

**Genio Dementia Project 2012
Guidelines and Criteria**



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Background

Genio has received funding from the Atlantic Philanthropies and the HSE to develop and test new service models which will improve the range and quality of community-based supports for people with dementia; to influence public policy and investment in this area; and to build the leadership in the field that is necessary in order to capitalise on the potential of the proposed national dementia strategy.

The project will focus on six main areas of activity:

Demonstration areas

Developing in approximately four geographic demonstration areas nationally, the provision and integration of person-centred, community-based supports to people with dementia and their families/carers that enable them to live longer within their local community – thus diverting them from institutional care;

Capability building

Supporting services and their personnel in demonstration areas to work with a person-centred focus and in a more collaborative and integrated way with enhanced awareness and skills; identifying barriers and solutions around integrative working;

Community Supports

Using a community development approach to identify and harness existing community resources (including all resources, not just those with a focus on older people), to develop community-based responses which use local strengths and resources to meet local and individual need. This will build a range of community supports across each area;

Developing Best Practice

Applying and testing principles and best practice models from other sectors including disability, mental health and children's services, for example, person-focus, early intervention, prevention, community integration, consultation and participation;



Learning Network

The development of a Learning Network across the four demonstration areas and beyond in order to share learning in a systematic way and to create a learning support for further areas;

Collecting evidence

Collecting quantitative and qualitative data from the demonstration areas to evaluate the community support models; to feed into learning networks which will be developed to extend models of community support; and to inform the development of the National Dementia Strategy.

This approach is aligned with Government policy, which emphasises the provision of services which support older people to remain at home, living full lives for as long as possible and supporting families and local communities in this aim (see Appendix 1 for a brief overview of the policy context).

Demonstration areas and project scope

Four geographical areas will be identified nationally. The Genio Dementia Project is seeking to have a mix of urban, rural and urban/rural locations. Ideally, the location should be of manageable size both in terms of geography and population (i.e. an urban location may have a smaller geographic area but a larger population). A population of around 2,000 – 3,000 older people is expected (i.e. a total population of approximately 20,000 – 30,000) but this may vary depending on the area.

As the aim is to address the need for community-based supports for those along the spectrum of dementia in a flexible, individualised way, there will be no artificial barriers to participation (such as age). Individuals with early-onset dementia will be included. No exclusion criteria are envisaged, although activities will have to be prioritised according to the resources available. Demonstration areas are sought that will have the potential to have broad reach and systemic impact.



Community Supports Model

The model of community support which will be developed will enable people with dementia to remain in their own home or similar setting through the provision of flexible, responsive supports to the person and the family, which enable the person to remain active, safe and connected to their local community. The model will also support the discharge of individuals who are inappropriately placed in nursing homes and other settings, back to their local community to receive community-based supports.

This model of support involves making use of the wide variety of generic community services as well as services that are provided specifically for older people. Generic community services include services and facilities such as Family Resource Centres, leisure facilities, community centres and sporting, leisure and social activities provided by a range of community groups. The inclusion of such services facilitates the development of inter-generational activities and mutual supports. Services for older people include day centres, home help, home care packages, active retirement groups, meals-on-wheels and so on. Services for people with dementia include day hospitals and day centres specifically for people with dementia. It is expected that this range of providers from these three sectors will be engaged in developing the Community Supports Model in the designated area.

The model will have high levels of integration, collaboration and skill sharing across all these services, organisations and groups. For example, the provision of dementia-awareness training and support to staff and providers in generic community settings, can facilitate the wider availability of such settings to people with dementia. This type of working will encourage the development of creative, cost-effective solutions to challenges and barriers that may be experienced.

There is considerable evidence to show that supporting carers in their caring role is a key intervention in ensuring older people remain at home. The model will include a wide range of supports for carers which are flexible, responsive and reflect a range of needs (for example, from support groups for carers through to intensive respite). The Community Supports Model will include a number of non-institutional respite options such as host families, and other family- and community-based respite



arrangements. Such options are currently being developed in the intellectual disability sector in Ireland.

It is also important to note elements/services that are not expected to be part of the model supported in this project. This does not infer that these services do not have an important role to play in a spectrum of services for people with dementia; rather that the model to be supported through this grant has a different focus. Thus, supports or services provided in settings such as nursing homes, hospitals or specialist units would largely be outside the scope of this grant. Similarly, specialist services would not be expected to be funded as part of the Community Supports Model proposed for this project. Large capital costs (e.g. for buildings) will be outside the scope of the grants, although capital funding for assistive technology will be considered.

Learning Network

One of the essential components of the Project will be the development of a Learning Network. Genio will oversee and support the development of this network which will offer opportunities to:

- **learn** about how to provide community-based supports for people with dementia and their carers in a cost-effective, integrated way;
- **share** learning, experience and problem solving;
- access peer **support** and **network** with others.

