Health Research Charities Ireland

CHARITY-FUNDED RESEARCH IMPACT STORY

Title of project: Including best practices and the voices of experience in developing post-diagnostic dementia support guidelines for people with an intellectual disability.

Project time frames: November 2020 - November 2023

Lead researcher: Professor Mary McCarron, Professor of Ageing and Intellectual Disability, School of Nursing and Midwifery, Trinity College Dublin.

HRCI Charity Funder: The Alzheimer Society of Ireland

OVERVIEW

People with intellectual disabilities are at a much higher risk of developing dementia. They may also get dementia earlier than others and can lose a lot of independence from even small changes.

The National Dementia Strategy has helped people with dementia, but it does not meet the unique needs of people with intellectual disabilities. This led Mary and her team to create special support guidelines for people with intellectual disabilities who are diagnosed with dementia.

THE 5 PILLARS

Over 124 people shared their views in workshops and events designed to open minds and spark conversations to help create these guidelines.

Five key areas, or "pillars," were identified as being most important for support:

1. **Living well with dementia**
2. **Sense of place and community**
3. **Dementia awareness and skills**
4. **Supportive infrastructure**
5. **Promoting autonomy**

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DISSEMINATION

These pillars were turned into 33 care standards, which explain how to provide better care. Tips and links to helpful resources were also included. People with intellectual disabilities were deeply involved in the research as co-researchers, helping to shape the project every step of the way.

To make sure the guidelines are widely used, a plan was created to share them with caregivers and services. The guidelines have been shared in academic papers, conferences, and through partnerships with groups like the National Dementia Office, the Alzheimer Society of Ireland, and the HSE.

IMPACT

These guidelines are already making a big impact. The National Intellectual Disability Memory Service (NIDMS) uses them to help caregivers and provide advice to disability services across Ireland. They also shaped a new strategy for dementia care (2025-2029) for people with Down Syndrome in Ireland.

The impact of this project will continue to grow. The National Dementia Office and the Alzheimer Society of Ireland will share the guidelines on their websites and use them in training. The HSE's Clinical Lead for Disability Services has also promised to help implement the guidelines widely, using digital tools and training to make them easy to use and sustainable.

The guidelines are available **online** and can also be accessed through **accessible videos** that explain each of the five key areas.

THE Alzheimer SOCIETY OF IRELAND