

Review of Nursing Home Support Scheme (Fair Deal)

A Citizens Information Board Submission (July 2012)

The primary function of the Citizens Information Board (CIB) is the provision of information, advice and advocacy in the broad area of social services, including health and personal social services. The agency has a statutory role to assist and support people, particularly those with disabilities, in identifying and understanding their needs and options and in accessing their entitlements to public and social services. The CIB carries out its role through its delivery partners: the nationwide network¹ of Citizens Information Services (CISs); the Citizens Information Phone Service (CIPS); the National Advocacy Service (NAS)² and the nationwide Money Advice and Budgeting Service (MABS). The CIB also develops and maintains the citizens' information website www.citizensinformation.ie. Queries from the public to CISs and CIPS cover a wide range of areas, including social welfare entitlements, disability-related matters, housing and health. Ten per cent of CIS users are aged 66 years and over. Not surprisingly, people in this age group have a higher than average proportion of queries relating to social welfare and health services. The CIB publishes a range of information resources aimed at older people.

In 2011, CISs dealt with almost a million queries from 660,000 clients and CIPS dealt with over 144,000 callers.

In addition to the provision of information, advice and advocacy services, the CIB also has a role to: support, promote and develop the provision of information on the effectiveness of current social policy and services and to highlight issues which are of concern to users of those services.

Introduction

The CIB welcomes the opportunity to make a submission on the review of the Nursing Home Scheme (Fair Deal). The inclusion in the Terms of Reference for the review of the consideration of the “balance of funding between long-term residential care and community services” is regarded by the Board as being significant and timely.

This submission draws on the experiences of Citizens Information Services and the Board's National Advocacy Service which provides independent, representative advocacy for vulnerable people with disabilities. NAS was established in January

¹ There are 42 CISs providing information, advice and advocacy through 268 locations nationwide.

² The National Advocacy Service provides independent, representative advocacy for vulnerable people with disabilities. It is a countrywide service managed regionally by five Citizens Information Services.

2011 and took over the work of 46 pilot advocacy projects around the country.

The Submission identifies firstly some of the issues reported by CIB delivery partners relating to both the implementation of the Fair Deal scheme and the gaps in provision for the long-term care needs of citizens. Secondly, the Submission sets out what the CIB see as the core components of an integrated response to the long-term care needs of the older population. These are:

- Planning for future needs
- Integrated needs assessment
- Balanced financial provision for community care and nursing home care
- Enhancing and supporting family care
- Timely access to long-term care support services

2. Experience of the 'Fair Deal'

The Fair Deal scheme was introduced on the basis of the core principles that long-term care should be affordable and that a person should receive the same level of State support whether s/he chooses a public, voluntary or private nursing home. The scheme was envisaged as enabling people in need of long-term nursing care and their families to access such care in a timely and transparent manner. It should be acknowledged that the Fair Deal benefits a significant number of older people and is a considerable improvement on the level of support available under the previous subvention scheme. However as Minister of State for Older People, Kathleen Lynch has stated 'the basis on which the Fair Deal scheme functions based on property values is far too volatile'. While many people have successfully negotiated access to the Fair Deal scheme and benefit from its provisions, there is evidence from CIB delivery partners that some citizens have encountered difficulties around accessing and using the scheme.

Aspects of the Fair Deal scheme that have given rise to concern include the following:

