Dementia Consortia:
Integrated networks to deliver individualised supports for people with dementia and their family carers.

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GENIO

Contents

1. Purpose

The purpose of this paper is to introduce, explain and describe the concept of dementia consortia. This paper brings together the experience and learning of dementia consortia established in Ireland to date, so that this form of integrated working can be developed further in Ireland.

2. Background

"First and foremost, people with dementia are friends, relatives, neighbours and fellow members of society. The fact that they have a specific medical condition is secondary. They have an inherent dignity, value and personhood which remains with them throughout the whole course of the disease and should be respected at all times (Alzheimer Europe, 2009)."

This statement eloquently captures a focus on dementia that is centred on the person and on human dignity. Until recently, dementia was interpreted and treated solely within a medical paradigm, with a focus on understanding the disease processes and finding ways of arresting or preventing them. Within an exclusively medical focus, there was little room to take account of the impact of the condition on the person with dementia, to hear their experience and voice. During the 1990's an impetus developed to look beyond the medical paradigm and to seek human, rather than medical solutions (Kitwood, 1997). This approach put the person with dementia at the centre of all caring activities, and thus broadened our understanding and conceptualisation of the condition.

3. The case for a new type of response for people with dementia

Over the years, many consultations have revealed that older people want to remain living in their own home for as long as possible. National policy on older people has for many years reflected this view, with a central aim of providing the necessary services to enable older people to remain at home living full lives for as long as possible. The National Dementia Strategy reaffirms a commitment in existing health strategy that older people should be supported to remain living at home for as long as possible. However, the allocation of resources in services for older people does not reflect this priority, as the largest share of the HSE budget for older people (72%) is spent on just 22% of all clients of the budget through the Nursing Home Support Scheme, known as 'Fair Deal'. The remaining 28% of the older persons budget is spent on a number of home support services for 78% of recipients of the services for older people (McKeown et al., 2014). This has led to acknowledged gaps in the continuum of services and supports for people with dementia in the community; *"...community support services for people with dementia and their carers are under-developed and fragmented in this country"* (Cahill et al., 2012).

One of the most important elements of a 'full life' is social connection and authentic contact and communication (Kitwood, 1997). Maintaining valued relationships and networks, as well as having the opportunity to build new ones, is vital for supporting the well-being of the person with dementia and their families (APS Group Scotland, 2011). However, misperceptions of the condition, and stigma can be significant

barriers to a person with dementia remaining socially connected and engaged. The 2012 World Alzheimer Report found that 49% of respondents felt that people with dementia are not included in everyday life, citing issues like access to programmes, transportation needs and stigma as the main barriers (Alzheimer's Disease International, 2012).

This points to the need for a wider constituency than professional services to be involved and to see that they have an important role to play in supporting people with dementia. Encouraging a community-based response to dementia requires a range of awareness raising and educational activities to address stigma and increase accurate knowledge and understanding of dementia. This need has been recognised and has led to a number of responses including the encouragement of 'dementia friendly communities' in Ireland , 'dementia friends' in the UK, Canada and many other countries, along with educational and information resources such as the series of 'Freedem' films[1] produced in Ireland (Brennan, 2015).

While maintaining personhood and social connection is key to the person 'living well' with dementia, we cannot ignore the fact that dementia is a medical condition and people need access to a range of specialist services at different points in their dementia journey. If we consider the trajectory of dementia from the time of diagnosis (if that is made), a complex array of interventions, services and support may be required. This includes but is not limited to general practitioners (GPs), public health nurses (PHNs) and other members of the

primary care team such as physiotherapists, occupational therapists and social workers; members of teams providing mental health services for older people, home help and other home support services, acute hospital service and long-term residential care services. Placing dementia in a broader public health context and considering the importance of prevention means that an even wider range of organisations have a potential role to play, with a remit for population health and not just older people.

The biopsychosocial view of dementia means that many agencies and organisations beyond health services have a role to play in providing services and supports for people with dementia throughout their dementia journey. The often long-term and deteriorating nature of dementia means that while families have the natural authority and responsibility to provide support for a family member, this support cannot solely be the responsibility of the family. It must also be kept in mind that 28% of people over 65 live alone and many of this group may not have family carers available to provide support. A further 29% live with a spouse who may not be in a position to provide care and support due to their own health needs (Central Statistics Office, 2012). There is growing recognition of the physical, psychological, social and economic impact dementia has on the person themselves, their families and carers, and society as a whole (World Health Organisation, 2012).

The broader societal context must also consider the extent of current and future need for dementia services. In 2006, it was estimated that there were approximately 41,700 people living with dementia in Ireland. This figure is projected to rise to between 140,580 and 147,000 by

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1 *freedemliving.com* This is a series of information films on dementia produced by the NEIL Institute in Trinity College Dublin with the support of Genio..

2041 (Cahill et al., 2012). It has also been estimated that the annual cost of dementia in Ireland is over €1.69 billion, with close to half of the cost attributed to the informal care provided by family and others, 43% to long stay care and 9% to other health and social care.

Finally, we return to the person. There has been an increasing recognition of the value of listening to people using services, as the 'experts' in their own care; *"accepting the personhood of people with dementia means giving them a much more formal role in decision-making at the micro care level and the macro policy level"* (O'Shea and Murphy, 2014). A variety of mechanisms are required to facilitate the participation of people with dementia directly in making decisions about their own care and in participating in local dementia consortia and national policy making and other forums.

We are at an inflection point in services for people with dementia. We have a new strategy, we have estimates of increased prevalence, we have a much better understanding of the many dimensions of dementia, not just as a medical condition but the emotional, psychological, personal, familial and environmental dimensions that we cannot ignore. We have new models of personalised support being demonstrated in Ireland which are attempting to address these issues and develop new responses.[2] Given this context and what we know, we cannot continue with 'service as usual', and with the projected demographic changes in Ireland, it is also clear that a response focused solely on long-term residential care will not be financially sustainable. It could be argued further, that a response that relies solely on the health and social care system to meet the diverse range of needs

of people with dementia is not appropriate as many actors and organisations have a role to play in meeting the range of needs and sustaining personhood.

3.1 Summary

In summary, the research evidence, the findings from consultations and Ireland's experience in supporting people with dementia and their families has shown that:

- The stated wish of older people is to be supported to remain at home living full lives for as long as possible.

- There is a need for ongoing community engagement and involvement so people with dementia have a full life.

