stated that, once contact was made, the service was extremely good and delays were reasonable.

#### Rate of Approvals

It was reported that long waiting times for approval are a cause of financial and emotional concern for patients and their families.

Several submissions referred to the reduction in approval rates for the Scheme (reported in the Irish Times on the 26<sup>th</sup> June). Concern was expressed that reducing the number of approvals issued will not ultimately lead to savings, and will lead to a growing backlog of deserving individuals if not fully addressed. In this context, it was noted that the system of releasing a certain number of approvals on a weekly basis in a demand led scheme should be changed. It was considered that, with 32 local offices<sup>3</sup>, this must be difficult to administer.

#### Reviews / Appeals

A number of suggestions were made regarding the review and appeal process. It was noted that there is no provision in the legislation for the HSE to systematically carry out reviews of financial assessment. However, individuals in receipt of support may request a review every 12 months. It was proposed that the legislation may need to be strengthened in this regard. Reference was also made to the fact that the legislation does not specify the date upon which the outcome of an appeal must be implemented. It was considered that the appeals process must be further developed and an appropriate time frame for decision introduced.

#### Miscellaneous

It was considered that people should not remain in acute hospitals while an application for the Scheme is being progressed. The view was also expressed that the Scheme makes it difficult to access nursing home care for people who are in crisis situations because it does not provide for emergency accommodation.

It was suggested that applications from palliative care patients should be expedited as these people may have a limited life span and their health can decline rapidly.

It was noted that applicants are allocated beds in nursing homes by the Local Placement Forum<sup>4</sup> on a chronological basis rather than a needs basis. It was considered that the local placement forum decision-making needs to be able to incorporate outside professional advocacy on behalf of older persons who require urgent placement.



<sup>3</sup> There are 18 Nursing Home Support Offices nationally which process applications for the Scheme. Applications are recorded on a central placement list, in order of determination, and funding is allocated in chronological order. This ensures equity of access to funding nationally.

<sup>&</sup>lt;sup>4</sup> It should be noted that the Local Placement Forum determines whether long-term nursing home care is the best option for the particular individual and may specify that certain care is required. It does not allocate beds.

"We all found the process frustrating – mostly because the questions we asked remained unanswered, and our sense was that the administrators we were dealing with did not fully understand the system themselves".

- "...the process lacks transparency in seeking information and is toilsome for the emotionally compromised family".
- "...many are daunted by the paperwork involved and often delay in completing the total application process."

#### **Funding**

There was a view that the HSE has persuaded an increasing number of people with disabilities/mental health issues to apply for the Scheme since its introduction. It was considered that people with disabilities/mental health issues should be funded from the budget relevant to the appropriate sector. It was also proposed that, if a mental health/disability facility is closed, and the residents transfer to a Nursing Homes Support Scheme funded bed, the budget allocated for the former residential facility should be transferred to the budget for the Scheme.

The anxiety caused by the suspension of the Scheme in 2011 was highlighted on a number of occasions. Concern was expressed that, in its current form, the Scheme is too expensive. There was a strong consensus that the Scheme must be adequately resourced to meet demand. There was also support for the budget for the Scheme to continue to be ring-fenced so as to ensure transparency.

Some felt that there was a lack of clarity regarding funding for the scheme. There was a view that the resource cap for the Scheme has led to delays in assessment and approval and a reduction in the rate of approvals. It was stated that the Scheme does not ensure access to care based on health needs rather than ability to pay.

There was concern that the additional funding allocated to the Scheme in Budget 2012 had not been provided and that this was contributing to the reduced rate of approvals. It was considered that the transfer of €13m to the Special Delivery Unit's Transitional Care Initiative should not have happened in advance of the review of the Scheme.

It was suggested that the principle of solidarity should be applied, i.e. the cost spread over a wider population and access to service based on medical need, with minimal bureaucracy.

It was pointed out that the principle of patient choice and the system of 'money follows the patient', which underpin the Scheme create difficulties for public nursing homes if they carry vacancies. This is because it is very difficult for public units to reduce staffing levels for sporadic periods of time when occupancy levels fall. The transfer to new funding arrangements for public nursing homes in 2012, i.e. whereby nursing homes must submit an invoice for payment on a named resident basis, was said to have been problematic as a result of poor communication and uncertainty.

Finally, it was highlighted that situations where the HSE had to provide emergency interventions in private nursing homes on foot of HIQA obtaining a Court Order to

cancel the registration of the nursing home had put additional pressures on the HSE both from a service and financial position.



"The scheme should be properly resources to meet demand. The funding crisis which occurred in the scheme in 2011 cannot be repeated."

"Given the significant forthcoming demands for the provision of long-term residential care services, the budget must continue to be 'ring-fenced and again delivered under a dedicated subhead. Providing dedicated, core-funding for Fair Deal ensures that the scheme is transparent and confirms 'Money Follows the Patient' as an underlying principle behind its operation."

"If the scheme is to continue, (and it should), the allocation MUST be ring fenced each year in future."

#### **Care Needs Assessment**

While it was highlighted that there should be equitable access to the scheme based on needs, concern was expressed that people may be placed in long-term nursing home care without provision for review and discharge if their condition changes<sup>5</sup>.

It was also suggested that the care needs assessment should trigger the financial assessment and completion<sup>6</sup>. There was a feeling that families may be applying for the Scheme in advance of a determination being made that long-term nursing home care is the most appropriate option because they are worried funding will run out.

One submission stated that the Common Summary Assessment Report (CSAR) is difficult to co-ordinate and complete in both hospitals and the community.



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"At present, all applicants need to be assessed. The bureaucracy of these assessments is endless."

<sup>&</sup>lt;sup>5</sup> It should be noted that the Nursing Homes Support Scheme is merely a system of financial support for people who require long-term nursing home care. All nursing homes are must be registered with HIQA and are inspected against the same Standards. The Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2009 provides that an individual care plan shall be developed and agreed with each resident, that this will be made available to the resident and that this will be kept under formal review as required by the resident's changing needs and no less frequent than at three-monthly intervals.

<sup>&</sup>lt;sup>6</sup> It should be noted in this regard that the Nursing Homes Support Scheme Act 2009 provides that the HSE cannot determine an application for State support unless it has been determined that the applicant requires long-term nursing home care (section 11(4)(a) refers).

#### **Financial Assessment**

#### Alterations to the Terms of the Assessment

It was noted that property prices have fallen since the scheme was introduced and that, as a result, the level of State support would be higher than anticipated. Consequently, it was considered that linking costs to the housing market is fundamentally flawed and too open to market fluctuation. It was proposed that we need to move to a system which is more based on individual circumstances.

Concern was expressed that the amount of income and assets that are taken into account would be increased. It was also felt that the three year cap should remain in place. It was noted that gross income is considered for means testing purposes and that, since 2009, many charges, taxes and levies have been introduced, the effect of which has been to reduce the net available income by as much as 25%<sup>7</sup>.

In contrast, some considered that the percentage of assets taken into account annually should increase, e.g. from 5% to 10%. This was justified on the basis that the statistics show that only very few applicants have opted for the loan option which indicates that there is cash out there and that there isn't as much hardship amongst the older people as some would think.

#### Allowable Deductions

A number of people were of the view that taking 80% of income into account does not leave the resident with sufficient income. In that context, the issue of allowable deductions was raised, with a number of submissions suggesting that the current list of deductions is too limited. There was a concern that the income retained by nursing home residents does not enable them to participate in day time activities offered in the community.

#### Treatment of Farms and Businesses

A number of suggestions were put forward regarding the treatment of farms and businesses under the financial assessment. It was noted that the farming community considers the treatment of farms to be unfair and is of the opinion that it should be reviewed. It was also felt that the current provisions around farms and businesses penalise those who try to care for an elderly person in their own home.

#### Review of the Financial Assessment

It was highlighted that individuals who are in receipt of financial support under the Scheme may seek a review of their financial assessment. Concern was expressed that the reduction in property values was resulting in increases in the amount of State support payable and that this would have implications for the sustainability of the Scheme.

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<sup>&</sup>lt;sup>7</sup> The Scheme provides for certain Allowable Deductions to be taken into account during the financial assessment. The definition of 'Allowable Deduction' includes 'levies required by law to be paid'. In addition, the Application Form states that 'New Weekly Income should be provided, i.e. your weekly income after Tax, PRSI etc. have been deducted'.

#### Miscellaneous

It was noted that some older people resented the fact that, in the event they would require long-term nursing home care, it would have to be financed by registering a mortgage on their family home, which was often their sole capital asset.

A query was raised about the treatment of the principal residence, specifically, whether it is in line with the spirit of the legislation that the proceeds of the sale of the house be assessed as cash assets (even if the person has already been in nursing home care for 3+ years). It was also suggested that, in a falling market, where the house is sold in order to maximise the sum available for the older persons care or because it is too expensive to insure and maintain, it is unfair that the 15% cap is lost.

Finally, it was also noted that the Department has confirmed that the minimum retained income threshold applies only if the applicant has applied for ancillary State support<sup>8</sup>.



"...it is incumbent on those who can pay should pay to an affordable and reasonable amount..."

