

Supporting Older People with Complex Needs at Home:

Evaluation of the HSE Intensive Home Care Package Initiative

Lay Summary

Fiona Keogh and Maria Pierce, February 2019

Background to the study

Most people in Ireland who have health and social care needs, including older people and people with dementia, prefer to remain in their own homes. Providing care to enable people to remain at home has been the policy objective in Ireland for many years. However, home care and wider community care services are fragmented, underdeveloped and underfunded compared to other services. Much of the care to enable older people to remain at home is provided by family members.

Demand for publicly funded home care services is greater than the level of services that are available. The low level of home care is a factor in the increasing pressure on acute hospitals. With the rising number of older people and the rising number of people with dementia, this demand is set to increase each year.

Home care in Ireland

There are three main forms of home care provision in Ireland;

- a. Informal care, which is provided by family members/friends in an unpaid capacity and makes up the bulk of home care;
- b. Home support services provided by the HSE (in the past this was called home help services and Home Care Packages). Home support services

are provided either directly by HSE staff, or by HSE contracting voluntary or private providers to provide the care. Home support services typically range from a small number of hours (1-6 hours per week) up to about 21 hours per week. Not everyone who needs home support receives it immediately and there are waiting lists. Home support services provide help with personal care such as dressing, bathing etc. as well as help with essential domestic duties related only to the individual client. In addition to these home support services, intensive home care packages are also now provided to some people. These usually provide a higher level of hours for people with more complex needs and are the focus of this study.

- c. The third form of home care is private care - arranged by the individual/family themselves and funded out of their own funds. This type of fee-per-service care is provided by voluntary agencies, private companies and individual paid carers.

The Intensive Home Care Package (IHCP) Initiative As part of a process of developing home care services, the HSE funded an Intensive Home Care Package (IHCP) initiative which commenced in 2014. The aim of this initiative was to provide a higher level and greater range of services to older people with complex needs and their families, to tailor home care delivery directly to the needs



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of recipients and to help address the pressures on acute hospitals. The initiative was part of the implementation of the National Dementia Strategy (NDS) and a portion of IHCPs was targeted at people with dementia.

What the study set out to do

Although home support is a very important service in Ireland, we don't know a lot about how it is delivered. One of the aims of the study was to provide a detailed description of what was involved in the delivery of intensive home care, including profiling the recipients of such care. As well as describing intensive home care, the study set out to answer a number of questions:

- a. What type of care is delivered in an IHCP?
- b. What is the impact on people who get an IHCP and their families?
- c. How long can people remain at home with an IHCP?
- d. How much does an IHCP typically cost?
- e. How does this compare with alternatives such as nursing home care or acute hospital care?

How the study was done

To answer these questions, we analysed anonymous routine data collected by the HSE on all types of IHCPs. Data was collected for three years; 2015, 2016 and 2017. To get more detail on the impact of the IHCP we interviewed a sample of people and/or their family carer who got a Dementia IHCP. We conducted 42 interviews, nine of which included the person with dementia, most of whom were interviewed together with their family carer. We also interviewed people involved in managing, organising and delivering the IHCPs in the HSE.

What the study found

Who got an IHCP?

Between December 2014 and December 2017, 505 people received an IHCP; 59% were people with dementia; 45% were older people who did

not have dementia and 6% were people with disabilities (all of the latter group, except one, were under 65 years of age). The people who received IHCPs had an average age of 78.2 years, over half were female (57%), over half were married (52%) and almost one third lived alone (30%). Almost all of those who got an IHCP had high or maximum levels of dependency (83%). Almost two thirds (65%) of IHCP recipients were discharged from an acute hospital; 27% of recipients were living at home and were deemed at risk of entering long-term care.

How long can people remain at home with an IHCP?

It was not known at the time that the initiative commenced at the end of 2014, how long these high support packages might last. For recipients whose package ceased in the course of the three years, the IHCP gave people an additional nine months at home on average, before death or entry to long-term care. Based on the data from this large sample, it can be expected that about half of all packages (52%) will continue to be active after 12 months. Over time, this proportion will fall, so that after 24 months it can be expected that slightly more than a quarter (28%) will continue to be active and after 36 months this will be close to zero. This demonstrates that IHCPs can help people with significant need to remain living in their own homes for considerable periods of time.