The network will be developed across the four demonstration areas primarily, but will extend to include those working in other areas. It is envisaged that the network will:

- provide training and support that is demonstration area specific and addresses issues particular to each area;
- provide across-demonstration area training and support that addresses common issues across the four demonstration areas;
- provide more general training and capacity building to demonstration area members and also to those nationally who are interested in developing similar services.



This training programme will be designed to assist the transfer of learning across projects, across the wider sector and also to policy/Government/national HSE level. Tailored activities will be undertaken to ensure multiple methods and opportunities for this to occur.

Collecting evidence

Genio will also design and manage a comprehensive research/evaluation study which will collect quantitative and qualitative data from the demonstration areas to evaluate the Community Support Models; capture the learning; and feed into Genio Learning Networks which will be developed to extend models of community support.

The process

When the demonstration areas are selected, one of the first steps in developing the project in each area will be the preparation of a detailed and comprehensive description of the area and population involved. This will include an age breakdown and some estimates of local need; and a description of available services, organisations and supports for older people in the area (some references and sources which may be helpful in this regard are provided in Appendix 2). An initial overview of this information is required for the Expression of Interest (see Section 9) but the first few months of the project will provide an opportunity to conduct a thorough audit of community resources and to bring together all relevant and interested organisations.

This proposed approach is similar to the community audit and development model used by Headstrong, which has proven to be effective in both gathering comprehensive information on the range of services and supports available to young people in a given area and in mobilising interest and support from the community and a wide range of organisations. Headstrong¹ have generated considerable learning on this approach which could be used to develop a similar approach for older people.

¹ www.headstrong.ie



It is envisaged that a community coordinator(s) will be employed to manage and oversee the development of the community support model in each area. The requirements and job description for this role will be agreed with Genio and each participating area. These individuals may be employed locally or centrally by Genio.

Each consortium and community coordinator will develop local, community-based responses to the identified need which are individualised and in keeping with the aims of the project. Each consortium will be supported through the grant funding, to provide the following core supports which will be common across all four demonstration areas:

1. **Respite:** Supporting carers in their caring role is a key intervention in ensuring older people remain at home. Access to a number of respite hours for each demonstration area will be available as part of this support. It is also expected that each demonstration area will develop a range of non-institutional respite options such as host families, and other family- and community-based respite arrangements.
2. **Support for primary care providers:** in the early identification of dementia.
3. **Assistive technology:** a wide variety of technological solutions to monitor and support older people are more widely available and there is evidence of their effectiveness and appropriateness for people with dementia.
4. **Carer support interventions:** provided at an early stage, directed at providing information and preparation for the progression of dementia, and the building of skills and provision of support along that trajectory.

Available grants

It is envisaged that the fund available for each demonstration area will be approximately €600,000 - €750,000 over the period of the project (3 to 3.5 years).



Grant application process and timelines

The process outlined here has been designed to allow for as much engagement as possible with potential agencies that may be interested and also to allow time to develop the most effective and localised responses while incorporating decision criteria and transparency into the selection process.

| Phase | Activity | Timeline* |
|----------------|--|--------------------------------|
| Phase 1 | Consulting with relevant agencies such as the HSE Older Persons Services, nationally and locally, Department of Health, Alzheimer's Society etc. | Sept-Nov 2011 |
| Phase 2 | Consortia invited to make Expression of Interest to Genio | 16 th Dec 2011 |
| Phase 3 | Expressions of Interest process closes | 20 th Jan 2012 |
| | Expressions of Interest evaluated and demonstration areas shortlisted | Week 23 rd Jan 2012 |
| | Round table interviews with shortlisted consortia | Week 30 th Jan 2012 |
| | Recommendations to Genio Monitoring Group and Trustees | Early Feb 2012 |
| Phase 4 | Supported planning phase (i.e. successful consortia develop detailed plan with the support of Genio and others) | Feb – May 2012 |
| Phase 5 | Delivery of Community Supports Model commences | Jun 2012 to project end |

*some dates may be subject to change



Expressions of Interest

Expressions of Interest (Eols) will be invited from groups or consortia of organisations, agencies and individuals representing stakeholders. Members of each consortium should reflect those with the greatest local knowledge and expertise in delivering the type of Community Support Model described above.

In order to ensure a true community-based model of supports is developed, it is essential that members of consortia extend beyond those agencies with a primary focus on dementia. Providers of what might be termed 'generic' services for older people should also be involved as this group represents a significant resource within the community. In addition, other community groups and agencies with no specific remit for older people should also be involved to extend the capacity for support into the entire community.

