



FRIDAY 12TH
DECEMBER 2014
GENIO
ANNUAL
DEMENTIA
CONFERENCE

Supported by the Atlantic Philanthropies & the Health Service Executive under the Genio Dementia Programme.



Listening:
The Lived
Experience

Understanding:
Exploring Value
and Values

Enhancing:
Collective
Approaches to
Change

This event brings together
healthcare professionals,
family members,
academics, carers and
volunteers working with
and supporting people
with dementia.

www.genio.ie

09.00 – 15.30

O'Callaghan
Alexander Hotel
41–47 Fenian Street
Dublin 2.

Schedule*

Friday 12th December

09:00 – 15.30

09.00 – 09.30		Registration & Tea/Coffee
Morning Session		Listening: The Lived Experience
09.30	Welcome	Mr. Hugh Kane, Chief Operations Officer, Genio.
09.40	Evaluation of flexible respite options	Dr. Suzanne Cahill, Research Associate Professor of Social Work and Social Policy, Trinity College Dublin (TCD) and Director, Dementia Services Information and Development Centre (DSIDC), St. James's Hospital Dublin.
10.25	“We’re in this together” The reciprocal influence between dementia and family relationships	Ms. Jenny La Fontaine, Young Onset Dementia Development Officer, Early Intervention Dementia Service, Worcestershire Health and Care National Health Service (NHS) Trust.
11.10	Family perspectives	Video presentation
11.15 – 11.35		Tea/Coffee Break
Mid-Morning Session		Understanding: Exploring Value and Values
11.35	Understanding people with Alzheimer’s disease A bio psycho-social approach	Prof. Steven R. Sabat, Professor of Psychology, Department of Psychology, Georgetown University, Washington.
12.25	Dementia and risk The contested territories of everyday living	Prof. Charlotte Clarke, Head of School, School of Health in Social Science, University of Edinburgh.
13.10 – 14.00		Lunch
Afternoon Session		Enhancing: Collective Approaches to Change
14.00	Dementia consortia Collective action for greater impact	Dr. Fiona Keogh, Director of Research and Evidence, Genio.
14.40	Experiences of consortium members	Video presentation
14.45	Building managed organisational learning	Prof. David Coghlan, Professor in Organisational Development, TCD.
15.30	Ends	

*Subject to change

Speaker Biographies

Mr. Hugh Kane

Chief Operations Officer, Genio

Hugh joined Genio in January 2011 where he is working to facilitate the development of a problem-solving focus to removing the barriers to increasing individualised supports. Hugh has worked in personal social services for nearly 40 years. He began his career in health as a Community Welfare Officer and moved into senior management in 1998 as Community Services General Manager. In 2000 Hugh joined the management team of South Western Area Health Board as Assistant CEO, and was subsequently appointed Deputy CEO in 2003. Hugh joined the Health Service Executive (HSE) in 2005 as Hospital Network Manager. He later worked as Local Health Manager for Wicklow with lead responsibility for disability services and after that took on the role of Assistant National Director for Dublin mid-Leinster. In 2009 Hugh was appointed CEO of the Mental Health Commission.

Dr. Suzanne Cahill

Research Associate Professor of Social Work and Social Policy, TCD and Director, DSIDC, St. James's Hospital Dublin

Suzanne has published over 40 articles/book chapters on ageing and dementia related topics during her career. Her current research interests include a National Disability Authority (NDA) commissioned project (i) developing guidelines for architects building and retrofitting home dwellings for people with dementia; (ii) a national survey of nursing homes and specialist care units regarding dementia care; and (iii) young onset dementia. She was the lead Principal Investigator in the research review undertaken for the Irish National Dementia Strategy and Senior Author of the report titled *Creating Excellence in Dementia Care*. Other recently completed projects include a national study of memory clinics in Ireland (2014); a systematic review of the public's knowledge and understanding of dementia (2014); a Centre for Ageing Research and Development in Ireland (CARDI) funded study of bereaved spouses' experiences of end of life care and dementia (2012); and a study examining dementia prevalence and quality of life in nursing homes (2010). Since 2001, Suzanne has taught undergraduate courses to Social Work and Social Policy students at TCD. In 2007, she was awarded a large grant from the Atlantic Philanthropies to promote research into psycho-social interventions in dementia care. Since that time, Suzanne has graduated many Masters students and several PhD students.

