

Care Alliance Ireland
Submission to NESF Project on the
Implementation of Home Care Packages

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Care Alliance Ireland is the National Network of voluntary organisations supporting Family Carers.

We aim to support organisations in their direct work of supporting Family Carers all over Ireland. We also provide information, education, and training, regarding the needs of Family Carers. We carry out research relating to Family Carers and promote interagency collaboration.

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In this document, Care Alliance Ireland outlines key points for the NESF Project on the Implementation of Home Care Packages to consider, particularly in relation to Family Carers issues.

Family Carers – The Context

It is difficult to pinpoint the exact number of Family Carers in Ireland. The 2006 Census figures suggest that there are in the region of 161, 000 Family Carers in the Republic of Ireland; while other sources suggest that this figure may considerably higher¹. The 2006 Census also identified 41,000 full time Family Carers. This means that the cared-for person requires full-time care and attention. In addition, many Family Carers cannot leave the home unless another person is present to take over their caring duties. In short, caring is driven by necessity rather than choice².

Caregiving in Ireland has traditionally existed in the private sphere of the home, reflecting a residualist state response. Carers' health has also been given low priority even though it is of fundamental importance for the sustainability of care to be continued to be provided informally. Research on Family Carers in Ireland is limited. International evidence is much more comprehensive. For instance, Singleton et al (2002) found that Family Carers are three times more likely to report ill-health than the non-carer population. O'Connell (2003) notes that carers are unable to participate in social and health types of activities, due to the burden of care. Irish work carried out thus far has shown that caring for an individual in the home can take a toll on the family carer's mental, emotional and physical health, with high levels of burden (O'Connor and Ruddle, 1998; Blackwell et al, 1992; O'Donoghue, 2003).

The most extensive piece of Irish research to date examining the health status of Family Carers was undertaken by Care Alliance Ireland (2008): *Health and Well-Being of Family Carers in Ireland: Results of a survey of recipients of the Carers Allowance*. The aim of this research was to quantify the reported Family Carer health of a random sample of 2,834 Family Carers in receipt of a state carer payment as compared in part to the national non-carer population of the SLAN 2002 Survey. It was found that in comparison to the general population that those Family Carers who responded (n=1,411) were less likely to report themselves in excellent or very good health. Family Carers presented a considerably less positive picture of quality of life in

¹Laverne McGuinness, National Director, Primary, Community and Continuing Care, HSE in her address to Caring for Carers Ireland National Respite Weekend and Conference, Ennis, March 8th 2008.

² Carers' Strategy Consultation Group (2008) *Submission to the National Carers' Strategy Process*

comparison to the general population. Carers also reported comparatively high levels of depression, back pain and anxiety. Negative aspects associated with family caring included restricted leisure hours and a high risk of being exposed to stress, emotional strain and social isolation. The extent of limitation posed by caring on leisure/ recreation appeared to be a key factor both in likelihood of health suffering due to caring and likelihood of low quality of life for carers.

Comparisons between cost of family care and state provided care

Family Carers are registered in relevant statistics as economically inactive while they are providing vital care to family members in the home, thus saving the exchequer considerable amounts of money. It is estimated that Family Carers contribute over €2.5 billion to the economy every year; this figure would otherwise have to be spent in the health service. The Carers Association estimated in its 2007 Pre-Budget Submission to the Government that every week 3.5 million hours is worked by 161,000 Family Carers. The weekly salary scale of a home help worker according to HSE salary scales (March, 2008, updated Sept 2008) is €56.77 based on a 39 hours working week. This is equal to €28,952.04 per annum. In addition the estimated cost of nursing home care is in the region of €800-€1,000 per week, whilst the cost of acute hospital care is in the region of €5,000 per week³. These weekly figures amount to €41,600-€52,000 per annum for nursing home care and c€60,000 per annum for acute hospital care. Both nursing home and acute hospital care are care options which have often become the default provision as opposed to the appropriate provision due to the lack of capacity within community care. Enhancing the capacity of family care, with adequate supports for such care, can directly contribute to a reduction in demand for expensive and inappropriate institutional care (Carers' Strategy Consultation Group, 2008). Many Family Carers find themselves in a position where by they are looking after Family Members for longer periods, while they await a hospital bed or are discharged early following treatment without adequate community care back-up.

³ 'A Fair Deal on Long-Term Nursing Home Care' – Speech by Mary Harney, T.C., Minister for Health. 12 December 2006 www.dohc.ie/press/speeches/2006/20061211.html Also Nursing Home Ireland, Radio Comment, April 2008

Observations on the Home Care Package Scheme:

Since 1988, with the publication of *The Years Ahead: A Policy for the Elderly* the aim of Government policy has been ‘to enable older people to remain living at home in dignity and independence for as long as possible or practical’. Indeed, the Government’s National *Primary Care Strategy* emphasises a shift in emphasis away from hospital to community-based care. However, Care Alliance Ireland believes the Home Care Package Scheme is not currently maximising its effectiveness in terms of maintaining a specific group of the older population in their own homes and supporting Family Carers in their role, due to a number of factors, as outlined below:

- There are currently no national guidelines regarding how admission to the scheme is decided or how income or means are assessed. In addition, there is no formal assessment of needs of the Family Carer in situations where they are providing significant care. Some HSE Administrative Areas assess income on the same basis as medical cards. Each HSE Administrative Area has responsibility for the operation of its own scheme. In practice, access to necessary support services by Family Carers and care recipients is often dependent on where one lives and whether there is an active support organisation in the area. It may also depend on a person’s (and or their family’s) ability to negotiate with health and social care personnel. The practice of making Carer ‘availability’ a factor in determining whether or not to allocate home and community care services is seen by many Family Carers as undermining their role. Recent consultations with Family Carers in Ireland heard of a general lack of and availability of sufficiently resourced care packages as well as considerable ambiguity and variability in what is currently being offered (Listening to Carers Report, 2008). Therefore, there is an urgent need to pinpoint the Home Care Packages Scheme under legislation. Indeed, Care Alliance Ireland as a member of the Carers Strategy Consultation group argued in 2008 for enactment of the Health and Personal Social Services Bill in order to clarify entitlement to health and personal social services. This should also include putting Home Care Packages on a statutory basis with specific provisions for such packages to be used to support Family Carers.