- A biopsychosocial response is needed to address the varied needs of people with dementia and their family carers at different points in time.

- There are significant gaps in the system such as the limited community-based response and often limited support for families.

- There is a lack of integration between the many services a person with dementia may access in the course of the illness.

- Dementia is usually a long-term illness

- The prevalence of people with dementia is projected to increase significantly.

- The configuration and cost of our current response is unsustainable.

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2 *genio.ie/dementia-programme*

4. A new response for people with dementia

In this context two key ideas emerged. Firstly, the need to develop individualised or personalised responses for people with dementia and their family carers that would meet their unique and full range of needs in a flexible and responsive way; and secondly, the need for a coordinated, inclusive approach to developing individualised dementia services and supports which would include a wide range of organisations and agencies. We called this a Dementia Consortium.

4.1 What are personalised or individualised supports?

The terms personalised or individualised are often used interchangeably. They essentially mean that supports are designed and arranged around the person, with primary control being exercised by the person along with their family/advocate as appropriate.

An individualised approach to supporting a person with dementia has the following characteristics:

- The person with dementia and their carer (or advocate as appropriate) 'design their own supports' that will enable the person to remain active and connected in their community.

- Adopts a 'normalising' approach to dementia.

- Is flexible and responsive, taking into account the stage of illness the person is at and recognising the unique life journey of the person to this point.

- Is focused on maintaining valued roles building on strengths and existing capacities, moving away from an exclusive focus on deficits.
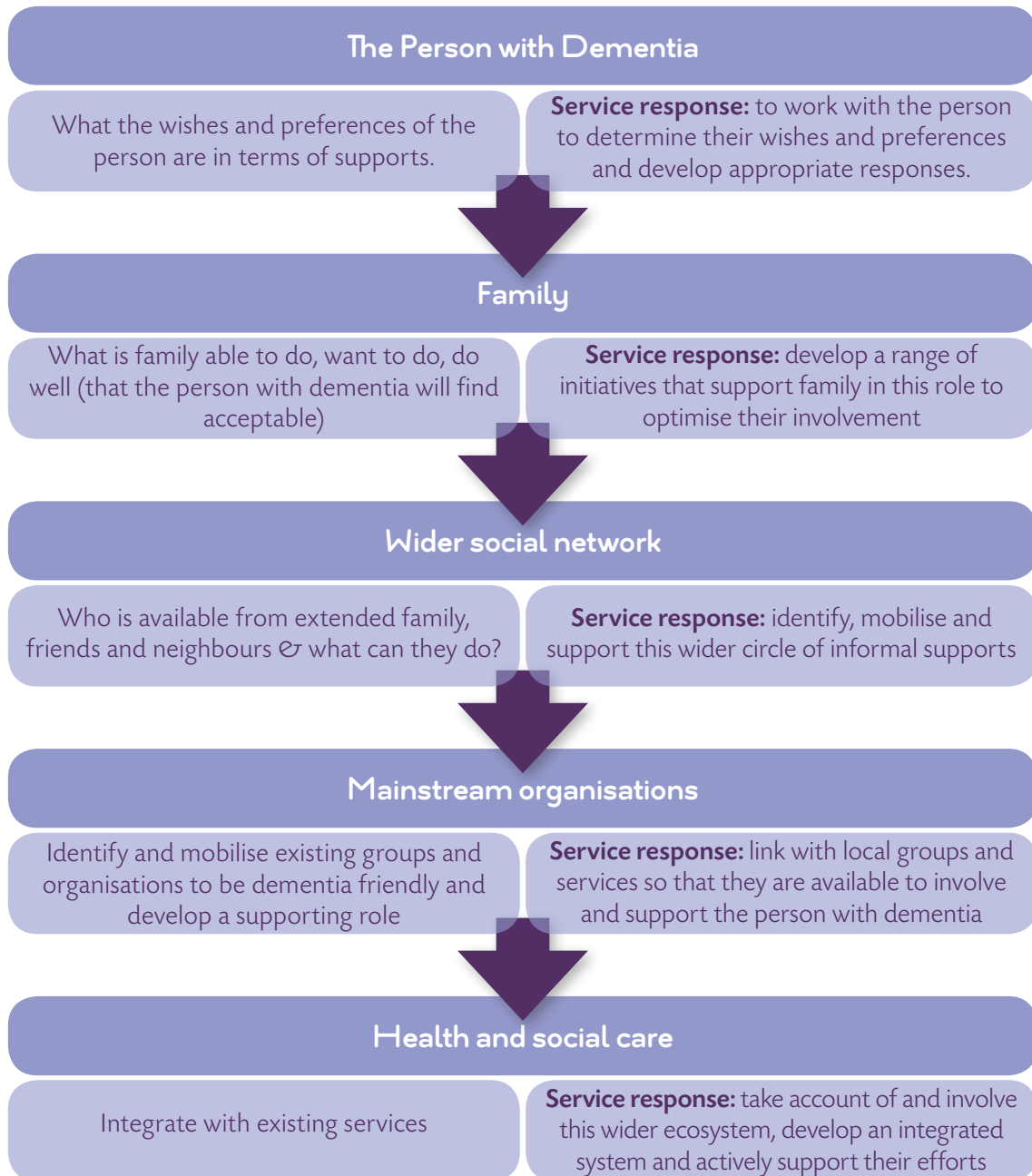
- Is delivered in the community fostering inclusion and participation rather than in segregated, stigmatising settings.

- Uses naturally occurring family and community supports in the first instance, then mainstream services and finally formal health and social care supports to fill identified gaps.

- Uses responses that are cost-effective and represent good value for money.

We describe supports developed in this way as individualised, as they have been designed by the person/family and relevant health professionals to meet their specific needs.

4.2 The concept of a 'care and support ecosystem'

Providing individualised supports is not just about making a wider 'menu' available to the person, although that is one part. Two key features are the involvement of the person/family in designing what support they get and the consideration and engagement of a wider 'ecosystem' of care and support. By their nature, individualised supports comprise a mixed package of formal and informal supports as this is usually the most cost-effective way to meet the social and psychological needs of the person as well as their health needs. Figure 1 describes different sources of support and what services can do so that all are engaged in playing a role in supporting people with dementia. The story in text box 1 provides an example of how this works in real life.

