



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin



An Intellectual Disability Supplement to
the Irish Longitudinal Study on Ageing

Understanding Family Strategies that Enable Long Term and Sustainable Home Environments for Older People with an Intellectual Disability.

Study Team

Dr. Damien Brennan, Prof. Mary McCarron, Prof. Philip
McCallion, Marianne Griffiths, Rebecca Murphy.

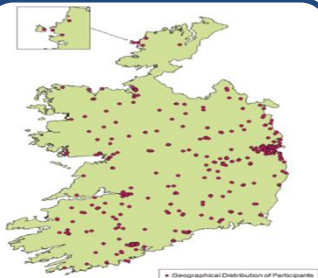


IDS-TILDA



Intellectual Disability Supplement to TILDA

- Identifying the principal influences on ageing
- Comparable with the general population study – TILDA
- Random sampling – National ID Database
- Elements – PIQ, Face to Face, Family Carer Questionnaire
- Inclusion – 40+Age, NIDD registered



Wave 1: 2010

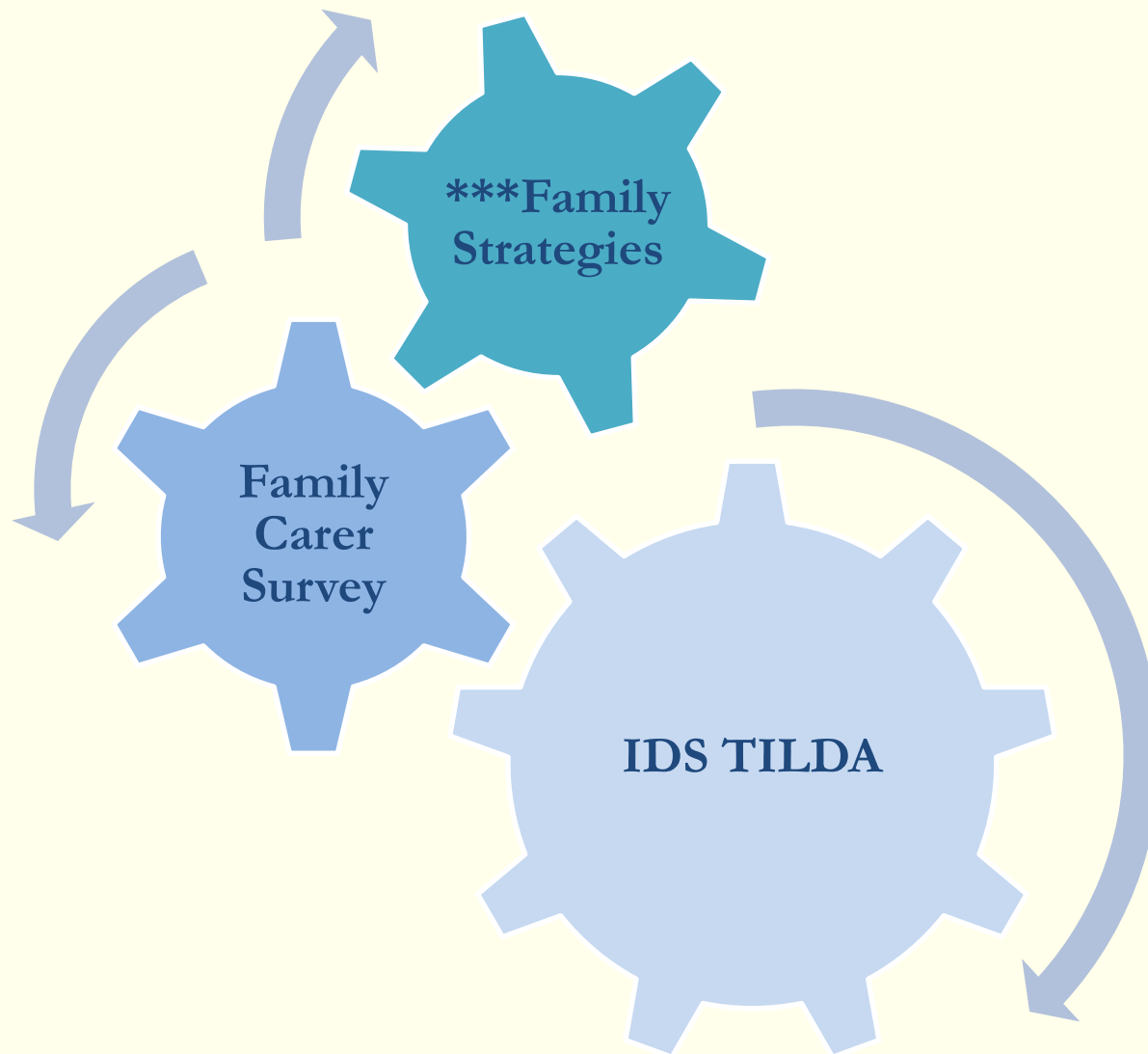
- 753 Participants
- 138 Services
- All levels of ID
- 55% Female; 45% Male
- Age 41 – 90 years
- All living circumstances



