Introduction

With an increasing number of people living into older age, Government policy on the provision and financing of long-term care is central to ensuring access to care appropriate to need and preference.

Age Action recognises the right to healthcare as a universal right. Older people have a right to the enjoyment of the highest attainable standard of physical and mental health. Hence, the provision of quality care and support in the appropriate environment is a fundamental human right.

Under the Nursing Home Support Scheme – often referred to as Fair Deal – the State offers financial support to people whose care needs indicate they require long-term residential care.

However, nursing homes are permitted to charge additional fees to Fair Deal residents for certain services, some of which they may be required to provide by HIQA. These are creating financial challenges for residents and their families as well as undermining a key principle of the scheme – that residents can choose the nursing home they prefer.

The context

In Ireland, long-term residential care is provided through a mix of public, voluntary and private provision. The majority of beds, 22,342, are provided by the private and voluntary sector, with the HSE providing 6,656 beds.

The number of people in long-term residential care is approximately 4 per cent of the population aged 65 and over but this can vary between individual counties, with 2.8 per cent in long-term residential care in Donegal, compared to almost 5 per cent in South Dublin.

Long-term residential care is financed through a combination of State support (general taxation) and a contribution from residents based on their means. The average contribution from residents amounts to approximately 25 per cent of the cost of care.

The Nursing Home Support Scheme (NHSS) or Fair Deal was established by the Nursing Home Support Scheme Act 2009. The aim of this legislation was to provide an equitable and standardised approach to the financing and allocation of long-term residential care.

The scheme is founded on the core principles of equity, affordability, need and choice. Anyone resident in Ireland, assessed as requiring nursing home care and needing support to pay for it, can avail of the scheme. People may choose any approved nursing home that can meet their needs and has a bed available.

2  http://www.ohchr.org/EN/ProfessionalInterest/Pages/CESCR.aspx
3  NHI Annual Private Nursing Home Survey 2014/2015, June 2015
5  ibid
The NHSS provides financial support towards nursing and personal care – bed and board, laundry service, basic aids and appliances – necessary to assist the person with the activities of daily living. In 2016, the NHSS provided support to 23,450 people.

Under section 40 of the Nursing Homes Support Scheme Act the National Treatment Purchase Fund (NTPF) negotiates the maximum price private and voluntary nursing homes can charge for long-term residential care services.

The HSE’s role is to administer the scheme which includes assessing applicant’s care needs and conducting a financial assessment to determine the contribution required from each resident.

This contribution is made up of three different charges:

- Residents must pay 80 per cent of their assessable income;
- An annual levy of 7.5 per cent on their assets from which the first €36,000 is exempt and;
- A levy of 7.5 per cent of the value of their home, if any, for three years.

The individual can defer the contribution required on his or her assets and home by obtaining a nursing home loan, known as Ancillary State Support, and the funds are recouped from the estate after the resident has passed away.

The perception has arisen that this is the extent of the contribution the resident must make. In reality, while the resident is not obliged to make any further contribution under the Fair Deal, the nursing home can impose charges for additional services, some of which they may be required to provide by HIQA.

### Additional charges

In recent years Age Action has begun to receive complaints from people concerned at additional charges imposed on them or on a family member who is in long-term residential care under the NHSS.

The nursing home is entitled to charge for additional services that it provides beyond those covered by the NHSS, but the amounts being charged, the transparency of the system and, in some cases, the dubious legality of the charge can cause serious problems for nursing home residents and their families.

Charges are normally set out in the resident's contract for care but there is nothing to prevent the nursing home from altering the contract once the resident is in place and imposing additional charges, which can be stressful for residents and their families.

This is particularly so for individuals on low incomes and the review of the Nursing Home Support Scheme found that 15 per cent of applicants for the scheme had no declared income other than the non-contributory State Pension. The average weekly income for applicants in 2014 was €281.7

The imposition of additional charges by private nursing homes for services such as social activities, doctor's service at weekends and excess incontinence pads, is making long-term residential care unaffordable to older people on low incomes even under Fair Deal.

These extra charges can be significant, ranging from a €50 per month charge for excess incontinence pads to €100 per month for a weekend doctor service, and must be paid out of the 20 per cent of his or her income remaining to a resident after their Fair Deal contribution has been made.