"At present the family home is protected, but surely anyone inheriting a house and owes 30% of the value to the HSE is still getting an exceptionally good deal. The percentage of assets doesn't affect the older person, it affects the greedy inheritors, so why not let them share the pain."

"We cannot afford it...why should any one else's children pay taxes to reduce the exposure of my estate and to save it for my children."

"In many cases the weekly sum with which many older people are left could only be described as pocket money."

"Some clients...continue to be quite unclear as to how the scheme operates, particularly in relation to the assessment of means relating to the family home."

#### **Ancillary State Support (Nursing Home Loan)**

It was considered that the ancillary State support element of the Scheme, i.e. the Nursing Home Loan, has facilitated cash flow for nursing home residents despite take up being less than anticipated. However, it was noted that the process is complex and causes delays in processing applications. A number of suggestions for improving the operation of the loan element of the Scheme were provided.

It was proposed that there appears to be an anomaly in the assessment of transferred assets whereby the applicant cannot avail of the loan as they no longer own the asset.

<sup>&</sup>lt;sup>8</sup> This is not accurate. The minimum retained income threshold is applied in all financial assessments. However, the manner in which applicants choose to append this retained income (including choosing not to opt for ancillary State support and using the minimum retained income threshold to pay for the portion of the contribution to care based on any chargeable assets) is a matter for themselves.

Difficulties regarding the identification of the 'relevant accountable person', i.e. the person responsible for repaying the loan, were noted. In the absence of the necessary details, Revenue cannot follow up on repayments<sup>9</sup>.

The issue of children inheriting the principal private residence and applying for a deferral of the loan repayment was raised. Under section 20(4)(a)(ii) of the Nursing Homes Support Scheme Act, the value of the property is taken into account and this can lead to situations where it is not possible for the HSE to grant a deferral.

The time taken to register Charging Orders was considered too lengthy. However, it was unclear as to whether this delay was due to the HSE or the Property Registration Authority.



"The system of provision of ancillary state support should be looked at is it is too cumbersome and off putting to applicants"

#### **Capacity Issues**

It was noted that the Care Representative process is very complex. It was considered that, in most cases, families require assistance of a solicitor to complete the process.

It was suggested that the issue of capacity should be awarded greater significance in the context of the Assisted Decision-Making (Capacity) Bill which is being drafted by the Department of Justice and Equality. It was also proposed that any revision to the Scheme should make provision for this Bill. It was considered that the Public Guardian provided for in the Assisted Decision-Making (Capacity) Bill should be given a supervisory role regarding Care Representatives<sup>10</sup>.

It was stated that many doctors do not want to sign the capacity report as they have issues with the legality of it. This was said to cause delays.

It was pointed out that the Ward of Court process is expensive, cumbersome and outdated. It can hold up applications for the Scheme. It was proposed that a mechanism to introduce flexibility in this regard is required. It was also suggested that the Enduring Power of Attorney process be simplified<sup>11</sup>.

<sup>&</sup>lt;sup>9</sup> It should be noted, however, that the Charging Order will remain on the property and will ultimately have to be discharged upon the sale/transfer of the property.

<sup>&</sup>lt;sup>10</sup> The Department of Health is in discussions with the Department of Justice and Equality regarding the Assisted Decision-Making (Capacity) Bill to ensure that persons appointed under that legislation would be able to act for the purposes of the Nursing Homes Support Scheme Act.

<sup>&</sup>lt;sup>11</sup> The Ward of Court process will be replaced when the Assisted Decision-Making (Capacity) Bill is enacted. This legislation will also cover Enduring Powers of Attorney.

What People Said...

"The issue of capacity causes difficulties and the Ward of Court process is often lengthy, giving rise to further delayed discharges in the acute setting"

#### Scope of 'Long-term Residential Care Services'

The Nursing Homes Support Scheme provides financial support for 'long-term residential care services'. It was considered important that there is clarity regarding the provision of services outside of 'long-term residential care services' and, in particular, as to what is and is not covered under the Scheme.

It was highlighted that greater clarity is required on what goods and services should be supplied by the nursing home under the contract of care/cost of care and what the HSE Primary care services should provide.

It was noted that, in some areas, particularly those with a high number of nursing home beds, the local Primary Care Team may not be resourced with the appropriate level of staff/funding to respond to the demands placed by residents with higher levels of dependency.

It was acknowledged that everyone in receipt of financial support under the Scheme retains their entitlement to all primary care services, including access to GP services, allied health professional input, drugs, aids and appliances etc. However, there was a sense that residents in nursing homes do not have adequate access to the rehabilitation therapies which they require. Concern was expressed that the proposal to reduce staff in public nursing homes will further exacerbate the lack of availability of allied health services to people in residential care.

It was pointed out that the Scheme does not fund many of the extras that would be considered routine as part of generalist palliative care, i.e. therapies, additional dressings etc.

It was considered that there is very little consistency or transparency as to how decisions are made regarding aids and appliances and what defines appropriate personal care.

What People Said...

"Include basic therapy services in the Fair Deal scheme which enhance capabilities of older people living in residential care as a basic human right to their highest attainable standard of health."

"In these facilities [private nursing homes], there is little or no access to allied health professionals in a routine way, nor social work."

#### **Uncooperative Applicants**

A number of submissions claimed that sometimes applicants to the Scheme do not fully cooperate with the application process or terms of the Scheme. Difficulties encountered in getting some applicants to provide the information necessary to complete an application, as well as difficulties in getting some applicants to pay their contribution were mentioned in this regard. It was considered that sanctions need to be agreed for situations where an applicant or their representative refuses to cooperate.

It was felt that the period of time allowed for families to submit information before charging applies (40 working days) is excessive.

The absence of co-payment legislation for community services was perceived as a disincentive for applicants to move from short-term to long-term nursing home care.



"The legislative provisions under Section 34 of the Act need to be strengthened, in particular to account for patients who refuse an appropriate placement or refuse to pay".

"Sanctions need to be agreed and implemented before the repayment bills become enormous and unmanageable for the individual/family."

#### **Under 65s / Complex Care Needs**

Concern was expressed that the continued reduction in the number of public beds with sufficient multi-disciplinary input to meet the needs of high dependency residents, combined with moves to drive down the weekly cost, will inevitably result in a poorer range of care options being available or will lead to the movement of a significant number of residents to hospitals.

It was highlighted that better consideration should be given to provision for exceptional cases, e.g. people with behavioural and psychological symptoms of dementia or acquired brain injuries, because it is generally difficult to maintain appropriate placements for such persons. This can contribute to delayed discharges and breakdowns in nursing home placements.

It was acknowledged that people under the age of 65 may apply for financial support under the Scheme. However, a shortage of beds for people under the age of 65 was noted. In addition, access to those beds that do exist was said to be difficult, sometimes requiring intervention by the local disability/general manager. It was also pointed out that restrictions regarding people under the age of 65 imposed by HIQA during the registration process can be problematic.

The suitability of the Scheme for people under the age of 65 was questioned because such individuals often require significant medical, nursing and therapy inputs which are not provided under the Scheme. Finally, it was considered that people under the age of 65 would have items of expenditure, e.g. travel costs to work, that would not generally apply to those over the age of 65.

A number of submissions alluded to reports of 'cherry-picking' residents with lower care needs by some private nursing home providers.

The issue of access to specific palliative care services was raised. There was concern that, where there is no or limited access to a hospice in-patient unit, patients may be admitted to a nursing home where they are liable for the cost. This was said to highlight inequity of access to palliative care and an unfair additional burden in palliative patients.

#### What People Said...

"...anecdotal evidence reported...suggests that some nursing homes are 'cherry picking' people with a lesser level of care and nursing needs thus making it more difficult for people with very high level needs to get a place. This may result in increasing pressure on the acute hospital system because of having to delay discharge."

"The Nursing Homes Support Scheme has given rise to discrimination against those who are under 65 years of age and who require care in a nursing home. In the first instance, the lack of bed capacity is an even more serious problem than that for older persons. There is a profound shortage of appropriate residential care for these applicants."

# COST OF LONG-TERM RESIDENTIAL CARE IN PUBLIC AND PRIVATE NURSING HOMES AND THE EFFECTIVENESS OF THE CURRENT METHODS OF NEGOTIATING/SETTING PRICES

#### **Cost of Care**

The cost differential between neighbouring nursing homes with the same number was raised, as was the cost differential between urban and rural nursing homes.

The policy of paying the same rate for private and shared rooms was referred to. It was stated that there is no incentive for nursing homes to move towards private rooms (per the HIQA standards) if they be paid the same rate as for a shared room.

It was felt that the cost of public nursing home care is excessive and, despite suggestions to the contrary, public nursing homes do not cater for more highly dependent people, therefore, their costs should be more similar to those of private nursing homes.

In contrast, it was also stated that public nursing homes often provide a higher level of care with physiotherapy, speech and occupational therapy, social activity and specialised care equipment and that comparing unfavourably the public and voluntary nursing homes, cost wise, to the private homes is unfair.

With regard to the provision of therapies in public nursing homes, it was claimed that these are being provided even though therapies have been disallowed under the Scheme. It was suggested that if residents were charged for these services, the Scheme would be more sustainable<sup>12</sup>.