Wave 2: 2013

- Similar Elements W1- W2 – additional objective measures, end of life
- 95% Retention. 708 participants (55.6% Females; 44.4% Males)

IDS TILDA & Family Carers



Aims & Objectives

Aim

- To describe family strategies that enable long term and sustainable home environments for older people with an Intellectual Disability.

Objectives

- Describe the decision making process within families caring for an older person with an ID
- Illuminate barriers and enablers for families with an older person with ID
- Identify best practice for supporting families with an older person with ID

Study Design

- **Qualitative Study Design**
 - Six focus groups with family carers
 - One focus group with family members with ID
- **Sample**
 - Purposive - Family carer questionnaire sample
- **Recruitment**
 - Postal recruitment packs & telephone follow up
- **Data Analysis**
 - Thematic utilising Nvivo

Study Design Process

- **Responding to families' needs**
 - Feasibility of focus group with family carers
 - Introduction of supplementary 1-1 interviews
 - 6 transcripts >>> 11 transcripts

- **Responding to families' concerns**
 - Feasibility of focus groups with family members with ID
 - Exploring alternatives
 - IDS TILDA networks with consultation groups

Data Collection

Five Focus Groups

- Cork
- Limerick
- Laois
- Louth
- Dublin

Six 1-1 Interviews

- Cork (x2)
- Limerick
- Offaly
- Wexford
- Leitrim



Emerging Findings

- **Barriers & Enablers to Family Caregiving**
 - Psychosocial capacity, formal & informal networks
- **Policy in Reality**
 - Ideology Vs. Practicality
- **Transitions of Family Caregiving**
 - Past, present, & future

Barriers & Enablers

Formal Supports

“I would die without that centre, talk about being chained to the Dail, ye’d find me day and night, they couldn’t do that, they just couldn’t” (Participant, Urban Focus Group)

“It’s their life, we may have jobs, friends, hobbies but I feel that with {sister’s name}, that is her life. I am only a part of it but her main life is the centre” (Participant, Urban Focus Group)

Barriers & Enablers

Informal Supports

“I haven’t anybody, I used to have a cousin and she used to take her but that’s kind of stopped over the last 2-3 years, [...] I do resent the fact that my two sisters aren’t involved, I do” (Participant, Urban Focus Group)

“none of her family have any interest. I have three sisters, counting carmel, four brothers and none of them, they’re gone, carmel doesn’t exist as far as their concerned. Some of them don’t come to see her, once a year and they feel that is their duty done and nobody has given one cent towards her up-keep, not one cent” (Participant, Urban Focus Group)

Barriers & Enablers

Fundamental Resilience & Love

As the fella said, carry on and do the best you can (Participant, 1-1 Interview, Urban)

Whatever comes, it comes, we'll struggle through it. I mean if the worst comes to the worst, I can always go outside and cut down a few ash trees and hope the neighbours won't mind, we'll get by somehow (Participant, Rural Focus Group)

I absolutely adore her, I love her and she is the grandparent that they didn't have, that the kids didn't have (Participant, Urban Focus Group)

Policy in Reality

“It’s not one size fits all, services are moving towards more independence and that’s grand, that’s advancement but for people of that era, age I don’t know, I don’t think, it’s the change of routine which can disrupt them so much” (Participant, 1-1 Interview, Rural)

“the government came up with this idea of taking people out of the institutions and put them into local communities which is grand, grand idea, but you have to follow it up with backup and with money and they haven’t. They have just withdrawn them all [...] and sort of have forgotten about them, they are the forgotten of Ireland” (Participant, 1-1 Interview, Rural)

Transitions of Family Caregiving

“My mother died and of course (brother’s name) had to be cared for, so I was the single one out of the other 10, they were all married and had children and families and had a life going on as the saying goes, so I said well somebody has to look after him. I didn’t see the option of putting him anywhere, I didn’t see that, it wouldn’t have been what I would have wanted for him”
(Participant, 1-1 interview, Urban)

“He would wreck her (daughter’s) family [...] She could never cope with (name), her life would be over, I mean he takes a lot of looking after, [...] (child’s name) would grow up without her mom” (Participant, 1-1 Interview, Urban)

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Working
to make Ireland
the best
place to grow
older

thank you



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