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Genio Dementia Programme

Evaluation of Year 2

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Introduction

THIS paper is a follow-up to the evaluation of the Genio community-based dementia programme which was undertaken in 2014 by Professor O'Shea on the first year of operation of that programme. By supporting integrated and holistic service models within a person-centred framework for people with dementia (PWD) in four demonstration sites, Genio aims to enable PWD to remain living in their homes and local communities for as long as possible and practicable. The four projects have stimulated community-based responses to meet the individual needs of the PWD in a more flexible and integrated manner. The services that are being provided vary due to the nature and origins of the consortia: in Stillorgan-Blackrock the programme is rooted in the HSE, Mayo has its origins in the Alzheimer

Society of Ireland, while in Kinsale and South Tipperary the consortia are located in primary care and old age psychiatry respectively. Through the evolution and production of best practice service designs and the development of a learning network, the Genio dementia programme aims to strengthen the evidence base, with learning stemming from the initiative also providing a potential pathway for the recently published National Dementia Strategy.

The first year of the Genio Dementia Programme saw progress being made in improving the lives of PWD across a number of key areas subsequently identified as priority action areas in the National Dementia Strategy. All four sites have increased awareness and understanding of dementia in

society through a variety of events, training programmes and partnerships. While different structures in each of the projects have resulted in different pathways to timely diagnosis and intervention, there have been noticeable improvements in personalised care in all sites. Community-oriented individualised supports such as information, social engagement opportunities, support workers, respite care and assistive technologies are being offered to PWD and their families/carers enabling them to live longer at home. Dementia-specific training and education programmes are being provided to relevant stakeholders. Each of the sites has a named point of contact assisting PWD to access information and supports, connecting them to services and providing a more integrated care pathway.

“ IN YEAR TWO, ALL SITES HAVE LEARNED FROM THE EXPERIENCES OF THE FIRST YEAR AND FURTHER DEVELOPED THE POTENTIAL OF COMMUNITY-BASED PERSONAL CARE FOR PEOPLE WITH DEMENTIA. ”

Genio Dementia Programme

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Due to the pioneering nature of the work being undertaken in the demonstration sites, Year 1 was one of learning and not without its challenges, with difficulties encountered in identifying people in need of supports, engaging with community-based organisations, fostering active participation of PWD and a slow uptake of Telecare and assistive technologies reported. These difficulties are typical of an early implementation phase and, in Year 2, all sites have learned from the experiences of the first year and further developed the potential of community-based personal care for people with dementia.

Consequently, Year 2 of the programme has seen recalibration in all four sites: new posts have been created in some of the sites; some project

objectives have been realigned; there has also been a renewed commitment to empowering PWD in providing individually tailored responses to identified needs. Meaningful advancements in the delivery of person-centred care have occurred, with a broader range of flexible and responsive services now available in all four sites. Progress has also been made towards embedding and integrating the projects within the HSE, although the degree to which this has occurred still varies across the sites. A renewed emphasis has emerged amongst the sites to focus on mainstreaming services developed in the demonstration sites to ensure future sustainability.

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2 Methodology

THIS study is a follow up to the Genio Dementia Programme Evaluation of Year 1, which examined the operations and impact of the Programme in 2013. The focus of this study is to generate information from the four demonstration sites in regard to developments during Year 2 of the programme. The main author Professor O'Shea has maintained strong links with the sites, particularly in regard to data collection and various aspects of resource allocation. As part of Year 2 evaluation, each of the four sites was asked to complete a semi-structured questionnaire. The questionnaire covered the following areas: realignments; the Consortia; HSE integration; understanding and attitudes; person-centred care, technology, key improvements and changes to services during 2014, year highlights; sustainability; and the National Dementia Strategy.

Professor O'Shea also visited each of the sites and interviewed the project leads and various members of the consortia. The purpose of these interviews was to elicit more detailed information in support of the questionnaire. Interviews also took place with Genio personnel, where additional information was received in relation to activities and interventions that took place throughout the year. An initial draft of this report was circulated to each of the sites for comments, clarifications and corrections. A copy of the semi-structured questionnaire is available in Appendix A.

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Realignments

2014 has seen both changes to, and realignments of, the original project objectives across the four sites. In Mayo, a change in the project lead triggered a review for the consortium of the aims and activities of the project and the adoption of an enhanced project plan, including a new line management structure. The existing consortium members were reminded of their roles as stakeholders and their roles as advocates for people living with dementia and to share the learning with their individual organisations. One of the fundamental learnings in Mayo from Year 1 was the need to increase knowledge about dementia within primary care providers, particularly general practitioners (GP). Consequently, there has been a shift of emphasis away from the memory assessment service towards increased funding for GP education and training in an effort to raise awareness of dementia among providers.

The Mayo consortium also reallocated spending from planned home from home respite to an expansion of individualised support services for people with dementia and their families; this was necessary due to the increased volume of referrals from the Dementia Advisor, PHNs and other health care professionals. The enhanced budget for individualised care has enabled higher levels of support to be provided for people living with dementia within their local communities across Mayo. There has also been a shift in the referral pathway to the Dementia Advisor service between 2013 and 2014. In 2013, 90% of the referrals to the Dementia Advisor service came from the assessment screening service; following the discontinuation of the service in June 2014, referrals to the Advisor service were predominately from HSE professionals. A review of the Dementia Advisor role and

where it should sit within the community framework is currently being undertaken by the Mayo Project.

In Kinsale, all objectives were realigned in September 2014 to a graded system of high/medium/low priority. The role of the Dementia Care Coordinator increased from 8 hours per week to 32 hours per week due to increased demand as K-CoRD became established, time constraints and availability of PHNs to spend time with PWD and their families in developing a person-centred response. A K-CoRD Support Worker/Activities Coordinator (community connector) role has been established to aid the development of social engagement connections at an individual level. A slow uptake of Telecare Packages in Kinsale resulted in some of the funding in this area being allocated to other activities, particularly to support more individualised supports for people with dementia. A major emphasis in Kinsale is developing person centeredness through improving the awareness of dementia and mainstreaming education and training programmes at all levels.

Although no changes or realignments to the objectives were required in Stillorgan-Blackrock in 2014, the scope of some of the goals was revised, specifically in the areas of Telecare and community awareness training. The priority now is to provide assistive technologies that help the PWD to maintain ability and functioning through careful assessment of the balance between risk and capabilities in their lives. This is a truly person-centred approach to implementation with the person's needs placed at the centre of the assessment process. Formal OT assessments are completed to identify need using this person-centred care approach.

Community awareness in Stillorgan-Blackrock has been enhanced through

information stands, community awareness events, local presentations to organisations such as active retirement groups and schools, the Facebook launch and the website. The management team also decided to align the targeted dementia training for retail and businesses with the DCU Elevator Programme, which is a national programme. While this delayed the roll-out of localised training in this area, it is likely to be much more sustainable and focused in the long-run. In terms of the embeddedness of the project, from the project's inception, PHNs in the Stillorgan-Blackrock area have absorbed the key-role function for dementia with the support of the Consortium, particularly the project lead and the project manager. As a result, no additional posts needed to be added during the year. This speaks strongly to sustainability and the potential for scalability of the various activities in the longer term.

The South Tipperary project saw a significant change in the methods by which the objectives are delivered, with a greater focus now on priority setting and a more formal relationship between resource allocation and needs assessment. Two new posts were created, a community connector and a clinical nurse specialist in dementia (DNS), thereby enabling the delivery of high quality and personalised interventions swiftly and effectively. The hiring of a DNS reflects the fact that the project sits in Psychiatry of Old Age and has a high level of engagement with PWD with mental health problems and agitation needs. The specialisation of this position informs many of the crisis response inputs, leading to more effective intervention. An explicit sixth step on *sustainability* was added to the programme to ensure that all actions taken are sustainable when the grant ends. The consortium in South Tipperary has been reinvigorated and is now, more than ever, the driver of the project.

4 Consortia

IMPROVEMENTS in the functioning and relationships of the various consortia, which play a vital role in the sustainability of the projects, occurred throughout 2014. In Mayo, the consortium engaged with Dr Paul Doherty from Genio following a change in project lead, and revisited the question of “why are we here?” This led to very significant changes (a new project lead, a flattening of the governance structure and a revised MOU), with the consortium itself now providing greater leadership and direct involvement in the running of the project. Previously a steering group was reporting into the consortium, with little opportunity for active engagement by the consortium in the decision-making process. The recalibration that has occurred is much more supportive of a more engaged and active membership within the consortium. It recognised the importance of facilitating sub groups of skilled personnel to engage in delivery of aspects of the project, but values above all the collective wisdom of the consortium in decision making for delivery of the project objectives. A revised Project Plan was developed and subgroups for specific actions were convened including: financial, clinical and staffing areas. The clinical group’s first action was to complete an in depth audit of the MAC service, resulting in clear findings informing a change in project objective.

The consortium in South Tipperary underwent significant changes in 2014. Three new PWD and a new family carer joined the consortium, while meetings were changed to monthly in order to enable PWD to participate more fully and to prevent the consortium from becoming a reference group

authorising decisions made by the Old Age Psychiatry (OAP) team and the project co-ordinator. Meetings for the subgroups associated with each of the 5 key aims were disbanded in favour of allowing the leads to call meetings when necessary and invite any and all consortium members to attend; this has increased and broadened participation by all consortium members. The management group of the consortium was strengthened by including the local HSE manager for Older Persons Services, with a view to encouraging mainstreaming and sustainability of the project.

The consortium in Kinsale has also worked to strengthen ties between the project and the HSE. The new project lead is also the Occupational Therapy Manager Cork South, a position which will allow her to develop K-CoRD’s links with HSE senior management and facilitate their active engagement in the programme of work. Collaboration with the HSE has increased; local Home Help Banked hours are being used for dementia training and for the provision of social support to PWD in the catchment area as a pilot, with the latter yet to commence. The Clinical Review panel was renamed the Care Review panel to reflect its wider membership and broader focus and are now included as members of the consortium, while two members of the Education Working Group have also been co-opted, one to the management committee and the other has assumed the role of the Dementia Care Coordinator. The Management Committee is the core of the consortium and the working relationship which has developed within this group is leading to more effective decision making

and to the development of K-CoRD’s strategic plan for sustainability with the Project Manager. The project has worked to build on existing relationships and to draw in outside expertise. 2014 saw a strengthening of relationships between members of the management team, consortium, K-CoRD and outside partnerships such as Kinsale Day Care Centre and St Luke’s Home Education Centre, Cork. According to the project lead a:

“cross-section of subject matter experts now sit on the management committee and this is its strength.”

In Stillorgan-Blackrock, the consortium was already embedded in the HSE. Participation by group members has remained strong and continued support from a much wider group of stakeholders has been experienced, as evidenced by the willingness of organisations and people to make time (CST, drop-in clinic), space (Rehab, Southside Partnership) and money (sponsorship of catering, 2nd exercise group) available to accommodate various initiatives within the programme.