Figure 1: Possible components of individualised supports – what services can do to develop a care and support 'ecosystem'

The Person with Dementia

What the wishes and preferences of the person are in terms of supports.

Service response: to work with the person to determine their wishes and preferences and develop appropriate responses.

Family

What is family able to do, want to do, do well (that the person with dementia will find acceptable)

Service response: develop a range of initiatives that support family in this role to optimise their involvement

Wider social network

Who is available from extended family, friends and neighbours & what can they do?

Service response: identify, mobilise and support this wider circle of informal supports

Mainstream organisations

Identify and mobilise existing groups and organisations to be dementia friendly and develop a supporting role

Service response: link with local groups and services so that they are available to involve and support the person with dementia

Health and social care

Integrate with existing services

Service response: take account of and involve this wider ecosystem, develop an integrated system and actively support their efforts

A woman with early onset dementia has a spouse who works full time and was concerned about the time that his wife was alone at home. The woman and her spouse worked with a service to identify what supports would work for them. She is being supported to continue to live well in her community with a package of supports and services which includes; support to take part in a musical memories choir and exercise class; an afternoon once a week with a volunteer who has been matched with this woman in the shared interest of walking; dedicated time from a paid support worker who provides an opportunity for the woman to engage in purposeful activities both in home and in the community for example to reconnect with art by joining a local art group; members of this group provide transport for this woman when outings are organised. A carer support group has provided the woman's spouse with a network of people living through the same experience with whom he can share his experiences. This package of supports enables the woman to have a full life at home and supports the carer to continue in his role of primary carer.

4.3 What is a dementia consortium?

A dementia consortium is a group of organisations, agencies and individuals who come together around the agreed goal of supporting people with dementia to live well in their local community. For all the consortia developed to date, this has involved engaging in a range of activities and developing new responses in support of this goal.

The realisation that no single organisation has the knowledge, skills and resources necessary to holistically support the person with dementia, their families and their communities formed the basis of the HSE & Genio Dementia Programme. This programme encouraged consortia to come together to develop a range of individualised responses and improve service delivery for people with dementia and family carers. The learning from these consortia is incorporated into this section along with evidence from other sources.

4.4 How is a dementia consortium different to any other committee?

We are familiar with other types of collaboration such as networks, which are useful when the concern is information sharing; coalitions, which work well in approaching a single issue which requires mobilisation; and local area partnerships which in Ireland have come together as a result of different Government initiatives and funding streams with a general focus on enterprise and local development. There are some similarities with dementia consortia and these different types of collaborations but the consortia have several unique characteristics:

1. **Developing a care and support 'ecosystem':** Dementia consortia provide a structured way of using formal state-funded resources from health and other sectors in combination with resources from the community and voluntary sector and unpaid/voluntary contributions to create a holistic, sustainable and individualised response that meets a wide range of needs of people with dementia and family carers – see the example in text box 1.

2. **Co-production:** Dementia consortia involve people with dementia and family carers in a meaningful way in the design of supports and services, for example spending time with the person

with dementia to learn about the their experience of navigating services and incorporating that learning into the design of services and supports

3. **Focus on the individual:** Rather than providing for the generality of 'people with dementia', the consortium strives to provide the individual with what they need as a person. Dementia consortia specifically focus on making an impact on the lives of people with dementia and not just growing services per se. The wider impact on services and the community occurs as a knock- on effect of this focus on building from the individual up.

4. **Explicit and agreed agenda and goals:** The members of the consortia work together to develop a shared vision and common agenda with agreed goals and outcomes and they explicitly commit to this as a group. There is a shared responsibility to achieve goals, sustain what has been achieved and build on progress.

5. **Mutually reinforcing activities:** The Dementia consortia uses the unique resources of different members in an aligned way to achieve their goals. For example, clinical services which work separately can combine to do specific pieces of joint working in support of the goals of the consortium. This does not necessarily require extra service resources but the support and coordination of the Consortium can bring about a 'new' service.

6. **Active membership:** Membership is not based on representation but on active involvement and contribution, and aligning the work of the individual or organisation with the goals of the consortium. Membership is reviewed and renewed regularly, based on what has been learned and the programme of work.

7. **Measuring progress:** Dementia consortia measure their progress towards their goals and outcomes they have achieved.

8. **Sharing learning:** The consortia actively work to reflect shared learning back into individual organisations and agencies to effect ongoing awareness and change for the wider population of persons with dementia.

One area we can learn from in developing dementia consortia is called 'collective impact' which offers a methodology to bring groups of stakeholders together in effective ways (See Appendix 1 for more details).

4.5 Dementia consortia in Ireland

Since 2012, 12 dementia consortia have come together in Ireland under the HSE & Genio Dementia Programme. This is a rapid growth for such a new concept. The thinking behind dementia consortia resonates with several positive features of Irish society which perhaps explains why it has gained such traction. Dementia consortia are a locally developed response, drawing on local talents, strengths and energy to meet a local need. It also taps into the tradition of meitheal[3], where families neighbours and others come together to provide a common effort for a common cause. The 12 dementia consortia in Ireland which have received funding for specific projects are listed in Table 1 overleaf. Further detail on the work of these consortia is at **www.genio.ie/ dementia-programme**.

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3 Meitheal is an old Irish term that describes how neighbours and friends would come together to help one another in the saving of crops or other tasks.

