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## Evaluation of the Community Outreach Dementia Project Leitrim

### Key Findings

HSE & GENIO DEMENTIA PROGRAMME





## EVALUATION OF THE COMMUNITY OUTREACH DEMENTIA PROJECT LEITRIM

### Introduction

The Community Outreach Dementia Project Leitrim (CODPL), based in Our Lady's Hospital Manorhamilton (OLHM) in Co. Leitrim, was one of several community projects funded by the Health Service Executive (HSE) and Genio Dementia Programme (Genio, 2015). It was designed to test out innovations in community care with a view to enabling people with advanced dementia and complex needs to remain at home longer and prevent unnecessary hospitalisation. At the same time, the project aimed to enhance home support for families through a 12 week intervention providing additional, flexible and responsive home care hours (including over-night respite and weekend cover) as well as telecare devices and other technologies. Dementia-specific educational initiatives were provided for service providers in the local area to improve their awareness and knowledge of dementia. The high level goal of the project was to improve the quality of life of people with dementia and their families. The CODPL is a positive example of learning in action, where objectives and corresponding interventions have been adjusted over time to respond to the needs arising in the community in a more effective way. During implementation the project's reach was progressively expanded to support people with advanced dementia in their transition from home to long-term care (i.e. the Nursing Home Support Scheme, also known as 'Fair Deal') as well as cases presented by the Public Health Nurse service as having outstanding needs, in particular in terms of carer burden. Thirty-five people with dementia and their carers benefitted from CODPL supports.

Trinity College Dublin and the National University of Ireland, Galway were commissioned to evaluate this two year project (2014-2016) and its four components:



### CODPL Evaluation Aims & Approach

An exploratory mixed method involving both quantitative and qualitative approaches was used to provide a comprehensive evaluation of the CODPL. The evaluation was underpinned by a framework called RE-AIM (Glasgow et al., 1999, Gaglio et al., 2013) which assessed project activity in terms of reach, effectiveness, adoption, implementation and maintenance.

#### Some facts about dementia in Leitrim:

- Leitrim is the most rural county in Ireland and has a large elderly population (14.8% of local people are aged 65 years and over), with a significant share (34.1%) living alone (CSO, 2012b). Together with Mayo, at 23.3% Leitrim has the highest old age dependency ratio in the country (CSO, 2012a).
- In 2011 it was estimated that 441 people were living with dementia in Leitrim, corresponding to about 1.4% of the local population (Pierce et al., 2014).
- The number of people with dementia living in the community is expected to double in the next 20 years due to population ageing.

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The evaluation examined the project's processes as well as its outcomes, looking at three key aspects:

Experience of dementia care  
- perspectives of service  
users and service providers



Comparison of the cost of  
'service as usual' to the cost  
of new approaches



Impact of the  
educational  
initiatives



### Key Findings Experience of the Person with Dementia

- Sample data revealed that project participants were a particularly vulnerable group, including older people (the average age was 86 years) at an advanced stage of dementia. They reported a moderate level of disability and poor quality of life (average QoL-AD score 27 out of a possible range of 13-52) at the beginning of the project, which continued to deteriorate as the disease progressed.
- A range of positive outcomes were achieved by the project for this group, including: enabling people with dementia at an advanced stage to remain at home for longer, facilitating early discharge from hospital and enhancing the quality of life of participants.
- Of the 30 participants who received project support, 29 continued to live at home during the project period. In addition, at least 15 of these people continued to live at home after the initial 12 week period of project support.

### Experience of Families

- In most cases the families participating in the project acted as main carers for their relatives with dementia and described their caring burden as moderate to severe, indicating an urgent need for support. Some of the carers noted that this stress had a negative effect on their own health, which in turn affected their ability to look after their relatives. This burden was further compounded by a feeling of being constantly restricted (e.g. being unable to work) and a feeling of isolation.
- Beneficiaries received support from the CODPL in the form of additional individualised home support hours to complement and enhance standard HSE services, ranging from 5 to 202 hours (in 14 cases more than 144 hours of care were delivered). The project also provided respite options to assist carers in coping, but these were subsequently replaced with a more engaging type of support, where the project hours were used, where possible, to facilitate meaningful engagement of the person with dementia. The care requests made by beneficiaries were considered modest.
- Recognising and assessing the person with dementia and their family members as a unit of care facilitated the delivery of a more personalised service.
- Families reported their experience of the CODPL support as being very positive. The provision of additional home care hours was considered the greatest benefit in terms of relief of carer burden. They found the supports to be of good quality and valued the flexibility in delivery. However, they expressed some concern regarding sustaining support given the resource constraints within standard community care services.