Overall the consortia across the four sites are characterised by strong, well-functioning management teams, which are driving the projects towards person-centred models of care. Year 2 brought forth many changes, most of which have served to strengthen and enhance the functioning of the consortia.

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Integration with HSE

THE DEGREE to which the projects have been able to embed/integrate within the HSE still varies across the four sites. Mayo have improved relationships with HSE management and the formal health and social care sector during 2014, but work is still needed to further enhance integration. In February 2014, the HSE management approached the CADM project to request a summary report on progress to date and a subsequent meeting took place. During this meeting the HSE acknowledged the significant progress made to date by the project and requested a formal submission for funding to be lodged with the HSE. It was felt that the CADM project could share learning to date so that more individuals could benefit across Mayo. The fact that the current project leader in Mayo is based in the County Council also opens up possibilities for a more holistic and integrated approach to the delivery of a range of community-based services to PWD which originate from outside the health services.

South Tipperary has made significant improvements towards embedding and integrating within local HSE social care structures. The HSE Manager for Older Persons is now on the management team in South Tipperary and has identified key areas requiring mainstream funding for sustainability: the Dementia Support Worker initiative; the Clinical Nurse Specialist in Dementia; and the Memory Technology Library. However, at the time of writing, mainstreaming conversations have not yet taken place at senior decision-making level. As the project enters its final year, finding a location for dementia services in South Tipperary post-project is seen as vital. Currently, the project is heavily embedded in the Old Age Psychiatry team, with all individuals referred becoming patients of the team and receiving at home assessments. It was always intended that the service would move out of Old Age Psychiatry and into the community as the volume of work

involved has proven to be overwhelming to the team as they also continue to deliver routine psychiatry services as well as dementia care, and it is also unnecessarily stigmatising for PWD to have to become psychiatric patients in order to receive the service. The appointment of the clinical nurse specialist in dementia is playing a major role in bridging this gap at the primary care level and joint visits with public health nurses have commenced.

In Kinsale, the new project lead is also the Occupational Therapy Manager Cork South and is actively working within the HSE to increase flexibility such that clients will be able to use their Home Care Package to 'buy social care hours'. While this remains a challenge, a number of realignments have taken place within the HSE which reflect the importance of the Genio project. The K-CoRD Dementia Care Coordinator and local PHNs and Home Help Coordinator are now making joint visits. The HSE has committed funding for travel so that the project is able to maintain its link to the EIPAH (a European initiative in healthy aging) and for Home Help Training. Furthermore, the HSE made a commitment to the use of Home Helps banked hours for the provision of social care with K-CoRD clients as a pilot initiative. Although this has yet to commence, home help hours offered to K-CoRD clients are now targeted at Home Helps with training in dementia. A training module developed by K-CoRD has been delivered to Home Helps in the area. As well as being a benefit to PWD registered with K-CoRD, it has a knock on effect in delivering a person-centred approach to all HSE home help users in the area.

The Living Well with Dementia (LWwD) project is very much embedded within the HSE LHO Dun Laoghaire and the learning from the programme is being implemented across the area. The collaborative working

together of all partners involved with PWD and their families in the LWwD project has demonstrated the potential of this approach to improve quality of life and is now being replicated in other primary care teams. The reach of the project has spread out into the wider LHO area, for example, a Dalkey based PHN and Dementia Champion provides training and support to staff in that locality and a dementia community awareness programme has also begun in the area. As integration and inclusiveness have been very much embedded from the programme's inception, re-configuration of HSE resources has not been required. A permanent information stand on dementia in the LHO public office, the participation and uptake by HSE staff at dementia training and awareness events and the PHN register of PWD are illustrative of the level of integration with the HSE. Positive conversations have taken place with the Community Health Organisation Chief Officer regarding the sustainability of specific initiatives under the LWwD project such as individualised supports following the end of Genio funding.

Overall, there has been a significant improvement in the integration of the four projects with existing formal provision within the HSE. Some projects, for example Stillorgan-Blackrock, are further along in this regard than others; this is mainly due to the community-care origin of that project and its strong relationship to the HSE from the outset. Similarly, in Kinsale the origin of the project within primary care has made it easier to establish relationships with general practitioners in the area. What is particularly noteworthy is the development of a better understanding amongst existing HSE providers in all four sites of the social model of provision underpinning the work of the Genio projects. This has, in turn, led to a more nuanced appreciation of the importance of individualised supports for PWD and their family carers.



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Public Understanding

ANECDOTAL evidence from the four sites suggests that understanding about dementia has increased in 2014 as a result of the work being undertaken. In South Tipperary, the role of the community connector is to work with PWD to help them engage more in community activities and to work with organisations to raise awareness about dementia, health promotion and prevention and how to live well with dementia. The role involves: speaking engagements; linking with organisations such as churches, meals on wheels and the HSE; and collaborating with different organisations to promote the benefits of exercise and diet in preventing dementia. The project website was launched and showcases all of the services and supports provided by the project, particularly the Memory Technology Library, and it provides information about dementia and how to live well with dementia. The project partnered with a local radio station (Tipp FM) to run monthly radio interviews covering matters such as experiences of family carers, assistive technology, diagnosis and early onset dementia. Evidence of the reach of this initiative is the very large phone queries to the project the morning after each radio slot. A public walk “Walk the 5 Steps to living well with Dementia” was held and was publicised on local media and on the project website. An international Dementia Conference was held in Clonmel and attracted a large audience. All of these activities have served to increase understanding about dementia and the supports provided through the project, as well as reducing the stigma surrounding the condition.

In Kinsale, community events have changed the visibility of dementia locally and have created conversations about dementia. Community events which took place during 2014 include: Café every Wednesday; quarterly ‘singing

café’ led by the K-CoRD singing group; five VISION (exploring the arts with new eyes) events; two community awareness events and one workshop. VISION is an arts programme which promotes greater inclusion of PWD by making art more accessible and is based on Meet me at MOMA (Museum of Modern Art, NY) and the Azure Project (Butler’s Gallery, Kilkenny). Throughout the year, PWD and their families/carers were invited to attend VISION events such as the ‘Now Wakes the Sea’ exhibition at the Kinsale Arts Festival where they were able to explore the exhibition with the curator. A community awareness event to provide information and increase dementia awareness was held in November and had nearly 100 people from a variety of community groups, local business, clubs and societies, health professionals and those living with dementia in attendance. Additionally, the project has partnered with other organisations and events such as Bealtaine, Kinsale Age Friendly Town, Kinsale Arts Festival and Positive Ageing Week. The project has benefited from local and national media coverage, and businesses have been very supportive of community initiatives and have responded well to the invitation to ‘customer service driven’ dementia awareness training. Similar to the LWwD project, Elevator Resources will be used for this training, which will run in collaboration with the Age Friendly Town Programme. A module is currently being developed on dementia awareness as part of the CSPE or Transition Year Programme. The level of volunteer engagement (28 volunteers, with more being recruited for social befriending and volunteer driver network) in K-CoRD and unsolicited donations from a number of organisations received are positive indicators of an increase in community awareness and reduction in stigma.

A major goal of the LWwD programme in Stillorgan-Blackrock is the establishment of a hub as a focal point for dementia related information and activities, which would be supported by the website. Currently, a community venue is being rented to deliver on this goal; however, the location is not very central for dementia awareness-raising and uptake has been particularly low for services such as the Drop in centre, which is a one to one advisory service for family or individuals concerned about dementia. However, other services which run from here, such as Siel Bleu exercise classes, have had very good attendance and are working well. The project is exploring the possibility of a more central and permanent dedicated space in a HSE Primary Care Centre building in Blackrock village to address footfall access issues in particular.

A number of additional steps were taken which have contributed to an increase in openness, awareness and understanding of dementia. These include: normalising dementia in local recreational groups, through exercise classes, bridge clubs, Azure-meet me at MOMA outings, music therapy, choirs and creative writing groups in libraries; demonstrating the abilities and talents of PWD through national media campaigns such as “See me not my Dementia”; starting the conversation about dementia in schools; engaging with the Tesco charity of choice initiative; and empowering PWD and their families to be comfortable talking about dementia. Most of these activities have been created and developed with other community organisations and groups contributing to a sustainable service: Azure with DLR Arts and Health; Siel Bleu is funded by local businesses; and Musical Memories was co-founded with DLR County Council. Cognitive Stimulation Therapy (CST) is facilitated by Occupational Therapy and there is a

6 Public Understanding

commitment to absorb this service into HSE formal provision.

The benefit of these types of activities is reflected in the following quotation from the wife of a PWD in Stillorgan-Blackrock.

“Before the project, I would never have told people that my husband had dementia. The carer's events made me comfortable to use the language and know how to ask family and friends how to really help.”

Dementia Awareness talks for community groups such as TY students, Dun Laoghaire active retirement members and citizens advice staff were given throughout the year, and a large community awareness event was held in May incorporating direct engagement with 120 local organisations in the lead-up to the event. Three community information stands on dementia were erected in high volume traffic locations (2 shopping centres & sports event), with a health care professional present at each. An increase in the willingness of people to come forward and engage in dialogue was seen between the first information event held in 2013 and the second event in 2014. As part of the awareness drive, DLR Libraries requested information packs for all staff in the wider county and are also promoting volunteer drivers. Two libraries have also worked with the project to stock a list of books on dementia and associated topics.

Likewise, there is a sense that a conversation on dementia has been instigated in Mayo. Because of the wide geographical spread of the county, a grassroots, organic approach to raising awareness of the project and dementia has continued- the use of social media has allowed the project to circulate information across the county, even reaching remote places such as Clare Island which also forms part

of the geographical area. Promoting awareness through collaboration with existing organisations such as Active Retirement Groups, Family Resource Centres, Mayo County Council, Leader Companies, CE Schemes, Department of Social Protection, Age Friendly Ireland Alliance and HSE Staff has extended the reach and influence of the project. Evidence of the success of this approach has been the increase in the number of organisations who are now actively seeking out the project to present to their particular cohort.

For example, a Family Resource Centre in Ballinrobe engaged with the project in early 2014, with 3 staff members attending the project's dementia awareness training evening. Following this it was agreed that PWD living within their community would be offered the opportunity to avail of social activities within the Family Resource Centre; their existing over 55's club was opened to PWD every Friday. The service was piloted, and then officially launched in September 2014. Transportation was arranged for those requiring it, and help is provided with weekly activities such as shopping and hair appointments. It is hoped that this model of support will be presented to the Regional Family Resource Committee as a means of reaching those living with dementia within these communities.

The project has presented to more than 1,500 people from various groups, including at an event jointly hosted by CADM, Mayo County Council and the Mayo Age Friendly County Programme in November which aimed to raise awareness of people living with dementia in the community and to improve their quality of life. A 'Trusted Tradesman Initiative' was a piloted scheme that was used to inform the Age Friendly Ireland initiative so that this scheme could be rolled out nationally; seven local tradesmen engaged and received dementia awareness training, a booklet was distributed by the local Gardaí in conjunction with Mayo County Council and the feedback was excellent.