It was noted that the proposal by the Minister for Social Protection that nursing homes carry the cost of paying workers on sick leave would result in an increase in the cost of care because nursing homes are a 'replacement worker' industry, i.e. if a member of staff calls in sick, someone else has to be called in to ensure that appropriate staff to resident ratios are maintained.

It was pointed out that the Nursing Homes Support Scheme Act stipulates that the cost of care for private nursing homes must be published. However, there is no express requirement in the legislation that the HSE do the same.

One submission noted references to the average cost for private nursing home care being  $\in 877$  per week. It went on to say that they have never come across a charge in the private sector which was less than  $\in 1,000$  per week<sup>13</sup>.

<sup>&</sup>lt;sup>12</sup> Allied Health Professionals do provide services in public nursing homes. However, these are not funded from the Nursing Homes Support Scheme subhead. Consequently, if residents were to be charged for these services, it would not impact on the funding available for the Scheme.

<sup>&</sup>lt;sup>13</sup> The cost of care in both public and private nursing homes is published on the HSE's website. The private nursing home list is updated as the NTPF renegotiates with nursing homes. Per the list of the  $6^{th}$  July 2012 − 80% of private nursing homes had a weekly cost of care of less than €1,000.

#### What People Said...

"There is a significant difference between NTPF agreed prices in rural v urban areas – can this be justified given that all Nursing Homes must meet the National Standards of Care (HIQA) and there are standard pay scales in operation, etc?"

"The reality is that the weekly cost of care in the public sector under Fair Deal is, on average, over 40% more than that provided to the private and voluntary nursing home sector".

"There is a myth that the HSE nursing home cater for more dependent people".

#### **Method of Determining Cost of Care**

It was considered that the National Treatment Purchase Fund's (NTPFs) pricing process lacks clarity and that a more transparent cost model needs to be developed. This review was considered an opportunity to introduce a more sophisticated, sustainable funding model which would be evidence-based and which would acknowledge the true cost of long-term nursing home care. This would ensure that providers can fulfil the requirements of the national standards and can invest in the provision of new builds and extensions. It was felt that there was an urgent and pressing need to address the issue of future capacity given the absence of investment over the past 12 months and the lead in time required to provide additional capacity.

It was suggested that the NTPF has unilaterally discriminated between nursing home providers and applied dissimilar conditions to equivalent transactions, insofar as it has been prepared to agree a flat fee per resident. It was also proposed that, in a limited number of cases, the NTPF appears to have deviated from its general approach in that it has agreed with a limited number of private/voluntary nursing home providers a price which acknowledged the higher costs associated with maximum dependency and specialised care services.

Since the introduction of the Scheme, it was felt that public and private nursing homes' funding has greatly reduced and that tendering arrangements have not incorporated up-to-date gerontological knowledge, therapy services as well as aids, incontinence wear and other services.

It was noted that the NTPF was given a role in relation to determining private sector costs, but that for agencies funded under Section 38 of the Health Act 2004, the task was undertaken internally by the HSE. It was considered that, as both provider and funder, this results in a clear conflict of interest for the HSE. It was suggested that the NTPF pricing role should be extended to cover HSE provided and funded agencies.

There was a view that the approach to determining the price of care in Section 38 funded agencies was not carried out in a consistent or systematic manner and that institutions are now being compared on the basis of questionable cost estimates.

It was observed that decisions made by the NTPF in the context of negotiations on agreed cost of care may have a considerable effect on the HSE expenditure under the

Scheme. It was suggested that this appears to run contrary to the HSE having overall responsibility for the administration of the Scheme.

It was pointed out that the NTPF is responsible for the negotiating the maximum agreed rate payable towards the cost of care. However, any attempts by the HSE to pay less than the agreed maximum rate have proved unsuccessful to date.

Several submissions suggested that the cost of care should be linked to dependency levels. It was noted that this approach would be possible given the proposed rollout of a single assessment tool for older people nationally but that, while in principle this would seem sensible, consideration should be given to how such a development would work in practice.

It was also pointed out that nursing homes incur increased costs when a resident becomes more dependent, and there is no facility to recoup these increased costs.

It was felt that the Scheme has eliminated competition from the private/public sector which reduces to a degree the quality of service.

There was a sense that costs incurred as a result of recommendations made by HIQA in the course of nursing home inspections are not being factored into the negotiation process, and should be. It was considered that the NTPF should have regard to the latest HIQA reports when negotiating with nursing homes and should not reward badly performing nursing homes.

It was highlighted that providers are not able to determine prices with the NTPF in advance of registration with HIQA. This, they said, makes it very difficult to build a business plan for the construction of a new nursing home because banks don't like this level of uncertainty<sup>14</sup>.

Access to accurate and meaningful data on the following was considered critical to informed public debate on the Scheme – unit cost of care (private and public), calculations of the costs of care for residents with higher and lower levels of dependency, staff-patient ratios for residents with different levels of dependency and calculations on the cost of incorporating basic supports (additional dressings, continence pads etc) and services (therapies, meaningful activities) into the overall package of care.

What People Said...

"...if you know you're guaranteed money, why work for it."

<sup>&</sup>lt;sup>14</sup> The legislation underpinning the Scheme does not preclude a nursing home from agreeing a cost of care with the NTPF prior to being registered with HIQA. In fact, the National Treatment Purchase Fund Board (Establishment) Order 2004 states that 'arrangements referred to in paragraph (1)(ba) [of Article 4] shall be subject to a condition that the nursing home is an approved nursing home or that the arrangements will not apply unless the nursing home becomes an approved nursing home' This acknowledges that the cost of care may be agreed with the NTPF in advance of registration with HIQA.

"..it needs to be a set price for all within the different regions based on the average of costs per region...if a nursing home disagrees, then it should be up to the home to opt out of the Fair Deal scheme."

"One size fits all" – fees are the same regardless of dependency/type pf resident. Specialised care needs (dementia, ABI) should be funded separately."

"There have to date been far too many different types of deals on offer from the NTPF."

"It is critical that the Fair Deal review addresses the balance between ensuring value for money and acknowledging the true costs of meeting the complex medical and disability needs of persons in the care of nursing homes. The price 'negotiated' with the NTPF does not take into account the differing levels of need of individual residents."

#### **Additional Costs in Nursing Homes**

Concern was expressed about the practice of additional charges being levied on residents by private nursing homes. There was a sense that there appears to be a growing number of instances where residents in private nursing homes are requested to contribute, on a regular basis, an amount of money in addition to the fees agreed between the nursing homes and the NTPF. Despite the Department of Health's Information Sheet on Payment of Fees, there was said to be a lot of confusion and misunderstanding in relation to a person's obligation to pay such fees or not. It was claimed that, in some instances, additional charges were levied without prior consultation or agreement and that these additional charges, which are not taken account of in the financial assessment, can cause hardship for residents and must be closely monitored and controlled.

Nursing homes are obliged to agree a contract for the provision of services with residents. It was felt that if, after a month, a contract is produced which outlines additional costs which have not been made known to the client on admission, it can be very difficult for the client to make the decision to move from the nursing home to another with more favourable pricing arrangements<sup>15</sup>.

There was a perception that additional charges are increasing to cover the costs of therapies and other services provided to residents, irrespective of whether they hold a medical card.

It was suggested that some nursing homes are demanding increased payments for people with higher care needs/who require one-to-one care.



"Is it fair that a nursing home resident who is eligible for a medical card and who has very limited mobility has to pay for transport to and from hospital, podiatry services, physiotherapy

<sup>&</sup>lt;sup>15</sup> It should be noted that the Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2009 stipulate that the contract must be agreed within one month of admission.

and incontinence wear. These additional services have amounted to as much as €600 per month..."

- "...some families need to use the 20% from a parent's pension to augment their own financial situation due to the severity of the present austerity measures. It is often not the people one would expect who renege on a commitment who do so and this area needs to be scrutinised a little more fairly for the patient's sake."
- "...nursing home added extras without consultation and without previous consent...There was no contract, just a booklet issued...At a time when one is completely broken hearted and mentally unable to cope it would be necessary to insist on the nursing home issuing a contract which would suit both parties."
- "...financial assessment does not take into account the added costs charged by the nursing home on the next-of-kin and, by not doing so, does not fairly assess all financial costs incurred by the client in the nursing home. These charges fall to the next-of-kin who are pressurised to come up with these payments out of their income...current loop-holes allow extras, that have not been agreed on, to be added and costs spiralling out of control...important that nursing homes produce less confusing contracts that clearly set out the terms and any extra charges that might accrue."

### BALANCE OF FUNDING BETWEEN LONG-TERM RESIDENTIAL CARE AND COMMUNITY BASED SERVICES

#### **Alternatives to Long-term Nursing Home Care**

It was suggested that there should be greater clarity as to what community supports are available to people, and the mechanisms to access these supports should not be overly bureaucratic. It was proposed that an audit of community care services be carried out to establish exactly what services are available, identify the deficits, plan effectively for the future and introduce greater transparency to the system.

There was a general consensus that investment in community supports and structures should be increased to enable people to remain in their homes and that long-term nursing home care should not be the only option available to people. The community supports referred to included care village settings (e.g. apartments with daily visit from nursing home staff, access to medication alerts, emergency call, meals etc), day care, home help, home care packages (which should include night nursing, primary care team supports, day care nursing and family respite, home help, equipment and bereavement supports), local/sheltered housing, rehabilitation, respite and access to geriatricians.