- I. There is an on-going concern about people's eligibility for the scheme. This is related to uncertainty about the availability of the scheme to individuals in need – this was manifested in the temporary suspension of the scheme at one stage in 2011 and, also, in ongoing references to the withdrawal of Fair Deal places in private nursing homes and the retrenchment in publicly provided long-stay nursing home care.
- II. Some clients of CIB service delivery partner services continue to be quite unclear as to how the scheme operates, particularly in relation to the assessment of means relating to the family home.
- III. There is some lack of clarity as to what additional services are provided under the scheme. It is clear that the Fair Deal scheme excludes provision for social programmes, therapies, dental treatments and chiropody. However, it appears that some people have had difficulty in getting essential items such as incontinence wear and specialist care equipment (e.g. wheelchairs) that should be provided under the scheme and in some instances people with medical cards are being charged for expenses relating to medical care. (See cases in Appendix)
- IV. While the Fair Deal scheme provides for people having a choice of nursing home (private, voluntary or public), the fact is that in many instances, the

preferred choice is not available and people may be pressurised into accepting a place in a nursing home not of their choosing and sometimes one that is not in their local area where they have family and community connections.

- V. The anecdotal evidence reported to CIB delivery partners 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.
- VI. Some families report feeling pressurised by hospital discharge teams to accept an alternative nursing bed, in cases where their first choice is not available. Under the Fair Deal, a person who refuses to accept one of the alternative options offered can be charged the daily rate of acute care for the time spent in hospital after Fair Deal approval. This is clearly an unsatisfactory situation.
- VII. There is some anecdotal evidence of instances where a family or individual has had to turn down a nursing home place because the nursing home did not have the type of specialised equipment required for their care.
- VIII. The on-going cutbacks in home care supports, such as home help or respite hours, can leave families with little choice but to consider Fair Deal, despite home care being the preferred option. It may also be the case that the reduction of community care budgets has resulted in families of highly dependent people in receipt of high cost home care services being encouraged to consider 'alternative' care arrangements which would be funded under the Fair Deal scheme thus easing the pressure on the community care budget.

An issue regularly highlighted by the NAS is the fact that there are some younger people inappropriately placed in long-term care residential settings, including people with an acquired brain injury, people with MS, stroke victims and people with Motor Neurone disease. NAS has also highlighted instances where people are placed in long-stay residential services without provision for review and discharge if their condition changes.

The reduction in the proportion of Fair Deal applications being approved raises important questions. There was a 25% per cent drop in the rate of applications approved under the Fair Deal scheme in 2011 and figures up to the end of April this year show the approval rate has dropped to 68%, with 2,885 of 4,242 applications processed being approved for funding under the scheme.³ While the balance were reported as having been withdrawn, a question remains as to how the needs of those who applied for nursing home support and did not get it are being met. It is reasonable to assume that these older people have significant care needs which need to be responded to either through community care programmes or family care but it is not clear how and to what extent these needs are being met.

3. Planning for Future Needs

Provision for the nursing care needs of the older population must take full cognisance of the existing and future demographic scenario and should be a key component of the review of the Fair Deal. The population of the 65 and over age group recorded in Census 2011 was 535,393, an increase of 14.4% from 467,926 in 2006. Compared to population growth of 8.2% in the State as a whole, this is one of the age groups which experienced greatest growth over the period. While caution needs to be

³ Minister for State for Older People, *Dáil Written Answers 21 June 2012*.

exercised in respect of population projections,⁴ nonetheless the projected increase in this age-group to 796,484 in 2021 (or 14.1% of the total population) is a factor that needs to be included in the planning of care support services. The number of those aged 80 and over is expected to rise by 45% over the next ten years from 130,598 (2.8% of the population) in 2011 to 189,051 (3.5% of the population) in 2021. This trend of increase in population ageing is expected to continue well beyond 2021. The projected increase from 2011 to 2041 is 160% (that is an increase in absolute numbers from 535,393 in 2011 to 1,396,585 in 2041). As a proportion of the population, this represents an increase from 11.4% in 2011 to 22.4% in 2041. The proportion of the total population in older age groups is of course dependent on fertility rates and migration trends both of which can fluctuate.

