

Intellectual Disability Supplement to TILDA Newsletter

Welcome to the first Intellectual Disability Supplement to TILDA newsletter. This is the first of our regular newsletters designed to keep you up to date on our progress.



Pictured at the launch of the IDS to TILDA is John Moloney T.D., Minister for Equality, Disability & Mental Health, Professor Mary McCarron, Head of School of Nursing & Midwifery, Trinity College Dublin and Margaret Gahan, Self-Advocate, Stewarts, Palmerstown who features on the promotional material of the study.

Message from Professor Mary McCarron, Principal Investigator

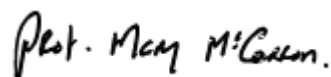
On December 3rd 2008, the International Day of Persons with Disabilities, the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (TILDA) was launched by the Minister for Equality, Disability and Mental Health, John Moloney T.D. Speaking about the study, Minister Moloney said *"It is very fitting in my view that we here in Ireland can mark the day in such a special way with the announcement of this significant endeavour"*.

While ageing in people with intellectual disability is an incredible success story, it is also a tremendous challenge, as we know little about the ageing of people with intellectual disability in Ireland or indeed in any country, and we now have an opportunity to hear their voices and gather critical information.

The inclusion of the Intellectual Disability Supplement to TILDA represents a major step towards building the evidence on which to base the development of sound policies in areas concerning older people with intellectual disability, and to integrate this population group into future national health and social care policies, and services.

The study will involve approximately 800 people with intellectual disability aged 40 years and over from across Ireland, charting their health, social, economic, environmental and psychological status as they age over a 10-year period. This is the first longitudinal study on ageing in people with intellectual disability in Europe, and the only study with the potential of comparing the ageing of people with intellectual disability directly with the general ageing population.

A study like this would not be possible without the support and commitment of people with intellectual disability, families and services across Ireland, and we are delighted with the positive feedback we have received since the securement of this study in September 2006. We look forward to keeping in touch with you on a regular basis.



Professor Mary McCarron
Principal Investigator
Intellectual Disability Supplement to TILDA

About us

The study, the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS to TILDA) is collaboration with TILDA and is being led by Trinity College Dublin.

The study will involve approximately 800 people with intellectual disability from all over Ireland. People will be randomly selected from the National Intellectual Disability Database (NIDD).

Participation in this study is voluntary. It will be carried out over a 10-year period and participants will be revisited every two years throughout this period.

A researcher with experience of working with people with intellectual disability will visit the participant and carry out a face-to-face interview asking questions about their health, lifestyle, living circumstances and quality of life. We will also take some important measurements such as height and weight.

A short questionnaire will also be administered to carers, where applicable. This questionnaire will explore the health and social needs of families and carers of older people with intellectual disability.

The findings from this study will act as a foundation upon which we can plan appropriate health, medical, social and economic policies and provide suitable health and social services for older people with intellectual disability in Ireland.

Progress: What has happened so far?

November 2006 - Launch of The Irish Longitudinal Study of Ageing (TILDA)

TILDA was launched by the Minister for Health Mary Harney in November 2006, to study a representative cohort of at least 8,000 Irish people aged 50+ charting their health, social and economic circumstances over a 10-year period. The study is being carried out by Trinity College Dublin in collaboration with inter-disciplinary scientific researchers from Dundalk Institute of Technology (DKIT), Economic and Social Research Institute (ESRI), National University of Ireland Galway (NUIG), The Royal College of Surgeons in Ireland (RCSI), University College Cork (UCC), University College Dublin (UCD) and Waterford Institute of Technology (WIT). For more information, log on to: www.tcd.ie/tilda

**Collaboration with The Irish Longitudinal Study on Ageing (TILDA), led by Professor RoseAnne Kenny, Principal Investigator of TILDA, offers a unique opportunity to compare the Intellectual Disability Supplement findings to that of the general ageing population in Ireland.

June 2007 - Establishment of the International Scientific Advisory Committee



Pictured from left to right back row: Ms. Edel Tierney, Ms. Mary Murray, Dr. Jean Lane, Dr. Philip Dodd, Ms. Janet Swinburne, Dr. Niamh Mulryan and Dr. Attracta Lafferty. Pictured from left to right front row: Dr. Kathy O'Grady, Ms. Caraíosa Kelly, Prof. Philip McCallion, Prof. Mary McCarron, Ms. Finnola Kelly, Ms. Finula Garrahy and Ms. Bernadette McGarvey. Absent: Dr. Fintan Sheerin, Dr. Janette Tyrrell and Prof. Roy McConkey

The Intellectual Disability Supplement to TILDA study has been set up by people who have extensive experience of working with people with intellectual disability. The committee consists of family members, researchers, nurses, physicians, psychiatrists, psychologists and service providers. The study is also supported by Trinity College Dublin, the National Intellectual Disability Database, the Health Research Board, Inclusion Ireland, the National Federation of Voluntary Bodies and the Health Service Executive.

