



COMMUNITY SUPPORTS MODEL FOR PEOPLE WITH DEMENTIA

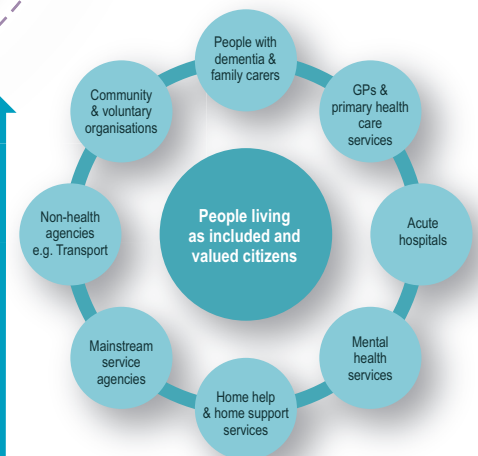
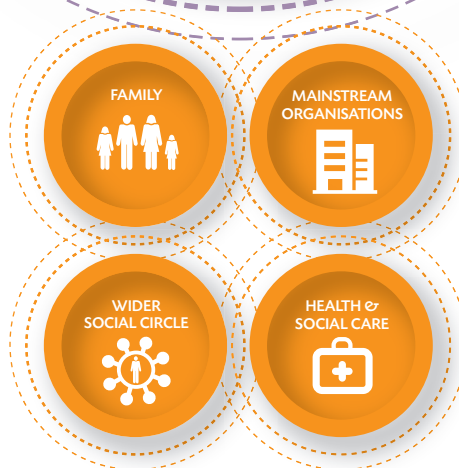
Service Design Summary Document



COMMUNITY SUPPORTS MODEL

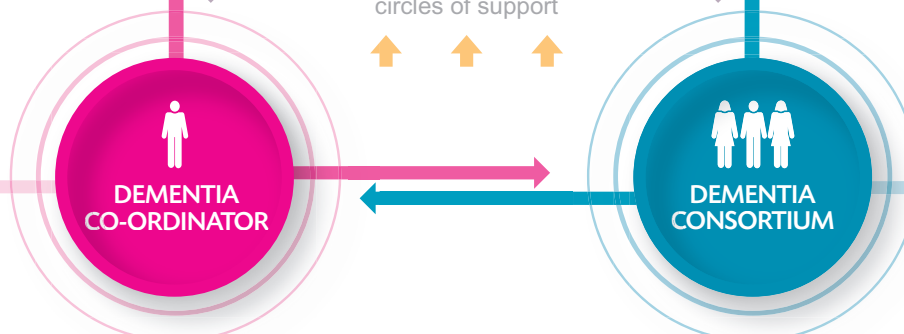


- Lead on developing & promoting a personalised approach to service delivery
- Single point of contact for a designated area providing specialist dementia information, advice & support to health and social care professionals
- Work with community to develop & promote integration of person with dementia
- Promote dementia awareness and education opportunities for family, community & health and social care professionals



AN INFORMED CARE AND SUPPORT ECOSYSTEM

Comprising a dementia aware community with knowledgeable and active circles of support



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Overview of the HSE & Genio Dementia Programme

The HSE & Genio Dementia Programme, with support from the Atlantic Philanthropies (AP) and the Health Service Executive (HSE), is developing and testing new service models in Ireland which will improve the range and quality of community-based supports for people with dementia; influence public policy and investment in this area; and sustain leadership and innovation in the field that is necessary to optimise the implementation of the National Dementia Strategy.

This approach is aligned with government policy, as expressed in the National Dementia Strategy for Ireland, which emphasises the provision of services which support people with dementia to remain at home, living full lives for as long as possible, and supporting families and local communities in this goal.¹

Core to the approach, is the personalising of supports and services and the promotion of personhood. This concept originates in work by Tom Kitwood at the University of Bradford, in the late 1980's. Personhood has been used as a fluid narrative in the context of this service design process – a narrative that respects and encourages autonomy, empowerment and social connectivity for people living with dementia, to ensure that they can live fulfilling lives in their community in the face of changing cognitive abilities. The HSE & Genio Dementia Programme has developed incrementally since 2012². In summary from 2012 to 2017 the full programme entails support for the following:

1. Nine dementia consortia/projects to develop and test a range of community-based supports for people with dementia and family carers. These include four initial demonstration sites – in Kinsale, Mayo, South Tipperary and Blackrock/Stillorgan – which completed their programme of work at the end of 2015 and a further five projects, which have been working since 2013 to design and provide supports for individuals who are at a more advanced stage of dementia and who present with more complex needs.
2. Three hospital-based consortia/projects that are developing integrated care pathways in the acute hospital sector for people with dementia. This is to ensure that access to and discharge from an acute setting for a person with dementia is as seamless as possible, and that their experience in an acute hospital is as good as it can be. One of these projects is based in a large teaching hospital in an urban area and the others are 'Level 2' hospitals also in urban areas.
3. Provision of technical support to the HSE to roll out Intensive Home Care Packages (IHCPs) for people with dementia and the development of indicators to monitor the quality and effectiveness of the same.