“I feel that I can confidently work on a job in the house of someone living with dementia and not feel awkward...the training has given me new tools to help me with my work.”

Building contractor who availed of the Trusted Tradesmen dementia awareness training in Mayo.

The Family Carer training was booked out in two towns with minimal effort at recruitment; a total of 36 family carers attended this training and one group has continued to meet each month as a support group for their area. There has also been a greater willingness from families to ask for information on dementia and an interest from schools in regard to dementia awareness training; 12 schools have availed of training to date-4 secondary and 8 national-totalling 265 pupils.

There is no doubt that the public awareness of dementia in each of the sites has increased significantly over the two years of the project. Some of this awareness has happened organically due to the myriad of social relationships that have been formed as a result of the development of the various Genio consortia. The consortia have facilitated an increase in awareness through their internal and external relationships with mainstream social care provision and through their members' direct engagement in civic, cultural and economic life. Bringing so many different groups together is bound to have a positive effect on the dementia narrative within local communities. That narrative must, however, have a language that is firmly based on personhood and person-centred care. Developing that common language is an on-going challenge that requires patience, conviction and measurement in order to develop a societal understanding of the potential and capabilities of people with dementia within the social care system and beyond.

7 Attitudes

ATTITUDES to dementia among the public, health care providers and families have improved over the past year in all four sites. Increased participation in community activities is challenging the stigma associated with dementia, as members of the community are now viewing PWD as still active in the community.

“They are just like any of us—just because the man has dementia, it doesn't mean that he stops walking, or going to mass or doing any of the things he always liked to do.”

Local citizen in Stillorgan-Blackrock

Community Gardaí were added to the consortium in Stillorgan-Blackrock, which has led to greater integration and collaboration with formal services among local Gardaí in relation to PWD living well in the community.

“Didn't think before involvement with LWwD that someone with dementia could live at home independently.”

Community Guard in Stillorgan-Blackrock

There has been increased participation at family carer's events in Stillorgan-Blackrock (160 families on contact list) and feedback from families suggests they feel more confident in their ability to support a family member with dementia.

“I feel more confident now in coping with emergencies.”

Participant in Stillorgan-Blackrock family carer training

In Mayo, a strengthening of the CADM brand has seen people more willing to engage directly and make that first difficult phone call; there is comfort in knowing that there is a willingness to support a PWD rather than write them off prematurely.

“When I made this call I never expected to feel so good. I'm grateful for the information and glad to know I am not alone.”

Family member in Mayo

In Kinsale, increased awareness and a shift in attitudes have contributed to earlier intervention and improvements in the delivery of appropriate care for some people with dementia. People with dementia are being discussed at an earlier stage of the care pathway allowing appropriate care planning to take place. GPs from outlying areas are also now referring their patients to K-CoRD in greater numbers as a result of increased awareness. While there is a realisation that a diagnosis of dementia is always going to be a challenge for families, changing attitudes will likely lead to a more open and earlier conversation thus ensuring that formal supports are provided in a responsive and flexible manner when needed.

The following quotes from PWD in Kinsale demonstrate how the project is changing the perspectives of PWD and helping to build stronger family relationships:

“That is extraordinary; there are other people like me out there; that is a comfort.”

“Sorry I didn't allow you to come visit earlier. I will keep in touch.”

There has been increased collaboration and sharing of knowledge between health care staff in many of the sites which is leading to earlier conversations with people about memory issues and increased referrals to the projects and improving pathways to diagnosis. For example, there is a view in Mayo that the availability of the new one to one support model has led to a shift in attitude, and consequently referrals are being received in a timelier manner and discussions are starting sooner. The active participation of the HSE on the consortium in Mayo and improved relationships with formal health and social care providers has facilitated a stronger and deeper understanding of the importance of person-centred care for people with dementia. There is a greater sense of coherence in relation to dementia in the county and more awareness of the importance of a person-centred approach among the various stakeholders. When the project first presented to the PHN's at their bi-annual meeting they struggled with the concept that the service on offer was an activity based support rather than a sitting service. Now, Public Health Nurses see the one to one individualised support service as

a social model of care as opposed to a 'sitting service,' as evidenced by the following quote from a PHN in Mayo.

“ I kept this referral for your project as I know you will engage with John on a social level, all he wants to do is keep up his gardening and visit the church. ”

Stillorgan-Blackrock has experienced a marked increase in sharing of knowledge and co-operation between health care staff in PCTs, POA and Medicine of the Elderly, which is enhancing quality of life and support for PWD and their families. Collaboration on joint-projects such as pathways to diagnosis, drop-in clinic rotas, MDT training opportunities (available for the first time) and carer events has been further enhanced. Relationships have deepened significantly among stakeholders through the forum, particularly in relation to function and role. Knowledge of who the other key stakeholders are and how to make contact with them has been key to widening and deepening integration in the area. For example, the community Gardaí have acknowledged that knowing the actual people involved in supporting people with dementia and who to get in touch with has really supported them in their role.

Attitudes in South Tipperary have also improved, especially within the HSE. Enhanced home help supports are now available to anyone with dementia who is in need, with the budget extended accordingly. PHNs are working with

the project to support PWD to remain living at home. This has extended to the acute care sector as well where the acute hospital staff have used gifts and donations from families to fund changes to make some wards more dementia friendly. It was notable that many nurses attended the conference from wards not associated with dementia care in an effort to learn more, recognising patients with dementia may enter their care for other reasons or due to hospital bed management.

In Kinsale, collaboration with the HSE has increased; local Home Helps banked hours are now used for dementia training and for the provision of social support to PWD in K-CoRD's catchment area. The HSE are allowing Home Helps to take time out to do Dementia Training, which as the quote below suggests has been very beneficial.

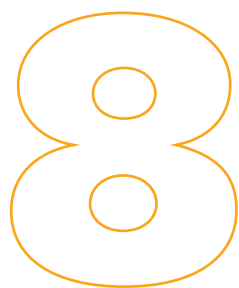
“ I have a better understanding now-it has really helped me in my job. ”

Home Help in Kinsale who completed City & Guilds Award in Dementia Awareness

Attendance at dementia conferences by health care professionals is also indicative of a change in attitude to dementia, and acknowledgement of the need to develop dementia-specific skills. In HSE LHO Dun Laoghaire, 25 multidisciplinary primary care team members attended an Interdisciplinary Dementia two-day awareness training course for care assistants, day care managers, home help managers, public

health nurses, occupational therapists, and physiotherapists. The head of each discipline attended the training so as to implement the training in their team practices. The attendance by HSE LHO Dun Laoghaire Managers at the DCU awareness training demonstrates a commitment to the sustainability of the LWwD and the importance of enhanced co-operation and sharing of knowledge.

“ I found the interactive approach to the day's learning very useful and the sharing of knowledge from people working in primary care. ”



Person Centred Care

A NUMBER of improvements to the care of PWD occurred throughout 2014 in the four sites as a direct result of the Genio programme. The second year saw the development of existing services and the launch of a number of new person-centred initiatives in the areas of: individualised supports, respite care and integrated care.

Individualised Supports

Prior to implementation of the project in Mayo, an individualised based support service did not exist. Now, the Community Action on Dementia in Mayo (CADM) One to One Support service allows the PWD to remain active and visible in their communities. The Early Activities Coordinator (EAC) service aims to keep the PWD visible within their communities; not by manufacturing a new interest or hobby but by supporting individuals to remain connected to past interests. It is offered on the basis of 'what do you need?' as opposed to 'this is what I can give you'. The service augmented existing ASI and Carers Association referral forms and assessment tools to ensure the collection of the appropriate data needed to establish a coherent and relevant support plan for people with dementia. This approach is now being used by The Carers Association to review their existing material nationally.

The past year has seen 89 clients avail of individualised supports and 4091 hours have been delivered. Activities have focused on a number of areas including: the maintenance of purposeful roles such as shopping routines, walking the farmland, hairdresser appointments,

as well as domestic chores like washing and baking; social engagements such as social dancing and coffee shop visits, including trips to the Alzheimer Cafe; and transport solutions to allow visits to happen. FETAC level 5 training has also been provided to relevant staff. In-house training was provided by the CADM team to all newly appointed Support Workers and all were asked to have their car insurance indemnified so that they could take their client out if this formed part of the activity. Up until this point, The Carers Association had never provided this level of service anywhere in Ireland.

The following quotes from PWD and their carers in Mayo illustrate the benefits of an individualised supports service:

“ Grateful...enjoys walking the land, trip...lifeline that is keeping him at home. ”

PWD

“ The man now has news to offer to the family about his day, benefitting his wife also. ”

Daughter of PWD

“ Mum getting on great, having her hair done at the hairdressers with the help of a support worker. Just very normal living. ”

Daughter of PWD

Other individualised supports within Mayo include the Dementia Advisor Service which provides support and information to PWD and their carers, signposting them to resources in their local community. The provision of timely information and support can be of immense benefit in enabling people to know what is available in their local area and to make appropriate decisions. The role also has the potential to support primary care personnel in the delivery of home based care for people with dementia. To date the CADM Dementia Advisor has delivered 151 face to face interventions, carries a monthly caseload of 25 clients and continues to raise awareness through training. The Dementia Advisor has also prepared a draft 'Dementia Specific Directory' for the county and it is hoped that this will be updated regularly. The DA is also responsible for the delivery of the Family Carer Training.

In South Tipperary, an evaluation of the Dementia Support Worker (DSW) initiative yielded significant changes to the way the service was provided. The purpose of home based support is to support people to remain living at home for as long as possible and to live active and fulfilled lives as active members of their community. Support is provided on an individual basis and is needs driven. Originally, a 10-week programme of support focused on getting people into mainstream activities was offered. This has been replaced with a 5-arm model which includes: the original structured goal-focused and time-limited support; low intensity continuous long-term support for targeted groups of people with dementia such as those with early

Dementia Advisor Case Study in Mayo: The Dementia Advisor (DA) was contacted by a daughter who was in Mayo General Hospital where her Mother had just been given a diagnosis of Dementia. The hospital was looking to discharge her. Her daughter was not happy to have her discharged as her mother lives on her own. On phoning to DA for advice, a meeting was scheduled for the following day. Over a 2 hour conversation with the DA, she was given the time and space to come up with a plan for their mother. Home help was accessed. EAC was organised as well as Telecare.

onset dementia or co-morbid psychiatric illness; continuous more intensive support for PWD on the boundary of placement into long-stay care; crisis intervention support; and carers' respite support. The person with dementia may move through the various arms in the 5-arm support model as their needs indicate. This change allows for greater flexibility to address the needs of the person in an individualised non-restrictive manner. The project is providing 150 hours weekly of support, and as some people leave the project, care hours are transferred to other people who need them; 150 people have received support to date.

