

Personalised Psychosocial Supports and Care for People with Dementia in the Community

Investigation of the value case

Executive Summary, 2018

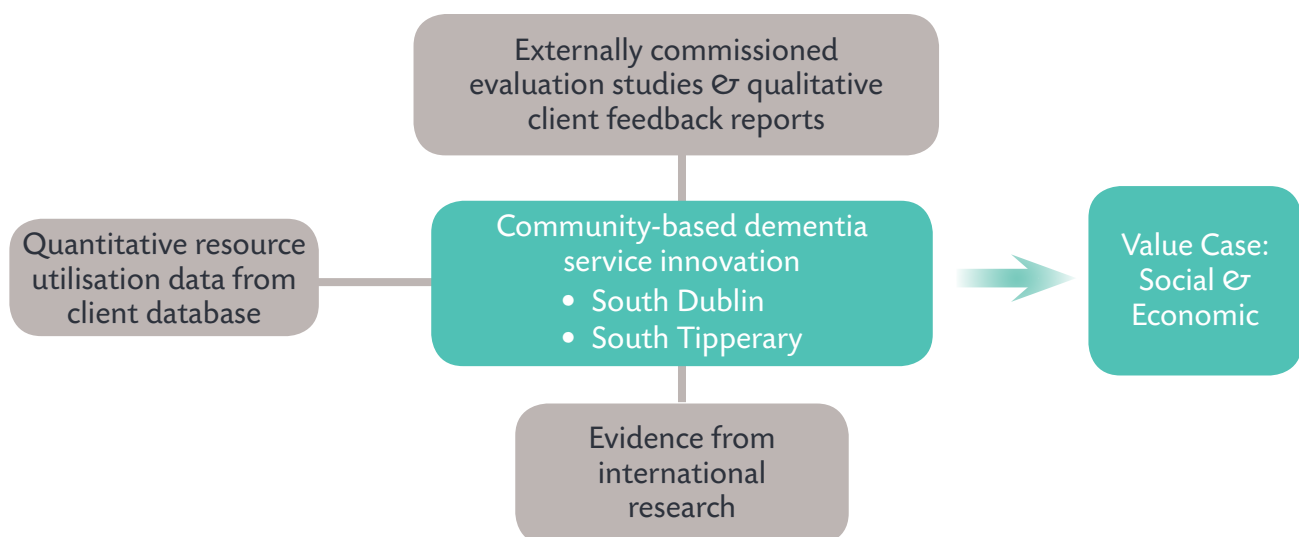
Kevin Cullen, Work Research Centre, Dublin; and Fiona Keogh, Centre for Economic and Social Research on Dementia, National University of Ireland, Galway (formerly Genio).

Context

It is widely acknowledged that community-based supports for people with dementia and their families have been underdeveloped in Ireland. The HSE & Genio Dementia Programme, through an alignment of goals and funding from the Health Service Executive (HSE) and the Atlantic Philanthropies, has been seeking to address this. The Programme develops and tests new service models to transform the range and quality of community-based supports for people with dementia in Ireland, and to change how we think about supporting people with dementia and their families. This is in line with government policy, as expressed through the Irish National Dementia Strategy, which aims to support people to remain at home, living full lives for as long as possible, and supporting families and local communities in this goal.

This Executive Summary presents a synopsis of the results from a study funded by Genio, with the support of the Atlantic Philanthropies, to assess the value case for these innovative community-based supports for people with dementia in Ireland. The study analysed Irish data and research evidence from the HSE & Genio Dementia Programme, and placed this in the context of the wider international research evidence. It aimed to: (1) provide a synthesis and analysis of the social care value and value for money of a range of psychosocial and other personalised supports; and (2) examine the case for their incorporation into mainstream care for people with dementia across the country. These aims are linked to one of the key actions of the National Dementia Strategy - the provision of integrated services, care, and supports for people with dementia and their carers, informed by principles of personhood and citizenship.

Evidence sources



The study focused on two substantial HSE-led demonstration projects funded under the HSE & Genio Dementia Programme, one in South Dublin (Stillorgan/Blackrock) and the other in South Tipperary. These projects were open to anyone with a diagnosis of dementia and so reflected 'real world' conditions. As a result, participants encompassed a very broad range of people with dementia and carers in their types and severity of needs, ranging from people who were at the early stage with mild symptoms to a substantial number with more advanced dementia and higher risk of entry to long-stay residential care in the near-term.

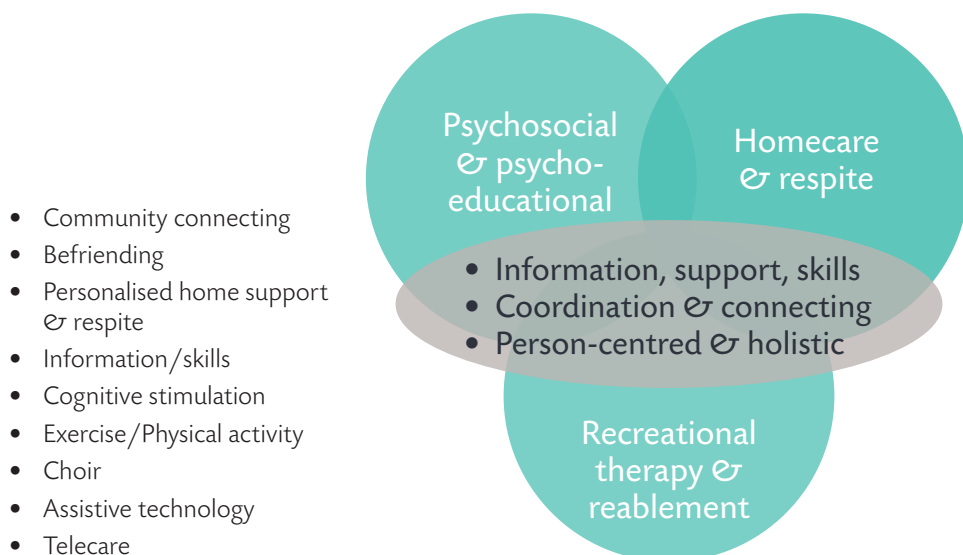
The projects provided a diverse range of supports, with personalisation and the promotion of personhood at the core of all of the supports and services developed and delivered. The term personalised, as used by the projects, is a broad term that describes the different ways to support the person with dementia to maximise their abilities and to remain living as full a life as possible. The diverse range of personalised supports developed and provided by the projects makes it difficult to neatly categorise them. For purposes of this report, the term psychosocial support has been adopted as shorthand, but this encompasses a broad range of supports developed by the projects. It includes a variety of reablement