¹ Department of Health (2014) The Irish National Dementia Strategy health.gov.ie/wp-content/uploads/2014/12/30115-National-Dementia-Strategy-Eng.pdf

² www.genio.ie/dementia-programme

This service design process is only focused on (1) above (i.e. community-based supports for people with dementia and family carers) and within that mainly the lessons from the first four demonstration projects that completed their programme of work at the end of 2015. However, in setting the context for the same it is important to acknowledge the coverage across Ireland that will be achieved from the dementia consortia/ projects entailed in the full implementation of the programme to 2017 as above.

Aims & Objectives of the Initial Demonstration Sites

The high level aims of the initial four demonstration sites - Kinsale, Mayo, South Tipperary and Blackrock/Stillorgan were as follows:

- To provide personalised, community-based supports to enable people with dementia to remain at home living active lives for as long as possible; and
- To use the personalised community-based supports model to support carers in their caring role so that people with dementia can remain living active lives in their own homes.

The specific objectives they worked to were as follows:

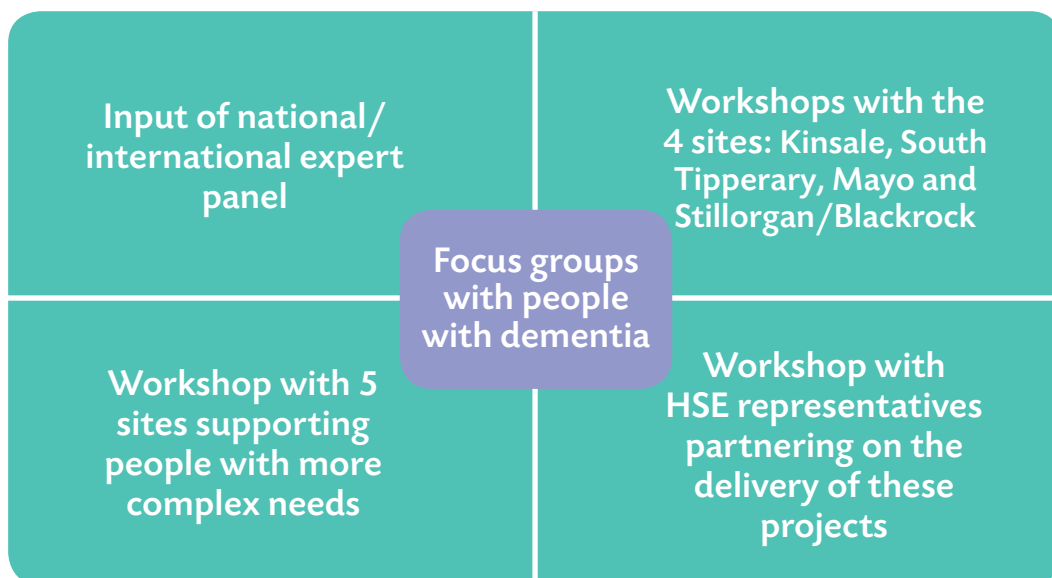
- To mobilise existing community supports (organisations and individuals) to play an appropriate role in supporting people with dementia and their carers;
- To create greater awareness of dementia, increase understanding of what dementia 'entails' and lessen stigma around dementia so that the community is more willing to be engaged in supporting people with dementia;
- To ensure the person with dementia and carers are centrally involved in the design of the content and delivery of the community supports, which should be based on identified need;
- To develop a range of personalised community-based supports, including assistive technologies; and
- To encourage greater integration across the range of community-based supports and services and formal health and social care services.

Service Design Process

A core imperative from the outset has been that the distilled learning from early demonstration sites, in terms of living well with dementia, would act as a catalyst for change, and apply at scale in Ireland. Thus a service design process was put in place to develop a comprehensive, evidence and practice based community supports model drawing on the most effective elements of the innovations across the four sites. The resulting Community Supports Model summarised in this document is intended to inform and guide the remodelling of current services to a personalised response and reconfiguration of associated resources. All of the above is set in the context of reinforcing core objectives expressed in the National Dementia Strategy and supporting implementation of the Strategy.

The service design process was iterative and consultative and took place from September 2015 to February 2016. The process engaged input from people with dementia; carers and families; professionals from the health and social care sector; academia; third sector organisations and volunteers; and an International Expert Panel. It culminated in presentation of draft proposals for the Community Supports Model proposals at the Genio Annual Dementia Conference in Dublin attended by c200 delegates on 3rd December 2015. The proposals in this report were finalised based on delegate endorsement and feedback thereafter.