It was noted that having a well resourced and managed community home support programme makes more economic sense, not to mention the fact that most people wish to remain in their home.

It was proposed that there be better planning for the needs of vulnerable older people living in the community and that improving community services could reduce premature admissions to nursing homes and unnecessary stays in acute hospitals. There was also a feeling that improved systems should be in place to enable a person to return home after an acute event.

Concern that any shift in the balance of funding between long-term nursing home care and community services would focus solely on formal community services was expressed. It was considered that every effort must be made to support carers through adequate financial support and by offering backup domiciliary care, suitable and flexible day care services, and respite care in a suitable setting to enable carers to have a break.

The establishment and development of Primary Care Teams was considered an essential part of any community-care based health service model as this would provide early intervention and support the preferred choice of the majority of older people to age in their home.

It was highlighted that for people who have care needs which are complex and intense (requiring specialist palliative care and end-of-life care), if the balance of funding were to shift towards community services, the care capacity would need to be at least equal to that delivered in a nursing home.

#### What People Said...

"The system of funding favours the residential care model because of the limited resources available to community based services versus those offered to nursing homes (public and private). In some parts of Dublin, for instance, there is a general limit of 14 hrs per week because of budgetary restraints. This situation contradicts public policy that purports to advocate for care at home. The stop-start nature of the provision of home care funding also works against consistent provision of community services leaving families worried about whether they will be left without the supports they need at some future date."

"...there is a need for more innovation. We need to have more daytime community services which can cater for both the social and medical needs of older people. There are examples in other countries where crèches and elder care units operate from the same building and the interaction between them is both useful and therapeutic. At one of our meetings a women told of how her mother who had dementia always responded well to babies with smiles and how it made her happy."

"We must get away from the mindset that Long-term Residential Care is the last and final placement and is a door that does not open out again."

"All too often the older person is very reluctant to move from their family home, for which there is no true substitute."

#### **Funding for Community Services**

It was considered that the Scheme economically incentivises older people to choose long-term residential care instead of staying at home, without due regard to their social needs and/or preferences. There was a general consensus that there should be greater flexibility of funding.

The need for a system for the transparent allocation of resources and care supports for community care as well as for residential care was highlighted. It was suggested that the budget for community services is not protected in the same way as the budget for the Scheme and that, in times of budgetary cutbacks, these services may become subject to cuts, leading to increased demand for long-term nursing home care (and adversely affecting financial sustainability).

It was also suggested that the existence of a separate subhead for long-term residential care<sup>16</sup> creates an incentive to maintain long-term nursing home beds at the expense of short stay beds.

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<sup>&</sup>lt;sup>16</sup> Funding for Long-term Residential Care is in subhead B12 of the HSE's Vote (Vote 39). This is effectively the budget for the Nursing Homes Support Scheme albeit that pre-Nursing Homes Support Scheme arrangements must also be facilitated from within the subhead, i.e. people in contract beds, people who choose to remain on subvention and people who were in public nursing homes prior to the commencement of the Scheme.

#### What People Said...

"...in this time of curtailed free community care, lack of Home Care Packages etc, once you cross a certain threshold of care needs unless financially liquid you have no choice but to go for a nursing home even if asset rich as you will not be able to afford the private care necessary."

"Community care services, though patchy, are vital and existing levels of service must be retained. These budgets are under threat; they must be protected against cuts and safeguarded from pressures in other parts of the health system."

#### **Access to Community Services**

It was considered that the allocation of community services is not always transparent and that issues of equity can, therefore, arise. The perceived lack of a clear and consistent approach to financial support for community services was considered to create a financial incentive to enter long-term residential care. It was suggested that there needs to be greater access to community services and dedicated funding for these services.

Several submissions referred to the lack of clear legislative entitlement to community services as a fundamental problem. It was felt that, as a result, there are no clear pathways to access services, no standardised instruments to assess need and no independent appeals mechanisms.

#### What People Said...

"...as Long Term Residential Care is currently the only service available to Older Persons which has a clear legislative basis for assessment of need and eligibility, with a dedicated budget, this option, it is felt, is often the first option considered – rather than the 'last resort'. There is no such legislative clarity of eligibility for many of the community support services... which are crucial if many older persons are to be maintained and supported in their homes and communities."

"There is no statutory entitlement to home care and community care services. Access to such services for older people is discretionary and unequal."

"...[there should be] clear, consistent and equitable pathways to community care services and entitlements for older people regardless of where they live."

"Virtually all health policy documents assert the desirability of promoting community care over residential care. Notwithstanding progress on a number of fronts, the range and focus of community based services falls far short of what is required to meet the diverse support and service needs of older people and their carers."

# EXTENSION OF THE SCHEME TO COMMUNITY BASED SERVICES AND TO OTHER SECTORS (DISABILITY AND MENTAL HEALTH)

There are two separate issues to be considered in this section -a) the extension of the scheme to community-based services and b) the extension of the scheme to other sectors (Disability and Mental Health).

It was proposed that, if the Scheme is to be extended, no person currently accessing services should be financially disadvantaged.

With the proposed introduction of the single assessment tool for older people, it was noted that there is an opportunity to standardise the process for providing care on the basis of need across the continuum of care. It was felt that having one budget could help to ensure equity across care groups and could also ensure that money follows the patient.

#### **Community-Based Services**

Submissions were broadly supportive of the possible extension of the Scheme to community-based services. It was felt that it could result in an improved model of care and potential savings for both the individual and the State. It was suggested that the Scheme has actively undermined home care services and that any amended scheme must address residential and home care as an integrated system.

It was noted that, in advance of any decisions being made in relation to extending the Scheme, there should be a transparent, informed and broad public consultation, preceded and informed by an analysis of how different models of funding and provision could meet community care needs.

It was considered important that budgets for different sectors would not be in competition with each other. The principles set out in the O'Shea study<sup>17</sup> against which potential financial schemes for the care of older people might be evaluated were said to remain valid, i.e. funding of LTC should be comprehensive; funding should not determine care requirements, care requirements should determine funding; should be a built-in bias towards home care solutions while retaining capacity for financing care in institutional settings; payment mechanisms should be prospective and case management should be used to determine needs; access should be based on need and should not be impeded by an inability to pay; efficiency and the quality of care should be enhanced rather than diminished by the funding system.

It was proposed that any new scheme for community services should be introduced on a statutory basis and should mirror the principles of the Nursing Homes Support Scheme in order to deliver a uniform assessment, equitable access, dedicated ringfenced funding, a co-payment model and budgetary allocation on an individual basis in accordance with care plan assessment and patient preference.

<sup>&</sup>lt;sup>17</sup> O'Shea, E. and Hughes, J. (1994) The Economics and Financing of Long-Term care of the Elderly, Report No. 35, National council for the Elderly

There was a suggestion that, if scheme were extended to community services, it might generate income for the HSE (which should be minimal given that people would be at home and have to pay bills etc).

Some submissions were opposed to extending the Scheme to community-based services. Reasons given included an objection to co-payments based on income and property; a belief that it is ageist to target people with long-term care needs; the fact that people who are less well off may be more likely to become ill and, therefore, disproportionately affected; and the view that people should not have to give up 15% of the value of their home in order to remain in it.

Finally, it was highlighted that any focus on community care services must address the question as to how the family caring system can be enhanced and how state funding mechanisms can support such care.

#### **Disability and Mental Health Sectors**

Views about the possible extension of the Scheme to the Disability and Mental Health sectors were more mixed.

Concern was expressed that Ireland does not have funding and service arrangements in place to enable some adults with disabilities/mental health issues to access non-institutional housing and supports. It was also proposed that the recommendation that there be no new admissions to congregated settings could result in more nursing home admissions without better person-centred planning and investment.

The general consensus was that, if the Scheme were to be extended to the Disability and Mental Health sectors, funding should be sourced from these sectors to support the fair operation of the scheme.

Concern was expressed that the financial assessment for the Scheme, in its current format, would not be suitable for people in community residences.

It was proposed that the extension of the Scheme to young people with a disability in small group homes or independent living units could lessen the likelihood of young people being placed in nursing homes inappropriately. It was also proposed that funding could also be extended to support people with mental health problems to live in the community in independent living units and to those with serious mental disorders in high-security units. The current situation whereby a person who moves from a nursing home to an Approved Centre in the same facility, and cannot retain their Nursing Homes Support Scheme funding was criticised<sup>18</sup>.

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receive financial support under the Scheme.

<sup>&</sup>lt;sup>18</sup> There are a number of facilities which have both a nursing home (registered in accordance with the Health Act 2007) and an Approved Centre (registered in accordance with the Mental Health Act 2001) on the same site. At present, the Nursing Homes Support Scheme only applies to the nursing home and if a person were to transfer from the nursing home to the Approved Centre, they could not continue to

It was noted that any extension of the Scheme to the Mental Health sector should be in compliance with Government Policy as enunciated in A Vision for Change.

On the other hand, it was considered that a fragmented and complex funding system will not help the task of linking key services for health personnel. It was stated that to pursue a policy direction which is likely to further complicate processes and fragment the care pathway is an ill advised strategy.