Another feature of the DSW initiative is that it provides car insurance so that the support worker can take people out and about in the community; a community connector is also available to work with the person to enhance greater community involvement if necessary. A Clinical Nurse Specialist in Dementia was recruited by the project in November, and is employed by The Carers Association. Her role is to assess all new patients referred to the project

in their own homes and to decide with them what supports are needed. Since commencing work, she has cleared a significant backlog of people who were waiting to be assessed and is now reviewing people who were seen in the earlier stages of the project. The project has also contributed to the development of more flexible HSE home help supports, which are also linked to the primary care team.

The comfort that family carers receive from having supports that are flexible and responsive to both the needs of the PWD and themselves, is illustrated in this quote from the niece of a PWD in South Tipperary.

A range of psychosocial supports are on offer in Stillorgan-Blackrock, with the past year seeing an expansion of social activities for people with dementia, even outside the immediate catchment area of the project. A total of 129 people have been identified and referred to the project to date. These people receive a mixture of support with some, for the moment, just availing of family carer information to others who receive a range of supports including combinations of respite care, information and training, social supports, befriending services, re-connecting services and CST. Personalised activities are offered based on the individual's interests and include: 2 exercise groups (60+ participants) delivered by Siel Bleu; 2

“ I was so worried how on earth I was going to manage when she came home from hospital. But straight away the project got on to me and they organised, which I thought was fantastic, that somebody come and stay the night in my house. That meant that I got a night's sleep. I hadn't had a night's sleep for nearly five weeks. ”

choirs in collaboration with HSE DLR Arts & Health (40+ participants); and a bridge group. A Life Story Writing Group and Art-looking Azure at MoMA for seven PWD and a family member have been planned for 2015, as has facilitator training for two of DLR Arts staff to ensure continuity in provision. These social activities are open to the community in general, for example the musical choir has broad community representation, not just people with dementia. The Musical Memories choirs won Chambers Award "Sustaining the Arts" category 2014 at the Excellence in Local Government awards and held an Easter performance for the local community in Deansgrange library, with another performance planned for Bealtaine in St. Raphaela's.

Volunteers engage with the project to offer one-to-one social supports, activities and transports. This is hosted by Southside partnership, with collaboration between the project and SSP to deliver bespoke recurring dementia training to volunteers. A total of 26 families have been supported through the in-home befriending programme, which provided 28 befrienders and 600 hours of support in 2014 (companionship, talking and playing cards), thus enabling PWD to reconnect with previous past times including golf, bridge and walking.

There are 55 people with dementia on the register in Kinsale, all of whom are currently being actively supported, with 31 of these receiving individualised supports across a variety of activities. Supports are being provided by a trained and skilled K-CoRD support panel, employed through two agencies, and a

panel of local Home Helps, with 5500 support hours provided in 2014. The maximum hours of support currently being offered is 10 hours per person; however, as dependency increases for people with dementia so too may support hours need to be raised. A dedicated support worker was employed in 2014 to enable those on the register to actively engage in the community. Activity led services such as a singing group; Arts & Crafts; Memory Group; and the Functional mobility programme are focused on engaging people with dementia directly in the community, thereby ensuring greater visibility and social inclusion. The venues for the café and the functional exercise class were relocated to community venues (Friary and Actons Hotel) to promote greater community connection and mainstreaming; both events are also open to the wider community as well as to people with dementia. VISION (Exploring the arts with new eyes) events actively engage the PWD and are facilitating social interaction between community members and PWD; this is contributing to a change in the perception of what it means to have a dementia diagnosis. The value of visual arts interventions such as VISION events in promoting social connectivity and challenging attitudes is reflected in this quote from a Community Arts Facilitator at VISION Events- Kinsale Arts Festival.

"This is one of the most engaged community art events I have ever facilitated-and I've done a lot over the years."

An innovative Dementia Day Care Centre was started in response to a gap in the services being offered and is predicated on the reality that PWD require higher levels of care with professionals who have received training in the field. The weekly respite initiative acts as both a support centre and a social outlet for PWD, and provides a break for family members and carers. In addition, aspects of personal care which the PWD may find difficult are addressed by trained staff.

One Support Worker at the Day Care Centre in Kinsale has observed the sense of community the day care is providing PWD:

"Day Care Centre on Mondays is different-like a family."

The project is working with the HSE to provide social care with Home Helps as a pilot initiative; 9 local Home Helps and 3 new members of the K-CoRD support panel completed City & Guilds Dementia Awareness Award, and home help hours offered to K-CoRD clients are being assigned to staff who have received training in dementia. The project has also developed an innovative and integrated dementia-specific primary care team meeting. The Care Review Meeting is attended by local GPs, PHNs, Home Help Coordinator and members of the PCT, and its role is to assess at risk persons, prioritise supports and discuss new models for provision of care.

A Carer's Group meets monthly and is facilitated by a Management Committee member. The group has had sessions with a local dementia trained nurse, occupational therapists, clinical psychologists and former carers. The dementia specific care aspect, including information and support from previous carers, are valued features of the group. K-CoRD is also planning to support the development of a peer support group for PWD in the coming year.

Respite Care

The projects are working to provide person-centred respite care which has greater flexibility and is more responsive to individualised needs. Overnight respite care will soon be available in all four of the sites.

In South Tipperary, respite care is provided in the home through the DSW initiative. The five arms of the DSW initiative allow for lengthy respite breaks of 3 to 4 hours, as well as overnight or daytime respite for crisis support. Model 5 of this initiative is a novel service which offers carers a 'One Off, Day Off'. Under this arm, carers who would like a day off to go shopping, to a wedding or to another event can request it and the project will provide care to the PWD at home, free of cost.

"The service is excellent; it works for both the PWD and the carer. Having someone to come to your home and give you a break and know that they can care equally as well as you is great."

Family Carer in South Tipperary

Individualised in-home respite care has also been provided in Stillorgan-Blackrock for over twenty people with dementia, up to end of life for some, equating to over 5,000 hours of support. The service is flexible, responsive and needs driven, incorporating overnight, weekend and emergency support. Dementia specific skills are mandatory for all workers employed in this area. Resources were also made available for emergency in-home respite, as well as for specific family events, which involved family carers being absent from the home for short periods of time.

A range of respite support, provided through direct provision, was on offer in K-CoRD throughout 2014 including: cover for the hospital stay of the main informal carer; crisis support for family members when the main carer was away; immediate supports when families first come into contact with the project and are in crisis; two outings organised for attendees of the Day Care Centre when it closed for 3 weeks in the summer; and supported respite in a local community hospital. In regard to the latter, the K-CoRD support worker followed the person with dementia in and out of respite care in the community hospital, leading to an increased sense of security for that the patient, as well as being a source of specialised support for the staff providing care.

The CADM programme in Mayo decided to shelve the Boarding Out Respite model in 2015 in favour of a more 'tailored' respite model-Overnight Support Model. This will allow a PWD to remain in their own homes when overnight support is required, and will be provided by Support Workers with FETAC Level 5 accreditation. It was agreed to pilot this model of respite for

a maximum of 10 families already within the CADM project and identified as having high dependency needs; or where an emergency level of overnight support was required to maintain the PWD in their own home due to illness of their carer, family event or where there was a history of night time wakefulness. This strand of the project was governed by the Clinical Sub Group and implemented by the Project Manager. An assessment tool was created specifically for this form of respite and took into account psychological/emotional behaviours, levels of communication, nutrition and mobility needs, as well as the carer's health issues, other responsibilities and access to other informal and formal supports. The findings are used to determine the level of support to be provided; one night per week is the standard level of support offered. To date, three families have availed of this model of support, with a total of eight assessments having taken place.

Integrated Care

A named key worker is responsible for co-ordinating and integrating care across the four sites, although different models operate in each depending on local structures and relationships. In South Tipperary, the project co-ordinator provides a single point of contact as a way of accessing information and support. They also have the dementia nurse specialist who is the key worker directly engaging with people with dementia and their families to identify need and make sure that appropriate services are delivered as required through the primary care team and other organisations. There is a clear role for PHNs as the key-workers in Stillorgan-Blackrock, linking to all services and participating in case conferences with

“Caring for S became a lot easier when I got in contact with K-CoRD. Up to this point I was struggling. I didn't know who to contact and felt I was being ignored. Previously S had had a turn and I was seriously considering long term care. However, after being in contact with K-CoRD I felt I could manage a lot better if supports were in place. It felt as though I had been running in circles for years chasing people but with K-CoRD, in a matter of weeks there had been huge progress. I was able to make some sort of plan. She loves it at K-CoRD too. At home she's very reserved and quiet, staying in her room a lot. When she's at K-CoRD she's so much happier and brighter.”

Husband of PWD in Kinsale

the PWD/family and a member of both the hospital and primary care team. The single point of contact in K-CoRD is provided by the Dementia Care Co-ordinator, who is enabling K-CoRD to provide individualised, integrated and flexible support; 2014 saw this role become better defined and more integrated into HSE services. It remains to be seen if this role will be supported by the HSE when the grant ends, or if it will be integrated into existing roles within the HSE (PHNs and Health Care Professionals).

In Mayo, the project manager plays the key role in integrating all aspects of care and support for people with dementia. The project manager provides overall leadership including: supplementing the work of the part-time staff members in their absence; undertaking assessments for the overnight service; and delivering the Telecare service. The project manager is also the main point of contact for the project and is responsible for the project's finances and administration. In addition, the Dementia Advisor and Early Activities Co-ordinator play important roles in regard to the signposting of existing information and services, as well as supporting the provision of

individualised care. The intention is to have the project supported by the HSE as an embedded service in the future and a submission in that regard will soon be made to the HSE General Manager at local level for consideration.

Person-centred care is at the heart of the Genio project. Individualised supports that reflect the needs and preferences of people with dementia and their families are now evident across all four sites. There has been significant progress in moving the care system to a personalised, individualised model that respects and encourages personhood, autonomy, empowerment and social connectivity for people with dementia. People with dementia are being asked what they need and every effort is being made to provide services that they want and value. Dementia has become a social phenomenon as much as a medical condition and holistic models of provision are now much more acceptable and prevalent in the four sites. The Genio approach is now influencing mainstream thinking as the formal system becomes more familiar with the social model of dementia, leading to the development of more integrated, embedded and transformative models of care.

9

Technology

EACH of the sites has worked hard to provide assistive technology to people with dementia and their carers. It has not been easy, mainly because technological intervention for people with dementia is relatively new and unproven making it difficult for people to make good or even informed choices in this area. While there are many competing technologies on the supply side many of them remain unproven and some have been developed without any input at all from people with dementia or their family carers. On the demand side, knowledge of technology is weak and people find it difficult to find the correct balance between using technology as a substitute or complement in the care of people with dementia. Finding the right fit between technology and need in dementia is a common concern for all relevant stakeholders.