The process of capturing the learning and innovations from the initial demonstration sites through the service design process was

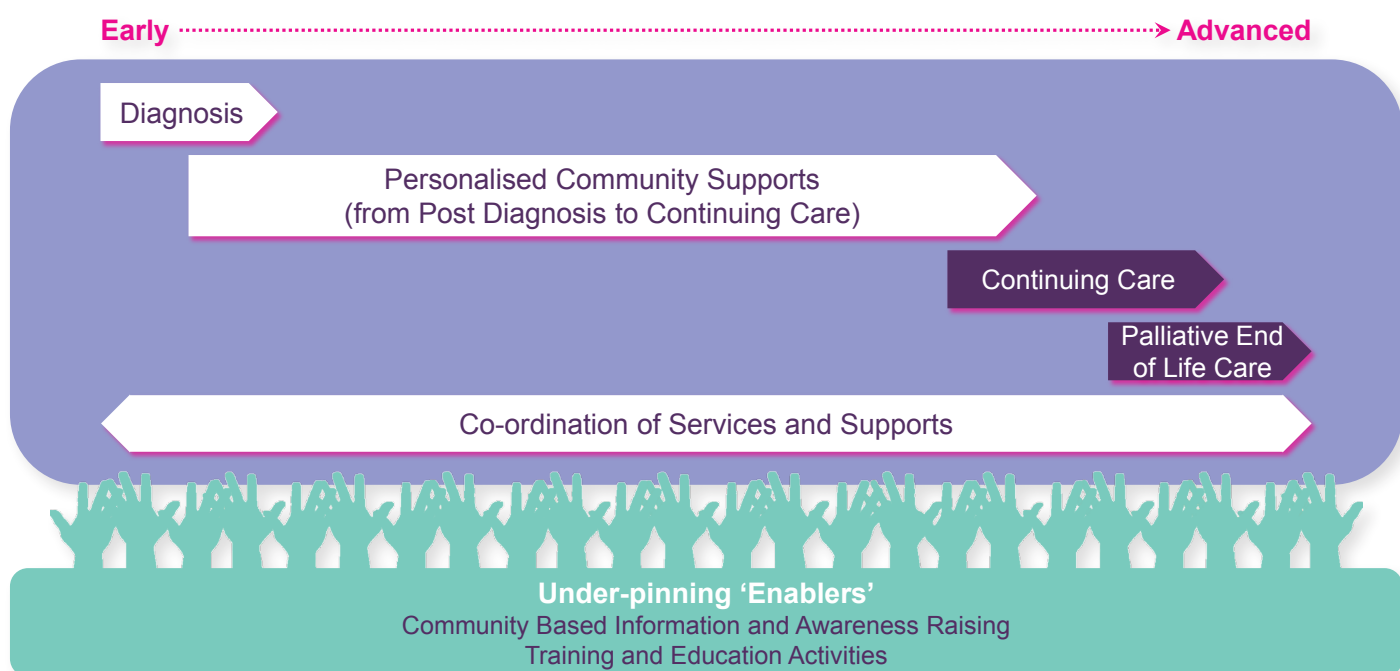


guided by the development of a Reference Framework as per Figure 1 overleaf. The framework is consistent with the 2009 World Alzheimer Report³ seven stage model for planning dementia services but also recognises that aspects of ‘the journey of dementia care’ may not be as sequential as the seven stage model would imply, for instance continuing care can occur in home settings forming part of personalised community supports and each component of service overlaps with others to at least some extent. The framework distinguishes between direct support to persons with dementia and their carers (the boxes shaded in white

in Figure 1) and activity that plays a positive reinforcing role to support provided at all stages throughout the dementia journey, such as information/awareness raising activities and training/ education, which are described as ‘underpinning enablers’ in Figure 1 below. In addition it should be noted that the demonstration of models of continuing care and palliative care, while an important part of the continuum, was not a primary focus of the four sites (these are shaded in purple in Figure 1 to distinguish them from the ‘white boxes’ that were fully within the scope of the service design process). Whilst these areas were

³ Appendix A: Seven stage model for planning dementia services (Alzheimer’s Disease International, 2009)

Figure 1: Reference Framework



not a primary focus of the sites, some did undertake aspects of the same where the same principles of personalised care applied.

The term personalised as applied to community supports in this framework, is a broad term used to describe different ways to support people with dementia to maximise their abilities and to remain living a full life. Personalised supports are based on the needs and wishes of the person with responses that are based on the person's interests and which enhance their abilities. Such supports include the range of clinical and medical services and also give equal weight to the range of supports and services that is required by the person in order to have a full, meaningful life. By way of example personalised supports can help a person with dementia to come to terms with a diagnosis; to help maintain a social life and relationships after diagnosis; help with maintaining ability – all with a view to retaining quality of life. The demonstration

sites evidence a wealth of learning in terms of models of effective personalised community supports, relevant from post-diagnosis to continuing care, which have been incorporated into this Community Supports Model. While the focus of these projects was the development of a personalised supports model for persons with dementia, the principles of the model equally apply to all older persons.

This summary document draws on a more detailed Reference Document on the Community Supports Model⁴ that documents each component of the model (and the associated evidential / practice base for the same) and also includes case profiles of people with dementia supported through the projects.