While the projected changes in the population aged 65 and over are striking, changes for the group aged 80 and over are even more dramatic. Over the same 30 year period, the number of people aged 80 and over is projected to rise from 130,598 to 457,962 – an increase of 250%. Census 2011 shows that 6% of the over 65 population (31,054 persons) were resident in communal establishments with 4,873 of those usually resident in hospitals which accounts for over 15 per cent of those living in communal establishments. It is also projected that, given our ageing population, the numbers of people with dementia will increase very significantly in future years. It is estimated that by 2041 the numbers of people in Ireland with dementia will have tripled to 140,000 people.⁵

These population projections require an imaginative policy response built around integrated planning and learning from policies in other jurisdictions. The fact is that an ageing population will require more provision of health and social care. In this context, it is imperative that Government identifies the provisions that must be made to create a society in which the independence and dignity of every older citizen is assured, and where they can be cared for in a setting most appropriate to their needs. This will require a substantial enhancement of the partnership between State provision and family care.

As part of a comprehensive future planning process, there is a clear need for an audit of community care services to map the services that are available, identify the deficits, plan effectively for the future and introduce greater transparency. Such an audit would be essential to the incorporation of community care services, as indicated, into the Fair Deal scheme.

4. Balanced Financial Provision for Community Care and Nursing Home Care

There is a broad consensus about the key elements of care policy for dependent older people:

- (i) Care should be provided in the community for as long as possible and the number of people in long-term residential care services should be kept to a minimum.
- (ii) Active ageing should be promoted.

⁴ *Irish Longitudinal Study on Ageing (TILDA), 50 Plus in Ireland, 2011, Barrett et al. 2011*

⁵ Cahill, S., O'Shea, M and Pierce, M. (2012), *Future Dementia Care in Ireland: Sharing the Evidence to Mobilise Action*, Living with Dementia Research Programme, Trinity College and Irish Centre for Social Gerontology, NUIG.

- (iii) Family carers should receive adequate back-up from the State.

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 service provision falls far short of what is required to meet the diverse support and service needs of older people and their carers. For example, there are a number of difficulties with home care packages, including difficulties in getting a package in the first instance; the package provided being inadequate to meet need; difficulty in getting information about home care options and eligibility; waiting lists for home help services; general shortages of community based services; people being inappropriately placed in nursing homes; the difficulties many people have in taking on an employer role when they are offered a cash grant and the need for carers to have supports in their own right.

The statutory provision of Fair Deal, in tandem with the 'discretionary' basis of home care supports, has inadvertently prioritised long term residential care over home and community care of older people. Because the provision of community care supports are at the discretion of the health service, many families have no choice but to place a loved one in residential care prematurely, when home help, day care or respite services are withdrawn, reduced or not provided at all. A recent Seanad report on the rights of older people recommends that homecare entitlements should be clarified and put on a statutory footing, similar to that of Fair Deal.⁶

There are a number of factors which relate to the ability of people to remain living in the community, including, in particular, the extent of disability and functional impairment; the availability of family-based care; and the availability and accessibility of relevant community services. While the balance of care between community and residential care is very sensitive to marginal changes in any of these factors, the availability of family care is critical for people with high level needs (e.g., people with dementia) living at home. Such care imposes significant financial and emotional costs on carers.

Community support services for people with high level care needs and their carers are underdeveloped and fragmented. There are gaps, mostly due to budget constraints and staff shortages, in the availability of many services, including: public health nursing, specialist services, for example dementia services, day care, respite beds, night sitting services, home help, meals service, laundry service, chiropody. The fact that many community care services are provided on a discretionary rather than a statutory basis creates problems for providers as well as service users.

While there has been significant expansion in service provision at community level since the publication of *The Years Ahead* in 1988, the fact remains that there is no clear legislative entitlement to the basic services necessary for living in the community – for example, home help services. This is in contrast to the clear legislative entitlement to general practitioner and hospital services and, more recently, to nursing home services provided for under the *Fair Deal* scheme (Nursing Homes Support Scheme Act 2009). It is likely that most people do not realise the implications of this legal deficit until they find themselves in a crisis or an emergency resulting from the diagnosis of illness, discharge from hospital with a disability or a transition to the role of family carer. It is unlikely that adequate funding will be provided for services unless there is a clear legislative entitlement, especially during times of severe economic stringency.