It was noted that many people with disabilities who live in the community receive supports and services provided by the HSE and voluntary organisations without charge. Their ability to sustain their health and participate in society depends on this provision. To change the terms and introduce the Nursing Homes Support Scheme in this area was considered totally unacceptable.

There was a belief that the Scheme should not be extended to the Disability and Mental Health Sectors unless the people in those sectors wish to be included under the Scheme.

As in the case of community services, an objection to co-payments based on income and property; the belief that targeting people with long-term care needs could be considered ageist, the fact that people who are less well off may be more likely to become ill and, therefore, disproportionately affected, and the view that people should not have to give up 15% of the value of their home in order to remain in it were highlighted.



#### Community-based Services

"...a small amount of support at the right time to a person living at home is sufficient to maintain him or her for much longer there."

"It is proposed that consideration be given to the extension of the co-funding model to both short stay beds and to community supports."

#### **Disability and Mental Health Sectors**

"Applying the Fair Deal Scheme to people living in the community with disabilities, including mental health conditions, is inequitable and a backward step, away from a just society."

"People should not have to pay for the health and personal supports that are required due to their disabilities."

"Older people with a disability or a mental illness should have access to nursing home care on the same basis as the rest of the population."

#### **MISCELLANEOUS**

#### **Nursing Home Capacity**

The closure of public nursing homes was considered a very worrying development given that most older people are entering nursing home care at an older age and have more complex care needs. It was felt that there should be an emphasis on the replacement and/or refurbishment of public nursing homes. Consideration must be given to the number of extra beds that will be required, how these beds will be funded and how community and primary care can be developed and funded in order to manage the demands that will be placed on the health service by a changing demography.

The closure of public beds was said to demonstrate a lack of planning by the health service. It was pointed out that any reduction in capacity in public nursing homes will place even greater demand on the capacity of the private and voluntary nursing home sector, particularly given the significant projected growth in demand in the years ahead.

Nursing home capacity was considered problematic in certain areas (e.g. certain geographic areas, residents who require ongoing mental health input, people with challenging behaviour and people under the age of 65).

The Scheme enables applicants to choose their nursing home. However, the applicant's first choice nursing home may not be able meet their care needs or may not have a vacancy. It was pointed out that the complexities and disturbances to the resident and their family when relocating to their first choice nursing home is time consuming and often causes real stress to the client (who may now be settled) and family. It was noted that the CSAR is often out of date when a person transfers from one nursing home to another. Added to that, there can be animosity when staff from one nursing home visit another current nursing home to carry out an assessment. Some families reported feeling pressurised by hospital discharge teams to accept an alternative bed when their first choice nursing home is not available. There was concern that, if you refuse one of the alternative options offered, you can be charged.

The 60km distance referred to the HSE's Standard Operating Procedure was considered to be too far for many people to visit a relative.

It was stated that current occupancy levels of 88-92% need to continue in order to ensure the viability of nursing homes. The optimal size for a nursing home was said to be 40 beds.

It was suggested that demand for nursing home care will soon supercede the capacity of the sector to meet requirements. A lack of availability of finance and negative changes to taxation arrangements were said to have affected growth in capacity. In this regard, uncertainty about the Scheme was mentioned as being a reason for banks not to provide funding.

#### What People Said...

"...the lack of beds in, for example, the Dublin North east region, means that people have difficulty finding beds quickly. Often in practice, people find a nursing home with a bed, but by the time they have received the funding, the bed has been given to someone else."

"Ongoing confidence in the Scheme is essential. Lending conditions and business investment plans are very sensitive to the public policy environment."

#### Care & Welfare Related Issues

The commitment in the Programme for Government that HIQA would have a role in the regulation and inspection of community services was welcomed.

The availability of HIQA reports online was praised. This, it was said, is a key part of banks ongoing credit risk assessment. Great emphasis placed on reports as it provides comfort that the nursing home is compliant with standards and is in a position to maintain its registration status. It was stated that it is essential that reports continue to be promptly available online.

#### Miscellaneous

There was a query about whether the administration of long-term residential care services for people who contracted Hepatitis C from the use of Human immunoglobulin Anti-D or the receipt within the State of another blood product or a blood transfusion should be managed by primary care services or by older persons services.

It was stated that initiatives designed to move people out of acute hospitals can be an inefficient use of public money because people can avail of it before their application for the Scheme is determined by the HSE. It was also considered to be inequitable because it supports access to funding outside the normal process. There was a feeling that people in the community were disadvantaged by such measures. It was suggested that this type of funding should cease and the funding should go to support the Nursing Homes Support Scheme instead.

It was reported that the lack of flexibility arising from the Scheme's statutory basis can sometimes be problematic.

It was proposed that universal health coverage would ensure prepayment and equal access to long term care and reduce the financial stress for older people and their families under the current Scheme<sup>19</sup>.

<sup>19</sup> It should be noted that the intention is for primary and hospital care to be funded mainly via the UHI system and for specialised and social care services, including long term care, to be funded by general taxation.

In a system where money follows the patient and where empty beds will not be funded, it was noted that it will be necessary to speed up assessments and also to issue families with a realistic time frame to view a facility.

With regard to the proposed new directorate structure of the HSE, it was noted that if all our health needs are to be addressed effectively within a functioning continuum of care, these directorates must function collaboratively and promote integrated working between the management and staff within and across directorates.

It was also suggested carrying out the review of the Nursing Homes Support Scheme in the absence of a National Positive Ageing Strategy was short-sighted and regrettable

### RECOMMENDATIONS FOR THE FUTURE OPERATION AND MANAGEMENT OF THE SCHEME

The following recommendations were made. For ease of references these have been categorised by theme is accordance with the list on page 9.

### On-going Sustainability of the Scheme Application Process

#### Access to Information

- 1. A 'one-stop' information shop should be established to address information deficits.
- 2. The development of a one-stop information point for older people encompassing cross-settings, multi-disciplinary information.
- 3. Training for those dealing with the public. Such training should involve documenting questions asked by families and the manner in which they are asked.
- 4. The exchange of information between the HSE and voluntary organisations could be improved.
- 5. A case-management approach be introduced for the transition to the Scheme, i.e. one person should assist the older person and their family with the process.

#### Literature on the Scheme

- 6. The literature on the scheme that is available should be simplified as it is open to misinterpretation and applicants have noted that they find it confusing/hard to understand. It was suggested that information on how to access the Scheme be presented in a much clearer, more user-friendly manner.
- 7. The Application Form and Information Booklet could be enhanced, e.g. examples of sections of the completed application form would be useful.
- 8. The list of nursing homes provided to applicants should identify the nursing homes which cater for people with dementia.
- 9. The development of plain-English documents with the National Adult Literacy Association (NALA) to endeavour to explain the Fair Deal in a manner which is cognisant of older peoples differing needs.

#### Data on the Scheme

- 10. There should be a commitment to publish an annual review of the Fair Deal scheme, including reports of the experiences of people availing of the scheme.
- 11. The Department should allow data on the Scheme to be explored by external agencies so that emerging trends can be captured in a transparent way.
- 12. Data should be configured to allow long-term monitoring of the scheme, to ensure that it is:
  - a) Providing the flexibility and quality measures to allow people with lifelimiting disease to be cared for in their place of residence for as long as possible (information concerning diagnosis/co-morbidities, place of death, number of admissions to acute settings etc could be very useful in examining trends),
  - b) Reaching those with the highest dependency needs or exceptional social care needs, and

- c) Ensuring equitable access for patients, across all diagnoses and all geographical areas.
- 13. The Department should host an interactive seminar with interested parties to tease out the issues.
- 14. Make data about the Scheme available publicly to facilitate a transparent and informed public debate on the future development of the Fair Deal model. The availability of such data would also facilitate better decision making around the planning and provision of respite, rehab and day care facilities.

## Planning for Long-term Care

- 15. There should be greater public awareness about the need for involvement of relevant care professionals, particularly front line staff, e.g. Primary Care Teams, GPs and Private Nursing Homes, in planning ahead for long term care.
- 16. The practice whereby individuals enter long-term nursing home care and subsequently apply for the Scheme should be discouraged as they may not qualify for financial support and be left with few alternatives.
- 17. There should be a campaign to get people to specify their wishes as regards long-term care and to sort out their affairs.

### Miscellaneous

- 18. Older people should be given the option of having access to an independent advocate.
- 19. For patients with palliative care and end of life needs, the speed of the process in securing support under the Scheme is very relevant. Palliative and end of life care patients' applications require special consideration analogous to the process of 24 hour fast-tracking of medical cards.
- 20. Focused education should be provided for solicitors who are dealing with the Scheme process on behalf of applicants. Many solicitors do not appear to have sufficient knowledge about the scheme.
- 21. Review the use of solicitors in applications to date to examine if such use is appropriate or not.
- 22. Amend the Nursing Homes Support Scheme Act to provide for a review of the financial assessment every 12 months.

### **Funding**

- 23. All individuals in receipt of respite services should be charged for the duration of their stay.
- 24. Given Ireland's ageing population, a fairer and more equitable system for funding long-term care is required.
- 25. The principle of solidarity should be applied.
- 26. Funding must be on a more solid footing and not be at the whim of budgetary decisions.