Ms. Jenny La Fontaine

Young Onset Dementia Development Officer, Early Intervention Dementia Service, Worcestershire Health and Care NHS Trust

Jenny has many years experience working in the NHS in England and within higher education, including as a Consultant Nurse and Admiral Nurse. She has specialised in working with people living with dementia and their families throughout most of her career. Her current role is a development post with a strategic brief to provide specialist advice and support to facilitate the development of services and specialist trained staff for younger people with dementia and their families. She has specialist interests in working therapeutically with families and people living with dementia and

in early intervention. She is in the fifth year of a part-time PhD with the University of Bradford, exploring the experience of frontotemporal dementia for intergenerational families over time.

Prof. Steven R. Sabat

Professor of Psychology, Department of Psychology, Georgetown University, Washington

Steven has received Georgetown College's Edward B. Bunn Award for Excellence in Teaching three times (1988, 1995, 2013), the Georgetown College Dean's Award for Excellence in Teaching (2003) and the College Academic Council's Award for Excellence in Teaching (2012). For the past 32 years, he has studied the intact cognitive and social abilities of people with Alzheimer's disease in the moderate to severe stages, the persistence of selfhood, the subjective experience of having the disease, and how communication between persons diagnosed and their caregivers may be enhanced. He has explored these issues in depth in numerous scientific journal articles and book chapters, presentations at national and international conferences, in his book *The Experience of Alzheimer's Disease: Life Through a Tangled Veil* (Blackwell, 2001) and in his co-edited book *Dementia: Mind, Meaning, and the Person* (Oxford University Press, 2006).

Prof. Charlotte Clarke

Head of School, School of Health in Social Science, University of Edinburgh

Charlotte is a nurse and has worked clinically and in education and research in the field of older people and with those living with dementia for 25 years. One programme of research has addressed risk management in dementia care, recognising that this is one of the most complex areas of professional practice, immensely challenging for family carers and presents particular challenges for people with dementia. A book written with colleagues on risk management and its contribution to improving quality of life was awarded the 2012 BMA Book Award (health and social care). Research projects have included leading the national evaluation of the National Dementia Strategy for England in relation to peer support and Dementia Advisors.

Dr. Fiona Keogh, PhD, Dip. Stats, Cert. Health Ec.

Director of Research and Evidence, Genio

Fiona has been working with Genio since August 2008. During this time she conducted the research for the report on *Identifying Effective Sustainable Services for People with Disabilities and Mental Health Difficulties*. Fiona has over 20 years experience in conducting health research in Ireland, in mental health and in the wider disability sector. Most recently, she wrote the report of the Expert Disability Policy Reference Group which was part of the Value for Money Review of Disability Services. Fiona has also worked for the Mental Health Commission, preparing and implementing a Research Strategy for the organisation and was part of the management team that implemented the *Mental Health Act 2001*. She worked as the researcher and writer for the Expert Group on Mental Health Policy and drafted much of the government's current mental health policy *A Vision for Change*. Fiona previously worked for the Health Research Board as the senior researcher in the

Mental Health Division and as the researcher on a comprehensive evaluation of a community mental health service in West Dublin. She is also an Associate Lecturer on the MA in Health Services Management course in the Institute of Public Administration.

Prof. David Coghlan

Professor in Organisation Development, TCD

David is a Fellow Emeritus of TCD and an Adjunct Professor at the School of Business. He specialises in organisation development and action research and is active in both communities internationally. He is author of the internationally popular, *Doing Action Research in Your Own Organization* (4th ed. 2014, Sage) and co-editor of *The SAGE Encyclopedia of Action Research* (2014).

Genio - Focus on Dementia

About Genio

Genio works to bring Government and philanthropic funders together to develop better ways to support disadvantaged people to live full lives in their communities. So far we are improving the lives of people with disabilities, mental health difficulties and dementia.