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### Impact on Cost of Community Care

- The vast majority of care for people with dementia supported by the COPDL project was provided by family members at no cost to the HSE.
- The cost of all the community care services funded by the HSE, including the services provided by the COPDL project to complement families caring, ranged from €236 to €1,009 per week, with an average of €504 per week.
- Assuming that the net cost of long-stay residential care is €813 per week (see full reports for details), for 27 of the 30 project participants the cost to the HSE of providing additional, flexible and responsive home care hours was lower than the cost of care in a long-stay residential setting and therefore represents a good use of resources.

### Impact of Technology

- The uptake of assistive technology provided under the project was lower than anticipated as only six families made use of the Telecare packages.
- The findings are indicative of the limited application of such technology for persons with advanced stages of dementia.

The total cost of care still remained less than the cost of a nursing home place



### Education and Training

- There was a high level of dementia awareness and knowledge among the service providers surveyed at the beginning of the CODPL. For this reason, the project educational initiatives were modest in scale and focused on complementing existing programmes.
- An education day, “Broadening Our Horizons”, and two “Life Story” workshops were run by the project with the objective of promoting a shift from task-orientated care towards more person-centred models of care. A total of 90 health care professionals were reached by these initiatives.
- The feedback received from participants was positive. Most of the attendants reported that they enjoyed the events and found the presentations of benefit, some suggested that they were able to apply the principles learned in their everyday practice. *“It’s improved me as a nurse, (...) it benefitted, I feel, the residents and their families”* (staff nurse)



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### Sarah and Orla's Story

Sarah (aged in her 80s) has advanced dementia with limited communication and mobility. She has been cared for by her daughter Orla (aged in her 40s), who lives with her, for a number of years. Orla works full-time so she pays for a large amount of private home help hours while she is in work, with a small amount of hours provided by the HSE. She provides the majority of care to her mother and receives very little support in her caring role from other family members. She is up during the night most nights with Sarah. She described the amount of time that her caring role consumes and its impact on her ability to meet up with friends or socialise.

Following referral by the Public Health Nurse, Sarah was enrolled in the CODPL. Despite some initial reluctance on Orla's part to become involved in the project for a number of reasons (e.g. a desire to maintain a routine, a concern that it would involve in-patient care for her mother, and resistance to the idea of having a home support worker in the house while she was there), once the project hours commenced, she found them hugely beneficial. She was provided with 12 hours overnight home support once per week. This was not available through standard HSE supports. She spoke about this additional support keeping her sane and giving her the energy to get through the rest of the week when she was assured of one night's rest. While originally she used some of these hours to go out and socialise, as her mother's condition progressed and she found the caring role more draining, she used all of these hours for rest and sleep.

When Sarah exited the project, the 12 hours were sustained by the HSE. Orla spoke of the worry she feels at the possibility of these hours being taken away as she feels they are such a lifeline to her. Since originally enrolling in the project, Sarah's condition has deteriorated a lot in relation to her physical state and mobility, as well as her communication and her ability to recognise people. Orla has requested additional support hours from the HSE but had not received any at the time of the interview. She continues to care for Sarah at home.



### CODPL Facilitators: Learning

- The consortium and steering group established to provide high-level oversight to the project brought together hospital, primary care and dementia-specific service perspectives that, if nurtured, could help drive culture, policy and system change in service delivery.
- A key strength of the project was the capacity for problem solving and flexibility, including: provision of hours at short notice for crisis avoidance and rapid response; provision of respite hours to families at times when HSE home care services were quite restricted such as evenings, overnight, at weekends and over the Christmas break; re-allocation of unused budget from telecare to home care hours. This approach was highly valuable in optimising outcomes for people with dementia and their families.
- The project structures (project office, consortium and steering group) for the most part, were successful in working towards attainment of project objectives and fit with a case coordination approach. The Project Officer role was deemed particularly important.
- The Public Health Nurses were the first point of contact, and as such, the 'face' of services to persons with dementia living at home and family carers seeking support. Knowledge of the community and their constant presence meant that the Public Health Nurses were able to develop relationships and monitor and respond to changing circumstances in a timely manner.