4 www.genio.ie/dementia-service-design

Community Supports Model

Consortium Model of Delivery

The optimal means to implement the Community Supports Model is through a consortium approach. A foundation of the learning from the initial demonstration sites has been that no single organisation has the knowledge, skills and resources necessary to holistically support the person with dementia, their families and their communities. As such all demonstration projects have been implemented by Dementia Consortia, representative of the seven broad interest groups in Figure 2, who came together around the agreed goal of supporting people

with dementia to live well in their local community.⁵

The consortium model allowed all parties to work together in a purposeful, structured and action-oriented way to co-ordinate formal state-funded resources from health and other sectors with resources from the community and voluntary sector and unpaid/voluntary contributions - to create a holistic, sustainable and personalised response that met a wide range of needs of people with dementia and family carers.

⁵ Keogh et al, (2016) Dementia Consortia: Integrated networks to deliver individualised supports for people with dementia and family carers - www.genio.ie/dementia-consortia-lp



Figure 2: Dementia consortium membership

In effect it has used the unique resources of different members in an aligned way to achieve collective goals entailing the delivery of an integrated and multi-disciplinary response to support people with dementia (and their carers). This model has created the space for leaders to emerge and for innovation to happen.

The model in effect provides access to a seamless 'care and support ecosystem' for the person with dementia (and their carer). This concept of integrated and multi-stakeholder support within the dementia projects is entirely in keeping with the delivery approach embodied in the Integrated Care Programme for Older Persons (ICPOP) recently developed by HSE.

Single Point of Contact to Co-ordinate Services and Support

At the core of the Community Supports Model is the existence of a single point of contact that co-ordinates services and supports for the person with dementia (and their family/ carer). Dementia requires both a clinical/medical and a societal/community response and as such a key consideration is ensuring that people with dementia have access to a 'care and support ecosystem' that integrates community and

voluntary organisations, mainstream services and health and social care services. Effective integration of all of the above offers the best opportunity to produce the optimal outcome for the person with dementia, their family and carers.

Implicit in this integration is the total interdependence of this role with the Dementia Consortium structure. In effect the Dementia Consortium provides access to all of the key players supporting people with dementia (and their carers) in a single place. It helps create the environment within which the Co-ordinator/ Single Point of Contact leads on the development of a personalised approach to service delivery.

Based on the experience of the demonstration sites, this role has been identified as a dementia specialist from a clinical background, to provide expert knowledge and coordination of services. The

"Ring here, ring there.....services fragmented...like looking for a needle in a haystack...the project provided a one-stop-shop"
Family Carer

"If you are organising what is an extremely complex care programme, you need somebody at the helm that you can touch base with because we don't have time day-to-day to do that" GP

"They made contact with me and came out to the house. We sat down and we went through why I wasn't comfortable and why I was anxious about leaving my husband at home on his own. You had input from everybody and I was able to have just one meeting and I didn't have to go from pillar to post" Family Carer

resource should be a single point of contact for a designated area providing specialised dementia advice, information and support and most importantly leading on promoting and embedding a personalised approach to service delivery across primary care teams and associated services.

Key functions of this role include:

- ➔ Being a single point of contact for a designated area, providing specialist advice, guidance, information and support to health and social care professionals;
- ➔ Developing existing dementia resources in the area to create an 'information and support hub' or one-stop-shop for persons with dementia and families;
- ➔ Promoting and supporting key workers/ primary care teams in the development of personalised support plans that use a combination of natural, informal and formal services as indicated by the person with dementia and their family's needs and wishes;
- ➔ Supporting collaborative and integrated working with local key workers through specialist input on need for coordination of supports for the person with dementia;
- ➔ Developing Training and Education opportunities for staff, family and volunteers;
- ➔ Promoting Dementia Awareness raising initiatives including community collaboration;

- ➔ Promoting integration for people with dementia in community participation;
- ➔ Supporting the development of peer to peer Support Groups for persons with dementia and family/carer; and
- ➔ Supporting the development of a volunteer network.

In order to act as a specialist and recognised 'dementia resource' to the area, this role should not have a case management function. Day to day case management should remain with the key worker locally, that is the health professional who has the most contact with the person at a particular point in time depending on their needs (this could be the Public Health Nurse an Occupational Therapist or other health professional). The learning from the demonstration projects highlights that this single point of contact role can be filled by existing skills and expertise within the health and social care system.

Mechanisms to Reinforce Timely and Sensitive Diagnosis

Whilst the processes around diagnosing dementia were not a specific focus for the initial demonstration sites, some useful learning around this did emerge. This was focused on the outcome of timely and

sensitive diagnosis, taking a personalised and person-centred approach, that facilitated better understanding and opened a channel to further information/support for the person and family.

In essence the learning confirmed that GPs/ the primary care infrastructure should continue to play a key role in assessing those over 65 years who present with the most common types of dementia. In addition and as recommended by the National Dementia Strategy, the learning highlighted that a confirmatory definitive diagnosis encompassing precise identification of the dementia sub-type should remain a specialist task, typically requiring referrals to the appropriate services of psychiatry/geriatric medicine and memory clinic services. The experience of the demonstration sites also highlighted that the latter should also play a particular role in diagnosing atypical cases/ rare forms of dementia and the particular need for clear diagnostic pathways to be in place for people with early-onset dementia.