Table 1: Details of Genio-supported consortia and dementia projects		
Organisation	**Location**	**Project Description**
Kinsale Community Response to Dementia (K-CORD)	Cork	This 3 year project is establishing a comprehensive community-based, person-centred response to dementia, by engaging concerned professionals and local citizens in a process of collaborative learning, planning and action.
Living Well with Dementia (LWwD)	Dublin	This 3 year project is developing a range of community-based supports for people with dementia which is responsive and highly integrated with the formal health and social care system.
Community Action on Dementia in Mayo	Mayo	This 3 year project is developing a dementia friendly community response for people with dementia to remain connected and engaged with life roles and activities of interest. An individualised support service will be delivered tailored to individual needs and will be further supported by a post diagnostic service that will inform and support families and individuals with future planning and care needs.
The 5 Steps to Living Well with Dementia in South Tipperary	Tipperary	This 3 year project is providing high quality, flexible, person-centred care in the home to people with dementia and their families in South Tipperary, helping people to stay living at home for as long as is possible.
Cork Integrated Dementia Care Across Settings (Cork-IDEAS)	Cork	This 3 year project will provide integrated care for people with dementia who may need hospital admission, providing suitable alternatives to admission, when appropriate, while supporting families/carers to continue to care for the person at home.
Connolly Hospital Integrated Care Pathways for People with Dementia	Dublin	This 3 year project will develop an integrated care pathway between acute hospital and community services specific to the needs of all people with dementia including those with complex disease.
Development of an Integrated Care Pathway for People with Dementia (DemPath)	Dublin	This 3 year project will develop a care pathway for people with dementia in order to integrate care across the Dublin South Inner City community and St. James's Hospital in a person-centred way.
Memory Matters Community Component	Kilkenny	This 2 year project will design and provide supports that are flexible and responsive to the person with dementia and their carer, particularly for those who present with more complex needs, which will enable them to remain in their own home.
Community Outreach Dementia Project Leitrim (CODPL)	Leitrim	This 2 year project will support an integrated response across community and day hospital to provide individualised supports for people at more advanced stages of dementia, and their families.
Flourishing with Dementia (FwD)	Louth	This 2 year project will support people with more complex dementia-related challenges to flourish in the community, developing individually tailored personal plans, realising their own potential and connecting to a more dementia-aware community.
The Crystal Project	Mallow	This 2 year project will facilitate individualised and integrated support for people affected by dementia living in Mallow and the surrounding hinterland.
There's No Place Like Home!	Roscommon	This 2 year project will work collaboratively across formal and community services to develop an integrated response that is individualised, flexible and responsive to the needs of people with dementia.

4.6 Who is in a dementia consortium?

There is a great variety of membership across individual consortia. This reflects the fact that they are locally developed in response to local factors such as perceived needs, existing services and service gaps, existing strengths and interests among community and voluntary groups and so on. However, there are at least seven key groups that are involved (see Figure 2).

1. People using services – people with dementia and family carers.

2. GPs & primary health care services.

3. Acute care services.

4. Community health and social care services:
   a. mental health services/psychiatry of old age services
   b. home help and home support services

5. Mainstream service agencies such as Gardaí, education, etc.

6. Non-health agencies, such as transport and county councils.

7. Community and voluntary sector groups and organisations.

A detailed list of current members of dementia consortia is in Appendix 2.

Figure 2: Some of the services and supports that have a role in supporting people with dementia to live full lives in the community

For a dementia consortium to run successfully, it is recommended that there is balanced representation across all of these seven key groups. Most of the people working in these organisations are used to attending meetings and participating in different fora. However, a dementia consortium provides an opportunity for a co-productive approach to addressing a complex social need (see text box 2). Dementia consortia have the potential to evolve beyond a framework to facilitate 'service user involvement'. They promote the principle of equal partnership, and provide a way for service providers and members of the public to work collaboratively in the design and delivery of services (Boyle and Harris, 2009).

TEXT BOX 2: Co-production – involving people with dementia and family carers

Co-production is an approach which aims to transform public service provision through a reshaping of the relationship between 'service user' and 'service provider' and has been defined as '...delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours. Where activities are co-produced in this way, both services and neighbourhoods become far more effective agents of change' (Boyle and Harris, 2009 p11). It is rooted in the concept that we can improve public services, and outcomes for those accessing services, by asking and supporting people to give something back. It occurs in the middle ground where user and professional knowledge combine to design and deliver services. (For more detail on co-production see Appendix 1).

Including people with dementia as members of consortia may take various routes. A person may wish to be a member of the consortium and can be supported well in that forum to actively contribute to the work. To date, most engagement of this nature has been from people with younger onset dementia. However, there are other ways to include the person, such as seeking representation or feedback from existing working groups of people with dementia who wish to feed into service design. In some instances it may be helpful to convene a local focus group of people with dementia to provide feedback. This route can be helpful in learning about the needs of people with dementia who are further along in their journey. One further option is to observe and collect learning from experiences of working with people with dementia as they navigate a system of services. This learning can be very valuable in informing service design as it identifies need at the later stage of the dementia journey. To optimise engagement and communication for people with dementia through any of the above routes requires some consideration. Above all, time to build trusting relationships is required. Time is really important to ensure sufficient understanding of the topic being discussed and to allow for feedback to be given. It is essential that the language used is straightforward and easy to understand and that issues are presented in a simple format. Various communication tools can be used which may be helpful for people to understand and communicate in discussions. Examples include visual aids such as pictures or objects, and communication tools such as Dementia Mats can support communication. A relaxed and informal setting will contribute to a good experience for the person with dementia.

In identifying potential consortium members a wide range of people need to be considered and the strengths and the resources they bring as members must be identified and articulated. The key to identifying potential members is establishing their interest in developing a new response for people with dementia and commitment to the common agenda that is developed by the consortium. Identifying members is an evolving process and should be given due time and consideration. Not all potential members may be identified at the initial stage, and there is a need for ongoing flexibility in membership in response to the evolving goals and activities of the consortium. There are key groups who are required to make the consortium effective (e.g. people working in formal health and social care services) but these people must come willingly to the consortium (i.e. not be 'co-opted'), display a strong motivation and interest to be part of the consortium and be in a position to make decisions for their agencies to act on and inform change within their own agency. The second group are persons within the community (either individuals or from groups) who have a high interest in the area, are keen to be part of a new initiative and are a strong force for change. It is important that there is a good balance of membership overall from the seven broad groupings described in Figure 2.

A dementia consortium is a different way of working and membership is **not** about representation for the sake of it. Membership must be a two-way process, that is, a consortium member must bring something to the table that they can offer to support the common agenda (it might simply be their time) and they should also bring back to their organisation, group or community the learning and new developments so that their own organisation begins to learn and change in response to what is required. This process is very well illustrated by a Community Garda member of a consortium who brings her expertise the group but describes how she has brought back what she has learned about dementia to her colleagues to better inform their interactions with people with dementia.

There is also a commitment to mutually reinforcing activities. This describes how a member's organisation or group continues to work on its own agenda, but where that agenda intersects with dementia, that they will align their activities to achieve the common, agreed agenda of the consortium. This is where the collective power of the different members becomes much more powerful as organisations are not pulling in different directions but are working towards a common goal.

5. Establishing a consortium

There is no hard and fast set of instructions to follow in establishing a consortium. Much depends on local interests and priorities and on networks and groups that might already be established in an area. The availability of innovation funding in the case of the Genio supported consortia was also an important catalyst in consortium formation. However, based on learning from the consortia in Ireland to date, the following steps have been identified to provide some guidance to those who might be supporting a dementia consortium to form.