### **Care Needs Assessment**

27. Applicants over the age of 85 should be accepted without a Care Needs Assessment.

- 28. The National Standard Operating Procedures for Local Placement Fora (LPFs) should be reviewed on the basis of information gathered through two internal audits.
- 29. There should be designated sections of the CSAR for the Multi-Disciplinary Team (MDT) to complete.
- 30. The CSAR needs to be adapted to capture a more comprehensive social profile of the client's and carer's home situation.
- 31. Co-ordinators of community based CSARs for the LPFs need administrative and nursing support as the workload is increasing.
- 32. Community based applicants need better access to comprehensive geriatric assessment. Geriatric medical departments should be resourced to reduce need for older people to attend/await outpatient appointments for these formal and necessary assessments.
- 33. It appears that, in some areas, all members of the team must agree unanimously on the decision. For people who have moved through the spectrum of the system from home help to home care packages it is suggested that there should be room for an element of common sense and judgement.
- 34. Materials should be developed to support considered care needs assessment upon the roll-out of the new single assessment tool for older people.

### **Financial Assessment**

### Alterations to the Terms of the Assessment

- 35. Increase the asset contribution to perhaps 8% or even 10%.
- 36. Increase the 'three year cap' to four years/20%.
- 37. Introduce a range of percentage contributions, gradient with the applicant's ability to pay.
- 38. Consider limiting State support at a defined ceiling of contribution (at rates less that the current prices agreed with the NTPF).
- 39. Decrease the asset disregard. This would reduce the level of State support paid, thus favourably affecting the ongoing sustainability of the Scheme.
- 40. Review the treatment of couples. When both members of the couple are in long-term nursing home care, the minimum retained income threshold is too high.
- 41. The legislation allows for interest to be assessed as income. Many people choose to invest for 3-5 years. Consideration should be given to giving the applicant the choice of having the interest assessed on a yearly basis (bank statements provide details as to how much interest has accrued at a given date) or at maturity to protect against a sharp increase in their contribution.
- 42. Regulations should be developed under section 46 of the Nursing Homes Support Scheme Act to cover hardship.

#### Allowable Deductions

- 43. The list of Allowable Deductions should be expanded. The following suggestions were offered:
  - a) Maintenance of the family home,
  - b) Additional charges by nursing homes,
  - c) Loans (such as those in credit unions/banks) that are not directly related to the home and life mortgages,
  - d) Young dependents,
  - e) 24 hr heating,

- f) Insurance,
- g) Care providers calling.

### **Asset Valuations**

- 44. Consideration should be given to putting in place a structure within the HSE to undertake valuations of assets by HSE Estate Managers. It is understood that a number of Estate Managers in the HSE have valuation qualifications. Also, the Estate Managers could carry out spot checks and assist the Nursing Home Support Offices to ensure that applicants are disclosing all of their non-cash assets in the State.
- 45. Does every property need to be valued by a professional at a cost of €200-€300? Hopefully when the register of sale prices is introduced later this year it may solve the matter.

## <u>Treatment of Farms and Businesses</u>

- 46. There should be a cap on the maximum percentage charge that can be applied to non-residential assets, in all circumstances, regardless of the duration of care. This would provide greater certainty for farm families and allow them to make the most appropriate decision in meeting the costs of care.
- 47. Clearer guidelines must be issued to determine 'sudden illness or disability'. The interpretation must also be broadened to include those who have been cared for at home for a short period, but subsequently require care in a nursing home.
- 48. The three year cap should apply to farms.

### **Transferred Assets**

49. Clearer guidelines must be developed relating to the treatment of assets that have been transferred within the five years prior to going into nursing home care.

#### Backdating of State Support

- 50. The current situation, whereby State support is backdated to the 27<sup>th</sup> October 2009 for anyone who has been in nursing home care since before the Scheme commenced, should be reviewed on the basis that it is costly and, at this stage, those people have had sufficient time to decide on whether or not they wish to apply for the Scheme.
- 51. The issue of backdated payments for people in contract beds who apply for the Scheme (although likely to be small numbers) should be considered.

### **Miscellaneous**

- 52. Full detailed calculation made in arriving at the amount of State support to be provided should be furnished to the applicant, and not just the final figure.
- 53. No credit is given for payments made prior to entering long-term nursing home care. This should be further explored.
- 54. From the commencement of employment people should pay into a scheme akin to the previous 'widows and orphans' scheme.
- 55. Section 27 of the Act provides an opportunity for the State to satisfy itself that all assets have been declared on the application form. This should be implemented more robustly and appropriate links should be established with the

Revenue Commissioners. This would deter people from providing misleading information and would result in cost savings.

# **Ancillary State Support (Nursing Home Loan)**

- 56. Omit the loan and increase the contribution instead.
- 57. Persons with cash assets in excess of €100K should not be eligible to apply for the loan, at least until their cash assets reduce below this level.
- 58. Transparent mechanisms should be in place to ensure efficient recovery of assets pledged against the scheme. In this way, the scheme can facilitate wider coverage of the targeted population and reach those most in need.
- 59. Solicitors require more timely access to redemption figures for ancillary State support (can take up to 8 weeks to get figures).
- 60. Regulations should provide that the HSE must apply for registration of the Charging Order within a certain short time frame, e.g. 4 weeks.
- 61. The Inland Revenue Affidavit should also include a specific question about. whether or not there is a charge under the Act. Solicitors acting in the administration of the estate of a deceased person do not have any role in any review of State support/Ancillary State support which may be undertaken by the HSE.

# **Capacity Issues**

- 62. Introduce safeguards to ensure that applications are not accepted unless the applicant is in agreement. Where an application has been lodged without the knowledge/consent of the person concerned, a valid reason must be documented.
- 63. Some applicants have no relatives to act on their behalf. Alternatively, they may have relatives with whom they are in dispute regarding assets. As a result, applications can go into limbo. The provision in the legislation allowing certain professionals to act on behalf of applicants has been ineffective in this respect. It is generally the case that professionals employed by the HSE or a HSE funded agency will not take on a role that involves ongoing accountability for a patient's finances, after they have gone into nursing care. An alternative system of advocacy or case management, possibly involving independent practitioners funded by the scheme, should be considered.
- 64. Perhaps a family member should be able to apply for the loan if the person has a poor MMSE/Addenbrooks assessment score.
- 65. Legislation should be introduced to simplify the processing of applications for those who have diminished cognitive capacity. The provision of 'guardianship' would be most beneficial.
- 66. Amend section 21 to provide that the test of capacity to apply for ancillary State support and consent to the charge, as well as the general principles and best interest provision of the Mental Capacity Bill, be adopted for the appointment of Care Representatives.
- 67. Consideration should be given to providing that any person wishing to object to the appointment of a care rep be obliged to do so by affidavit submitted to the court within a set short timeframe.

# Scope of 'Long-term Residential Care Services'

- 68. Package should cover ancillary services such as dressings, continence pads etc. so that the patient is kept as well as possible for as long as possible.
- 69. Greater clarity should be provided on what exactly is included in the agreed cost of care.
- 70. Consideration should be given to expanding the goods and services covered to include all items inspected under the Care and Welfare Regulations (social activities/hairdressing/patient transport etc), otherwise residents are expected to meet these additional costs from the remaining 20% of their income.
- 71. Local arrangements regarding dressings/incontinence wear should cease and one national policy should be in place.

# **Uncooperative Applicants**

- 72. Amend the Health Act 1970 to account for patients who refuse an appropriate placement / refuse to pay.
- 73. Extend Section 53A of the Health Act 1970 to non-acute facilities.
- 74. Try to discourage practice of people who have been approved for State support waiting in hospital pending outcome of application for the loan.
- 75. Reduce the period of 40 working days provided for in section 10(7) of the Nursing Homes Support Scheme Act (with discretion for the period to be extended if there are extenuating circumstances).
- 76. If a person refuses to pay their contribution, perhaps attach charges to person's earnings / deduct at source for persons in receipt of State pension.
- 77. The HSE should put in place a regional specialist team / designated officer to work on difficult to solve / non-payment of charges or non-cooperation cases.

# **Under 65s / Complex Care Needs**

- 78. The Scheme should be extended to provide nursing support packages in homeless supported housing projects, including for under 65s.
- 79. Residential care options for people with dementia need to be developed to facilitate:
  - a) Supported housing models,
  - b) Specialist care units (using the Teaghlach Model),
  - Access to dementia palliative care interventions in all residential settings, and
  - d) Specialist care units/options for people who are <65. Specialisms should be developed with mental health services and neurological services.

# Cost of Long-term Residential Care in Public and Private Nursing Homes and the Effectiveness of the Current Methods of Negotiating/Setting Prices

### **Cost of Care**

- 80. Reduce the number of public nursing home beds because they're so expensive.
- 81. Price should cover all costs (clinical and social). Additional costs should only be sought by nursing homes in exceptional circumstances.
- 82. All rates in Dublin should be cut. It is actually cheaper to run a nursing home in Dublin.