In South Tipperary, significant progress has been made to advance the use of Telecare and assistive technology to enable PWD to remain at home through the development of the Memory Technology Library (MTL), the first such library in Ireland for PWD. The library targets PWD, family members/carers and health professionals and aims: to raise awareness of Assistive Technologies; to create a demonstration and advice service that highlights the benefits and limitations of AT, including a home trial of some devices; and to help people make informed choices about AT. The library has had over 240 visitors, 21 assistive technology devices loaned and returned, while 5 families have had Telecare packages installed for free as part of the project. Visitors are invited to fill in a questionnaire and provide feedback on the MTL, with the advice from family carers then disseminated to other attendees. In 2014, 177 questionnaires were completed which have provided valuable learning about the MTL: 98%

of visitors rated the MTL as very useful; the majority of visitors recorded that they were not aware of what technologies might be available for PWD, including carers and staff; visitors have all stated that the library has enhanced their understanding of AT devices as they are able to see them in action and discuss with an OT; and 82% of people that were loaned devices went on to buy the technology, showing a good match of AT to PWD/family carer needs (this may be related to OT assessment prior to loan).

The MTL has also demonstrated that low cost devices can be effective at improving quality of life and assisting family carers. Calendar clocks, which provide reassurance regarding orientation, have proven to be the most frequently loaned device, with families reporting changes in behaviour such as PWD being calmer and not asking questions repeatedly of the carer, better sleep patterns and less disturbances, and relationships becoming less tense. Differences in how devices are valued between the various roles have also been seen, with carers/PWD more interested in devices that enhance quality of life and health professionals more interested in devices that assist with risk reduction.

Feedback received from PWD, their family members and carers has largely been positive as demonstrated by the following quotes.

“ Knowing that my wife knows that I'm out of bed, aware that I'm on the move... very useful...worked every time... ”

Client feedback on the Motion Sensor and Pager in South Tipperary

“ Very useful...the very minute Jack puts his legs out of the bed it would go off, I could have a proper sleep, otherwise I'd be waiting to for him to get up...well worth the money... all positive, the best part I found was that I could sleep. ”

Wife's feedback on the Motion Sensor and Pager in South Tipperary

In Mayo, progress has been made with the technology element of the project; 25 Telecare referrals have been received to date and 23 tailored Packages have been provided. Initially the uptake was slow, but following an information event and discussion with individual PHNs referrals increased. The main reason for referral was either concerns about a person falling or peace of mind for the carer. A small number of referrals were directly to aid a PWD in continuing to perform a task such as being able to take their own medication, help with finding small objects such as keys/remote control/reading glasses or to assist a person with telling the time. One carer described the audio/visual monitor installed in her house as a 'God send' as she had to frequently sleep on a mattress beside her mum or spend the night going up and down the stairs just to 'look in' on her mum.

“ I don't know myself... it's been a godsend. ”

Family Carer in Mayo

In Stillorgan-Blackrock, 7 technology support packages have been provided since the commencement of the project.

The project is also providing GPS trackers to a small number of people with early onset dementia. Recently, a technology exhibition was held for PWD and their families, PCT and the wider health community, with more information available on the website.

“ The tracker has given me huge peace of mind. On one occasion it helped me locate P quite some distance from home.”

Wife of PWD in Stillorgan-Blackrock

Although the uptake of Telecare packages has been lower than expected in Kinsale, some progress has been made; 3 installations of the Ambient Assisted Living (AAL) System occurred in 2014, with an additional 3 being installed in early 2015. Two carers who actively attend the Carers Support Group and whose husbands both have dementia have expressed the view that the AAL

system gives them peace of mind. They specifically mentioned that when they themselves are away from home, they can, via the CareZapp App on their smartphone, log on to the Activity platform which shows exactly where their husbands are within the home, thus relieving their anxiety knowing that their husbands are safe at home. The low demand for technology is being evaluated, and a new approach which offers an initial installation trial period of 6 weeks without any commitment to enter into a contract or retain the service is expected to address this issue. Additionally, a demonstration home has been developed and aids have been sourced and sold directly to families. Assistive technologies have also been demonstrated and made available to the Carers Group. K-CoRD also sponsored a prize at CIT's APPrentice competition for an app to help PWD.

The case study below illustrates the benefits of Telecare for people with dementia and their families in South Tipperary.

It was evident in the Year 1 evaluation of the Genio Dementia Programme that the development and adaptation of new technologies was always likely to lag behind other interventions across the four Genio sites. Establishing needs and wants in regard to dementia technology is a slow process that requires knowledge and understanding on the part of people with dementia and their families on the demand side, and similar insights for providers and budget holders on the supply side. There has been progress, however, in relation to technology in the past year through direct provision and through education and demonstration projects that have enhanced knowledge about the role and potential of existing technologies amongst people with dementia and their families. Technology is now being used to augment person-centred care for significant numbers of people, and the technology laboratory in South Tipperary is a model in knowledge transfer with regard to dementia technology.

Technology Case study in South Tipperary

The Project Lead in South Tipperary identified Mary (aged 90), a client with dementia who had been admitted to a nursing home following a fall at home but who strongly wished to return home. Her family reported that she was more confused in the nursing home and did not want to be there. The Project Lead identified that Telecare might be useful to support Mary's return home and her nieces were invited to the MTL to see Telecare in action and discuss their specific concerns. The OT completed a home visit and assessment. This assessment enabled the OT to explore how Telecare would work in reality, taking into account the home environment, Mary's routine, potential risks to be monitored and knowledge of the care package of support being provided. The family then met with the Project Lead and agreed that they would like to be involved with the pilot Telecare project. Telecare has been installed (fall, smoke, movement sensors). Mary was also allocated an enhanced home care package from the HSE home help coordinator. This entails four visits a day by the home help, an initiative encouraged by the Five Steps Project. Mary is due to return home in the coming weeks.

case study

10

Training and Education

THE LWWD PROJECT has worked hard to improve family awareness and education regarding dementia. Seven family carer information events, with an average of 60+ participants, were held throughout the year, as was a 6 week practical and intensive family carer training for 15 family carers. A customised 6 week “Healthy Food Made Easy” programme was also provided. The content of each carer event has been informed by the wishes of families in regard to structure and content. These programmes facilitated knowledge building and sharing, peer support and encouragement and increased awareness. The project has also worked to build capacity and knowledge for volunteers. Throughout the year, 7 training events were held, covering topics such as dementia awareness, communication skills, first aid and protection of older people. Two volunteer recognition events were held, which provided an opportunity to gain knowledge and share experience, and the LWwD Volunteer Handbook was launched. Volunteers also attended the Carers information events.

“ It is reassuring to find that what I feel as a carer is quite usual and being experienced by many others. ”

Mrs C Family Member in Stillorgan-Blackrock

K-CoRD made a number of advances in the area of education. Education needs assessment which was originally planned and developed for Kinsale PCT is now part of the National Dementia Programme that will be linked to the roll

“ It is certainly my opinion and the family's opinion that without the information and education that we've got from the LWwD programme. I don't think we would have managed to keep mum at home for as long we have done and I think we wouldn't necessarily have been able to care for her in as positive a way as we have done. ”

Family Member of PWD in Stillorgan-Blackrock

out of the National Dementia Strategy. Former project lead Dr Tony Foley, in collaboration with Prof Greg Swanwick, has written a reference guide for dementia for use by GPs nationally and this was launched by the ICGP in June of 2014. The project is collaborating on an on-line e-learning dementia course which is still in production, and they are liaising with St. Luke's Home Education Centre to develop a FETAC 5 module for dementia awareness. This will then become a core module of home help training nationally, further opening up the possibility that it will become a requirement for all private agency support workers.

A 2-day training course is provided to newly recruited Dementia Support workers in South Tipperary. This year places on the course have been allocated to care staff from local nursing homes and district hospitals to promote dementia awareness and knowledge among generic providers of care. Dementia training and education throughout the year also included a Social Workers study day, a Public Health Nurse study day, training of volunteers through The Carers Association and an Old Age Psychiatry study day.

In Mayo, the CADM project has provided FETAC training, family carer training, volunteer training and dementia awareness training to a total of 320 people. As there was no existing community support staff in Mayo, CADM undertook to work collaboratively with ASI and the Carer's Association, to recruit and train staff who would be hosted by both organisations in order to develop a workforce suitably skilled in dementia for the Mayo area. This has resulted in more than 35 Support Workers receiving dementia awareness training before they took up posts within the project and were paired with clients in the community. CADM paid for FETAC 5 level training to be delivered to candidates for the role of support worker and augmented this with a half day of dementia training to ensure a shared level of understanding of a person-centred approach to the care of people with dementia. As the CADM brand grew, so too did demand for dementia specific training. Training was delivered to: staff and volunteers in Ballina District Hospital; tradesmen under the Age Friendly Mayo 'Alliance'; 10 Family Resource Centres; and to the community on Clare Island. Training and awareness around dementia will continue to be a main feature for the CADM project in 2015.

11

Key Improvements

PERSON-CENTRED care for PWD has improved in each of the four sites as a result of the work undertaken in 2014. In Mayo, the availability of the one to one support service has increased significantly, with 4,091 hours provided county wide in 2014. This also represent the first time within County Mayo that agencies such as The Carers Association and ASI have had staff working within the community. The service supported 2 families when the primary carer was hospitalised by allowing flexibility around the support hours being delivered to the PWD and has allowed people to remain living at home with their families; one family was supported by the service to take their loved one back home from residential care.

The project in Stillorgan-Blackrock offers a variety of individualised social supports, which complement existing healthcare supports. The key-worker, who is the PHN or CPN, works with the PWD and their family to formulate a holistic person-

centred care-plan determined by the person's life story, preferences and needs. The care-plan is very much integrated with existing HSE services such as Meals-on-Wheels, Home Help, Day Centres, Respite and the LWwD project services. A 6-week Cognitive Stimulation Therapy (CST) group for people with mild to moderate dementia, who are referred by a PHN or GP, was piloted by LWwD. This involved a series of themed, group activity sessions designed to help people strengthen their cognitive capacity; facilitated by a Primary Care Team Senior OT; these sessions aim to actively stimulate and engage PWD, while providing an optimal learning environment and associated social benefits. A second CST programme began in January 2015. There is a continued strong interworking between the Dept. of Old Age Psychiatry, Medicine of the Elderly and PCT which facilitates good relationships with community care providers when people are diagnosed with dementia for support and follow up. A care pathway is expected

to be developed some time during 2015. Feedback from clients indicates that the project is enhancing the quality of life of PWD and their families. An account of how the project provides a care plan and supports which promote enablement for the PWD and ensures they receive the right care in the right place at the right time can be found in the case study overleaf.

In Kinsale, the project is keeping people at home, active in their communities and family carers are acknowledged. Care and support are being provided in a person-centred way, with post-6 month interviews suggesting that people consider themselves to be in a better place now than before their involvement with K-CoRD. The Dementia Care Co-ordinator engages with the PWD and their family to explore and identify their needs using both standard clinical and psycho-social tools before linking back to the Care Review meeting. This latter forum ensures an integrated approach to personalised care.