Older people in long-term residential care may also be charged for therapies such as physiotherapy in places where demand for these from HSE Primary Care exceeds supply, resulting in the de-prioritisation of nursing home residents. These allied health services are almost non-existent for private and voluntary nursing homes. While residents retain their entitlements the HSE fails to deliver.\footnote{7}

Accessibility is an essential component of the right to healthcare and this includes ensuring that long-term care is affordable. By and large, \textit{Fair Deal} effectively facilitates this but the failure to tackle additional charges imposed by nursing homes is creating a financial burden on older people and their families.

In many instances, residents cannot opt out of paying these charges even though they may be unable, due to their health status, to participate in social activities. Others find themselves obliged to pay for ‘doctor services’ even while possessing a full medical card.

It also restricts the spending power of a nursing home resident. Instead of being able to spend the money remaining to him or her on books, hobbies, clothes or gifts to family members, they must pay the nursing home for additional services they may or may not want, and which are not regulated.

The right of the spouse or partner of the person in residential care to live with dignity is also under threat where additional charges are levied, as they are placed in the position of having to meet these costs to ensure the continuation of care for their loved one. The current safeguards in the NHSS to ensure contributions to the cost of care reflect individual circumstances do not take into consideration these extra costs.

\textbf{Undermining choice}

A key principle of the NHSS is that under the scheme individuals can choose from any of the participating nursing homes where beds are available.

However, Age Action is aware from social workers of cases where older people have been unable to choose the nursing home they prefer because they cannot afford the additional charges.

Older people, or their families, with limited means face charges that can range from €15 to €100 per week and in some cases nursing homes seek a large cash deposit before admitting a new resident, which can be impossible for some families to provide.

“A family I have been working with has just spent days visiting nursing homes in the south Dublin and Wicklow area,” one social worker told Age Action. “They’re being quoted extra charges of €85 a week and they simply can’t afford that.”

“I have one patient whose family just can’t pay anything extra and because of this she is now on the waiting list for a public nursing home bed,” said another.\footnote{8}

The Department of Health makes clear that a resident’s “choice of nursing home is not connected in any way to the level of your contribution to care” but the daily reality for many older people and their families is that their ability to pay is the determining factor in choosing a nursing home.\footnote{9}

Those participating in the Nursing Home Support Scheme who are of limited means find themselves with limited choices. When the scale of additional charging has reached the point that it is undermining a core principle of the scheme, action must be taken.

\footnotetext{7}{Statement from Nursing Homes Ireland.}
\footnotetext{8}{Statements from social workers working with older people with some details removed to ensure they cannot be identified.}
Voice of those affected by nursing home charges

Michelle rang Age Action about her mother who is in a Dublin nursing home. Her mother has a medical card and her own doctor but the home is still introducing a charge for a Doctor Service because they provide a house doctor for the residents. She is also being charged for ‘excess’ incontinence pads. The home has refused to supply an itemised bill.

Michelle contacted the NTPF and the HSE who confirmed the charge was illegal. She engaged a solicitor to challenge the charge but was told by nursing home management that if the charge is not paid they will cease to provide nursing home care to her mother.

Michelle’s story

Conor’s mother is in a nursing home under the Fair Deal Scheme and must, therefore, pay 80 per cent of her income as her contribution.

Out of the money remaining to her she must pay the following:

• €50 per month for incontinence wear;
• €222 per month for social activities;
• €10 surcharge on the three “free” chiropody visits per year;
• €100 per month for “doctor services”.

This list of additional charges, by no means exhaustive, comes to a grand total of €4,474 per annum.

Conor’s story

Making a complaint
Under the Health Act 2007, all nursing homes must register with the Health Information and Quality Authority (HIQA) and comply with the National Standards for Residential Care Settings for Older People. To ensure compliance with these standards, HIQA carries out inspections of nursing homes. In 2015, there were 411 inspections of 343 centres and 4,050 corrective actions were required.

However, HIQA cannot investigate individual complaints or allegations made against nursing home such as might be made regarding unfair charges.

Since August 2015 the Office of the Ombudsman has been able to accept individual complaints from nursing home residents.

Age Action is concerned that this facility is not widely known among nursing home residents and it not clear what efforts have been made by the HSE to ensure Fair Deal participants know they have this option. In 2016 the office received only 30 complaints.

