



DEMENTIA SERVICES
INFORMATION AND
DEVELOPMENT CENTRE

*promoting excellence
in dementia care*

The Dementia Services Information and Development Centre

ANNUAL REPORT 2014

Introduction

A key aim of the Dementia Services Information and Development Centre is to make Ireland one of the best places in the world for people to live well with dementia and to die in dignity cared for by family members and by service providers with a thorough understanding of Alzheimer's disease and the related dementias.

The year 2014 was significant as it culminated in the launch of the Irish National Dementia Strategy on 17th December. The launch was presided over by the Taoiseach, Enda Kenny, the Tanaiste, Joan Burton and the Minister for Social & Primary Care, Kathleen Lynch. The Strategy, which contains the blueprint for government policy over the next five years, is underpinned by the research review – **Creating Excellence in Dementia Care in Ireland**, a report which was written by staff from the DSIDC and from NUI Galway and funded by the Atlantic Philanthropies.



(l-r) Mary Sutton of Atlantic Philanthropies, Minister Kathleen Lynch and Helen Rochford-Brennan, Chair of the Irish Dementia Working Group, at the launch of the National Dementia Strategy in Government Buildings on 17th December 2014

Conferences & Seminars

During 2014, the DSIDC hosted four large conference/seminars, which attracted audiences of between 60 to 150 health service professionals and family members. The first, a Memory Clinic conference titled: **"Dementia: More than Memory"**, was co-hosted with the Mercer's Institute for Successful Ageing (MISA) and took place at the Trinity Biomedical Sciences Institute in May. Two other seminars/events took place in May, linking in with a study visit from the world renowned, distinguished Professor Steve Zarit and his wife Dr Judy Zarit from Penn State University. The first was an evening seminar on the topic of Respite Care, held in the Royal Irish Academy in Dublin and chaired by Professor Des O'Neill.

The second event, which was a **Mini-Symposium on Dementia**, was held in May and was opened by the Provost of Trinity College, Dr Patrick Prendergast. The keynote speaker was Professor Steve Zarit and guest speakers included Professor Eamon O'Shea, Professor Charles Normand and Dr Caroline O'Nolan.

The occasion was also used to showcase the recently completed PhD of Dr Ana Diaz Ponce which investigated quality of life and cholinesterase inhibitors amongst a sample of Memory Clinic patients.



Professor Steve Zarit

The final public event was our winter conference, which took place in Dublin Castle in late November. It attracted an audience of over 150 health service professionals and focused on the much-neglected topic of **Young Onset Dementia**. It involved local and international speakers including Professor John Keady, Professor Simon Meade and Mr Per Kristian Haugen all of whom are practitioners and researchers with a keen interest in the topic. The powerful opening address was given by Helen Rochford-Brennan.



(l-r) Dr Andrea Bobersky and Dr Ana Diaz Ponce pictured at the symposium on dementia; Trinity College Dublin



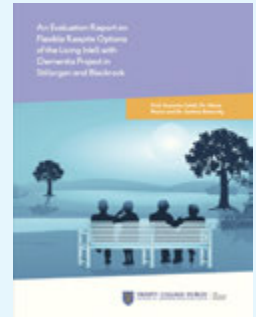
(l-r) Mr Gerry Martin, Dr Siobhan Hutchinson, Professor Simon Mead, Mr Per Kristian Haugen, Ms Helen Rochford-Brennan, Professor John Keady and Professor Suzanne Cahill

Research Studies

During 2014, the DSIDC completed the data collection and analysis of a new research study on dementia conducted across 602 Nursing Homes in Ireland. The purpose of this study was to investigate the numbers and location of specialist care units across the ROI and to examine in particular the extent to which these facilities complied with best practice principles on dementia care. Based on the key findings from this study a detailed report and a new booklet titled "Specialist Care Units for People with Dementia in Ireland: A Guide for Family Caregivers and Health Service Professionals" have been developed.



The Genio commissioned research involving **Respite Service Evaluations** (South Tipperary and Stillorgan/Blackrock) came to fruition at the end of 2014 with the publication of the two evaluation reports and a third new report reflecting updated dementia prevalence rates in Ireland based on 2011 Census data.



These papers can be downloaded from our website www.dementia.ie

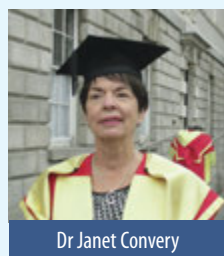
Towards the end of 2014 the DSIDC received an award from Dublin City University for its research report titled: **Dementia and Home Design from a Universal Design Approach**. This report was based on work commissioned by the Centre for Excellence in Universal Design at the National Disability Authority. The project was undertaken by Associate Professor Suzanne Cahill (PI), Dr Maria Pierce, Tom Grey and Professor Mark Dyer.



(l-r) Tom Grey; Professor Suzanne Cahill; Neil Murphy; Minister Kathleen Lynch; Dr Maria Pearce and Professor Mark Dyer at the National Disability Authority.

The study was commissioned to inform the development of design guidelines, to be used by built environment professionals and all relevant stakeholders to design new and retrofit existing dwellings for people with dementia, their families and carers through a Universal Design Approach. The research involved several different phases, including strong engagement with built environment professionals and also people with dementia, their families and carers. This was done through a collaborative, inter-sectoral approach.

During 2014, the LiD Programme graduated two PhD students, Dr Ana Diaz Ponce, and Dr Janet Convery. Dr Convery's thesis was on the topic of Dementia and Housing with Care.



In May five staff from the DSIDC's Living with Dementia (LiD) research programme attended and delivered a Symposium at the **22nd Nordic Congress of Gerontology**. The central theme of this Symposium was the subjective experience of dementia and psychosocial service interventions.