Essential members of consortium would include:

- Carers and individuals with dementia/representative older people
Community groups with a focus on older people
- Organisations/community groups with a focus on carers and families
- Voluntary/not-for-profit organisations with a focus on dementia
- GP(s) and other primary health care providers such as public health nurses, home helps etc.
- Providers of 'mainstream' services for older people, for example, HSE day centres
- Other mainstream voluntary and community groups and initiatives

Desirable members of the consortium include:

- Psychiatrists of Old Age and other mental health professionals;
- Geriatricians and others from the acute hospital sector involved in the medical care of older people

Each consortium should have a nominated member who is responsible for all communication with Genio regarding the Expression of Interest process. This nominated member will be given a mandate from the consortium to represent all members. Consortia should have clear processes for decision-making, consultation among members and communication.



Content of the Expression of Interest

Details of the project

This section requires contact details along with some basic details about the consortium and proposed project.

Description of the project

Description of the demonstration area for the project:

This will have three parts:

1. A narrative description of the geographic demonstration area, along with the list of District Electoral Divisions (DEDs) covered and the total population and the population over 65 by 5 or 10 year age groups.
2. An estimate of the need within the population based on local knowledge and established estimates of the prevalence of dementia, ideally with indicative numbers along the spectrum of dementia (e.g. estimates for undiagnosed dementia, severe dementia and early onset if available).
3. A brief outline of the resources currently available and agencies/organisations involved with older people in general and older people with dementia in the demonstration area.

What is proposed:

- the aims of the project over the 3-4 year period of the grant
- the key activities to be undertaken
- a description of the way in which people with dementia will be consulted and involved
- ways in which individuals and carers will be 'recruited' into or included in the project
- a detailed description of the range of community-based supports which will be developed
- a description of the ways in which natural supports will be included
- a consideration of how the issue of stigma will be dealt with
- details of the ways in which the model will support the discharge of individuals from nursing homes, acute hospital and other settings
- details of how the various elements of the project will be coordinated and managed
- a description of expected outcomes for the range of stakeholders involved



- a description of the phasing and rolling out of the various activities over the life of the grant and associated targets and performance indicators
- a description of the 'vision' - what dementia services will look like at the end of the project period

Budget & sustainability

Indicative costings:

Details of costs over the life of the project, based on the proposed activities should be provided. A detailed budget must be submitted which outlines the funding required from the grant and the contributions from consortium members, which may include money, staff or other resources.

Note: The proposed model must represent value for money and represent a cost-effective alternative or addition to supports and services already provided. Cost-effectiveness will be a key criterion in assessing Expressions of Interest for selection.

Sustainability:

Details of how the activities undertaken in the project will be mainstreamed into the overall offering of service provision; and how current resources will be reconfigured to support this should be provided here. The project must be sustainable at the end of the funded period (3-4 years).

Note: Sustainability is a key criterion in the assessment of the Expressions of Interest and the community-based support model proposed for each area must be sustainable in the long-term. To achieve this, reconfiguration of existing resources for older people may be required, along with greater use of mainstream community resources and natural supports.

Governance

How the consortium plans to work together:

The management and governance processes for the consortium should be described in detail; how decisions will be made; how responsibilities will be assigned and managed etc., and details of the nominated member for communication will be required

Consortium

Details of all members of the consortium:

This will include standard contact details and a brief description of the organisation/individual and what they have to offer



Capacity:

A description of the range of competencies and experience which will be required to successfully implement the project must be provided across the members of the consortium, along with an indication of the level of commitment of each consortium member.

Expression of Interest process

Expressions of Interest applications must be completed via the Genio on-line application system www.genio.ie/dementia-application. Application must be submitted by 5.00pm on Friday 20th January 2012. Expressions of Interest received after the deadline will not be considered.

Evaluation process for Expressions of Interest

Initial screening of all Expressions of Interest (EoI) submitted will be undertaken by Genio. Only those EoIs which most closely fit the criteria will be prioritised for further consideration. Evaluation of EoIs may include interviews with applicants and site visits. Shortlisted EoIs will be reviewed by a Monitoring Group which is comprised of members from the Office for Older Persons, the Office of Disability and Mental Health, Atlantic Philanthropies, senior HSE managers in Older People, Disability and Mental Health and Genio. Final decisions in relation to grant approval will be made by Trustees of the Genio Trust.