Since 2010, we have awarded funding to 227 projects nationally to provide over 5,500 people with individualised supports in the community. In addition over 9,000 families, carers and staff have received information and training.

Our approach has three elements, one of which is the releasing of funds on a competitive basis to encourage innovation and cost-effectiveness. These funds are outcome-focused and performance-managed. The second is the support and training of key stakeholders to manage and implement required changes. Thirdly, we undertake and commission research to measure impact.

Genio Dementia Programme

The Genio Dementia Programme, with support from the Atlantic Philanthropies and the HSE, is developing and testing new service models which would improve the range and quality of community-based supports for people with dementia; influence public policy and investment in this area; and build the leadership in the field that is necessary in order to capitalise on the potential of the proposed new 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 achieving this.

The Genio Dementia Programme supports projects led by consortia which include people with dementia, families and carers, mainstream organisations and community groups, older people's services, hospitals and nursing homes.

The programme has three key focus areas:

1. Community-based models of support for people with dementia

Having undergone an in-depth and competitive screening and evaluation process, four regional projects were selected for funding in Ireland. These projects are undertaking seven main areas of activity:

- **Demonstration areas** - Developing 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.
- **Capacity building** - Supporting services and their personnel in the four regional projects 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 regional projects, and beyond, in order to share learning in a systematic way and to create a learning support for projects in other 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.

A fifth Cognitive Health Project was awarded funding to develop and share online films which would promote positive cognitive health behaviours.

2. Integrated care pathways in the acute hospital sector for people with dementia

This part of the programme focuses on the acute hospital sector to develop an integrated care pathway for those living with dementia so that they can access acute services in a planned way and return home promptly. Through a competitive application process, three hospitals were selected for funding. Outputs expected from projects include:

- **Documented care pathways**
- **New models of support developed in acute settings and linking to community settings**
- **Transferable learning**
- **Clarity around implementation e.g. training, infrastructure, skill mix etc.**
- **Improved cost-effectiveness**

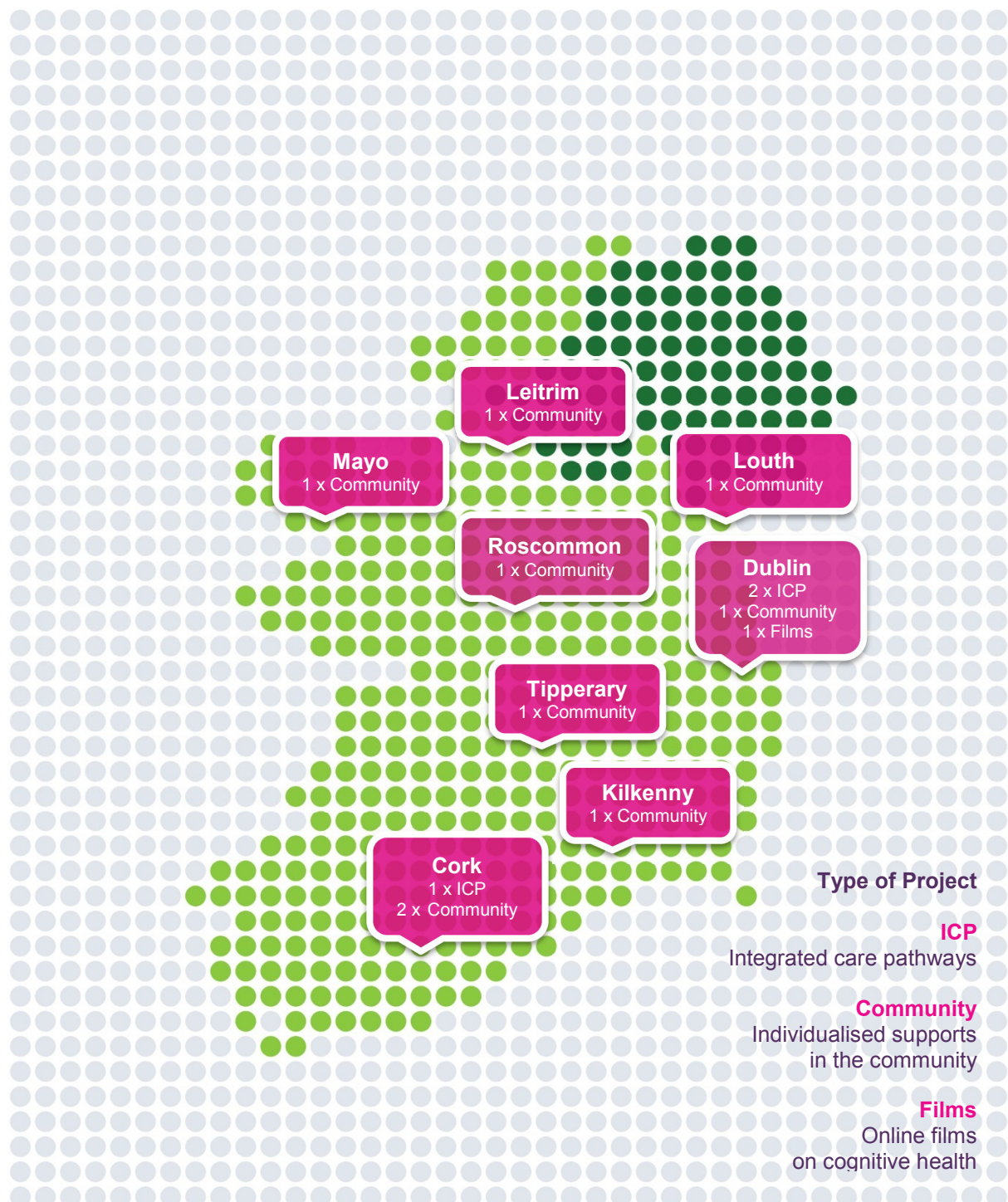
3. Individualised supports for people at an advanced stage of the dementia journey

