



DEMENTIA SERVICES INFORMATION AND DEVELOPMENT CENTRE  
*promoting excellence in dementia care*

# Annual Report 2013



Events 2013: *[top]* Associate Professor Suzanne Cahill, Professor Des O'Neill and Minister Kathleen Lynch at the launch of the DSIDC website, December; *[below left]* Clíodhne Hamilton, a family caregiver, speaking at the website launch; *[below right]* Dr Siobhán Ní Bhriáin, Professor Greg Swanwick and Mr Maurice O'Connell at the Third National Memory Clinic Conference, May.

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## Overview of 2013

The **Dementia Services Information and Development Centre (DSIDC)** is a National Centre for Excellence and is committed to best practice in all aspects of dementia care. The year 2013 was significant for DSIDC, as during the year partnerships were forged with new groups including engineering and architectural staff from **TrinityHaus** in Trinity College Dublin and staff at **Genio**, where the DSIDC is involved in the evaluation of two community-based respite projects.

During 2013 the Department of Health appointed a Working Group to oversee the development of the National Dementia Strategy. This Working Group, on which the DSIDC is represented, met several times during the year to progress dementia policy reform. The Health Information and Quality Authority (HIQA) appointed a Working Group to oversee the review of residential care standards; DSIDC has been commissioned to act in a consultancy capacity, advising HIQA on the dementia aspects of this review.

The year also saw a major re-working of the DSIDC website. The newly-designed website – [www.dementia.ie](http://www.dementia.ie) – was launched in December 2013 by Kathleen Lynch, Minister of State with responsibility for Disability, Older People, Equality and Mental Health, at a public event hosted in the Royal Irish Academy before an audience of some 50 clinicians, researchers, academics and formal and informal caregivers.

Other highlights during the year included two workshops (one in late-June and the other in late-October) co-hosted by DSIDC in collaboration with TrinityHaus and convened by the National Disability Authority. The purpose of these workshops was to provide preliminary findings to stakeholders based on a new research study investigating the topic of architectural design and dementia. This project, when completed, will result in the development of guidelines for architects involved in building new dwellings or retrofitting pre-existing houses for people with dementia.

2013 saw the completion and submission of four PhD theses (Andrea Bobersky, Treena Parsons, Janet Convery and Ana Diaz Ponce). Following an application to Genio to support the customisation of St James's Hospital, to train hospital staff, to forge links between community and acute care services and to make the hospital dementia-friendly, in December 2013 the hospital was awarded a large grant to undertake this work. This project is being led by Professor Brian Lawlor, with considerable input from the staff of DSIDC along with a consortium of staff from other areas.



*Associate Professor Suzanne Cabill and Minister Kathleen Lynch at the DSIDC website launch*



*Professor Des O'Neill and Dr Caitriona Crowe in the Royal Irish Academy*

## Conferences and Seminars

Towards the end of April 2013 the **Third National Memory Clinic Conference** was co-hosted by DSIDC and the Mercer's Institute for Successful Ageing (MISA). The conference, *Multi-Disciplinary Assessment and Diagnosis in Neurodegenerative Disorders*, involved both Irish and international speakers.

Also during April a large seminar on the topic of *The Environment and Dementia* was hosted by DSIDC in Trinity College Dublin; it attracted an audience of some 120 architects, planners and researchers. The guest speaker was Dr Hilda Verbeek, a Neuropsychologist from the University of Maastricht, who presented findings from a Dutch/Belgian study investigating the effects of small-scale design on the quality of life of people with dementia.

In early November the DSIDC and HIQA co-hosted a one-day seminar at St James's Hospital, targeting the training of HIQA inspectors. The seminar was organised to broaden inspectors' skill-base and open up the debate about regulation, inspection and best practice in dementia care. Topics were carefully selected to be of practical relevance to inspectors and included a policy overview with new dementia prevalence data and talks on environmental design, communication and dementia, quality of life and medication and the challenge of polypharmacy in nursing homes. Some 60 HIQA inspectors attended this event which, in common with all DSIDC events, was fully evaluated.

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## Education and information

In Autumn 2013 DSIDC launched a new extra-mural course, *Understanding Dementia*. Some 20 family caregivers attended, including several male carers, some of whom had relatives with early-onset dementia. The course ran for six weeks, it was provided free-of-charge and was very well evaluated. Due to its success the course will be repeated in early 2014.

During the year DSIDC staff continued to provide education to healthcare professionals nationwide and contributed to a number of conferences, seminars, lectures and national and international networks.

A 13-week undergraduate module on *Ageing and Dementia* was taught to some 40 third- and fourth-year Social Work and Social Policy students at Trinity College. A new module, titled *Partnerships in Care*, was also designed, its aim being to provide staff with opportunities to reflect on relationship-centered care and to improve communications between nursing home staff and relatives of residents. The course will be piloted in two nursing homes during 2014.