⁶ Seanad Report on *The Rights of Older People* published 21st June, 2012.

The National Council on Ageing and Older People, the Equality Authority and, more recently, the Seanad Public Consultation Committee Report on the Rights of Older People have argued that community care should be underpinned by clear legislative entitlement. It is likely that such legislation will be necessary if the optimum balance between State funding for residential nursing home care and high-level community care is to be achieved. Such provision would also result in a more transparent system of service delivery which would create a more supportive environment for family carers.

It has become increasingly clear that the 'even playing field' promised by Fair Deal has resulted in even greater disparity and inconsistency, most notably the widening gap between the statutory entitlement to long term residential care through Fair Deal and the current discretionary nature of home and community care services. Without legislation to underpin access to these services, provision of community care for dependent older people is problematic and unreliable.

This was highlighted by the Ombudsman who stated that the State has "*divested itself of the legal obligation to provide care*"⁷ and suggested that "*the absence of legislation has meant there is a lack of certainty over what the HSE's obligations are or what people can expect from the State in terms of basic services. It also means there is a lack of transparency in decision-making about the allocation of resources*"⁸. This shortfall in community care supports was also referred to in a recent report on dementia services⁹ which concluded that:

Family caregivers in Ireland do not receive the supports needed to enable them to easily sustain the care role. In the absence of regular breaks (respite), some studies have shown that the decision to place a relative in long-term care is more related to carers' own subjective feelings of stress rather than to objective indicators such as the severity of the dementia (p.15).

There is a need for the development of an innovative approach to community care provision for highly dependent older people that will:

- Be based on composite and integrated needs assessment
- Acknowledge the person's home as the preferred care setting in most instances
- Explore in the longer-term how to provide a statutory entitlement to community care supports
- In the short-term, ensure that people have at least the same level of State funding support for home-based community care as they have for residential nursing home care

⁷ Paper presented by Emily O'Reilly, Ombudsman at the McGill Summer School, Co. Donegal, July 2010.

⁸ Paper presented by Emily O'Reilly, Ombudsman at the Medico-Legal Society of Ireland function, February 2012.

⁹ Cahill, S., O'Shea, M and Pierce, M. (2012), *Future Dementia Care in Ireland: Sharing the Evidence to Mobilise Action*, Living with Dementia Research Programme, Trinity College and Irish Centre for Social Gerontology, NUIG.

5. Integrated Needs Assessment

Single Needs Assessment is acknowledged in many jurisdictions as central to identifying and meeting the care and other support needs of vulnerable people. This approach is aimed at providing a holistic approach to the financing, management and delivery of services. It seeks to provide the context for the development of priorities for provision and the procedures to access resources and services and the implementation of an individual care support plan accordingly. It is based essentially on matching resources to the person's needs. *Towards 2016* identified the need for a Single Assessment Tool (SAT) to be used for the care needs assessment of older people nationally. Given some concerns amongst health and social professionals regarding a suitably robust SAT, it was agreed with the Minister for Health to implement *The Common Summary Assessment Report (CSAR)* as an interim measure to meet the legislative requirements under Fair Deal and the HSE undertook to develop an official SAT thereafter. A working group was established in 2010 to select, pilot test and recommend a SAT for use in Ireland. The working group are nearing completion of their work and have selected InteRAI¹⁰ as the preferred assessment tool. Carers' representative organisations in Ireland have expressed concern regarding InteRAI's limited consideration of the needs of carers and have recommended the addition of a dedicated Carer Needs Assessment¹¹ 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.