What is the impact of an IHCP on recipients with dementia and their families?

From the interviews with the sample of people with dementia and their carers, we found that;

- ➔ Quality of life did not deteriorate significantly for the majority of people with dementia in the sample which is important considering the progressive nature of dementia. The carers' rating of the person's quality of life improved slightly but not significantly after the package was in place.
- ➔ The majority of carers and people with dementia were satisfied or very satisfied with their package.

- ➔ In general, the quality of life of carers was also maintained with the package. Family burden decreased slightly but not significantly as measured by average scores before and after the package was put in place. However, carer burden is complex and is also affected by other demands and stresses in the carer's life, for example, combining caring with working and/or raising children.

From the sample of people with dementia, we found that the packages worked well for families:

- ➔ when home care workers were well trained, particularly in relation to dementia care and person-centred care;
- ➔ when there was certainty or predictability in terms of scheduling;
- ➔ when there was consistency in terms of carers and continuity of care;
- ➔ when hours were organised so that there was time for a break for the carer;
- ➔ when there was good communication between the provider and the family.
- ➔ Problems arose when one or more of these conditions was not in place, for example, when there were lots of changes in care workers or when there was a lack of communication with carers and so on.

What type of care is delivered in an IHCP?

The major component of all of the IHCPs was hours of care provided by home helps and home care workers. We looked at differences between IHCPs for older people (Standard-IHCPs), for people with dementia (Dementia-IHCPs) and for people with disabilities (Disability-IHCPs).

- ➔ Hours provided by a Standard-IHCP: range 14 to 168 hours, average 45 hours per week.
- ➔ Hours provided by a Disability-IHCP: range 28 to 168 hours, average of 47 hours per week.
- ➔ Hours provided by Dementia-IHCPs: range 6 to 168 hours per week, average of 39 hours per week.

IHCP recipients with dementia received fewer hours per week on average than recipients without dementia (6 hours fewer on average). The average number of hours did not change much when we excluded outliers (i.e. the small number with very low and very high hours).

At the outset, there was no way of knowing if the IHCP Initiative would result in changes to the way in which home care was organised for people with dementia. An analysis of the data for the 42 in-depth cases showed there were three distinct types of packages, demonstrating the main ways in which services went about organising Dementia-IHCPs in response to the IHCP Initiative. These were described as:

- ➔ 'Classic IHCP' characterised by several short visits per day with a focus mainly on personal care;
- ➔ 'Block' IHCP which had longer and more discrete blocks of hours, thus providing care for the person and some respite for the family carer;
- ➔ 'Combination' IHCP which had short visits and blocks of care and enabled the provision of personal care, carer respite and meaningful occupation for the person receiving care.

It is important to emphasise that these package types were not in place at the beginning of the initiative as different options from which individuals could choose. These types were identified as patterns in the data which was collected on the IHCPs:

- ➔ The range of different responses that were implemented through IHCPs, and the differing content of the package types, is new to the Irish system.
- ➔ The volume of support is much greater than previous support models.
- ➔ There is also a move away from a 'one size fits all' approach to one where different bundles of care were created to respond to the specific needs of the person with dementia and family

caregivers. This new understanding could very usefully influence how home care is delivered in the future, with the possibility of matching care more closely to the needs of the person and family.

What does an IHCP typically cost?

Using data from the 505 IHCPs, we found;

- ➔ the average weekly cost of the IHCPs for a person with dementia was €925,
- ➔ for an older person with complex needs (Standard IHCP) the average weekly cost was €1,024;
- ➔ for a person with a disability the average weekly cost was €1,137.
- ➔ The average weekly costs did not change much when we excluded outliers (i.e. the small number with very high and very low costs).

From the sample of 42 IHCPs for people with dementia, we were able to obtain more detailed information on the cost of informal care provided by family members. There are different ways of trying to put a value on informal care. One method showed that informal care cost an average of €593 per week. Other methods produce higher estimates for the value of informal care. (More details are in the full reports).