5.1 Some steps in establishing a dementia consortium

1. **Horizon scanning** - This process involves identifying individuals who might be interested and identifying what organisations/groups are already in existence who have a similar mission:

   - Who in a defined area is interested in developing person-centred community based supports for people with dementia?

   - Who has a formal role in this area?

   - What community and voluntary groups are interested? What groups or committees are already in existence (e.g. Age Friendly County committee)? Also look beyond those whose remit is 'older people' to groups like Macra na Feirme, Muintir na Tire, Neighbourhood Watch and so on.

   - Identify the range of people who form part of the community networks of people with dementia, including retail staff, post office workers, pharmacists, priests, bank staff, real estate agents, taxi drivers and security officers, who may potentially have a role to play as members of a consortium (Irving et al., 2014).

   - Approach people with dementia and family carers who might be interested in participating. Text box 2 describes different ways of doing this.

2. **Identify and invite individuals and organisations to participate** - At this stage it is important to have a very clear ask and to communicate the role of consortium members and the expectations of being a member. This is not a representative committee where people are just expected to turn up because a certain organisation 'should be represented'. Everyone is there to

contribute and actively participate. Individuals who do participate on behalf of an organisation need to be at a level where they can commit to their organisation aligning its activities with those of the consortium where relevant and appropriate. See Text Box 5 for some guidance.

3. **Develop a shared culture** - This is not a step as such but an ongoing process. It is important to attend to, as the tone of the group and shared understanding begins to develop at a very early stage. Often where people who are involved in and work in the same sector come together, it is assumed that there is a shared understanding of the issue, although this is not always the case. It is important to allow time for each member to articulate and explore their own understanding of dementia and what it means to support people to live well in their own communities. This allows the group to explore their own local context and work collaboratively to identify issues that are important to them (Alzheimer's Disease International, 2012). See Text Box 5 for some guidance.

4. **Agree a common purpose and goals for the consortium** - This really leads from the discussions described at step 3 where the shared understanding of dementia and what can be done locally leads to clarity of purpose and agreement on goals. It is important that the purpose and goals are formally signed up to by the members. While high level goals can be agreed early on, in reality this task is ongoing with greater refinement of goals and outcomes being developed on an ongoing basis (see Text Box 4). The measurement of outcomes should

also be agreed and supported by the consortium in a practical way. There are many frameworks and tools available to assist groups in this task (see Appendix 3).

5. **Set up structures that will support the goals the consortium is working towards** - Resist the urge to set up too many formal structures too early. Wait until there is as much clarity as possible on the common purpose and goals. The structures and mode of working of the consortium should be based on what you want to achieve. For example, you may develop sub-groups focused on specific activities that have been agreed as ways of achieving the goals of the consortium.

6. **Regular meetings and continuous communication** - It is important to maintain momentum and keep activities moving along – even though progress can at times be slow. Regular meetings between all members of the consortium allows for continuous communication, an essential element in developing trust amongst members and creating a common vocabulary (Kania and Kramer, 2011). Celebrate successes as they occur and share and communicate with all interested parties using a variety of media and methods.

7. **Review, modify, change and learn** - All successful organisations and groups regularly review what they are doing and make changes based on what they learn. This is especially true of a dementia consortium where different options may be tried on a small scale to find the best fit for a local area. There is a need for flexibility in the goals of the consortium to allow the group to capitalise on the strengths of its members, and to evolve in response

to changes in audiences, changes in the context, and changes in the social expectations of those being targeted (Alzheimer's Disease International, 2012). Ongoing review and updating of objectives and goals is valuable and external facilitation can help with this task. The consortium should also be open to updating membership as part of reviews, where people may move off the consortium as a specific action is completed and new members may be recruited based on emerging priorities.

TEXT BOX 4: Balancing the process of agreeing goals and objective with the need for flexibility

While it is important that a clear and common purpose and goals are agreed by the Consortium, these should be reviewed regularly as initiatives develop. This flexibility allows for quick adaptation and refocus based on what is being learned on the ground. However, too much flexibility can lead to a drift in focus and projects losing sight of their original aims and objectives. Consortia appear to have been able to utilise the collaborative working of the group most effectively where specific outputs were defined as a series of actions to be taken, rather than pre-determined solutions to be achieved. While specific objectives and outputs appears to have an impact on how effectively the group can work collaboratively, it is the process of continual reflection, review and feedback that has helped each consortium identify where they have been too rigid in their approach, and where modification of objectives may be required.

TEXT BOX 5: Some of the challenges in developing a consortium

The unique value of a consortium lies in the richness of the collaboration between its individual members. However, collaboration is not something that will happen automatically when a group of people are brought together. For example, if the aims and objectives of the consortium are driven by one individual or organisation, the resources of the group as a whole are lost, and the full complexity of the issue at hand may be overlooked. Capitalising on the skills and knowledge of all members without allowing any one voice to become overly influential is a continuous challenge within the consortia. Good facilitation is one essential element in meeting this challenge. Exploring, recognising and articulating the strengths and resources of each member is another strategy to ensure that there is no 'tokenistic' membership. In order to build on people's existing capabilities it is necessary to explicitly articulate that each member of the consortium has a role to play in both the design and delivery of services (Boyle et al., 2010). This may be particularly applicable for members of the public who have been invited to be part of the group as it may be assumed their role is confined to articulating a viewpoint rather than being actively involved in designing and implementing solutions to identified barriers or gaps. These are challenges faced by many Consortia. Knowing that these can occur it is useful to have actions and strategies available to deal with them proactively as they arise.

5.2 Facilitators for successful dementia consortium working

Using the experience of supporting 12 consortia to date and including learning from other sources (Nesta, 2013) we have identified several features which facilitate successful consortia working. While these should not be rigidly interpreted as essential requirements, their presence greatly facilitates dynamic, innovative and responsive dementia consortia.

1. **Funding** - The consortia listed in Table 1 above came together to respond to a call for funding to develop innovative responses to supporting people with dementia. A learning point is that access to funding is a key driver in encouraging stakeholders to come together, who don't usually work closely together, to deliver a shared goal. This doesn't necessarily have to be a large amount of funding but it is helpful in encouraging action and creativity.