- It would appear that the rapid development and roll out of Home Care Packages since 2006, whilst welcome, has not been accompanied by a commensurate level of development of and funding for other primary care supports and specifically case management. Active and comprehensive case management for each Home Care Package appears to be weak at best and non-existent in many cases. Often it falls to a family member to facilitate sufficient communication between the various service providers, in the absence of a named case manager. International evidence documenting the benefits of active case management is widespread,(NCAOP,2003) but unfortunately in the absence of an well developed infrastructure of community social work and or of functioning Primary Care Teams, case management is often delivered totally inadequately, if at all. Such an approach places all stakeholders at risk.
- Feedback we have received from various quarters' points to some difficulties in the low level of integration between traditional home help services and the more recently introduced Home Care Packages scheme. Whilst the evidence for this contention is limited and anecdotal, nonetheless we feel that this merits further reflection and analysis.
- Home Care Packages in some regions can require the family member to register as an employer, to pay employer's PRSI and to contend with issues relating to public liability insurance. These regulations act as a significant deterrent for many older people, their spouses or for Family Carers who might otherwise avail of the Scheme (NCAOP, 2008). This option needs to be presented as one of many rather than the only option. The Citizens Information Board (2007) notes that older people and Family Members caring for older persons in the home are ill informed of the nature of the employer/ employee relationship which is formed under the Scheme.
- There is some evidence that that priority is given to older people who are about to be admitted to, or who are already in acute hospitals – the result is that a vulnerable section of the older persons population e.g. those who need care at home but do not necessarily need hospital care, are not always having their needs met.

- The Home Care Package Scheme may be seen as a ‘cost-saving’ measure and a way of reducing ‘bed blockers’, rather than as a support mechanism for older people to continue to live at home independently. The National Council of Ageing and Older People (2008) notes that service providers tend to view the scheme as a means of securing early discharge of older people from acute hospitals, reduction of inappropriate re-admissions or the reduction of pressures on A&E departments.
- Evidence collected during a range of consultations with Family Carers across Ireland shows that many Carers felt ‘taken for granted’ by HSE services in decisions regarding the allocation of home care supports. Applications for support in the home may be rejected because of a presumption that there is a Family Carer available to do the job, without a full assessment of the family situation and open consideration of needs and constraints of all relevant parties. Such an approach is an antithesis of a ‘shared’ model of care (Listening to Carers Report, 2008). We therefore believe that in parallel with any comprehensive review and development of Home Care Packages, that a distinct Carers Assessment process needs to take place in each situation, the UK model being one to consider.

See www.carersuk.org/Information/Helpwithcaring/Carersassessmentguide

- According to HSE Figures in 2007 over 11,500 people benefited from Home Care Packages. At the end of 2007 8,035 people were in receipt of a Home Care Package, being an increase of 63% over the numbers in receipt of a Home Care Package at the end of December 2006. In 2008 over 11,987 people benefited from Home Care Packages (including those who availed of respite from this resource) and 8,990 people were in receipt of a HCP at any time. It is proposed that in 2009 this level of investment in community-based long-term care supports will be maintained i.e. the HSE will spend €120 million on the provision of 4,700 home care packages⁴. However, in light of the increasingly tight budgetary constraints, we are not confident that such a level of service provision will in fact be delivered. Even so, the figures proposed would equate only to benefitting 11,500 people, with 8,700 people in receipt of a HCP at any time. The NCAOP (2006) estimated that between 12,322 and 15,808 older people needed intensive home care supports in 2006. As a result of a continuing ageing in the

⁴ Correspondence with HSE, Services for Older People, 12th February 2009

older population in Ireland, these figures would be expected to be somewhat higher at present and point to a significant ongoing deficit in provision. A shift of resources, perhaps even at the expense of costly acute hospital care and often unnecessary nursing home care, towards the development of additional Home Care Packages is required.

- The *Long Term Care Report* (2008) proposes that the provision of home support packages will complement, rather than become a substitute for informal care provided by family members and others, indeed, informal care will remain the cornerstone of care policy. However, what is necessary is rather than an automatic presumption on the part of the state on the availability of Family Carers to provide care to older people in the home, there is a need for additional and adequate support services for Family Carers. Such support services should be geared towards ensuring that Family Carers are in a position to make choices regarding the extent to which they are involved in care work and in employment outside their caregiving role. In practice, this would mean that Family Carers could combine care work and paid work outside the home with the help of support services that they could rely on. In terms of actual policies, this would require significant expansion of flexible, mostly home-based services, especially respite and home help in addition to occupational therapy, physiotherapy, chiropody, social work and counseling services (CSCG, 2008).

Conclusion

Unless the current gaps in the Home Care Package Scheme are addressed, Care Alliance Ireland believes that a situation will remain whereby Family Carers in Ireland will continue to be forced to provide care to older people in the home due to what is often experienced as an inequitable and inadequate Home Care Package Scheme. In contrast to this, where expectations placed on Family Carers are reasonable and adequate, and where supports are in place to assist them in their role, caring for older people with medium to high levels of dependency in the home can be an enriching and rewarding experience.

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