Even with publicly funded IHCPs, some families paid out of their own funds for private care, amounting to an average of €391 per week across all recipients.

When the full range of costs are included (i.e. IHCP hours, primary and community care, consumption and housing);

- ➔ the estimated weekly cost to the exchequer of home care for people with dementia in this sample was, on average, €1,124 per week.
- ➔ Adding family care inputs to care raises the average cost of intensive home care for people with dementia to €1,717 per week (i.e. €1,124 + €593).

- ➔ Adding private care paid for by the client and/or their family, increases costs further to €2,108 per week (i.e. €1,124 + €593 + €391).

How does this compare with alternatives such as nursing home care or acute hospital care?

The average weekly cost of residential care varies depending on the type and location of the nursing home:

- ➔ In public long-stay facilities, it costs an average of €1,526 per week
- ➔ In private nursing homes it costs an average of €1,149 per week in Dublin and €909 in the rest of the country.
- ➔ Average acute care costs are difficult to calculate, but have been estimated at €5,992 per week.

IHCPs cost much less than acute hospital care. The weekly cost of IHCPs for the exchequer is lower than Dublin nursing home costs and public long-stay facilities and broadly similar to nursing home costs outside Dublin. Adding informal care costs to the exchequer costs raises the overall cost of home care relative to residential care, as does the inclusion of private home care costs.

The conclusions and implications

The provision of IHCPs for older people with complex needs has been effective in a variety of circumstances; in urban and rural settings; for people with maximum and high dependency levels; for people with families needing support and those with little or no family or informal care (30% lived alone); and for people who were at the end of life.

This study provides evidence that;

- ➔ It is feasible to discharge people with high needs (both those with and without dementia) home from acute hospital and support them to remain at home;
- ➔ People can be supported at home for an additional nine months on average, before death or entry to long-term care;

- IHCPs offer an important addition to the menu of home support options for older people;
- They seem to be effective at targeting those at highest risk of admission to nursing home care;
- They cost less than public nursing home places and some private nursing home places and cost much less than a bed in an acute hospital.

However, there are ongoing barriers to the development of an intensive home care model of service, even when money for packages is available. In particular, a shortage of suitable home care workers can lead to delays in putting IHCPs in place in some circumstances. Information and training can also be important facilitators for the development of home care provision. The relevant staff in different parts of the system (e.g. hospital, social care, community care, primary care) need to be aware of the potential of IHCPs, particularly in regard to the type of person most likely to benefit from this type of intervention. If we want home care to be more tailored or personalised, the people

organising and delivering home care need to have sufficient training in this form of provision and the home support system needs to be integrated, flexible and supportive in order to deliver it.

The results from this study indicate that investment by the HSE in IHCPs can keep people living at home for longer, including people with significant levels of disability and cognitive impairment. However, even with significant additional spending on IHCPs, informal care and, increasingly, private care is still needed to keep older people with complex needs living at home for longer. Home care in Ireland is essentially a family-provided care system. Without family care, it is difficult to see community care services as being a viable alternative to residential care. This makes the provision of responsive, tailored support to older people, people with dementia and their families all the more important to ensure that home care is a viable option into the future.

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More detail on the study, how it was carried out and the findings can be found in three reports:

Keogh, F., Pierce, M., Neylon, K., Fleming, P., O'Neill, S., Carter, L. and O'Shea, E. (2018). *Supporting People with Complex Needs at Home: Evaluation of the HSE Intensive Home Care Package Initiative*. Dublin: Genio. www.genio.ie/dementia-report1-ihcp

Keogh, F., Pierce, M., Neylon, K., Fleming, P., O'Neill, S., Carter, L. and O'Shea, E. (2018). *Supporting Older People with Complex Needs at Home: What Works for People with Dementia?* Dublin: Genio. www.genio.ie/dementia-report2-ihcp

Howard, E., Quinn, A., Coen, A. (2019). *Developing Integrated Personalised Supports for People with Dementia: Recommendations based on learning from the implementation of a programme across eight sites in Ireland* Dublin: Genio. www.genio.ie/dementia-report3-ihcp