supports on an individual or group basis, with a strong focus on connecting (or re-connecting) persons with dementia with activities in the community. Both projects also allocated substantial resources to personalised home supports, aiming to simultaneously provide respite for carers and positive, person-centred, benefits for persons with dementia.

Impacts for persons with dementia and family carers

Analysis of the extensive body of evaluation evidence from the projects found that the programmes of supports helped many persons with dementia and their family carers to live well with dementia. This included benefits for the person with dementia, for family carers, and at the wider family level. Each form of support proved useful for many people who used it. In addition, many people used a combination of the supports and gained substantial value from having the possibility to select from a variety of supports and receive tailored support packages designed to meet their preferences, circumstances, and needs. The results are congruent with the evidence from the wider international research literature indicating the value of psychosocial and other personalised supports, the importance of tailoring supports to relevant and achievable domains of gain, and

A range of psychosocial and other personalised supports



Some key areas of benefit for persons with dementia and their carers

Person with Dementia	<ul style="list-style-type: none"> • Enhanced personhood • Gains in subjective wellbeing • Enabled to live longer at home
Family Carers	<ul style="list-style-type: none"> • Reduced burden and negative impacts on wellbeing • Enhancement of more rewarding aspects of caring • Reduction in opportunity costs of caring
Couples/Families	<ul style="list-style-type: none"> • Relationship-related gains • Satisfaction from sustaining living at home

the particular value from supports that target gain for both the person with dementia and family carer.

Resource allocation and value for money

Economic analysis and value for money analysis of data on support hours provided to each person shows a potential for substantial cost avoidance through prevention or delay of entry to nursing home care. The demonstrable quality of life and subjective wellbeing gains provide a crucial and essential component of the social gain and value-for-money case. In their own right, these gains for persons with dementia and family carers represent considerable value for the health and social care system, even before considering the potential long-stay residential care cost avoidance.

From a national resource allocation perspective, a relatively small percentage increment in the standard allocation of social care supports for dementia care could enable provision of additional, personalised psychosocial supports for a large number of persons with dementia. Additional budgetary resourcing on its own will not necessarily lead to delivery of such supports to people with dementia, and the projects employed a local consortium model which

was key to the success of the approach. This involved HSE-led coordination and funding, with implementation and delivery in association with a local consortium.

Conclusions

RESOURCE ALLOCATION AND VALUE FOR MONEY: KEY POINTS

- Reflecting the personalised model and variety of psychosocial supports on offer, there was wide variation across service users in the mix of supports used, patterns of usage over time, and total number of hours used
- Overall, levels of project support were low, averaging between 1 to 2 hours per week per person; on an aggregate national basis, just a modest addition to the 'usual' social care allocation for older persons would enable widescale national roll-out of the approach
- According to an economic analysis by O'Shea and Monaghan (2016), the estimated potential cost avoidance for 181 people over a fifteen month period is €3 million, using this approach.

There is a demonstrated and compelling value case for provision of personalised psychosocial supports as part of care for people with dementia living in the community in Ireland. This is underpinned by an extensive range of evidence from the projects and from the wider research literature. The incremental costs, over and above standard care costs, are relatively small and represent good value for money in delivering on dementia policy and the National Dementia Strategy. In addition, there is the potential for substantial savings from delay or avoidance of long-stay residential care costs.

The evidence presented in this report indicates a strong case for resourcing the provision of personalised psychosocial supports across the trajectory of dementia, including the personalised supports of lower intensity demonstrated by these projects. These lower intensity supports could reach large numbers of people with dementia and family carers, particularly at an earlier stage, and could then be scaled and reconfigured to respond as individual need increases. The projects show that it is practically feasible to implement

these types of services at local level within HSE community care services. The basic model could be replicated in every area across the country, whilst allowing for tailoring and fine-tuning to local needs and capacities.

References:

O'Shea, E. and Monaghan, C. (2016) *An Economic Analysis of a Community-based Model for Dementia Care in Ireland: A Balance of Care Approach*, National Centre for Social Research on Dementia, National University of Ireland, Galway.

This study was funded through the Genio Trust, with the support of The Atlantic Philanthropies.

The report can be cited as:

Cullen, K. & Keogh, F. (2018) *Personalised Psychosocial Supports and Care for People with Dementia in the Community: Investigation of the value case*. Genio, Dublin.

wrc

WORK RESEARCH CENTRE



© Work Research Centre and Genio, 2018

A copy of the Executive Summary and full report is available at:

www.genio.ie

Disclaimer:

The views expressed in this report should not be taken to represent the views of Genio, the Genio Trust or of its funders; the Atlantic Philanthropies, the Department of Health and the Health Service Executive. Any errors or omissions are the responsibility of the research team.