Practice-based dementia registers played an important role in some of the sites, in supporting community resource planning and in enabling proactive provision of supports, thus facilitating crisis avoidance. The key issue is that any form of register needs to have a purpose to onward community supports (i.e. it is not merely a mechanism to monitor trends in the prevalence of dementia in

the locality). For example, recording this information routinely in the person's file and flagging it appropriately, makes it easier to send this vital information if the person is referred to an acute setting. The learning in the projects is consistent with intentions expressed in the National Dementia Strategy, which commits the HSE to 'take measures to ensure appropriate recording and coding of dementia in primary care and the development of practice-based dementia registers'. In addition dementia registers offer synergies with the planned implementation of the Single Assessment Tool (SAT)⁶, in that implementation of the same will provide information to populate dementia registers and further reinforce anticipatory planning that is pro-active and not reactive.

Finally, with the acknowledgement that GPs are often the 'first port of call' in terms of the process of diagnosis, the experience of the demonstration sites indicated the value of training and support for GPs in diagnosing dementia, including the availability of evidence-based guidelines for dementia diagnosis and disclosure.⁷

6 The SAT is referenced as a planned action in the Irish National Dementia Strategy. Deployment of the SAT for older people is intended to assist in assessing need and allocating services and supports in the most effective way possible.

7 Dr Tony Foley of the Kinsale demonstration project drafted a reference guide on dementia for GP's www.icgp.ie/go/library/catalogue/item/7BA666D7-BE51-45F2-138D256A9F394D34. There has also been the opportunity to leverage from work being addressed through other initiatives such as the PREPARED initiative in University College Cork (UCC).

Importantly, the existence of the community based supports within the demonstration projects acted as an incentive to GPs to diagnose as they had something concrete and local to offer the person with dementia. This can help address reluctance that may have existed in this regard to date, due to service gaps in information, support and services available to people who are newly diagnosed.

One to One Post-Diagnosis Information Sessions and Support Groups

A range of information and support structures were put in place by the demonstration sites for persons with dementia (and their family/carers) around dealing with diagnosis, information and ongoing support.

The first component of this in the Community Support Model is the provision of one to one post-diagnosis information sessions for newly diagnosed persons and family members, where these are made by prior appointment. The experience of the demonstration sites indicated that this mechanism of providing information and support in the early stages worked much more effectively than group sessions.

The second component of this in the Community Support Model relates to

“I need a place to call home, being part of a group, and accepted as part of it and a sense of not being on your own” **Person with Dementia**

“There was an opportunity to discuss and address any aspect of care or concern which arose. Also, any issue that could not be addressed at information evenings was followed up as soon as possible. All the talks were very practical and very informative” **Family Carer**

Support Groups and the experience of the demonstration sites indicates that these have been very valuable (for the person with dementia, their family/ carer and the volunteers who support them). Factors associated with successful support groups include the following and should be a reference point for future delivery of the same:

- A clear aim to the group in terms of the reasons why they meet (this might be primarily social for people with dementia, primarily information for carers etc.);
- Establishing from attendees what they want to happen in the group or what information they want, and responding to those identified needs;
- Appropriate facilitation i.e. knowledgeable facilitators who can respond to questions if it's an information group and non-intrusive

facilitation if it's a peer support group/ social group;

- ➔ Use of small groups, or with larger groups, use of small groups within that setting so that individual queries can be addressed; and
- ➔ A welcoming, non-health service environment with a social component thus 'normalising' the event and dementia.

Personalised Supports: Community Connector(s) to Support Connection/ Reconnection

The demonstration projects all worked to support connection or reconnection of people with dementia with activities and interests previously enjoyed. They used existing community initiatives through securing an allocation of places for people with dementia in the same. Activities and interests included by way of example; dance, choir, walking club, shopping, community garden, community allotment, Golf Club, Men's Shed, art club and social club. A key feature of this work is not just creating a larger 'menu' of activities for people with dementia, but that time is taken to establish the interests and strengths of the person with dementia and matching

them to people or activities which reflect the priorities and interests of the person.

The main component in the Community Support Model emanating from the learning in this regard is the need for dedicated resource(s) in the form of community connectors. The learning from the sites indicated that the process of setting up supports to maintain connection/ support reconnection requires time to develop relationships, allay any concerns, build knowledge, and support engagement opportunities. These community connector roles may be fulfilled by existing staff or trained volunteers from within community

"When you have dementia your world gets smaller and smaller, and maintaining connection with your local community and neighbourhood activities is a vital part of living well at home. Just someone to help you go shopping, go to the bank and connect/reconnect with activities of interest" **Person with Dementia**

"A few of us in the club got together and organised some shorter walks that we could all go on together. Walking was in the man's genes. Why wouldn't we support him to continue to do what he loved?" **Leader of Walking Group talking about supporting a person with dementia in the group**

and voluntary sector organisations. The community connectors played a key role in developing links with community organisations to facilitate individuals engaging with previous and new activities in the community. These links supported the

organisation or group to enable them to feel confident in their engagement with people with dementia as well as support to the person with dementia themselves i.e. it is a 'bridging' function.