2. **Support for the consortium** - There are several functions that need to be carried out in order for the consortium to work most effectively. Administrative support is required to coordinate the work of the consortium itself (meetings etc.) and to coordinate the various activities undertaken by, or on behalf of the consortium, facilitating communication and dealing with the many logistic and administrative details necessary for the consortium to run smoothly. Depending on the extent of integration with existing formal service structures and personnel, this role may be significant in terms of the time and resources required, or it may not if much of the activity is undertaken by others. Different models have been in place in the different sites to date. In

many consortia, the project manager/ coordinator (a time-limited post to support the innovation) has effectively become a 'single point of contact' for dementia locally. The need for an identifiable centre, service or person to be the 'dementia resource' locally is an important function and one that is recognised in other jurisdictions such as France.

The importance of having adequate support to co-ordinate a collaborative group such as a dementia consortium is highlighted by the literature on collective impact where a separate entity, called a backbone organisation, takes on many of the supporting functions (Kania and Kramer, 2011). Other functions that may be required are facilitation at different times (for example in developing a shared vision and work plan), establishing a shared measurement system and collecting one agreed data set to evaluate the work of the consortium and whether outcomes are being achieved. All of these functions do not necessarily have to be vested in one person. The consortium should consider how best these roles should be performed given existing staff in participating organisations, the roles and tasks and resources that are available.

3. **Roles and responsibilities** - The key role is that of consortium lead. This is usually the person who has taken the initiative to start the consortium and is often a person with sufficient knowledge and standing to pull together a wide group of stakeholders. An effective consortium lead is someone who is focused on problem solving, but willing to let the group

come to a solution themselves rather than promoting their own particular point of view; someone who has a clear vision for the consortium, but can adapt to new perspectives and resources as they arise. Finally, a Consortium lead needs to have good knowledge of the current local community and community groups, and be aware of developments ongoing outside of the consortium. A consortium will function most effectively with a leader who has excellent facilitation skills and the knowledge, skills and personality to establish and build essential relationships. Much of the work the leader undertakes is intangible, which can lead to it being assumed or over-looked. Building effective relationships can take a number of months or even years (Kania and Kramer, 2013) and is time-consuming. Where this role is beyond the scope of any one individual, it may be taken on by the management committee. Whether fulfilled by the project lead or the management committee, the importance of this role must be explicitly acknowledged and dedicated time given to it. A contingency plan to support a changeover of project lead may also be required.

4. **Decision-making processes** - Agreed processes are required as to how all decisions will be made in the Consortium. There doesn't have to be one single decision making process. For example, the consortium may decide that consensus is important for some areas such as fundamental values and high level goals but consensus decisions are very unwieldy for day-to-day operations. Several dementia consortia developed a Memorandum of Agreement or similar document to clarify and record the processes for decision making as well as the high level goals and objectives.

5. **Structures** - The strength of a consortium comes from the interaction and collaboration between its wide group of members, and a number of structures and resources are necessary in order to ensure the smooth and effective running of the group. Most have used additional structures to optimise the working of such a large group. For example, smaller management or steering committees have been established which have responsibility for implementing the decisions of the larger group, and make decisions on a day to day basis on behalf of the wider group. Other consortia have established a number of working groups with responsibility for addressing key areas, such as training, assistive technology or individualised supports. Some have created time limited sub groups, created to address specific actions, once complete subsumed back into the consortium membership.

There are a number of advantages and disadvantages to establishing smaller groups and committees within the consortia. While smaller groups can promote a sense of individual responsibility for achieving the aims of the consortia, and ensure people are working within their area of expertise, they can hinder the effective collaboration of the consortium as a whole, impeding the process of forging new relationships to develop innovative solutions to identified need. While the development of sub-groups has been successful in some consortia, others

have chosen to disband their subgroups as they felt they had hindered the working of the consortia as a whole. This highlights the fact that consortia cannot work successfully in a 'one size fits all' model, as the manner in which structures emerge and are implemented are more important than the actual structures themselves.

6. **Governance** - A range of options have been adopted for corporate governance, with several consortia being led by the HSE although other arrangements were put in place for some consortia, with one company being established, one committee for an unincorporated association and two hosting arrangements with other agencies such as the Alzheimer's Society of Ireland and the Southside Partnership. Care needs to be taken so that parallel structures are not developed unnecessarily. The creation of other entities (such as a company) can be quite onerous and it is wise to explore other options to ensure robust governance. Clinical governance rests with individual organisations engaged in service provision to people with dementia.

7. **Action plan** - The consortium needs to collaboratively build an action plan with milestones and deadlines. This will be the concrete output from the process of agreeing a common purpose, goals and outcomes as described above in the steps to building a consortium.

5.3 Sustainability

There are two considerations under the heading of sustainability; the sustainability of the consortium itself and the sustainability of specific initiatives

developed and delivered by the consortium or its members. In terms of the consortium itself, it may or may not be sustained as an entity depending on the role it has. It may be a time-limited initiative, to develop and encourage innovative service delivery either through modifying existing services and developing new ones. Evidence from the consortia members is that this is an effective way of having real integration of purpose across a range of stakeholders. This may mean that some consortia continue as a local focus for dementia services.

In terms of the initiatives, activities and services developed and delivered by the consortia, a number of approaches to sustainability are relevant, depending on the initiative itself and other factors. Five approaches to sustainability have been identified and are described below. Beyond these specific approaches, the work carried out by each consortium to raise awareness of dementia amongst the public and give people new understanding of dementia is expected to have a long term impact by changing the culture within services and community and reducing stigma.

1. **Life limited initiative** - Some activities are by their nature, one-off and do not need to continue indefinitely, for example, the development of printed resources such as information booklets. Once these resources are produced there is generally not a need for an ongoing stream of activity and funding.

2. **Embedding a service/initiative within local community structures or activities of local voluntary groups** - Connecting and building relationships with local community initiatives and structures has been

evident in all consortia. By linking to previously established community groups, people with dementia have become active participants in on-going weekly activities. For example, local exercise groups have been developed that are open to all; the arts officer and sports officer in two county councils have developed activities for all that are inclusive of people with dementia; a carer support group initially developed by a consortium was then supported on an on-going basis by an existing carers association.

3. **Provide support for peer support networks** - These networks have been developed in a purposive way by several consortia, for example carers groups, but with a low level of support they can be encouraged to continue as peer support networks run by the individuals themselves. For example, a carer support group has formed as a result of family members attending ASI family carer training. While this is in the early stages, the group wish to continue and organise themselves with a low level of support from the consortium.