6. Enhancing and Supporting Family Care

While the ability of dependent older people to remain in their own home is determined by a number of different factors, including the extent of disability and functional impairment and the availability and accessibility of relevant community services, the availability of family care is critical for dependent older people living at home. Significant numbers of older people who have a need for health and social care support receive this support from family members. The Irish Longitudinal Study on Ageing (TILDA)¹² findings show that the relative contribution of support from non-family (20%) was far out weighted by the support received from family (67%).

"The relatively low numbers in this "non-family" category emphasises the heavy predominance of informal sources and in particular spouses and children in providing care for older people" (p. 217).

The TILDA study also showed that:

- Half of 50-64 year olds with surviving parents provide help with household tasks to their parents, on average for 10 hours per week;
- One- quarter provide their parents with personal care, on average for 18 hours per week
- Nearly one- quarter of older people in Ireland provide some form of help to their neighbours and friends,

"Families continue to be the most significant source of care for dependent older people in almost every country in the world. These informal family supports may

¹⁰ This is an internationally developed computer based tool to assist in the assessment of older persons. It is designed to assess the medical, rehabilitation and support requirements of the person

¹¹ Carer Organisations Submission to the SAT Working Group, July 2011.

¹² *Irish Longitudinal Study on Ageing (TILDA), 50 Plus in Ireland, 2011, Barrett et al. 2011*

become increasingly important as policy-makers in most OECD countries express reservations about being able to meet the increased demand for formal (State) supports. A key policy relevant question is, therefore, to what extent family support is available in times of need' (p.29).

It has also been suggested¹³ that many family caregivers may feel guilty about asking for help and often allow their own health and well-being to be adversely affected by the demands of the caring role.

As the State reduces the provision of critical services and supports (as a result of budget cutbacks), the onus of care on family carers increase. Anecdotal evidence suggests that hospitals are discharging increasing numbers of highly dependent people who require significant medical and nursing care while, at the same time, there is a reduction in vital community care supports such as Home Helps. This has clearly major implications for the sustainability of care by families. Factors such as the extending out of the retirement age, women's increased participation in the workforce aligned with the gender dimension of caring (64% of carers are women) may mean that family care may not be available to the extent that it has been previously.

The focus on community care services in the Fair Deal review, if it is to be meaningful, must obviously address the question as to how the family caring system can be enhanced and how State funding mechanisms can support such care in a manner that maximises its contribution.

7. Timely Access to Long-term Care Support Services

One of the key features of an inclusive care support system is that people have access to nursing care when they need it in a manner of their choice, as far as the latter is reasonable. There is, therefore a need for a system for the transparent allocation of resources and care supports for community care as well as for residential care. Such a system should set out clearly the criteria used in assessing older persons' eligibility for home care supports, including home help, Home Care Packages and respite hours. This should also state clearly what supports people in receipt of a Carers Allowance payment are entitled to and how this care is to be supplemented by the State.

While many older people experience a relatively good quality of life in later years, there is evidence that some are exposed to abuse and ill treatment in one form or another. A 2010 study by the NCPOP, *Abuse and Neglect of Older People in Ireland, Report on the National Study of Elder Abuse and Neglect*, found that elder abuse and neglect are the potential outcomes of complex interactions between a multiplicity of social, economic, health, social isolation, education, environmental and individual characteristics. The study further indicated that a multi-agency approach is needed to produce a multifaceted response to target prevention with a focus on resolving the mistreatment. It is reasonable to suggest that the availability of adequate support services in the community would create a context for minimising the level of elder abuse.

¹³ Cahill, S., O'Shea, M and Pierce, M. (2012), *Future Dementia Care in Ireland: Sharing the Evidence to Mobilise Action*, Living with Dementia Research Programme, Trinity College and Irish Centre for Social Gerontology, NUIG.

