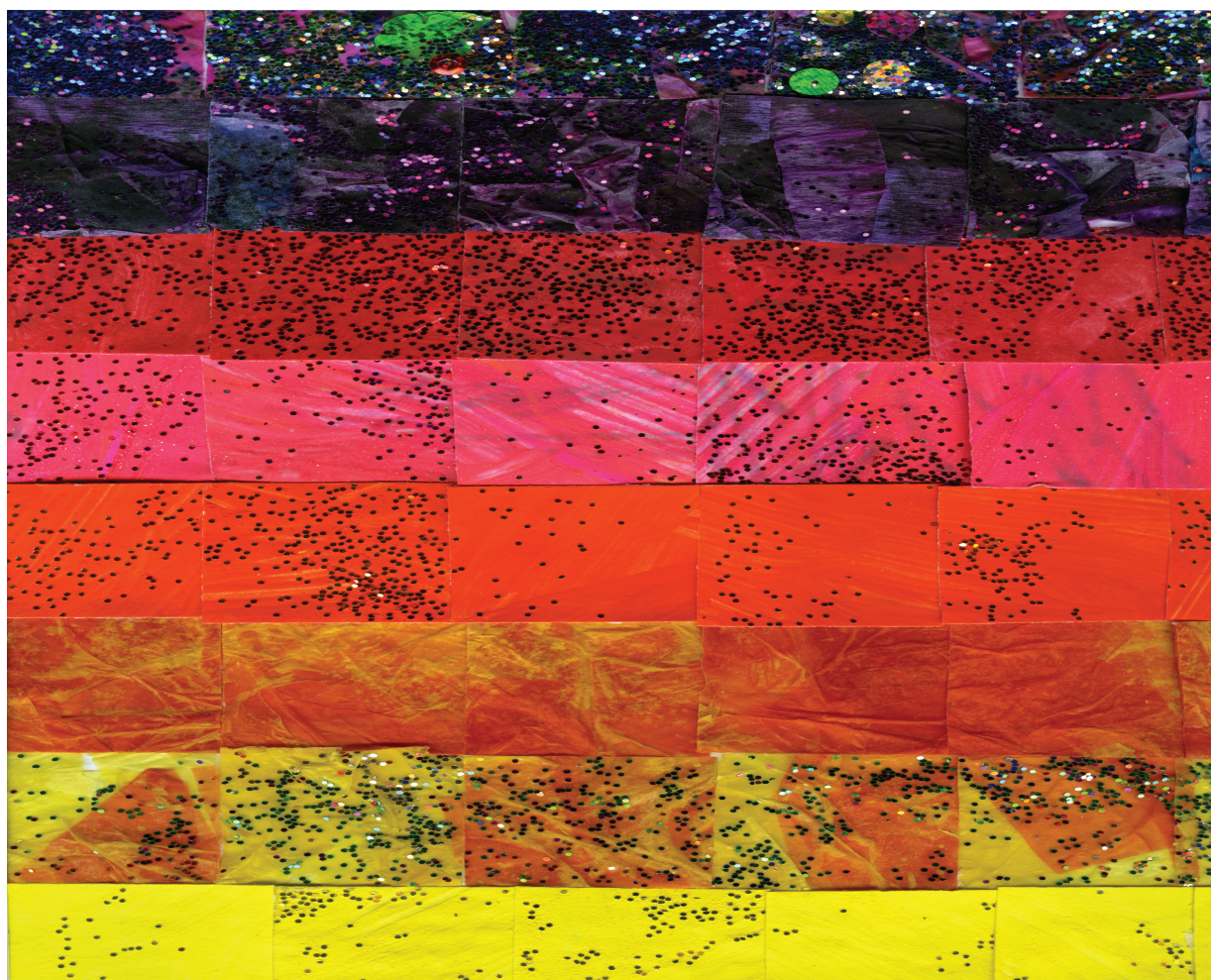


# An Intellectual Disability Supplement to The Irish longitudinal Study on Ageing

Pilot Report December 2009



The colours represent our journey through life



## Preface

I am delighted to publish this report on behalf of the IDS to TILDA research team.

This report is about the pilot study; what happened and what is next.

The things we learned from this study will help us do the main study better.

I would like to thank all of you who took part in the study and all of the people who sent in the artwork, which you can see in this report.



Yours Sincerely

*Prof. Mary McCarron.*

Professor Mary McCarron  
Principal Investigator

Intellectual Disability Supplement to TILDA



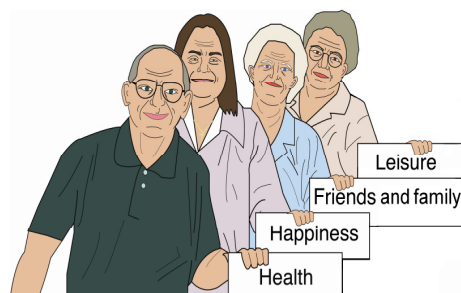
## Why are we doing this study?

This study is about people who are growing older with an intellectual disability in Ireland.

The National Intellectual Disability Database tells us that people are living longer.

We do not know much about people as they age in Ireland.

It is important to learn about people's



- health
- happiness
- and lifestyle

as they get older.

Then we can plan for the future together.



## What did we want to find out?

In this study we wanted to find out

- if people wanted to do the study
- were the questions easy or hard for people to answer
- if the information booklet and showcards were useful



## What did we find out?

66 out of 160 people chose to take part in the study.

Nearly half of people independently consented to take part.

Very few people living with their families decided to take part.

A quarter of people answered all the questions themselves. Other people asked or needed someone to help them.

Most people found the information booklet useful and easy to understand.

People who used the showcards found them useful.

**'It was a privilege, I was proud to tell her all about me, and how I was getting on and all the things I do in my life. I liked it when she came to visit me because I like people to visit me, I liked her company and I told her I was very happy.'**



Barry Griffin, Pilot Study Participant, Western Care Association 2009



## Next steps

Make sure everyone knows that people can have support to do the study.

Changes have been made to the information leaflet and consent form.

The interviewers and people who took part thought some changes also needed to be made to the questions.

All of the changes have been talked about by people with an intellectual disability, families and other professionals.

The main study will start in January 2010.

'The study being undertaken by IDS-TILDA will help us plan for the future needs of people with an intellectual disability and will provide us with very important and very necessary information. It is a much welcome development.'

Ms Deirdre Carroll, CEO, Inclusion Ireland 2009



## Entrants of the Logo Design Competition

Ann O'Brien, Ann Glynn, Betty Jago, Patricia Dunne, Philomena Murray, Audrey Downs, Geraldine Gray, Kathleen McGannon, Meave Murphy, Mary Gillen, Orla O'Brien, Philomena O'Brien, Pauline O'Connor, Bernadette O'Connell, Bridget Farrelly, Roseanne Houston, Christina Mooney, Marie Therese Corbett, Mary McCormack, Enda Hegarty, Mary Ellen McHugh, Tom Wilson, Gerard Moran, Martin Quinn, Mary Walsh, Brian Slevin, Patricia Maloney, Mark Duffy and Bernie Fox.

Together lets work towards making Ireland the best place to grow older

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