

Submission to the Department of Health on the White Paper on Universal Health Insurance (UHI)

May 2014

About Us

Care Alliance Ireland is the national network of voluntary organisations supporting Family Carers.

Our vision is that the role of Family Carers be fully recognised and valued in Irish society. We exist to enhance the quality of life for Family Carers. We work with caring organisations to provide better information and support to Family Carers. We provide opportunities to collaborate on initiatives including National Carers Week, a multi-agency and multi-disciplinary Family Carer Research Group, and joint policy submissions. We act as a distribution channel for information on Family Carer issues. We actively encourage collaboration in all our projects. We provide cohesion to organisations working to support Family Carers. We commission relevant research that supports focussed and quality interventions in the lives of Family Carers.

There are approximately 274,000 Family Carers in the Republic of Ireland. Family Carer support is provided by a number of organisations, some dedicated solely to carer support, and others who support carers as part of their response to individuals with specific conditions. We support our 98 member organisations and other agencies in their work with Family Carers. Our legitimacy derives from our membership base, which includes all Irish carer organisations, and the majority of disease/disability-specific organisations providing services to Family Carers. Our membership is comprised of large and small, regional and national, organisations.

Note

We have consulted our member organisations in preparing this submission; however, the submission is not to be seen as the collective views of Care Alliance members. We expect that many of our member organisations will make or have made their own submissions. The focus of our submission is the implications of the UHI proposals for Family Carers.

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Specific Observations on the UHI Proposals

Care Alliance Ireland welcomes the introduction of a single tier health system.

- In the interests of social solidarity, and acknowledging the wide range of disabling conditions that affect the clients of our member organisations, we would propose that a wide basket of services be available under UHI. We note the opportunity to make submissions on this matter at a later date.
- We note with great concern the absence of an explicit reference to Family Carers in the 89-page discussion document, despite the fact that Family Carers provide more than 80% of care to those with dependencies, and are often significant providers of care to relatives in hospital or acute or long-term care. This omission is at odds with the 2012 National Carers Strategy, which articulates the vision of Family Carers as 'partners in care'. This principle of partnership should be respected regardless of the location of the provision of care, whether in the community, at home, in hospital, or in an institutional setting.
- There is only one occurrence of the word 'carer' in the document; this occurs in the context of decision-making in integrated health and social care. This is insufficient and fails to take account of either the large number of Family Carers or their contribution to society and the economy.
- We are particularly concerned that the guiding principles on page 17 make no reference to families, let alone Family Carers. While we acknowledge the need for the system to be patient/client centred, health and social care services cannot operate in isolation from the wider family support system. Gantert et al. (2009, p. 46), writing specifically in relation to the provision of home care support services, point out that 'models of care provision have shifted away from the more individualistic "person-centred" or "client-centred" approaches that tend to focus on the client (Post, 2001) and towards models such as the "partnership approach" (Adams & Clarke, 1999) and "relationship-centred care"'.ⁱ
- We are concerned about the statement on page 40 (reference 23) that insurance would only be purchased by the State on behalf of those who lack the capacity to contract where a formal attorney or guardian exists. Firstly, we are not aware of the term 'attorney' being in common usage in Ireland, and, secondly, we understand that only a small percentage of those who may be deemed to 'lack the capacity to contract' have a guardian in law. We would expect that the process of applying for financial support would take account of some people's need for assistance with applications, perhaps by relatives

or carers, and that objective guidance would be available to allow such relatives or carers to make informed decisions about which insurer to choose for themselves, and for those they care for.

- While we agree in principle with the concept of the money following the patient, we are keen that processes be put in place to protect Family Carers from being sidelined. Again, this speaks to the 2012 National Carers Strategy vision of viewing Family Carers as ‘partners in care’. Disability cannot be viewed in isolation from the wider family unit, in particular where there is considerable Family Carer involvement.
- We have some concerns about how a new insurance model would give due recognition to the situation where a previously healthy and independent person becomes suddenly dependent. It is not always possible to reasonably or realistically plan to be a Family Carer – the role is often thrust on people – and we question whether an assessment of a person’s likelihood of becoming a Family Carer should influence the type of insurance package to be chosen. We are concerned that the changing funding model may lead to Family Carers being less able to access supports independently of the person with the care dependencies. We foresee that, in the case where the insurer or level of insurance of the dependent person is different to those of the Family Carer, the Family Carer may be at a disadvantage with respect to the services available to him or her in the caring role. The essential point is that the support available *directly* to the Family Carer should be independent of the type/level of insurance held by the person with care dependencies.
- Noting that social and long-term care may remain outside the remit of UHI initially, and also noting that this could change in the medium-term, we have concerns about how insurance providers may seek to opt out of offering insurance plans that comprehensively address the likely future support needs of Family Carers. We feel that this may negatively affect the overall availability of specific Family Carer support interventions, namely, home care support, carer support groups, advocacy, and flexible respite care.
- We look forward to considering the review of integrated service areas, as we believe these types of services are often critical to sustaining and supporting Family Carers in continuing to care.
- For UHI to work, we believe that community care services must be better resourced. Legislation that places home care supports on a statutory footing, similar to the Fair Deal scheme, is required to leverage such resources.

'Guiding support for family carers'

- We see a risk in the proposals that, in the interests of maximising profits/minimising costs, Family Carers would come under unreasonable pressure to keep a person with dependencies outside of the 'system'. Whilst care in the community is indeed generally preferable to hospital/residential care, rigorous safeguards need to be in place to ensure that efforts to avoid hospital/residential care are supported by the provision of an adequate level of accessible and flexible community based care. Indeed, we see a risk that inordinate pressure will be placed by gatekeepers of insurance-based services on Family Carers, and also on existing stretched social and community care providers. Benchmarks for access criteria will need to be carefully considered and reviewed regularly. We note the current roll out of the interRAI assessment tool in this regard, and request assurance that it has the capacity to be used effectively within the UHI model. We also have a concern that the proposed Carer Needs Assessment tool might be open to manipulation by health insurers; for example, an assessment of the capacity of family to provide care that fails to meet objectivity criteria could hide a real need for acute care services.
- We acknowledge the positives in endeavouring to keep people out of expensive acute services, and welcome the focus on prevention and the use of the lowest level of care needed. We contend, however, that the savings accrued from such an approach must be directed towards enhanced resourcing of primary care, and, in particular, formal home care, and direct support of Family Carers. This approach would appear to be in keeping with the Future Health policy document.
- We note the occasional inconsistent use of terms, notably the reference to social and long-term care on page 5 and the reference to social and continuing care on page 9. Are these the same thing?
- From consultation with Family Carer organisations in the Netherlands (the model currently being proposed for Ireland being similar to the Dutch model), there would appear to be a particular need to have available to Family Carers and the wider family the option of purchasing enhanced Family Carer support insurance. It is not clear from the discussion document how this would work.

ⁱ Gantert, T.W., C.L. McWilliam, C. Ward-Griffin and N. Allen (2009) Working it out together: Family caregivers' perceptions of relationship-building with in-home service providers, *Canadian Journal of Nursing Research*, 41 (3): 45