Enhancing Access to Information

The CIB has consistently highlighted the important role information plays in supporting people at all stages of the life-cycle. The role of information is particularly important at key transition stages such as decisions about long-term nursing care. It is also the case that citizens sometimes need additional assistance with accessing and interpreting information and, as already stated, should be given the option of having access to an independent advocate. The role of the advocate operates along a continuum from the provision of information on rights, options and choices, to providing support and assistance to people in asserting their rights and in making decisions. While health care professionals generally see themselves as acting as advocates for their patients, there may be an information deficit in that the healthcare professionals may not always be fully cognisant of the care support options available. It is also the case that there is a huge gap between those who are computer literate and proactive in their search for information and those who are not – the latter group are not well provided for under current arrangements. This should be a key consideration in any new provisions for needs assessment related funding supports.

8. Overview

The Review of the Fair Deal should be integrated into the overall vision for the health and social services as they apply to older people in need of high support and nursing care and should be integrated with four other relevant strategies currently under consideration – the Dementia Strategy, the Positive Ageing Strategy and the National Strategy for Carers and, most, importantly the roll out of the Primary Care Strategy.

The need to rationalise the availability of scarce resources must be balanced with a focus on transparency and equality in the delivery of community care services. The provisions of the Fair Deal cannot be easily applied to the community care sector. Rather what is required is a significant review of the community care system and its various mechanisms in order to ensure that the State, community and family caring systems are dynamic partners. The unique features of the community care sector must be acknowledged as should the clear preference of people in regards to where they wish to live out their lives. Just as the State is under severe financial pressures, so are many families and this fact needs to be acknowledged in whatever mechanisms are in place for funding community care.

While maintaining a throughput in the use of acute hospital beds is clearly an important consideration, the preference of older people and their families in terms of their preferred choice of nursing care is also a key consideration. It is of critical importance, therefore that people are not forced into a nursing home against their wishes because of pressure to discharge from hospitals in situations where necessary community care supports are not in place. This is particularly important in the case of people who are nearing end of life.

A clear articulation of the respective care responsibilities of the State, including community care services and the family and a clear statement of Government intent in this regard must be at the core of any new integrated 'fair deal' system. Also essential is the need to move as far as possible towards a seamless service involving the four pillars of health and social care – the acute hospital, the community service support structure, the family caring system and the residential nursing care sector. The State's responsibility to work in partnership with families in the provision of adequate support services for a relatively small but very vulnerable section of people (5% of older population) must be as much of a consideration in the Fair Deal review as the need to manage scarce state resources. Any moves towards the greater privatisation of nursing support services undermine the concept of social solidarity

and erodes the traditional responsibility of the State in responding to this area of need.

Appendix: Fair Deal Review – Cases dealt with by Citizens Information Services

Below are some sample cases dealt with by Citizens Information Services which highlight some of the issues with the Fair Deal scheme.

Case 1

Elderly gentleman in Nursing Home, on Social Welfare Payment, applied for Fair Deal and funding was approved under the scheme. He has no home of his own, was a council tenant so the funding was based on his SW pension. The client should be left with 20% of his income as pocket money. However, the Nursing Home applies an additional service charge of €125 per month, which is not included in fees under the Fair Deal Scheme, the nursing home has also rang the sister to pay for an ambulance call out to bring the patient to hospital. This patient has a medical card.

The sister is receiving demand letters from the nursing home accounts section regarding her brother's bills. She is making up the shortfall from her own pension even though she has a family of her own to look after. The liability is not hers and the contract of care is not with her but her brother. She is very stressed and upset.

The Fair Deal Scheme is not covering all the costs of nursing home care with additional charges being imposed on family members who are afraid to do anything in case their family member is affected.

Case 2

Elderly gentleman in nursing home has funding approved by Fair Deal scheme. His wife attends to him daily to make sure he is fed and kept hydrated as this has been a problem in the past in the home. She has received bills recently for pressure bandages and for blood tests taken in the home. This patient also has a medical card and his need for pressure bandages occurred after his arrival into the home. The patient's wife is making up the shortfall again from what's left of the family income and has now depleted savings.

Medical card patients are entitled to free blood tests and bandages should be supplied as part of their care package.