It is important to highlight that the deployment of the community connector(s) happened through the Single Point of Contact/ Co-ordinator role with links to key players in the Dementia Consortia as appropriate. Their work and indeed all of the other resources involved in the provision of personalised supports on a one-one-to-one basis to persons with dementia always came about through these mechanisms – ensuring a holistic, informed and integrated approach at all times.

Personalised Supports: Maintaining Ability

Supports to maintain ability, typically were derived from a very person centred engagement that required a depth of knowledge about the person, their biography and their current condition. The goal of this input was to prevent premature disability or disconnection from life by the person with dementia. As the person progressed through their journey with dementia, this engagement

typically adapted to their prevailing ability and interests.

By way of examples across the sites, personalised supports to maintain ability focused on maintaining function for the person to remain living well at home while simultaneously reducing the demands on carers. In some instances, access was facilitated to more supportive group activities involving specialist support. In this scenario, it is important that persons attending have the opportunity to engage around their tailored plan in each session as opposed to being involved in timetabled activities.

The key learning is that this support was best provided as a 'one to one' support and through a model of a pre-agreed and sufficient 'block of hours' in the person's home or their community. This block of hours was key to ensuring that the person

"Time for the person with dementia is important in not diminishing the person, but it certainly helps to diminish the problems" **Person with Dementia**

"We have Geraldine coming to us twice a week, which is brilliant. She arrives here around half twelve, she'll have a chat then with mam and dad for 10 or 15 minutes, and then mother will leave, she'll come out here, or come across the road or do whatever she wants to do. Geraldine will take Dad for the next two hours, and do the few exercises with him, Geraldine will bring him for a walk over the road, and they'll even have a game of cards before she goes home - he enjoys that" **Family Carer**

with dementia had sufficient time to engage well, at their own pace and that there was a break for the carer.

These supports happened at least weekly and more regularly where appropriate, had a focus on enabling and maintaining function and were provided by support workers and volunteers with dementia training with a focus on enabling and maintaining function. The experience of the sites was that support provided in this very personalised way had a very positive effect within the family as the person's unique identity and value was to the fore.

Personalised Supports: Responsive and Quality Respite Support(s)

The traditional concept of 'respite' was revisited or challenged in many of the supports that were developed within the demonstration projects. Instead of being solely a service for carers, the idea of adding value to the experience for the person with dementia, and of incorporating a range of activities and interventions which provided 'a break' for the carer but enhanced the time spent with the person as well was developed.

Flexibility of provision was key, again with a 'block of support hours' agreed on an individual basis for use by

the family within the month at a time that suited them and the person with dementia best rather than a pre-determined offer. Typically this ranged from blocks of hours, to overnights and weekend cover as required. People who were supported in this way were generally in the later stages of dementia, presenting with complex needs, with evidence of significant demands on carers. In some instances the ability to respond immediately and put in place 'respite' supports for a short period as required by individual situations prevented an escalation towards hospital admission on several occasions.

Reflecting on the above the main component in the Community Supports Model emanating from the learning is that the traditional notion of respite, which is arguably pejorative and outdated, needs to be recast as something positive (with added value)

"We were scared how to manage discharge from hospital...the project put in somebody staying overnight to support this time"

Family Carer

"Daycare and respite has been a lifesaver for me, without which I could not have looked after my wife for so long"

Family Carer.

"I was so worried about how I was going to manage when she got home, 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 I got a night's sleep, I hadn't had a night's sleep for nearly five weeks"

Family Carer

for the person with dementia as well as providing a break for the carer. In effect the quality of the experience gained has to be of a sufficiently high quality to truly enable disconnection from the focus on the disease/demands of care. Allied to this in designing a response to crisis situations, the Community Supports Model emphasises that proactive supports are readily available so that crisis interventions should be rarer. Many issues described as crises are often the result of issues that can be predicted if the full context is considered, for example, where people living with dementia are living alone or with a person of similar age. The experience of the initial demonstration projects is that a continuum of personalised supports which proactively responds and is flexible to changing needs should address 'expected crises' more effectively.

Personalised Supports: Tailored Use of Assistive Technology/Telecare

The initial demonstration sites all included Assistive Technology and/or telecare provision within their service innovations. One site developed an Assistive Technology library (lending clocks and calendar clocks, simple to use radios and mobile phones, medication reminders, and other devices) which attracted wide-scale interest and other sites developed small scale demonstration areas for Assistive Technology. Assistive

Technology loaned from the library was found to be useful in many but not all cases. Benefits of some of the simple low-tech devices included improved time orientation, communication and engagement.