This part of the programme is focussed on the development of individualised supports for individuals who are more advanced on the dementia journey. Through a competitive application process, five community projects were selected for funding. The aim of these projects is to design and provide supports for individuals who present with more complex needs related to the more advanced stage of their dementia, which will enable people to remain in their own home or similar setting through the provision of flexible, responsive supports to the person and their family. It is envisaged that individualised supports developed will also target inappropriate delays in discharges from acute hospitals and also responses that support complex cases in the community so that admission to acute settings can be reduced or avoided.

Details of Genio-supported dementia projects

Title	Location	Amount	Summary description
Cognitive Health Project	Dublin	199,052	This 1 year project developed and shared online films which will promote positive cognitive health behaviours. Films available at www.freedemliving.com .
Living Well with Dementia (LWwD)	Dublin	700,000	This 3 year project is a community based dementia project that builds on the foundations of circles of support - family, neighbours, community groups.
The 5 Steps to Living Well with Dementia in South Tipperary	Tipperary	700,000	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 and providing compassionate and dignified palliative end of life care.
Kinsale Community Response to Dementia (K-CORD)	Cork	632,825	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.
Community Action on Dementia in Mayo	Mayo	699,579	The 3 year project is providing a system of service provision for people with dementia in Mayo which is person-centred and based within the person's own community.
Development of an Integrated Care Pathway for People with Dementia (DemPath)	Dublin	500,000	This 3 year project will integrate care for people with dementia across the Dublin South Inner City community and St. James's Hospital in a person-centred way.
Cork Integrated Dementia Care Across Settings (Cork-IDEAS)	Cork	498,500	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	500,587	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.
Flourishing with Dementia (FwD)	Louth	100,000	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.
Memory Matters Community Component	Kilkenny	100,000	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.
The Crystal Project	Mallow	100,000	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	100,000	This 2 year project will promote excellence, innovation and creative ways of supporting people with dementia to remain in their own home.
Community Outreach Dementia Project Leitrim (CODPL)	Leitrim	100,000	This 2 year project will set out an integrated pathway for people with dementia and their carers from acute/community services, day hospital and home.

Geographical location





Thank you for attending
this event. For more
information visit
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