4. **Redirecting existing HSE funding to support alternative service delivery models** - This involves demonstrating effectiveness and building relationships with relevant HSE personnel so that existing resources can be redirected. One example is the use of home help/ home care package funding to provide the dementia-specific and individualised home support options for people with dementia and their family carers that have been developed in various consortia.

5. **Establishing new relationships between healthcare professionals and embedding new practices within current HSE systems** - All consortia recognise the importance and value of building new relationships. Often building new working relationships between healthcare professionals simply requires administrative support. The work of establishing a suitable time and location for meetings, setting an agenda and facilitating meetings has led to new regular multidisciplinary meetings taking place. Once established, positive outcomes from the meetings will help service providers see the benefit of maintaining these new connections.

6. Conclusion

This paper set out to introduce, explain and describe the concept of dementia consortia by bringing together the experience and learning of dementia consortia established in Ireland to date. The aim was to illustrate how these groups can be established and to identify useful approaches and strategies so that a collaborative group can be as successful as possible. Dementia poses a multi-faceted challenge and the case is made that an 'all of community' response represents the most effective and sustainable way forward.

Bringing together the appropriate stakeholders to form a Dementia Consortium is only the first step in the journey towards meeting specific goals through successful collaboration. Each consortium had to dedicate time to establishing and building relationships, both within and outside of their groups. Dedicated time for the management of the projects had to be negotiated, and the groups had to ensure their aims and objectives were defined enough to keep

them focused, yet flexible enough to allow them to utilise the skills and strengths of their group and their communities as they emerged. Though they face many of the same challenges, the consortia have evolved differently in their local areas, capitalising on their strengths and constantly reviewing their activities to ensure that they are working as effectively as possible. This has been a rich learning experience, with consortia willing to take risks to find what structures and processes work best, learning from both their successes and failures.

Although the work was challenging, what has been achieved has been significant[4]:

- Over 250 people from the health services and wider community have been actively involved in 12 dementia consortia

- 1,028 people with dementia and 1,406 carers have directly benefited from a range of individualised supports

- At least 181 people with dementia were supported to delay their entry into long-term care, with a further 11 people discharged from nursing home or acute care to be supported at home

- Close to 5,000 people have received information about dementia and over 2,300 staff have received training in dementia.

Evaluations of the programme have concluded that *"It is a model which in our view offers people with dementia purpose, allows them participate, encourages growth and freedom from negativity, stigma, embarrassment and nihilism. In summary it is a model which we would argue empowers the individual with dementia and reflects*

a community and societal response to the challenge of dementia" (Cahill et al., 2014) and that *"Meaningful advancements in the delivery of person-centred care have occurred, with a broader range of flexible, responsive services now available in all four sites"* (O'Shea and Monaghan, 2015).

The dementia consortia described here have demonstrated the significant and lasting changes that can be made both to existing services and in terms of new initiatives which can be developed locally. Their work has helped make the vision of 'living well with dementia' a reality for over 2,000 people with dementia and family carers. It is hoped their work and this guide will encourage and support others to work collaboratively to improve the lives of people with dementia.

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4 All figures are up to end 2015

Appendices

Appendix 1 – Co–production

Co-production is an approach which aims to transform public service provision through a reshaping of the relationship between 'service user' and 'service provider'. Co-production has been defined as:

'...delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours. Where activities are co-produced in this way, both services and neighbourhoods become far more effective agents of change' (Boyle and Harris, 2009 p11).

At its heart co-production recognises the untapped skills and resources available in the population engaging with public services, and works to utilise those skills in such a way as to benefit services and empower the people accessing services. It is rooted in the concept that we can improve public services, and outcomes for those accessing services, by asking and supporting people to give something back. It occurs in the middle ground where user and professional knowledge combine to design and deliver services.

In every co-produced initiative the details of service delivery are necessarily different, as each service is developed on an ongoing basis, continually changing and reacting to utilise the unique strengths and meet the unique needs of the people involved. However, a number of shared key characteristics of these projects have been identified and researchers have found that co-production is strongest when it embodies all six of the themes below:

- Recognising people as assets.
- Building on people's existing capabilities.
- Promoting mutuality and reciprocity.
- Developing peer support networks.
- Breaking down barriers between professionals and recipients.
- Facilitating rather than delivering.

The shared value base of co-production and individualised support is clear through these themes which are characteristic features of good quality individualised supports.

Collective impact

Collective impact is a deceptively simple concept. It is based on the principle that large-scale social change requires broad cross-sector collaboration, as no single organisation has the skills, knowledge or scope necessary to implement effective change. This is certainly the case in dementia, where providing effective, responsive and personalised supports requires multiple agencies and organisations to work well together.

The concept of cross-sector collaboration is not new and terms such as inter-agency practice, interdisciplinary working and multidisciplinary teams are common in both policy documents and the research literature. However, attempts at engaging in meaningful cross-sector collaboration often meet many challenges, and many projects do not fulfil the potential envisaged for them. The collective impact model arose from closely studying collaborative groups that were successful at effecting large scale societal change, and identifying the common factors between them. Five conditions have been identified that are necessary for effective collective impact; agreeing a common agenda; having a shared measurement system; engaging in mutually reinforcing activities; having continuous communication and being supported by a

backbone organisation (Kania & Kramer, 2011).

Collective impact offers a methodology to bring groups of stakeholders together in effective ways, co-production offers a framework for involving people using services in effective ways and both are directed towards the delivery of individualised supports for people with dementia.