Case Study in Mayo

The project manager received a call a week before Christmas from a family carer. Her mum had been admitted to long term care 3 ½ weeks earlier. She had lost 1.5 stone, had stopped eating and communicating. The project manager asked how CADM could help to which the family carer replied "I don't know". The project manager asked "what is it you want to do?" to which the family carer replied, "I want to bring her home." The project manager advised that she would reactivate the one to one support hours previously used and that she would also provide additional hours over the coming weeks to give the family time to get all the other relevant services in place or reactivated. The project manager also advised that a tailored package of Telecare could also be ordered to assist the family carer for their mum. 3 days later the family carer rang to say that her mum was now at home, had started to eat again and was talking.

"It's the best decision we ever made, we're delighted to have mam home again, thank you."

case study

Case study Stillorgan-Blackrock

Tom is a physically well person under age 65 who was referred to LWwD by the Dept. of Old Age Psychiatry. Initially the need identified was for information for family members and a befriender to accompany him to pursue his interests as his wife continued to work 3 days/week. A care plan was agreed with the family and PHN, OT and CPN and a volunteer was identified and introduced. Tom was referred by the OT to the Cognitive Stimulation Group which was being formed. He became familiar with the exercise group, which took place after CST group, and continued to attend after the CST ended. As his dementia progressed, the need for additional support was identified. He began attending day-care for 2 days per week and a GPS tracker was requested to support his independence and going for short walks. His wife felt a carer support was also necessary at this time as he could no longer remain home alone for long periods and the care-plan was revised to ensure linkage with the existing supports.

case study

In South Tipperary, the DSW initiative was developed significantly during the year and a 5-arm support model is now in place which tailors the provision more accurately to individual needs. The previous model of group sessions 6 weeks post diagnosis around the county was reviewed due to low attendance and the new approach of an individual follow up session was developed with a greater uptake. The support sessions are prescribed to the PWD, and family meetings are arranged as needed to share information around the wider family group. The project now provides 150 weekly hours of support. HSE enhanced home help support, which is targeted at PWD living alone or on the verge of placement, is now available and is in addition to the project's support. The Memory Technology Library is available as an information and resource hub. In general, there is a feeling that families and PWD understand that the project is working to improve the

services and supports they receive; this is evidenced by the positive feedback received both verbally and in writing.

"I was delighted with the speed with which the service was put in place... imagine our surprise and delight when she stated that the service would commence the following day."

"My mother has been consulted and talked to... and appreciated that she has a choice in the matter."

Family Members in South Tipperary

A workbook "This is Me, Be with Me" was developed in South Tipperary which aims to capture the essence of the person simply, in a workbook form. This is a valuable tool which will promote the person with dementia at the centre of care and will help those interacting with and caring for the person with dementia understand the preferences and interests of people with dementia, how they communicate, their life story and what is and is not working for them. The workbook will serve to enrich the time the DSW spends with the person with dementia while also supporting them to make choices and have more control over their lives. This workbook will accompany the person on hospital admissions and has already made a positive contribution to the care landscape. Research questionnaires for PWD, for families and for health care providers have been developed to encourage a conversation early on in the illness about people's end of life wishes.

"For him getting out of the house is very important. K-CoRD has been brilliant; M (K-CoRD carer) is great they get along very well. He kind of lights up when you mention K-CoRD, that means a lot to him. It's brilliant for me too, I can have time off. It gives me a break but it also allows me to enjoy him while he's here at home too. He likes to be out and about, he gets agitated when he isn't active. However, after being out he's happy to come home. The K-CoRD supports mean I can cope better and he can cope better too."

"I enjoy being out and about. K-CoRD lets me do that. I enjoy singing at the café and the trips out. It's nice to be with people who are just keeping me company."

Husband and Wife in Kinsale

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Year Highlights

SIGNIFICANT progress has been made towards improving the quality of life for PWD and their carers in all of the sites. The breadth of the work undertaken has been impressive, impacting on public perception and understanding of dementia, personhood, integration of care, availability and range of supports and empowerment of PWD. With this in mind, each of the sites was asked to select what they consider to be the top highlights and successes for 2014.

In South Tipperary, the role of the community connector, establishment of the memory technology library, the dementia conference, development and expansion of the DSW initiative and the project website were all referenced as highlights. The home based support element of the project aims to support people to remain at home for as long as possible as active members of the community. Qualitative evidence suggests that the expansion of the DSW initiative is significantly delaying the need for long term care and improving the quality of life for PWD and their carers.

The Community Connector has undertaken an impressive body of work since coming on board in February

2014. She has given talks in all the libraries, day care centres, resource centres, men's sheds and GP practices; and she has linked with the ICA, churches, Meals on Wheels, SuperValu supermarkets and pharmacies to promote the project and provide information. The Community Connector has teamed with the Sports Partnership and their Fit for Life programme to promote the benefits of exercise in preventing dementia and for carers and PWD; and also collaborated with the HSE health promotion unit to promote the benefits of a Mediterranean diet in the prevention of dementia. Currently, the focus is on an intergenerational project with a local secondary school to promote mutual learning between older PWD and TY students.

The Memory Technology Library is the first one developed in Ireland for PWD. A location was identified for the venue which has mainstream appeal and is easily accessed from the general hospital to maximise use. Extensive research was conducted on standalone products and Telecare, and many products were trialled with PWD. Included in the venue are a mock up bedroom and living room so that the devices can be demonstrated

and people can purchase the products directly from the suppliers.

Officially launched in 2014, the project website showcases all of the services and supports provided by the project. It provides regular updates on activities and events organised by the project and all of the MTL resources are available on the website. There were 4,000 hits in January 2015 alone. During Positive Ageing Week, the project held an international Dementia Conference, which included a number of notable speakers and sold out immediately. In light of the impact of the conference, this is something the project would like to make an annual event.

Choice in respite provision, co-operation between the different organisations involved in the consortium and awareness and training for families through family carer events were chosen as the top three successes for the year in Stillorgan-Blackrock. Respite options include social supports (choir, exercise, and bridge), individualised in-home supports, befriending and reconnecting with past activities, emergency in-home respite and hospital respite. These options address the social needs of PWD and their families, in addition to their health care and personal care needs.

“ I believe the person I was caring for would have been in long term care one and a half years before she eventually went in without the Dementia project. ”

Carers in South Tipperary

“ It was a lifeline that enabled me to care for my aunt at home for longer than I would have otherwise been able. ”

“ It is the first time in over 30 years I feel as happy as I have ever been since I got in contact with the home support service. Every Wednesday I wake up in the morning my heart is so light. ”

“ I met Mrs P in outpatient today. Her family were singing the praises of choirs and the exercise groups. They had found these supports incredibly helpful, in particular the social dimension which helped their mother and also themselves in continuing to support her to remain participating in the community. ”

Consultant Physician in Geriatric Medicine
in Stillorgan-Blackrock

The emergency in-home respite was utilised twice in 2014 and is designed to be available to key workers to draw down where they identify carer stress or where the main carer is admitted to hospital.

Relationships between the different organisations involved in the consortium were strengthened and enhanced throughout the year improving collaboration across a range of stakeholders and activities, each contributing their own knowledge, expertise and experience, and creating positive changes in the lives of PWD and their families. Family carer events are often the first point of engagement with the project. In addition to the knowledge they provide, these events enable carers to connect with others who are experiencing similar journeys. Friendships and natural peer support groups have formed from these events.

The key successes in Kinsale were: the establishment of a robust system

of referral, assessment and case management of a PWD on the K-CoRD Register; the joint K-CoRD and HSE Care Review meeting; and the broad range of individualised supports on offer to PWD in Kinsale and the surrounding area. The Dementia Care Coordinator ensures that gaps in care needs are met by the project in a flexible and responsive way by coordinating the required supports and linking with HSE supports.

“ I feel like becoming involved with K-CoRD was a huge benefit to us, they're really remarkable... especially Maura (DCC). When I was having surgery I don't think I would've coped so well without K-CoRD. I would've been so much more stressed and upset about my separation from T. ”

Wife of Person with Dementia in Kinsale

Care is provided by a skilled support staff through the K-CoRD panel; trained home helps and support workers are integral to the effective roll out of community care.

“ It is of huge importance that our home helps have received this dementia training as they are the people who can act as first responders if there are issues. ”

K-CoRD Project Lead

“ This particular group [Home Helps] were wonderful to work with as they brought a wealth of experience to the 'classroom'. ”

K-CoRD Care Coordinator and Trainer

The joint K-CoRD-HSE Care Review meeting allows in-depth discussions between the relevant parties involved in dementia care (GPs, K-CoRD and HSE staff) leading to a more integrated, comprehensive and holistic view of the social and medical needs of PWD. This approach provides an alternative to the traditional medical model of dementia care in primary care. The menu of supports being provided by the project emphasise increased social inclusion at community events, in addition to formal supports. It is hoped that this is leading to greater awareness of dementia in the community, and the events are supported by K-CoRD's network of volunteers.

“ My husband has difficulty driving for the past while as he had a heart attack. We can't get out and about as much as we used to and I need assistance moving around but I don't think he should be pushing a wheelchair. K-CoRD is good especially for company it's nice to see new people. The events I enjoy the most as they are someplace to go and see new people. ”

PWD in Kinsale

In Mayo, successes for the year include the delivery of the one to one support model, the advancement of Telecare/Assistive Technology and the mid-term review of the project in May 2014. The one to one support model and the expansion of the Support Worker Team across the County of Mayo are significant milestones in the journey towards more individualised care for people with dementia in Mayo. And equally so for the project, in light of the fact that this model did not form part of the original application and neither ASI nor The Carers Association ever had people working out in the communities until now. Furthermore, there has been growing recognition by healthcare professionals that this is a community based social model of care as opposed to a 'sitting service,' and this change in attitude has resulted in appropriate referrals accessing the service. The project has successfully worked to marry the interests and hobbies of the support worker with that of the PWD. For example, a support worker who was raised on a working farm was paired with a gentleman with vascular dementia who had farmed all of his life. His family were about to sell the last of his 3 cattle, but held onto them once they realised that the support worker was taking their dad to see the cattle during her visits and that they were also walking the land and feeding back little jobs that needed doing. They noticed an improvement in their dad because of this naturally paired activity.

“He knows when to expect her...he has his coat and hat on and his wellies by the door... it's great to see him enjoying the outdoors again.”

Family Member of PWD in Mayo

There has also been a gear shift in recognition of the Dementia Advisors role; initially referrals were self-referral or relied on the memory screening service but in 2014 there has been a complete overhaul of the referral pathway with PHNs, GPs and other healthcare professionals making the referral directly on behalf of the person.

Up to December 2013 there had only been 2 packages or Telecare/Assistive Technology installed under the CADM project. In 2014, Telecare found its place as an additional support to families as part of a range of services provided under the CADM project and other external agencies, resulting in a total of 23 packages being installed. The tailored packages varied from audio/visual monitors, electronic pill dispensers, wrist worn fall sensors, bed and chair sensors, door sensors, cookers guards and keyhole cameras. The main reason for referral to this service was for 'peace of mind'; while some carers were wary of using Telecare, most in fact did not even realise it existed until they engaged with CADM.