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### Emily and Jane's Story

Emily is a woman in her 90s who has mixed dementia, which is at an advanced stage. Her daughter Jane, who is in her 60s, lives next door to her and has been caring for her mother for several years. Jane gets little support from other family members and has given up work to care for her mother. She described her burden caring for her mother as high level and felt that there was more and more to be done each day. She spoke about always feeling like she was on 'high alert'. Emily was referred to the CODPL by the Public Health Nurse and was granted an additional 12 hours of home support provided during the day.

These additional care hours were primarily used for supervision and assistance with transfers, but included also reminiscence therapy and social interaction. The main benefit reported by Jane was that it allowed her to go out to do her shopping and catch up on other important chores. The benefits to Jane were short-lived, however, as Emily's mobility deteriorated, so she had to remain in the house during these hours to assist the home help because of the requirement for two people for lifting and moving her mother.

When Emily left the project, 10 project hours were sustained. Jane paid privately to fund the additional 2 hours as she felt she could not continue to care without them. She spoke very positively about these hours and felt she could not have kept Emily at home as long as she did without the help provided.

**She could not have kept  
Emily at home as long as she  
did without the help provided**



### CODPL Challenges: Learning

- Real world projects of this nature benefit from a built-in preparatory and set-up phase targeting engagement with all stakeholders and addressing required adaptations so that all are aware of and can respond to what the initiative entails.
- There was some delay in the involvement of the Public Health Nurse role, which had an impact on project development and roll-out.
- The gaps identified by the project in community care services for people with advanced dementia and their family carers were primarily a lack of flexibility in provision of home support hours and too few hours available. The project was successful in addressing these gaps using additional resources such that the total cost of care still remained less than the cost of a nursing home place for 27 of 30 participants.
- Embedding innovations into standard HSE services presents challenges for service providers at the levels of care delivery and administration, such as the ability to provide the flexibility evidenced as valuable to families through the project. The CODPL also highlighted important systemic issues within the wider health and social care context, such as the limited funding base for home care given the demand and the lack of availability of staff to provide home care.





## EVALUATION OF THE COMMUNITY OUTREACH DEMENTIA PROJECT LEITRIM

### Sustaining the Community Outreach Dementia Project Leitrim

- Embedding the project innovations into existing services proved to be challenging due to wider budgetary constraints within the health service and the resource limitations of existing community care services.
- In common with many parts of the country, home care agencies serving Leitrim have limited capacity to provide services and to facilitate flexibility in the provision of home supports due to the lack of appropriately trained staff. This wider issue needs to be addressed if the gains in this initiative are to be sustained.
- The project had developed and begun to implement a plan for the further development of dementia care services in the region, including a dementia education programme for home support staff; an education programme for Public Health Nurses; the adoption of the Zarit Burden Interview to assess carer burden (Zarit et al., 1985) as part of standardised assessment; and establishment of a 'Cogs' club (i.e. a service designed to help people with dementia to improve their memory and overall mental function through the use of Cognitive Stimulation Therapy). This was submitted to the HSE to inform future interventions beyond the life of this project.
- The sustainability of project gains must be considered in the context of broader national developments (e.g. development of an integrated care programme for older persons) and will require finding a balance between local community needs and sectoral constraints.

### Recommendations for Enhancing Dementia Care

- The adoption of a person-centred approach to care that focuses on the relationship between the Person with Dementia and their families.
- The provision of additional, flexible and more responsive home support hours is a key action to enable the Person with Dementia to remain at home for longer and to support family carers. This is in line with the recommendations by the National Dementia Strategy for more flexible support.
- Facilitating and supporting more dementia-specific care coordination approaches to care within existing healthcare roles is important to enhance the quality of services provided to People with Dementia.
- Centralising the provision and coordination of community care and primary care services for People with Dementia might be beneficial as they often fall between the cracks of a range of services.
- For the effective implementation of Telecare it is essential to take account of appropriateness, purpose and timing for those living with advanced dementia and their families.
- Educational initiatives related to dementia must be embedded as part of ongoing educational programmes for service providers.
- A re-conceptualisation of the provision of community care services and a move away from a focus on physical care requirements would be required in order for the project outcomes to be maintained and for the project ethos to continue within standard health services.
- In line with best practices on quality implementation frameworks (Meyers et al., 2012), the experience from this project points to the importance of a substantial set-up phase for any future initiative of the complex and evolving nature of the Community Outreach Dementia Project Leitrim. This is essential to ensure preparedness in terms of resources, services and stakeholders and how they interface with one another. Similarly, the basis for monitoring and evaluation should be established at set-up point.





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