Criteria for evaluation of Expressions of Interest

All Expressions of Interest will be evaluated and scored against the following criteria:

1. Appropriateness of area selected
2. Content of project description
3. Number of Individuals (people with dementia and carers) to be reached
4. Appropriateness of budget headings and costs
5. Value for Money
6. Sustainability
7. Governance
8. Consortium Capacity
9. Consortium composition



Appendix 1

Policy context

The Years Ahead.. A Policy for the Elderly was produced in 1988 by the Working Party on Services for the Elderly and sets out government policy for the development of services for older people in this country. The objectives set out in *The Years Ahead* were as follows (p.38)²:

- to maintain elderly people in dignity and independence in their own home;
- to restore those elderly people who become ill or dependent to independence at home;
- to encourage and support the care of the elderly in their own community by family, neighbours and voluntary bodies in every way possible;
- to provide a high quality of hospital and residential care for elderly people when they can no longer be maintained in dignity and independence at home.

The policy described the services that would be provided to meet these objectives which should be “*comprehensive, equitable, accessible, responsive, flexible, co-ordinated, planned and cost-effective*” (p.39) and over 120 recommendations were made.

The availability of adequate community-based services has been a consistent gap in service provision for older people which has served to undermine the stated policy objective. This has been described by O’Shea; “*unfortunately, the ability of dependent older people to remain in their own homes has been compromised by the failure of successive governments to allocate sufficient resources to community care*”³.

² Working Party on Services for the Elderly (1988) *The Years Ahead...A Policy for the Elderly*. Dublin: Stationery Office

³ O’Shea, E. (2007) *Implementing Policy for Dementia Care in Ireland: The Time for Action is Now*. Dublin: Alzheimer Society of Ireland
<http://www.alzheimer.ie/eng/Resources/Research/Implementing-Policy-for-Dementia-Care-in-Ireland-The-Time-for-Action-is-Now>



The Action Plan for dementia was commissioned by the National Council on Ageing and Older People in 1999⁴. The plan was developed in light of the lack of implementation of the recommendations of *The Years Ahead*⁵. The Action Plan was designed to “*strengthen the capacity of the health and social care system to meet the needs of people with dementia and their families and carers*”, and was based on six core principles:

- Person-centred models of care which respect the preferences and rights of the person with dementia;
- Comprehensive provision;
- Bias towards home care solutions;
- Care requirements to determine funding;
- Needs-based provision;
- Evidence-based practice linked to national quality and outcome targets.

The Action Plan made 33 recommendations at a cost of approximately £45 million in 1999 (approximately €73 million in 2007 prices). It was envisaged that this investment would be made over a three year period to address the gap between need and the existing level of provision for people with dementia.

The Government’s 2001 Health Strategy Quality and Fairness accepted the general thrust of the Action Plan and committed to its implementation over a seven year period. Although there have been some improvements in enhanced training and education, increased at-home respite care, additional specialist dementia units and more consultants in old age psychiatry, overall progress has been slow in implementing the Action Plan⁶.

⁴ O’Shea, E. and O’Reilly, S. (1999) An Action Plan for Dementia. Dublin: National Council on Ageing and Older People.
http://www.ncaop.ie/publications/research/reports/54_Action%20Plan%20for%20Dement.pdf

⁵ Ruddle, H., Donoghue, F. and Mulvihill, R. (1997) *The Years Ahead Report: A Review of the Implementation of its Recommendations*. Dublin: National Council on Ageing and Older People. Report No. 48.
http://www.ncaop.ie/publications/research/reports/48_Years_Ahead_Review.pdf

⁶ O’Shea, E. and O’Reilly, S. (1999) An Action Plan for Dementia. Dublin: National Council on Ageing and Older People.



Ireland has, as yet, no national dementia strategy, although a strategy is in preparation. The findings from this project will feed into the development of this strategy on an ongoing basis.



Appendix 2

Resources

Census 2006 Vol 2: Ages and Marital Status

http://www.cso.ie/census/census2006results/volume_2/census_2006_volume_2.html

O'Shea, E. and O'Reilly, S. (1999) An Action Plan for Dementia. Dublin: National Council on Ageing and Older People.

http://www.ncaop.ie/publications/research/reports/54_Action%20Plan%20for%20Dement.pdf

O'Shea, E. (2007) *Implementing Policy for Dementia Care in Ireland: The Time for Action is Now*. Dublin: Alzheimer Society of Ireland

<http://www.alzheimer.ie/eng/Resources/Research/Implementing-Policy-for-Dementia-Care-in-Ireland-The-Time-for-Action-is-Now>

This report contains estimates of dementia prevalence by County in Ireland based on the ERODEM estimates.

Directory of Service for Older People in Galway City.

<http://www.icsg.ie/Library/documents/Directory%20of%20Services%20for%20Older%20People.pdf>

This report is an example of a comprehensive description of the services available for older people in a locality.

Haase, T. (2005) *Early-Onset Dementia: The needs of younger people with dementia in Ireland*. Dublin: Alzheimer Society of Ireland.

<http://www.alzheimer.ie/eng/Resources/Research/Early-Onset-Dementia-The-Needs-of-Younger-People-with-Dementia-in-Ireland>