“I never knew it existed, it's great it just gives us peace of mind to know mam is safe.”

Family Member of PWD in Mayo

The Mayo review evoked a lot of discussion around the 'why are we here?' question which allowed everyone involved to reevaluate their contribution to the project to date and helped the consortium focus on the individualised needs of the person with dementia.

The review process itself facilitated a 'reenergising' of the project and those connected to it. It gave the consortium space and opportunity to recalibrate resources and energy towards the needs of people with dementia. Arising from this process, the consortium made important priority-based decisions, leading to a renewed focus on the provision of individualised supports for people with dementia.

13 Challenges

THE FOUR demonstration sites are piloting innovative, complex community-based supports and services to PWD and are at the forefront of a cultural shift in how dementia care is provided. Not unexpectedly, some difficulties were encountered developing and implementing the new initiatives. The lessons learned from dealing with these challenges can be applied to some of the initiatives proposed under the new National Dementia Strategy allowing for a more efficient implementation process.

One of the major challenges facing all of the projects is how to actively engage with, and hear the voices of PWD. K-CoRD has found that it takes considerable energy and commitment to keep the profile of PWD and their needs at the forefront of decision-making, as there are many other demands on HSE staff and GP time. Consequently, K-CoRD has resolved to commit more time and resources to involving PWD in the planning and organisation of events and support services. To this end, the project is getting to know people with dementia and 'working group' or 'peer support group' formation is taking place organically at the K-CoRD Café.

Stillorgan-Blackrock has found that many families are still speaking on behalf of the PWD, rather than allowing the voice of the person with dementia to be heard at times of key decision-making. It has also been difficult to convene a focus group of PWD due to low attendance and passive rather than active participation in the group. The project is committed the full

engagement of PWD in the project and are looking at ways to enhance communication and active participation. In South Tipperary, some of the original PWD consortium members were no longer able to attend meetings due to cognitive deterioration and related health difficulties. The project addressed this by moving the meetings to monthly and refreshing the consortium with three new PWD.

The sustainability of the volunteer commitment demanded in all sites will need to be addressed as well, if programmes are to continue into the future beyond current Genio funding. Reluctance on the part of families and PWD to sometimes engage with the individual befriending services and a lack of in-house resources to manage the programme have made it difficult to provide a comprehensive service across some of the sites. In Kinsale, the project is partly addressing this issue through the development of a more localised volunteer driver network and is liaising with local groups and the ASI in developing the volunteer network. Working with people who are vulnerable, where there is on-going risk that needs to be considered, has perhaps led the sites to be overly cautious with some of the decisions in relation to volunteering and befriending. Linking the volunteers more closely to existing formal care providers would also likely improve acceptance rates among people with dementia and their families. Training and education in the specifics of dementia is also important for volunteers, as are specific peer support mechanisms that acknowledge the difficulties sometimes

encountered in developing meaningful relationships with people with dementia.

Developing the role of an overall Connector for dementia within local communities and figuring out how the role links with existing HSE work practices has been a challenge across the four sites. It is not yet clear if and how such a role will be supported by the HSE, or whether it will be integrated into existing formal care provider tasks when the project is completed. But it is an important job and remains the conduit that links needs to resources, as well as facilitating an integrated approach to care. The merits of having someone with dedicated time to provide information, support and direction for people with dementia and their families is evident across all the sites and cannot be underestimated. Having a key Connector for dementia facilitates better decision-making and increases the likelihood that fragmented resources can be brought together quickly to meet the immediate needs of people with dementia.

Changing attitudes and perceptions of dementia is a slow process and one that requires the engagement of whole communities. As part of that organic process of persuasion, more resources will be required for education and public awareness campaigns that highlight the importance of communication, social engagement and visibility for people with the disease. It is not enough to simply know more about dementia. We have to know more about the personhood aspects of dementia and what that implies for communication and

connectivity at all levels of society from the personal to the public. Dementia is not something that we do rather something that we are. Evidence from all of the sites have highlighted the need for future endeavours to employ a bottom up approach to changing attitudes, where people are self-motivated and want to engage directly with people with dementia, rather than seeing the creation of a dementia friendly environment as being an end in itself, or confined to changes in physical infrastructure.

Efforts to reconnect PWD with former activities in all sites have sometimes not been as effective as hoped for a myriad of reasons including: inadequate supervision, deterioration of skills and scheduling. Similarly, there has been a low uptake of in-home overnight respite, as families and PWD are not always comfortable with the carer staying overnight in their home. Transport continues to be a challenge, despite efforts to address this in all sites through volunteer drivers, activation of community groups and community transport. In Stillorgan-Blackrock there may now be an opportunity to share a transport resource with the community Gardaí as a way of dealing with this issue.

It is important to match the individual needs of people with dementia with the skill sets of local volunteers and various social providers. If the maintenance of personhood and the maximisation of capabilities are important goals, then it is important to bring together people that are a good fit for each other. Sometimes geography can

create difficulties in ensuring that optimal matches occur. Occasionally, there was not an appropriate match between the identified need of a person with dementia and a local accessible resource that met that need in the implementation of the one-to-one support service in Mayo. This sometimes meant bringing in resources from elsewhere, which was not always feasible given existing budget constraints. Linking resources to need is always a problem, particularly in a large geographical area where local ties and distances matter both for attachment and funding.

The Memory Clinic in Mayo was envisaged at the outset as a flagship services but a review undertaken by the Clinical Subgroup in mid-2014 identified that it was not fulfilling its intended role. Out of a total 164 people referred and screened, only 18 were diagnosed as having dementia. Some who had dementia were already diagnosed but were inappropriately referred to the clinic, or were self-referring. Consequently it was concluded that the resources could deliver greater value if reallocated to other services that would have more immediate and practical benefits to PWD and/or their carers. There may still be a role in the future for a Memory Clinic but a prerequisite will be to ensure more appropriate and focused referrals. One measure being adopted by CADM is the provision of a dementia 'master class' for GPs in the county to be delivered by a GP who is nationally recognised as having dementia expertise. This has the potential to improve both diagnosis and referrals in the future.



14 Sustainability

AS we move into the final year of the grant, the projects are focusing on mainstreaming their work to ensure the sustainability of their initiatives after the life of the grant. In South Tipperary, there has been a concern that the project would trickle on for several months or years with a tiny budget left unspent and expectations from the HSE that they could continue to deliver services as usual. With this in mind, the project has been very explicit with stakeholders, particularly the HSE that this is a three-year project that will come to an end in October 2015. The focus is now on how to sustain the valuable resources and supports post-project through an examination of potential governance, staffing and funding options. Areas which have been identified for mainstreaming, either by the project or the HSE Manager for Older Persons, include: The DSW initiative; the Clinical Nurse Specialist in Dementia; the Community Connector Role; and the Memory Technology Library. The HSE Manager for Older Persons has said that the DSW initiative should continue to be provided post-project. A series of meetings began in November 2014 to clarify priorities and the options available including: a facilitated meeting of the Old Age Psychiatry team; a review of the MTL with the geriatricians and OTs; and a meeting with Genio.

Kinsale has undertaken a review of their aims and activities with a view to how their four aims might be sustained after the lifetime of the project. A meeting has taken place with HSE senior management around how the individualised support model by the Care Co-ordinator and trained support workers might be sustained. Agreement has been reached to deliver dementia specific training by the Care Co-ordinator to all home helps in the area, and to begin using 'banked home help hours' as additional support hours. HSE management has expressed an interest in rolling out this training to all home helps in the south of the county. The project

is working to integrate social care (dementia support workers) and personal care (home helps) for the purpose of training. The Clinical Review Meeting is aligned strongly to the PCT meeting because of its specific focus. The membership has broadened to include the full PCT members and is now led by a GP; this model is expected to be self-sustaining given the personnel involved in the project. The three educational pieces: the ICGP reference guide; the development of FETAC 5 module for dementia awareness; and the educational needs assessment to inform training module for health care professionals will be sustained through the relevant educational bodies. The work already undertaken by K-CoRD has been incorporated with the AFCC Cork to ensure a dementia focus to Kinsale becoming an age friendly town. A Dementia awareness programme and student involvement has been established in the local secondary school. K-CoRD has partnered with Cassala and CIT-NIMBUS centre to develop assistive technologies and subject to positive outcomes, they may be interested in a longer term commitment. Discussions are underway to develop and host a demonstration centre of aids and technologies in the primary care centre. K-CoRD is also a member of COLLAGE-Collaboration on Ageing and is an active member of 3 action groups within the partnership which will be important if EU funding is to be explored.

When the project in Mayo was ASI led, sustainability was focused on maintaining the roles of the Memory Assessment Co-ordinator, the Dementia Advisor and the Early Activities Co-ordinator and associated roles within the ASI service. With the substantial changes that have occurred over the last year, the issue of sustainability is being reassessed by the consortium members at this time. It is thought that the Dementia Advisor role could be maintained with ASI services, using funding from within that organisation. The individualised

support service is greatly valued by The Carers Association and they have expressed an interest in continuing with it after the lifetime of the grant. To this end, they have stated they will seek funding to ensure that provision can be maintained. A submission to maintain the services associated with the project has been requested by the HSE local manager. This is now a further opportunity for sustainability. A workshop to develop the consortia's ideas on the future of the project and to inform the content of any submission to the HSE has taken place, with more planned in the coming months.

In Stillorgan-Blackrock, positive conversations have taken place with the Community Health Organisation Chief Officer in relation to the sustainability of the LWwD project. While there has been a verbal agreement to maintain the existing hours of support when the project ends, the project lead wishes to have a more formal agreement in place. A meeting was requested with HSE senior management to discuss this issue, alongside the securing of premises for hosting Telecare and group scheduled activities and the embedding of the community hub service within primary care. Genio representation at this meeting was also requested. It is hoped that the premises for hosting Telecare will be located within HSE buildings and would incorporate space for a memory resource library and display space. Southside Partnership has already broadened their programme for events for older people, and people from the LWwD project have been invited to engage in these various activities. DLR Arts and Health project has agreed to co-fund choir activity and they will also fund art facilitators to integrate the Meet me at MOMA series into the DLR arts plan. The project lead has also sourced a free PR service to assist exploration of potential funders for other social activities.

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National Dementia Strategy

THE recently published National Dementia Strategy (NDS) endeavours to improve the lives of PWD by advancing the principles of personhood and citizenship across the health and social care continuum. It represents a renewed commitment by the government to provide patient-centred, flexible, community-based supports which enable older people to remain at home, living full lives. There are six priority action areas:

- **Better Awareness and Understanding**
- **Timely Diagnosis and Intervention**
- **Integrated Services; Supports and Care for PWD and their Carers**
- **Training and Education**
- **Leadership**
- **Research and Information Systems**

These are all areas in which Genio has worked to foster innovation in the care of people with dementia; and the four demonstration sites provide a unique opportunity to develop and test new service models. The Genio Dementia Programme has already made a positive contribution to the development of the NDS, and learning stemming from work being undertaken in the four sites has the potential to feed directly into the implementation of the Strategy, providing a pathway forward.