- 83. The provision of activities to residents should be included in the pricing model as they are a key requirement of HIQA.
- 84. Cost of care should be the same across the board. Everyone has to meet the same standards.
- 85. The published cost of care should display and detail (separately) all additional charges for each nursing home. This would give residents and their families visibility of the full cost of care. Alternatively, the practice of publishing the price list should be re-considered. The resident contribution remains the same regardless of the NTPF price and is largely irrelevant to people when choosing a nursing home.

# **Method of Determining Cost of Care**

- 86. There should be a set price per region.
- 87. Reduce the price paid for a shared room.
- 88. Reduce prices paid in Dublin and on the East Coast.
- 89. Allow tiered costs of care reflecting different levels of patient complexity/dependency/care needs.
- 90. A mechanism needs to be agreed for calculating the cost of care in new public nursing homes.
- 91. Public beds should be priced in the same manner as private and voluntary in the interests of transparency.
- 92. Standard multi-year deals should be the norm and should be tied to a suitable inflation index as well as to any national wage agreements that come into force in the future.
- 93. The Department of Health should take steps to examine and competitively negotiate the cost of care in both the public and private sector, in order to protect the viability of the scheme, resulting in savings for both Government and the individual.
- 94. A clear method of outlining the 'real' costs of beds, in both public and private settings, including the costs of care and services required by the individual should be developed in order to facilitate accurate long term budgetary planning.
- 95. A mechanism should be allowed for public nursing homes to re-negotiate the weekly cost of care depending on the level of need of the applicant.
- 96. Would favour longer contracts (over a 3/5 yr rolling basis; subject to annual review) going forward. Creates greater certainty when assessing financial projections for the purposes of loan repayment capacity. Short term nature of contracts creates a high degree of uncertainty and can be a major obstacle for the bank in credit risk evaluation on certain transactions as this income stream constitutes a major part (often the great majority) of a nursing homes income for loan repayment purposes.
- 97. An enhanced rate should be introduced to meet the costs of providing care for people with complex needs. This will help to ensure people with dementia are not excluded from nursing homes due to the cost of providing specialist care.
- 98. There should be a list of the Cost Components applicable to care in all settings which can be used to arrive at a cost of care. The NTPF must undertake a rigorous exercise to identify the cost components in the public system which account for the range of difference. Once identified, decisions will have to be made as to how any additional costs will be dealt. These could include a

decision to exclude/include them in the cost of care or deal with them under a different budget heading.

# **Additional Costs in Nursing Homes**

- 99. A table of suitable extra charges should be agreed nationally for services provided outside of the contract such as physiotherapy. Otherwise the provision of physiotherapy etc. should be priced into the care needs of residents.
- 100. Consideration should be given to assigning responsibility for support in circumstances where a dispute arises over additional fees to a single national point of contact who can provide general guidance and filter those queries that should be dealt with privately by the resident from those that are in apparent breach of existing agreements and followed up.

# **Balance of Funding Between Long-term Residential Care and Community Based Services**

# **Alternatives to Nursing Home Care**

- 101. Better resourced community services and more sheltered housing should be available.
- 102. More use should be made of local housing associations / Voluntary Housing Associations (VHAs) to ensure that people do not enter nursing home care at an inappropriately early stage.
- 103. There needs to be greater emphasis on service diversity in order to reduce reliance on nursing homes.
- 104. Recommend re-visiting the Community Unit models of care which were initiated in the late '90s where the vision was to provide a continuum of support and care within the locality/community of each older person as they required it.
- 105. A portion of the funding from the Scheme should be used to fund supported housing projects. The Scheme should be reconfigured to support older people moved to supported housing (regulated to ensure standards) and not just nursing homes. Supported housing care should be put on a stronger footing.
- 106. Cork Pathfinder Project (or similar action research projects) should be used to explore how services can be restructured to prevent admissions for frail elderly at end of life (and who could be supported to remain at home or in their nursing home).
- 107. Funding should be available up to the same level as nursing home costs to provide meaningful options to people with dementia to remain at home as long as that is possible.
- 108. All applicants for long-term nursing home care should be assessed for home care in the first instance.
- 109. Give people an allocated budget, cash grant or voucher designed to meet their particular needs/preferences. Provide support and advocacy where necessary.
- 110. Provision of Hospital in the Home nationwide would reduce the need for long-term nursing home places. Should be full support from the State for Hospices in the case of end-of-life situations.
- 111. People with multiple chronic conditions should be supported to manage their own health locally. Diagnosis and management of conditions such as dementia, stroke, falls, incontinence, bone health and immobility should be available in the community.

112. As an alternative to the Scheme – the person could live at home with skilled medically trained healthcare workers available on a 24/7 basis, either resident in the home on a rotation basis, or working in the home on a shift rota, perhaps indispersed by family care periods. The Fair Deal initiative could still apply, drawing up to 15% of the asset value. Obviously, some material changes may be necessary to the home to facilitate the care necessary.

# **Funding for Community Services**

- 113. Should be able to use funding to procure community or nursing home care, as appropriate.
- 114. The Scheme should be reconstituted to ensure that financial assistance is also available for older people who wish to remain living in their own homes with support.
- 115. It is proposed that all funding for residential care be included under the one subhead which would allow for flexibility to use all available beds to meet local demand, with the model of money follows the patient, as is currently used for long-term nursing home beds. Indeed, it may also be beneficial to utilise this model for Home Help/Home Care Packages so that older people may choose from a menu of services appropriate to their needs.
- 116. Funding for community services should be merged with funding for long-term residential care and patients made aware of the range of options available to them. If further funding were available for Home Care Packages, it would reduce the demand for long-term nursing home care and pressure on the health budget.
- 117. Budget for community based services should be increased and over time its effect on the admissions to LTRC can be quantified and studied.

# **Access to Community Services**

- 118. Access to community services should be based on a transparent, objective and equitable process that is highly responsive to emerging needs.
- 119. There should be access to a uniform assessment of needs and the needs of carers and access to a register of professional home-carers. There should be a clear timeline for implementation of the single assessment tool for older people.
- 120. There should be the facility for families carers in crisis situations to apply for loans/funding to supplement or supply care in the home. Situation where carers/families due to financial constraints have to chose the hospital A&E due to lack of care options should be avoided.

# Extension of the Scheme to Community Based Services and to Other Sectors (Disability and Mental Health)

# Community-based Services

- 121. Management of the total overall budget (community and residential) could be operated under the responsibility of the specific care group and funding allocated to individual cases appropriately.
- 122. The Scheme should be expanded to include the supports currently offered under Home Care Packages, so that a package of care is offered as a defined option to families looking to meet the care needs of their relative. Consideration should

- be given to each patients needs on an individual basis and a package of care tailored to suit accordingly, whether that be a Home Care Package or long-term nursing home care, this should be one assessment, and patients should be able to move seamlessly from one package to another as their needs change.
- 123. If the Scheme is extended to community services an entitlement to home care services should be established, access to the patients preferred care setting should be ensured, there should be greater investment in any information campaign, nursing homes should apply a more equitable approach in selecting residents, there should be clarity around the definition of basic needs and necessary care equipment, and the single assessment tool for older people should be extended to address the needs of carers.
- 124. Any revised scheme should reflect the following principles an entitlement to community care supports, transparency in the allocation of services and resources, a 'whole system approach' to the delivery of health and community care services and there should be specific guarantees (in terms of an enforceable SLA) for individuals opting for 'Home Care' Support Scheme.

### Disability and Mental Health Sectors

- 125. Extending the Scheme to the Disability and Mental Health sectors must be managed separately under Disability or Mental Health clinical care programmes in line with Department of Health policies as the care needs of each of these care groups and the individual care needs are different and demand that professional speciality is leading the care programme with the specific skills in these teams to address their much longer and often more complex care needs. This is specifically true for clients who have a long term mental health and life altering disabilities/diseases.
- 126. As the scheme is currently constructed, older persons with a mental illness may access the Scheme, but older persons with a mental disorder may not. As the number of elderly admitted on a detained basis in small, and a smaller number require continuing care within an Approved Centre setting, access to the Fair Deal supports for this particular subgroup would represent a safer and more appropriate approach than extended inpatient care within an acute psychiatric setting. This limitation should be reviewed for the small number of older persons who have a mental disorder and require access to a continuing care beds in an Approved Centre setting.

### **Miscellaneous**

# **Nursing Home Capacity**

- 127. There should be an emphasis on replacement and/or refurbishment of public nursing homes.
- 128. Increasing supply in a way that is viable for operators and lenders needs to be undertaken on an orderly basis to avoid surplus capacity in the market. Accurate assessment of required capacity is in all stakeholders interests, as is a public policy commitment to such a level. Ideally, capacity needs would be set out on a regional basis so as to avoid imbalances.

- 129. A clear Government strategy going forward, alongside consistent implementation at a policy and operational level will instil confidence and certainty for nursing home owners, residents and backs/lenders.
- 130. Consider fast-tracking and encouraging an increase in the supply of new long term residential beds in areas where demand is greatest.