Appendix 2

Table N: Examples of members of existing consortia by key groups	
Group	**Member in existing consortia**
People using services	Person with dementia Family carer Former carers Other informal carers (e.g. friends, neighbours etc.)
Primary health care	GP PHN Occupational Therapist Social Worker
Acute health care	Director of Clinical Services Nursing Home Representative Palliative Care services Director of Nursing Community Liaison Team members Manager Older Person Services Members of Medicine for the Elderly clinical team Discharge Liaison Patient Liaison Social Workers Consultant Geriatrician Consultant Psychiatrist of Old Age Consultant Neurologist Lead Physician Acute Medicine Clinical leads Emergency Department Personnel
Community health and social care	Director of Public Health Nursing Director of Nursing Community Mental Health Psychiatry of Old Age team Manager of Older Persons Services Home Care/Home Help Manager
Non-health agencies	County Council Family Resource Centres Local Area Partnerships An Garda Siochana Universities and Institutes of Technology
Community and voluntary sector groups and sporting and cultural organisations	ASI Carers Association Western Alzheimer's Association Irish Hospice Foundation Older Persons groups e.g. Active Retirement Groups St Vincent de Paul Macra na Feirme Chamber of Commerce GAA Golf club Etc.
Others	Local business – accountants, banking and solicitors involved Credit Union Local media Enterprise Boards Local partnerships/Leader groups Interested individuals

Appendix 3 – Tools and frameworks for developing agreed goals and objectives

A number of different frameworks have been developed to support and guide groups through the process of understanding a complex issue and identifying aims and objectives. From the literature on collective impact, Hanleybrown et al. (2012) suggest that the first step in this process is to define the boundaries, agreeing what areas are within the remit of the work of the consortia, and which are not. The next step is the development of a strategic framework for action. This allows the group to focus on the tasks they wish to achieve without becoming bound by a set of pre-determined solutions. A strategic action framework describes the problem or issue being considered, outlines a clear goal for the desired change, encompasses a number of key strategies to drive the desired change and identifies a set of principles that guide the groups' behaviour. The strategic action framework is not static, but continually adapts with learning gained from trialling key strategies.

Jordan et al. (2013) describe another method of supporting groups to identify their ultimate objectives and actions; The Integral Process for Complex Issues (TIP). This method allows groups to explore the complexity of an issue and enables them to identify the most important elements that need to be worked with. During this process, individual members understanding and examples of the difficulty are organised into categories. The group then looks at causal relations between each of the categories to identify key areas of concern and discuss potential actions on each issue.

There is helpful information and resources at following links:

- collectiveimpactforum.org
- ssir.org/articles/entry/collective_impact
- www.global-arina.org/TIP/TIP.html

References

ALZHEIMER'S DISEASE INTERNATIONAL 2012. *World Alzheimer Report 2012: Overcoming the stigma of dementia.* London, England: Alzheimer's Disease International.

ALZHEIMER EUROPE. 2009. *General Recommendations: Social Support Systems* [Online]. Alzheimer Europe. Available: http://www.alzheimer-europe.org/Research/European-Collaboration-on-Dementia/Social-Support-Systems/General-recommendations?#fragment1 2015].

APS GROUP SCOTLAND 2011. *Promoting Excellence: A Framework for all Health and Social Services Staff Working with People with Dementia, their Families and Carers.* Edinburgh, Scotland: Scottish Government.

BOYLE, D. & HARRIS, M. 2009. *The Challenge of Co-production: How equal partnerships between professionals and the pubic are crucial to improving public services: A discussion paper.* London, England: NESTA.

BOYLE, D., SLAY, J. & STEPHENS, L. 2010. *Public Services Inside Out: Putting co-production into practice.* London, England: NESTA.

BRENNAN, S. 2015. *FreeDem Films Dissemination Report.* Dublin: NEIL Programme

CAHILL, S., O'SHEA, E. & PIERCE, M. 2012. *Creating excellence in dementia care: A research review for Ireland's National Dementia Strategy.* Ireland: DSIDC's Living with Dementia Research Programme, School of Social Work and Social Policy, Trinity College; Irish Centre for Social Gerontology, National University of Ireland.

CAHILL, S., PIERCE, M. & BOBERSKY, A. 2014. *An evaluation report on flexible respite options of the Living Well with Dementia project in Stillorgan and Blackrock.* Dublin, Ireland: Trinity College Dublin.

CENTRAL STATISTICS OFFICE 2012. *Profile 2: Older and Younger.* Dublin, Ireland: Central Statistics Office.

HANLEYBROWN, F., KANIA, J. & KRAMER, M. 2012. *Channeling change: Making collective impact work.* Stanford Social Innovation Review [Online]. Available from: http://www.ssireview.org/blog/entry/channeling_change_making_collective_impact_work 2015.

IRVING, K., PIASEK, P., KILCULLEN, S., COEN, A.-M. & MANNING, M. 2014. *National Educational Needs Analysis Report: Building Dementia Skills Capacity.* Dublin, Ireland: Elevator Programme.

JORDAN, T., ANDERSSON, P. & RINGNÉR, H. 2013. *The Spectrum of Responses to Complex Societal Issues: Reflections on Seven Years of Empirical Inquiry.* Integral Review, 9, 34-70.

KANIA, J. & KRAMER, M. 2011. *Collective Impact. Stanford Social Innovation Review* [Online]. Available from: http://www.ssireview.org/articles/entry/collective_impact 2015.

KANIA, J. & KRAMER, M. 2013. *Embracing Emergence: How Collective Impact Addresses Complexity.* Stanford Social Innovation Review [Online]. Available from: http://www.ssireview.org/blog/entry/embracing_emergence_how_collective_impact_addresses_complexity 2015.

KITWOOD, T. 1997. *Dementia Reconsidered: The Person Comes First.* Buckingham, England, Open University Press.

MAISONS POUR L'AUTONOMIE ET L'INTÉGRATION DES MALADES ALZHEIMER. 2008. *Alzheimer Plan 2008-2012: 44 measures* [Online]. France. Available from: http://www.plan-alzheimer.gouv.fr/-44-measures-.html 2015.

MCKEOWN, K., PRATSCHKE, J. & HAASE, T. 2014. *Individual Need Collective Responses: The potential of social enterprise to provide supports and services for older people.* [Online] Available from: http://kieranmckeown.ie/wp-content/uploads/2014/01/69.-Individual-Needs-Collective-Responses.-National-Business-Case-for-Social-Enterprise-Older-People-231213-L.pdf.

NESTA 2013. *Networks that work: Partnerships for integrated care and services.* London: Nesta Innovation Unit.

O'SHEA, E. & MONAGHAN, C. 2015. *Genio Dementia Programme Evaluation of Year 2.* Ireland: Genio.

O'SHEA, E. & MURPHY, E. 2014. *Genio Dementia Programme: Evaluation of Year 1.* Galway, Ireland: Irish Centre for Social Gerontology.

WORLD HEALTH ORGANISATION. 2012. *Dementia: Factsheet No. 362* [Online]. Available from: http://www.who.int/mediacentre/factsheets/fs362/en/ 2015.

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