All of the projects have invested significant amounts of resources, energy and time in promoting better awareness and understanding about dementia. A major focus has been on creating links

in the community and working with local organisations and business; efforts have been made to connect PWD with social activities and community supports such as Alzheimer Cafés, social and sports clubs; while education and training in relation to dementia has been central to activities in all of the sites. In South Tipperary, the newly created post of Community Connector has proven vital to enabling PWD to engage more in community activities, raising awareness about dementia and about health promotion and prevention, with an emphasis on living well with dementia. HSE health promotion has now incorporated a dementia strand to their current programmes in South Tipperary, particularly in the area of nutrition. While the approaches may differ between sites, it is apparent that improvements in this area are well underway, and the stigma associated with dementia is being reduced.

The NDS has laid out a number of Actions to be taken in the area of Timely Diagnosis and Intervention. Paramount among these is that the HSE is to develop a National and Local Dementia Care Pathway to describe and clearly signpost the optimal journey, including appropriate interventions. This will necessitate the development of dementia-specific reference material, guidance on national and local pathways to investigation and diagnosis and information about health and social supports available in the local community. The four demonstration sites are uniquely situated to provide valuable knowledge and information in this area, as the sites are located across a range

of care settings. In Kinsale, diagnosis is led by GPs, and a Dementia Reference Guide, which focuses on the values of timely diagnosis, was developed and presented to more than 300 GPs at the ICGP Summer and Winter Schools and other GP educational events.

In South Tipperary, timely diagnosis and early intervention are provided through the memory clinic and clinical services in geriatric medicine. The project obtains a GP referral letter when individuals make contact seeking supports and a clinical team performs an at-home assessment, with all those referred becoming patients of OAP. This work has proven overwhelming at times and necessitated the hiring of a Clinical Nurse Specialist in Dementia to assess all new patients and decide with them what supports may be needed. It is envisaged that her locus of operation may eventually move to within the primary care team.

A monthly drop-in memory clinic is available in Stillorgan-Blackrock and is staffed by health-care personnel with advanced training in dementia. The project has identified a need for this service to be more centrally located in order to enhance access; it is hoped that this activity will move to HSE Primary Care Centre in the coming year. Additionally, it has been suggested that there could be an ageing well day in every primary care centre.

In Mayo, the CADM Dementia Advisor contributed to the deliberations of the Advisory Group that assisted in the

development of the National Dementia Strategy. Subsequently, in mid-2014, the ASI appointed seven Dementia Advisors in different parts of the country. The value of this role was recognised in the Strategy, “The HSE will consider the provision of Dementia Advisors on the basis of the experience of the demonstrator sites, with an appropriate number of such Advisors to be dedicated to the needs of those with early-onset dementia.”

At the heart of the Genio Dementia Programme is a desire to provide a range of holistic person-centred, flexible and responsive supports and services that are determined by the PWD’s needs and preferences. As the dementia care journey can sometimes be complex and difficult to negotiate, the projects have focused on the co-ordination and integration of services across the care continuum. Facilitating integrated care provision in each of the four sites is a single point of contact that is responsible for matching resources to need and coordinating the supports required, identifying gaps in coverage and linking mainstream services with project supports. As the NDS is implemented, it will be important to examine how this Connector role can be supported or integrated into existing services. K-CoRD developed integrated Care Review Meetings, which are dementia-specific PCT meetings whose role is to assess at risk persons, prioritise supports and discuss new models for provision of care; it is attended by local GPs, PHNs, the Home Help Coordinator and members of the PCT. The impact of this approach could be evaluated as a model which might be replicated at a national level.

It is imperative that those caring for or interacting with PWD receive the appropriate, dementia-specific training to ensure that they have the necessary skills to provide high-quality and effective care to the individual. Training and education have been a major focus of the Genio programme, with diverse offerings being provided. The past year has demonstrated willingness on the parts of health care professionals, volunteers and carers to actively participate and share knowledge at various training events. A number of materials have been developed by the projects, including a reference guide for dementia for use by GPs nationally developed in K-CoRD, and a City & Guilds accredited dementia module which will hopefully soon be FETAC 5.

While research may not be an explicit aim of all four projects, the work being done is producing valuable insight into the needs and preferences of PWD and their carers in each of the four locations. Learning from the four sites regarding documentation, referral pathways and the implementation process could serve as a template for future endeavours. The PHN register of PWD in Stillorgan-Blackrock, GP dementia registers created in local medical practices in Kinsale and a database of all PWD known to the project in South Tipperary are providing better local estimates of PWD and allowing for improvements in planning. The registers in Kinsale are also facilitating audits of the quality of dementia care being offered in the practices.

To truly improve the quality of life for PWD and their carers, major cultural and organisation changes are needed. For

this to happen, effective leadership is needed at every level. All four projects are providing leadership in dementia care at consortium level and through the development of a single point of contact. Leadership is integral to providing integrated pathways and consistent, quality care. As these roles become better defined, evidence suggests that there is a need for a dedicated person with protected time to lead on developing a holistic community response to support the PWD to live well. The Genio programme is providing a model for the delivery of dementia care in the community and its sustainability needs to be directly linked to the implementation of the National Dementia Strategy.

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Conclusion

THE Genio dementia programme continues to impress in terms of its ability to deliver individualised, person-centred care to people with dementia. The second year of the programme has been characterised by recalibration across the four sites leading to a more sustained focus on priority setting, thereby ensuring that scarce resources are directed to those who need them most. Information and local knowledge remain key to ensuring that dementia needs continue to be identified and met. In that regard, co-ordination and connectivity have been greatly enhanced by the work of the dedicated community connectors and link persons in the four sites. The overall project lead continues to be vital in providing direction and energy to the difficult task of keeping all stakeholders focused on the delivery of person-centred care. Bringing and keeping together so many stakeholders in pursuit of a common purpose remains an important outcome of the project. In the final year of the project the twin key objectives should be to incorporate the voice of the person with dementia more directly in all of the sites and to work closely with the formal care system to ensure sustainability of the programme and the continuation of an individualised, community-based approach to the care of people with dementia.

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Key Learning Points

1. There has been a significant improvement in the integration of the four projects with existing formal provision within the HSE. Some projects, for example Stillorgan-Blackrock, are further along in this regard than others; this is mainly due to the community-care origin of that project and its strong relationship to the HSE from the outset. Similarly, in Kinsale the origin of the project within primary care has made it easier to establish relationships with general practitioners in the area. What is particularly noteworthy is the development of a better understanding amongst existing health and social care providers in all four sites of the social model of provision underpinning the work of the Genio projects. This has, in turn, led to a more nuanced appreciation amongst all stakeholders of the importance of individualised supports for people with dementia and their family carers.


personhood and person-centred care. Developing that common language is an on-going challenge that requires patience, conviction and measurement in order to develop a societal understanding of the potential and capabilities of people with dementia within the social care system and beyond.
2. The public awareness of dementia has increased significantly over the two years of the project in each of the sites. Some of this awareness has happened organically due to the myriad of social relationships that have been formed as a result of the development of the various Genio consortia. The consortia have facilitated an increase in awareness through their internal and external relationships with mainstream social care provision and through their members' direct engagement in civic, cultural and economic life. Bringing so many different groups together had a positive effect on the dementia narrative within local communities. That narrative must, however, have a language that is firmly based on

on the supply side. There has been progress, however, in relation to technology in the past year through direct provision and through education and demonstration projects that have enhanced knowledge about the role and potential of existing technologies amongst people with dementia and their families. Technology is now being used to augment person-centred care for significant numbers of people, and the technology laboratory in South Tipperary is a model in knowledge transfer with regard to dementia technology.
3. Person-centred care is at the heart of the Genio project. Individualised supports that reflect the needs and preferences of people with dementia and their families are now evident across all four sites. There has been significant progress in moving the existing care system to a personalised, individualised model that respects and encourages personhood, autonomy, empowerment and social connectivity for people with dementia. People with dementia are being asked what they need, want and value. Dementia is seen as both a medical condition and a social issue. Consequently, holistic models of provision are now much more acceptable and prevalent in the four sites. The Genio approach is also influencing mainstream thinking as the formal system becomes more familiar with the social model of dementia, as increasingly evident in Mayo, leading to the development of more integrated, embedded and transformative models of care.
4. Establishing needs and wants in regard to dementia technology is a slow process that requires knowledge and understanding on the part of people with dementia and their families on the demand side and similar insights from providers and budget holders

Appendix A

Genio Dementia Programme: Year 2 Evaluation Questionnaire

1. Have there been any changes or realignments to the original project objectives during 2014? If changes to the objectives have occurred, what has changed and why?
2. How would you characterise the functioning and various relationships within the Consortium and what, if anything, has happened in 2014 to either improve or disimprove functioning and relationships within the Consortium?
3. Do the public in your area have a better understanding now about dementia than they did this time last year? If yes, what do they know better and why?
4. Have attitudes to dementia in your area among the public, health care providers and families changed for the better in the past year? Give concrete examples of how attitudes have improved, if that has been the case.
5. Specify the improvements, if any that have occurred in regard to the care of people with dementia in your area in 2014 directly as a result of the Genio project. In particular, specify any new services, or any development of existing services, that have come on stream during 2014 in the areas of:
 - individualised supports
 - respite care
 - technology
 - single point of contact
 - Other advances connected to, or influenced by, the Genio programme.
6. Describe in detail the top three highlights/successes that have occurred within your Genio programme in 2014. Where possible, provide data, individual testimonies, case studies and vignettes to support your arguments
7. Has the Genio project become more embedded/integrated within HSE social care structures in 2014? Has any reconfiguration of resources/budgets taken place within the HSE to reflect the importance of the Genio project and its place in the overall care network for people with dementia in the area? If yes, describe the organisational, funding and resource allocation changes that have occurred; if integration has not happened, why do you think it has not happened?
8. What has not worked in relation to the Genio project during the past year? For example, it might be services that you have not managed to implement yet or fully, it could be relationships with the HSE, or an absence of integrated provision, or Consortium relationships etc. What have you learnt from this failure that tells us something about the difficulties of rolling out an innovative, complex community-based programme like Genio? Remember figuring out what did not work is as important as recording what did work and we will treat it sensitively in the report.

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9. How would you describe care for people with dementia in your area now compared to this time last year? Is it better, the same, or worse? Give examples of real changes to people's lives that have occurred. Is it possible, for example, to report on one or two individualised journeys through the project, detailing how the individualised supports system responded to people's changing needs in a person-centred way.
 10. The upcoming National Dementia Strategy will focus on six priority action areas: better awareness and understanding; timely diagnosis and intervention; integrated services, supports and care for people with dementia and their carers; training and education; research and information systems; and leadership. In what sense, if any, is your Genio project aligned with these priority areas? What can be learned, if anything, from your experience in any, or all, of these priority areas that could help in the implementation of the National Strategy?



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