Telecare was provided as a pilot service in all initial demonstration sites, although generally in fairly low volumes. The evaluation of

"Some of these tools help bring discipline and structure to daily routine and to provide the motivation to deal with daily challenges" **Person with Dementia**

"Very good for memory, it reminds you every day, it's really a second person in the house" **Person with Dementia that trialled a Calendar Flip Clock from The Memory Technology Library**

"This gives her independence. You can monitor but she still feels she is doing her own (thing).... Otherwise I'd have to be going in and out of the room all the time..." **Family Carer**

the telecare programmes found that it was especially useful for the carers, with all those in the evaluation reporting positive benefits. Reassurance and alerting family carers when the person with dementia needed assistance were the most commonly reported benefits.⁸ In some cases, carers felt that telecare enabled them to help the person with dementia remain living at home for longer than would otherwise have been possible. There were also some negative impacts, including nuisance factors because of noisy

⁸ www.genio.ie/at-evaluation

or over-sensitive technology and, sometimes, dilemmas about the trade-offs between invasion of privacy and benefits for the person with dementia. In all cases, carers felt that the positives outweighed the negatives, often substantially.

Reflecting on the above the main component in the Community Supports Model emanating from the learning in this regard is the importance of a good assessment and how the telecare and Assistive Technology needed to be carefully tailored, taking into account characteristics of the person, the carer and the home environment. It is however important to note that telecare is not always appropriate and / or a simple solution and is not a substitute for personal contact. Finally, information and demonstration products are very helpful in providing potential users with the opportunity to explore and trial how Assistive Technology/ Telecare can improve quality of life for people with dementia (and their carers).

Underpinning 'Enablers' (Community Level Awareness Raising and Training / Education)

The successful delivery of all components of the Community Supports Model is reliant on the 'underpinning enablers' illustrated

in Figure 1 previously, i.e. community based information/ awareness raising and training/ education.

The experience of the demonstration sites illustrates that community information and awareness raising played a positive reinforcing role to support provided at all stages throughout the dementia journey. The projects undertook a wide range of activities in this regard but found there was a gap to be bridged between learning/ awareness and active participation. As such, a deliberate strategy had to be deployed centred on targeted information /awareness raising actions around knowledge transfer and active participation. This deliberate strategy was based on both efforts to change attitudes (e.g. through destigmatising the 'loss of self' that a person with dementia experiences) and efforts to change behaviour through stimulating active involvement of the community in a way that 'adds value' to the person's life and recognises their personhood. The latter required targeted engagement with groups/ networks in the community, and took time and skill to navigate across sectors with a 'specific ask' - for instance to provide practical support to people with dementia to enable them to reconnect with activities and interests previously enjoyed. This moved work such as 'dementia friendly communities' to another level of active participation - i.e. 'dementia supportive communities' - where there was

a strong recognition within the community of the role they can play in supporting people with dementia and a significant number who became actively involved. In effect a supportive 'community of interest' was created that contributed more broadly to building citizenship and social cohesion.

In terms of training and education all of the components encompassed in the Community Supports Model must be provided by individuals that have the necessary dementia specific skills and competencies to provide high quality, person-centred care and support. The experience of the demonstration sites is that there is a role for a range of personnel in providing these personalised supports (with the exception of Co-ordinator/ Single Point of Contact role which requires specific skills and qualifications as per Section 5 above). Individuals providing these personalised supports could be dementia advisors, dementia support workers, specially trained home helps, private agency staff and volunteers (where the latter have a paid/ staff resource to supervise, support and co-ordinate the volunteering inputs).

All of the demonstration sites provided training and education to all of these constituencies as well as family carers. Some of this drew on existing resources within the HSE, DCU Elevator Programme and others, but adapting where necessary to local need (e.g. to incorporate an inter-disciplinary/

cross-sectoral focus consistent with the breadth of interests in the dementia consortia). Other elements of this included the development of bespoke training as new offerings for particular audiences. These consisted of events to reach a broad audience through conferences, sessions and modules targeting groups such as health professionals and tailored courses and educational toolkits for GPs, health professionals and support workers. A significant gap encountered in this area was practical training which moves beyond 'person-centred' to real personalised support. To address this Genio has been developing a training programme in Supported Self-Directed Living (SSDL), which originated in work in the disability and mental health sector, but which is being tailored to train staff supporting people with dementia. This will include a module for family carers.

Overall the opportunities for shared education and learning opportunities across disciplines and sectors has benefited all parties as they are supported to share and explore common challenges and are provided with greater understanding of how to support the person with dementia to maintain active engagement in activities and life roles.

Analysis of Resource Allocation and Costs

An economic analysis of the four initial demonstration sites has been conducted by Professor Eamon O'Shea and colleagues in the National Centre for Social Research on Dementia⁹. The analysis has focused on persons with dementia on the margin of residential care in each of the sites, and quantified the various supports and interventions they received to determine the potential of the Community Supports Model in delaying institutionalisation/ reducing the need for same.

The study found that of the 568 people with dementia who were included in the study, 181 (32%) were estimated to be on the boundary of care between community and residential care. The estimated weekly average cost of community care per person with dementia on the boundary of care, including HSE provision and supports from the projects, was €207 per week against an average cost per week of €967 for residential care. When the costs of housing and personal consumption for the person are included the average cost per week increases to €418 per week. Including the costs of informal care increases the costs further, depending on the method used for valuing informal care.