We are also aware from dealing with nursing home residents, family members and social workers that there is a great deal of reluctance to pursue complaints or to speak publicly about these problems.

Many of the callers to our information line are concerned that if the nursing home becomes aware that they have contacted Age Action or are seeking to make a complaint that there could be negative repercussions for the family member in the nursing home.

Industry’s response
Nursing Homes Ireland (NHI) is the representative body for private nursing homes in Ireland. In discussions with Age Action the organisation made clear that nursing homes must be transparent in pricing for long-term care and it provides all members with a Template Contract for Care.

12 Correspondence with Ombudsman’s office.
13 Conversation with Nursing Homes Ireland representative.
It also agrees that the refusal of nursing homes to provide cost and billing information as outlined in examples provided by Age Action is unacceptable. The NHI points out nursing homes are obliged to provide services to residents that are expressly excluded from the Fair Deal scheme by the National Treatment Purchase Fund.

The NHI argues that, in this situation, nursing homes have little choice but to pass on the additional costs of such services to the resident.

**Government’s response**

The issue of additional charges under Fair Deal was examined as part of the review of the scheme carried out by the Department of Health in 2015.

It found that: “Issues have arisen in relation to additional charges being levied on residents by some private operators, which may be presented as optional, but which residents and families see as mandatory in practice.”

The review went on to acknowledge:

“There are cases where extra activities (e.g. social activities) incur a mandatory charge even though some residents are not in a position to avail of them because of their dependency levels. A very serious issue would arise if an operator were to seek payment from residents for items which are covered by the NHSS, the medical card or any other existing scheme.”

The review recommended:

“7) Nursing homes should have a published fee schedule showing all the costs associated with being a resident.
8) Consideration should be given to introducing a new provision under the scheme to prohibit the levying of additional charges for any service or facility from which residents cannot readily opt out without penalty while remaining as residents of that facility, or in which they cannot participate because of the level of their dependency.”

Even though these recommendations are quite minimalist there is no indication of any significant progress on their implementation.14

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14  https://www.kildarestreet.com/wrans/?id=2017-03-21a.2502&s=pringle#g2503.q
Next steps

The review of the NHSS recommended that the HSE consider including in the Deed of Agreement with facilities details of additional charges, opt-out arrangements and confirmation that residents will not be charged for extra services that they cannot participate in because of their dependency level or lack of capacity.\textsuperscript{15}

Widening the statutory responsibility of the Health Service Executive to include the regulation of additional charges in long-term residential care facilities will provide transparency. But it is unlikely to address the affordability of living in long-term residential care if the State continues to turn a blind eye to rising nursing home charges.

If older people are to have real choice of long-term care residential facilities, and live with dignity, the issue of additional charges must be addressed.

Minister for Health

1. Publish a comprehensive report outlining progress in implementing all of the recommendations contained in the \textit{Review of the Nursing Home Support Scheme – A Fair Deal}.
2. Amend the operation of the Nursing Home Support Scheme to ensure that residents can opt out of additional services in which they cannot participate because of their level of dependency.
3. Require all nursing homes participating in \textit{Fair Deal} to submit their fee schedule to the NTPF for publication online.
4. Widen the statutory responsibility of the National Treatment Purchase Fund to include the auditing and regulation of charges in long-term residential care facilities to ensure charges are consistent and not exorbitant, coordinating with HIQA to ensure nursing homes are not caught between the regulator and the funder.
5. Amend the fees charged under the NHSS to enable nursing home residents with an assessed income of €300 or less to retain a minimum of €60.

Health Service Executive

1. Write to all nursing home residents receiving support under the NHSS to ensure they are aware they can take complaints about their care or treatment to the Office of the Ombudsman – ensure that all new recipients are informed of this facility when they join the scheme.
2. Change the system of financial assessment under \textit{Fair Deal} so that if necessities like therapies, incontinence wear, a doctor at weekends and other resources are outside of what is covered under \textit{Fair Deal}, then the assessment must include these costs in determining the personal contribution required.

The work of the Age Action policy team is supported by the Scheme to Support National Organisations, funded via the Department of Housing, Planning, Community and Local Government, and administered by Pobal.