DSIDC had significant involvement in cross-institutional training during 2013. This included contributions by DSIDC staff to postgraduate courses in TCD and UCD (the MSc in Gerontology), to the HSE National Dementia Programme and to the DCU Elevator project. Significant contributions were also made by DSIDC staff to the SONAS training programme and the SONAS annual conference. This collaboration with other organisations helps to maintain the philosophy and ethos of quality dementia care in Ireland.

## Booklets

During 2013 a new booklet designed for people either worried about their memory problems or those recently diagnosed with dementia was written. The booklet, titled *Coping with the Early Stages of Dementia*, provides a plethora of information on a range of services available to people dealing with this stage of dementia.

The Memory Clinic booklet was also updated during the year to reflect current service provision in this area.

## Information and Consultancy Service

Throughout 2013 DSIDC staff responded to many queries, both from healthcare professionals and from the public at large. Enquiries were received from all parts of the country, with significantly higher rates in the Leinster region. The majority of enquiries came from private individuals and from the private nursing home sector.

A number of design consultancies were carried out by staff from DSIDC during the year, assisting organisations to enhance the living experience of clients who have dementia by improving their environment. Staff from the Centre also participated in the Clinicians' Round Table forums, engaging clinicians in open discussion during the consultation process for the National Dementia Strategy.

National and international networks, steering committees and projects in which DSIDC staff participated during 2013 included:

National Steering Group for Dementia Friendly Communities

Trinity Haus and National Disability Design Project

Education Committee for Enhancing and Enabling Wellbeing for the Person with Dementia

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 the St Joseph's Centre Development Plan

The Alzheimer Café

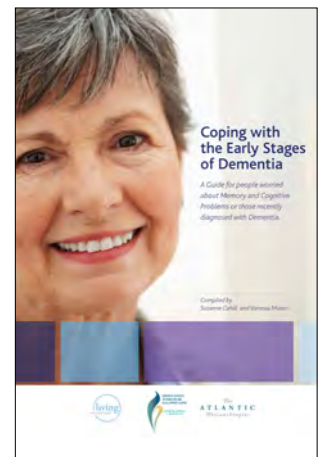
Dementia Palliative Care Group

National Council for the Blind Ireland

DeafHear

ALONE

Siel Bleu



DSIDC booklet, launched in December 2013



Dr Maria Pierce presenting preliminary research findings at the National Disability Authority Workshop held in late-October

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## Research

During 2013 a number of large competitive grant applications were written and three new research projects were undertaken. One of these was a national survey of nursing homes and specialist care units, undertaken by the DSIDC to ascertain the location and numbers of these units around the country. Findings from this study will be presented at a DSIDC conference due to take place in Dublin in May 2014. Results will also be used to compile a report and to design an information kit/booklet for members of the public who may be in search of suitable dementia-specific nursing homes in their locale.

The DSIDC's **Living with Dementia programme (LiD)**, funded by the Atlantic Philanthropies, came to completion at the end of 2013. This research programme has been very positively evaluated and has been successful in raising public and professional awareness about dementia. To date a total of 17 public seminars have been hosted, with expert guest speakers sharing their knowledge and expertise from as far afield as the US, Australia and continental Europe. These speakers have brought state-of-the-art experience and practice to the attention of those in Ireland who are responsible for policy development and for the design planning and delivery of dementia services.

The LiD programme has graduated six masters and two PhD students to date and, in early 2014, three other PhD students will sit their *vivas*. Common themes straddling this externally-funded programme of research include the role of non-pharmacological interventions in dementia care; stigma; formal and informal caregiving and policy responses.

A national survey of Memory Clinics in Ireland was completed and submitted for publication during the year ([http://journals.cambridge.org/repo\\_A91Mb1EJ](http://journals.cambridge.org/repo_A91Mb1EJ)) and a report on the evaluation of a new model of respite in South Tipperary was written and submitted to Genio.

A research paper, showing new data on dementia prevalence rates, was presented at the Genio annual conference on dementia at Bewley's Hotel, Dublin, on the 5<sup>th</sup> December.

## Governance and Structure

The DSIDC continues to operate with five staff, two of whom are employed part-time. DSIDC occasionally co-opts the expertise of associate trainers.

Two Steering Committee meetings were held during the year (February and September) and Mr Maurice O'Connell, a long-standing member of both of the Committees, retired from the ASI after 15 years service. Everyone at DSIDC would like to thank Maurice for his ongoing support of our professional work.

We would also like to welcome Mr Brian Fitzgerald who joined the Steering Committee during 2013, along with other new members of the Advisory Group, Mr Pearse Finegan and Fiona Crehan. We would also like to welcome back our Director, Associate Professor Suzanne Cahill, who has now returned to DSIDC full-time having spent the past six years at Trinity College overseeing the Living with Dementia programme.



*The DSIDC team [L-R] Associate Professor Suzanne Cahill; Cecilia Craig; Lorraine Lovely; Andrea Bobersky; Dearbhla O'Caheny; Dr Siobhán Ní Bhriáin. [Absent from picture: Matthew Gibb].*

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