January 2008 – National Logo Design Competition



Mary McCann and Bernie Fox at the IDS to TILDA launch viewing the submissions received for the logo design competition held in January 2008.

People with intellectual disability from across Ireland were invited to enter designs to represent the IDS to TILDA study logo. This competition proved very successful and we would like to thank everyone who entered. The winning logo now represents the study.

Did you know?

One of the greatest success stories of modern times is the increasing number of people with intellectual disability living into old age. However, this success is also one of our greatest challenges as we know little about the ageing of this population group in Ireland.

Improvements in medical care, the control of infectious diseases, and the move to community living and improved healthcare services have contributed to increased life expectancy.

Significant health inequalities including a higher level of unmet needs and difficulties in accessing health care still exists, when the experience of people with intellectual disability is compared with the general population.

For people with moderate, severe and profound intellectual disability, the changing age structure is particularly pronounced. This has major implications for service planning in the years ahead because for these individuals the demands on health services are most acute.

The majority of individuals with intellectual disability in Ireland continue to live with their families. As these caregivers age some will no longer be able to provide this care and increased availability of residential supports may be needed.

September 2008 – First Round of Funding Secured

The Intellectual Disability Supplement to TILDA secured funding from the Health Research Board. The funding committed supports the main part of the first three-year stage of data collection and analysis. Additional resources are being pursued to support the remaining part of the first three-year stage and subsequent stages of this 10-year study.

December 2008 – Launch of the Intellectual Disability Supplement to TILDA



Mary Martin and Aeneas O'Meara viewing the first national photographic exhibition on 'Celebrating Ageing in Persons with Intellectual Disability', on display at the official launch of IDS to TILDA on December 3rd 2008.

On December 3rd 2008, the Minister for Equality, Disability and Mental Health, John Moloney, T.D., officially launched the IDS to TILDA in Trinity College Dublin. The launch was well attended by people with intellectual disability, families, services and academics.

Special thanks to everyone who submitted photos for the exhibition "Celebrating Ageing in Persons with Intellectual Disability". Over 200 photos were received and displayed at the launch. The exhibition will travel around services and key events throughout 2009/10.

February/March/April 2009 – National Consultative Workshops



Members of the Walkinstown Association Advocacy Group at one of the regional workshops held in Dublin.

A number of consultative workshops have been carried out to provide a platform for people with intellectual disability to meaningfully participate in all aspects of the research design and development of the study. The workshops also make sure that we include the views and opinions of people with intellectual disability when we are making decisions.

The workshops were held in several different services nationally and helped us to get very useful feedback on the study materials. These consultative workshops will be ongoing with groups throughout the country as the study progresses. If you know of any group that would like to get involved in future workshops, please contact the research team.

Research Team

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The IDS to TILDA team is also supported by a number of advisors from a wide range of disciplinary backgrounds with particular expertise and experience in research.

The funding support of the Health Research Board and the School of Nursing & Midwifery, Trinity College Dublin is gratefully acknowledged.

April 2009 – Commencement of the Pilot Study

Final preparations for the pilot study are currently underway. The pilot will commence in early April 2009 and will involve 80 people with intellectual disability from three different services in both urban and rural locations around Ireland. The services participating in the pilot are the Daughters of Charity Service in Dublin and Áras Attracta and Western Care Association in Co. Mayo. Letters of invitation will be sent to people with intellectual disability shortly and we look forward to meeting those who decide to take part.

The main study will commence in October 2009.

Your help and support is really appreciated

This study relies on your support. We will need help from people with intellectual disability, families and services in order to make this research a success. The questions we ask in this study are vital to identify the factors that influence healthy ageing, and to successfully inform policy and provide suitable health and social services for people with intellectual disability in Ireland. We hope that if you or someone you know is selected to take part in this study that it will be an enjoyable experience and that together we can work towards a brighter, happier and more informed future for older people with intellectual disability.

National Photographic Exhibition



The first national photographic exhibition "*Celebrating Ageing in Persons with Intellectual Disability*" displayed at the launch of the IDS to TILDA is currently travelling around services and different key events in Ireland. If there is an event coming up where you would like us to showcase this exhibition, please contact the research team.

Upcoming events include:

- Inclusion Ireland AGM "*Living Life to the Full*" on 27th - 28th March 2009 in Monaghan.
- "*Positive Choices*", the largest European Conference celebrating the contribution of students in Intellectual/Learning Disability Nursing in Ireland and the UK, on 24th April 2009 in University College Cork. For further information go to <http://conferencing.ucc.ie/conference/>
- 10th World Down Syndrome Congress "*Lifelong Living and Learning*" on 19th - 22nd August 2009 in Dublin. For further information go to <http://www.wdsc2009.com>
- International Conference – "*15 Years after Salamanca: Inclusion - A School for All*" on 12th - 13th November 2009 in Dublin. For further information go to <http://www.fedvol.ie>

For further information and to provide your feedback and input for forthcoming Newsletters please contact:

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