The analysis also examined the potential cost of care if these 181 people had been institutionalised rather than cared for in the community. An estimated total cost of residential care of €5,552,265 was calculated, based on a 50 per cent chance of people ending up in residential care for the average

length of time spent in the project (63.53 weeks). The overall estimated potential saving associated with the programme was €3,169,561 if the comparison is with HSE and project support costs.

The potential cost saving of €3,169,561 does not include informal care that is relatives/ family carers who on average spent c15 hours a day supporting the 181 people identified as being on the margins of residential care within the projects. While their time is not a 'hard cost' to the system that can be included in the €207 per week figure above, it is an important consideration. If the system had to replace their input there would be a hard cost incurred or similarly if the carer has forgone employment in order to be a carer there is an opportunity cost associated with the same. In fact if informal care is included in the overall calculations, community care becomes more expensive than residential care, highlighting the central importance of family care for people with dementia.

The conclusion of the study is that: *"...it is possible to increase the availability of personalised supports to augment existing HSE provision and still not exceed residential care costs, even when personal consumption and housing costs are included in the analysis. Investment in personalised supports for people with dementia is good value for money for the HSE, especially for people on the boundary between community and residential care. The time is right to radically change the resource allocation system for community care in Ireland to reflect the social model of care. For a relatively small investment in innovative, personalised supports lives can be transformed and residential care costs postponed."* [p.24].

⁹ O'Shea, E & Monaghan, C. (2016) An Economic Analysis of a Community-Based Model for Dementia Care in Ireland: A Balance of Care Approach National Centre for Social Research on Dementia NUIG www.genio.ie/economic-analysis-dementia

Concluding remarks

In thinking about the future replicability of the Community Supports Model it is important to note the coverage across Ireland that will be achieved from the existing dementia consortia/ projects entailed in the full implementation of the HSE & Genio Dementia Programme to 2017.

In addition through the existing projects over 1,400 HSE staff have been upskilled in new service models that have improved the range and quality of community-based supports for people with dementia. Over 250 people are active members of dementia consortia. As such, these individuals are leaders in their respective fields and geographic areas and most of them are HSE staff. In many cases HSE staff have led the project work and in other instances worked with leaders from other sectors/organisations. A key learning within all of this is that mindset/ attitude and context is as important as the requisite skillset being in place. In effect much of what has been achieved is linked to facilitating existing staff to work differently in an enabling and supportive environment where qualified risk-taking/ innovation was possible. All of this suggests that there is significant capacity to build on from the demonstration projects in aiming for wider replication.

In looking ahead it is important to set any plans for replication within the context of the new governance and management structures for the delivery of community

health services within the HSE. In July 2015, as part of the significant reform programme in line with Government's 'Future Health' policy, the HSE established nine Community Healthcare Organisations (CHOs) across the country as a new means of delivering health services. CHO's provide community healthcare services outside acute hospitals, such as primary care, social care (including for older people), mental health, and other health and well-being services. These services are delivered through the HSE and its funded agencies to people in local communities, as close as possible to their homes.

There is currently at least one Dementia Consortium in all but one of the CHO areas. This represents an important resource and body of experience in supporting the implementation of the National Dementia Strategy into the future.

An important context for further implementation of the Community Supports Model is the recent development of the Integrated Care Programme for Older Persons (ICPOP) by HSE. The purpose of the Integrated Care Programme for Older Persons is to work with all relevant partners in shifting the model of care towards supporting older persons to live in their own community and to receive the right level of co-ordinated care in an appropriate location. The focus and ethos of the planned ICPOP programme is entirely in keeping with the

proposals that have emanated from the service design process, for the Community Supports Model, from the HSE & Genio Dementia Programme to date.

The demonstration sites have considerably improved the range and quality of community-based supports for people with dementia in Ireland, with the ongoing programme to 2017 offering the opportunity to build further on this. Implementation of the full programme to 2017 will achieve coverage right across Ireland with at least one dementia consortium/project having been implemented in every one of the new CHO areas. As such there is/will be a legacy of leadership skills and innovation in the field to contribute to optimising the implementation of the National Dementia Strategy.

This service design process, in distilling the learning and innovation from early demonstration sites, has identified the key components of a comprehensive Community Supports Model that can act as a catalyst for change, and apply at scale in Ireland. The evidence summarised in this document, indicates that the approach offers good value for money, provides a feasible model to avoid or delay entry to residential care and is good for people with dementia enabling them to live fulfilling lives in their community in the face of changing cognitive abilities. Finally, an important feature of the demonstration projects has been the opportunity they have had to 'reshape' the usual or expected interaction of people with health and social care services, building relationships of trust which helped ensure people got the right supports in the right place at the right time.

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Genio innovates by working with Government and private funders to develop better ways to support disadvantaged people to live full lives in their communities. So far we are working to improve the lives of people with disabilities, mental health difficulties and dementia.

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