Speakers included: **Dr Maria Pierce, Dr Emer Begley, Vanessa Moore and Dr Andrea Bobersky.**

Towards the end of the year a very detailed study involving a **Systematic Review of the Literature on the Public's Knowledge and Understanding of Dementia** was accepted for publication in the journal Alzheimer's disease and Associated Disorders. In association with other collaborators, a large grant application was also submitted to the HRB for an ICE award which if successful will support quantitative and qualitative research on Young Onset Dementia.

Education & Information Services

Throughout 2014, in-house workshops continued and were well attended. These included the Foundation in Dementia Care Workshop, Responsive Behaviours, Activity/Life Story and Leadership in Dementia Care. A new workshop titled **'Partnerships in Care'** was successfully piloted during the middle of the year in one nursing home. The Centre also partnered with Our Lady's Hospice, Harolds Cross and co-facilitated a three day course for all professionals working in the area of dementia care. This was a success and was repeated in the Autumn.

During 2014 the DSIDC continued to deliver the extra mural course **"Understanding Dementia and Promoting Family Caregivers' Quality of Life"**, an evening course designed to up skill family caregivers and promote their well-being. The course was provided free of charge and was very well evaluated. Due to its success the course will be repeated in early 2015.

A once off successful seminar on sensory impairment and dementia was also hosted by the Centre in St James's hospital in Spring and held in conjunction with **DeafHear** and **National Council for the Blind in Ireland**.

During the year, staff from the DSIDC continued to play a significant role in the **teaching of Trinity College, Dublin's post-graduate MSc courses in Gerontology and in Dementia**. These courses are attended by a range of health care professionals.

A number of lectures on dementia related topics were given to various professional and voluntary groups. Attendees spanned a range of professions such as social workers, nurses, psychologists and other allied health care professionals.

The DSIDC continues to work with the **HSE's National Dementia Education Programme** in facilitating workshops, training of trainers and revision of programmes. A number of offsite workshops were requested from nursing homes and other residential organisations with ageing populations. The DSIDC continues to facilitate programmes for the Dublin region of the HSE Staff Health, Safety & Welfare Department.

In May the DSIDC began to contribute to the formal work of the St James's hospital led dementia project - **Dempath**. The main objectives of **Dempath** is to improve partnerships between community and acute care services, reduce the need for hospitalization and length of time in hospital, provide early intervention, and educate the hospital workforce about dementia.

Ultimately **Dempath** is designed to improve the experience of the person with dementia in an acute general hospital. Two staff members from the DSIDC are involved in leading out on core aspects of this project. The Centre also worked with the South Dublin **'Living with Dementia'** Genio project.

Other highlights during 2014 include the introduction of our new five-week interactive programme for secondary school students titled **"Will Grandad Remember Me: A Dementia Awareness Programme for Schools"**. The course teaches students about risk factors for dementia including the adverse effects of poor nutrition, cigarette smoking and excessive alcohol consumption and about cognitive reserve and protective factors for dementia.

Several of these students have grandparents who have dementia and with whom they have very close contact.



A Group of Students from CBS James's Street

During 2014 staff from the Centre contributed to a number of conferences, seminars and lectures. Paper presentations were given at the **Waterford Skills Chambers Conference, CARDI Colloquium, the Genio Annual Conference, Sonas apc** and at the **InterDem day at Alzheimer Europe** in Glasgow.

Information and Consultancy Service

Throughout 2014, enquiries were received by DSIDC staff from all parts of the country with significantly higher rates in the Leinster region. The majority of enquiries came from private individuals and the private nursing home sector. The DSIDC website continues to be a valuable information source for health service professionals and the general public. During 2014, a new web-site page was designed to assist GPs in the challenges often confronted when assessing and diagnosing a person with suspected memory and/or cognition problems and communicating the diagnosis to the person and their next of kin.

A number of design consultancies were also carried out by staff from the Centre throughout the year, which enabled organisations to enhance the lived experience of their clients who have dementia by improving their environment. The majority of these requests were from the residential sector. In November the DSIDC were visited by a group of Estonian developers interested in designing dementia specific units who sought staffs' expertise in design for dementia.

DSIDC staff participated in a number of national and international networks, steering committees and projects during 2014 including:

- National Steering Group for Dementia Friendly Communities
- Scientific and Advisory Panel Alzheimer's Society
- Trinity Haus and National Disability Design Project
- Dementia Elevator Project
- InterDem
- South Tipperary Dementia Project (Genio)
- Living Well with Dementia (LWwD) South Dublin (Genio)
- The Social Workers Special Interest group on Ageing
- The St John of God's Task Group for St Joseph's Centre Development Plan
- The Alzheimer Café
- Atlantic Philanthropies
- HIQA Advisory Group for Thematic Inspections focusing on Dementia Care
- DemPath Project
- National Referral System for Memory Clinics
- National Council for the Blind Ireland
- DeafHear
- ALONE
- Siel Bleu

Governance Structure

The DSIDC employs five staff, two of whom work part-time. It occasionally co-opts in the expertise of Associate Trainers.

During 2014, Steering Committee meetings were held in February, June and October and the Annual Advisory Group Meeting took place in February.

In September, **Dr. Siobhan NiBhriain** stepped down as Chair of the Committee and we would like to take this opportunity to thank Siobhan for her professional guidance.

We would also like to welcome **Dr. Declan Byrne** as the new Chairperson of the Steering Committee.



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Top Floor, Hospital 4 | St. James's Hospital | James's Street | Dublin 8 | Ireland
Tel: +353 1 4162035 | Fax: +353 1 4103482 | Email: dsidc@stjames.ie
Web: www.dementia.ie