### Care & Welfare Related Issues

- 131. The Scheme should adopt the following guarantees (per the European Charter of the Rights and responsibilities of Older People in Need of Long Term Care):
  - a) If and when you enter residential care, the conditions and costs of your residence should be set out in an explicit contract. Information about your rights and responsibilities should be clear and transparent. You have the right to receive advice prior to, and at the time of, your admission.
  - b) Before concluding or amending an agreement or contract for residential care or other services, you have the right to be fully informed and advised on the content and the possibility of making any future amendments to the agreement, including services and fees. Information about your rights and responsibilities should be clear and transparent.
  - c) You should be made aware of and given opportunities to participate voluntarily in social life in accordance with your interests and abilities in the spirit of solidarity between generations.
- 132. People entering nursing homes should be informed of their contractual obligation under Fair Deal and that providers may have recourse if fees are unpaid by them.
- 133. The role and responsibility of the GP in looking after residents under Fair Deal needs to be clarified. GPs are particularly concerned about the GMS fees they receive for residents under the age of 70.
- 134. An audit should be conducted to ascertain the number of residential units which achieve or fail to achieve Standard 16 re. End of Life Care in the *National Quality Standards for Residential Care Settings for Older People in Ireland*.
- 135. Nursing home units should be required to provide adequate training for staff around end of life care.
- 136. Older People and their families must be engaged in the process of drawing up individual care plans.

### Miscellaneous

- 137. Government should commit to a detailed audit of long-term care for older people which would:
  - a) Conduct a detailed financial analysis of the totality of the NHSS, including direction financial costs, indirect financial incentives, revenue and capital,
  - b) Complete a details financial analysis of HCPs,
  - c) Review funding models in other jurisdictions,
  - d) Map the range of services, residential, respite and community based in Ireland.
  - e) Define and assess outcomes of various interventions both residential and community, including health profile and dependency levels of the older person,

- f) Ascertain service users and families views on the preferred choices of care and how these can be achieved,
- g) Review international evidence and best practice models for LTC,
- h) Report and recommend levels of services and best models of care for Ireland over the next 10 years.
- 138. Beds should not lie idle. They should be used for respite if not used for long-term nursing home care.
- 139. Housing design and public spaces must be planned and developed on a 'whole of life' basis and must be suitable for all across the life cycle.
- 140. More and better use of technology should be employed as a way of delivering services and providing assisted living.
- 141. Any initiatives introduced by the Special delivery Unit must have Standard Operating Procedures which are compatible with the Nursing Homes Support Scheme legislation, Regulations and Guidelines and do not act as a disincentive for persons to co-operate fully with the process.
- 142. There should be greater development of service links between hospitals, GP services and nursing homes to allow, where appropriate, for expert health professionals to go to nursing homes rather than residents go to hospitals.
- 143. There needs to be greater emphasis on primary prevention and on ways of avoiding/delaying dementia; expansion of dedicated and flexible community based services; development of small-scale, appropriately designed, residential care units; enhanced information systems on the number of people with dementia, severity of the disease, placement patterns and quality of life.
- 144. The single assessment tool for older people should be progressed. It was noted in this regard that organisations representing carers have expressed concern regarding InterRAIs limited consideration of the needs of carers and have recommended the addition of a dedicated Carer Needs Assessment on the basis that an assessment of a dependent older person cannot be done in isolation from their environment and, particularly, an assessment in respect of the availability or not of family care supports and how such supports can be optimised.
- 145. A carers record of care to should be maintained within the home. Nurse Led Carers Clinic confidential support, information, practical assistance, advice and advocacy. Patient Discharge Summary. ICT solutions should be considered.
- 146. The purchasing, delivery and communication of services for the elderly should be repackaged in a way that achieves a lowering of prices while maintaining (if not improving) service.
- 147. Where a nursing home becomes unapproved due to the absence of a pricing agreement, consideration should be given to allowing the 'approved' status to continue in respect of those residents in situ at the time of the termination of the price agreement.

# **Appendix 1**

# A: Newspaper Advertisement - Call for Submissions



# Review of the Nursing Homes Support Scheme, *Fair Deal*

The Nursing Homes Support Scheme, Fair Deal, is a statutory system of financial support for people who require long-term nursing home care. A commitment was made on its introduction in October 2009 that it would be reviewed after three years.

Written submissions are now invited from those with an interest in the area to inform the review.

Submissions should be sent by email to fairdeal@health.gov.ie or by post to Fair Deal Review, Room 204, Department of Health, Hawkins House, Dublin 2 to arrive not later than close of business on **Monday**, **16th July 2012**.

Please note that submissions are subject to the Freedom of Information Acts 1997 & 2003. It is intended to publish a short summary report of submissions received.

Further details, including the Terms of Reference for the Review, are available at www.doh.ie on the Public Consultations page.



# **B:** Notice from Department of Health Website – Call for Submissions

The Nursing Homes Support Scheme, *Fair Deal*, is a system of financial support for people who require long-term nursing home care. The Scheme commenced on the 27<sup>th</sup> October 2009 and replaced the previous arrangements in respect of both public and private long-term nursing home care.

A commitment was made when the Scheme was introduced that it would be reviewed after three years. The reason for allowing this period to elapse is to ensure that established and validated trends and statistics will be available in order to inform the work.

We would now like to hear from any individual, group or other body that wishes to make a contribution to the review. This includes agencies and other bodies in the public, private, voluntary or community sectors. We would also welcome submissions from residents in nursing homes together with national groups or organisations that reflect the views of their members.

Submissions should be sent to:

Fair Deal Review, Room 204, Department of Health, Hawkins House, Dublin 2.

or by e-mail to fairdeal@health.gov.ie

The closing date for receipt of submissions is close of business on Monday, 16<sup>th</sup> July 2012.

Written submissions will be subject to the provisions of the Freedom of Information Acts 1997 & 2003 and may be subject to release. If a person making a submission considers that any element in it is sensitive, those elements should be clearly identified and the reasons for the sensitivity should be specified. The Department will, where possible, consult with the person about any information which he/she has identified as sensitive information before making a decision in response to a request for release under the Freedom of Information Acts.

Please note that a summary report of submissions received will be published on the Department of Health website after the closing date passes.

### **Terms of Reference**

Terms of Reference for the review are:

Taking account of Government policy, demographic trends and the fiscal situation -

1. To examine the on-going sustainability of the Nursing Homes Support Scheme,

- 2. To examine the overall cost of long-term residential care in public and private nursing homes and the effectiveness of the current methods of negotiating/setting prices,
- 3. Having regard to 1. and 2. above, to consider the balance of funding between long-term residential care and community based services,
- 4. To consider the extension of the scheme to community based services and to other sectors (Disability and Mental Health), and
- 5. To make recommendations for the future operation and management of the scheme.

Information on the Nursing Homes Support Scheme and the relevant Act and Regulations can be accessed via the following link: http://www.dohc.ie/issues/fair\_deal/

# Appendix 2

# List of Submissions Received in Alphabetical Order

- 1. Age Action
- 2. Alzheimer Society of Ireland
- 3. Bank of Ireland
- 4. Bridhaven Nursing Home
- 5. Caring for Carers
- 6. Citizens Information Board
- 7. Crowe Taft, Nuala
- 8. Danielis, Vis
- 9. Devlin, Jim
- 10. Disability Federation of Ireland
- 11. Fianna Fáil
- 12. Fitzsimons, Patricia
- 13. Fortune, Deirdre
- 14. Guy, Carol
- 15. Haven Bay Care Village
- 16. Health and Community Care Ireland
- 17. HSE, Dublin South City
- 18. HSE, Dublin South East/Wicklow ISA
- 19. HSE, ISA Dublin South Central
- 20. HSE, Nursing Home Support Office, Cork
- 21. HSE, Nursing Home Support Office, South Tipperary
- 22. HSE, Office of the Assistant National Director for Older Persons
- 23. Irish Association of Older People
- 24. Irish Association of Palliative Care
- 25. Irish Association of Social Workers
- 26. Irish Congress of Trade Unions, Retired Workers' Committee
- 27. Irish Council for Social Housing
- 28. Irish Creamery Milk Supliers Association
- 29. Irish Farmers' Association
- 30. Irish Heart Foundation
- 31. Irish Hospice Foundation
- 32. Irish Medical Organisation
- 33. Irish Senior Citizens Parliament
- 34. Mansfield, Elizabeth
- 35. McCarthy, Dr. Patricia
- 36. Mental Health Commission
- 37. Millbrae Lodge Nursing Home
- 38. Mullan, Claire
- 39. Murphy, Caitríona

- 40. Nagle, Kevin
- 41. National Federation of Pensioners Associations
- 42. National Financial Abuse of Older People Working Group
- 43. NTPF
- 44. Nursing Homes Ireland
- 45. O'Brien, Dr. Paul
- 46. Office of the Ombudsman
- 47. Older and Bolder
- 48. Our Lady's Hospice and Care Services
- 49. Private Nursing Home
- 50. Revenue Commissioners
- 51. Social Justice Ireland
- 52. Society of Trust and Estate Practitioners, Ireland
- 53. Solicitors for the Elderly
- 54. Stephanie Dempsey
- 55. Stephanie Dempsey
- 56. Tara Winthrop Private Clinic
- 57. The Carers Association
- 58. The County Limerick Housing Services Ltd
- 59. The Royal Hospital Donnybrook
- 60. The Voice of Older People, Donegal
- 61. Wall, Andrew



