



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

Executive Summary

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THE INTELLECTUAL DISABILITY SUPPLEMENT TO THE IRISH LONGITUDINAL STUDY ON AGEING

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The research team wish in particular to thank the carers and people with an intellectual disability who participated in this study. Their generosity in taking time to share their unique insights into caring in the family setting is much appreciated. It is hoped that this study will contribute to a fuller understanding and better recognition of this important caring relationship.

Executive Summary

Most people with an Intellectual Disability (ID) in Ireland now live with their family and people with an ID are now living longer (outliving their parents in most cases). This reflects both family desires to provide such care within the home and public policy expectations that there will be less reliance on out of home care with associated costs and that people with ID be maintained in their own homes and communities to the greatest extent possible. There is a long established literature on the stresses and strains that family carers experience but little data on successful family strategies and family and community characteristics that enable long-term and sustainable family environments for people with an ID as they age.

Study Aim

The overarching aim of this study was to describe family strategies that enable long term and sustainable home environments for older people with an Intellectual Disability.

Study Objectives

The objectives of the study were to;

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

Research Process

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) is the first ever such study to be conducted in Ireland or in the EU. With its nationally representative sample, and opportunities for comparisons with the general population, IDS-TILDA is increasing understanding of how lives change in the ageing of people with intellectual disability. Integral to Wave 2 of IDS-TILDA is the “Carer’s Self-Completion Questionnaire” which has been completed with 62 carers of older people with an ID living within family settings. This questionnaire highlights key areas of concern for these carers and families. Funding from the NDA has enabled more in-depth interviews and focus group meetings to be conducted with a purposeful sample of these family carers; providing a rich source of qualitative data specifically focusing on the internal family strategies that sustain older people with an ID within the family context.

- Data for this study was gleaned from in-depth interviews and focus group meetings with 17 family carers.

- Participants were recruited from a pre-existing pool of 62 family carers of older people with an ID living within family settings who had completed the 'carer's self-completion questionnaire' in Wave 2 of the IDS-TILDA study. From this sample, 48 family carers had consented to be contacted again about future research.
- In total, 17 out of the 48 family carers contacted participated in this study.
- 5 focus groups and 6 one-to-one interviews were recorded and transcribed and analysed.
- Study findings were further validated through consultation with an IDS-TILDA advocate who has an ID.

Key Findings

Literature Review findings

A review of the literature indicated that there are a variety of push-pull factors which may facilitate or hinder family capacity to support their family member with an ID in the home. Some of these push-pull factors are:

- **Formal supports:** There is a general consensus in the research literature that an adequate provision of quality and appropriate formal support services (e.g. day centres, supported employment, respite care, domiciliary support, and financial support) is integral to assisting the sustainability of family caregiving. However, previous research has found that relations between services and families can be tenuous with family carers reporting deficits in the supply and quality of formal support services for older people with an ID, and their level of respectful engagement and involvement with families.
- **Relational caregiving:** There is increased evidence that family caregiving is not a dyadic relationship between carer and care recipient. Family members with an ID offer many positive contributions to the family system including practical care tasks, emotional support, and companionship. Such reciprocity of caregiving may assist to inform the longevity of family caregiving.
- **Family coping and adaptation:** Contemporary research suggests that over time family carers' demonstrate potential to adapt and develop resilience to the challenges of family caregiving. The development of caregiving expertise and utilisation of accommodative and problem solving coping strategies are associated with positive wellbeing. Further, current research also suggests that a family's attitudinal perspective can also mediate the effect of caregiving challenges and thus assist to sustain family caregiving capacity.
- **Compound caregiving:** Research literature suggests that the incidence of compound family caregiving is increasing and will continue to do so in forthcoming years. Family carers' adoption of additional caregiving roles, to

various members of their family, may have a detrimental impact on caregiver's quality of life and wellbeing. This in turn may result in a reduction in the long-term sustainability of family caregiving.

Empirical research findings

Present sustainability of family caregiving

- A fundamental love, devotion, and commitment between family carers and their family member with an ID appeared to inform the longevity of caregiving within the family home. However, such 'love labour' within the family setting is difficult to measure and cost.
- Family caregiving capacity was compromised by evident limitations and anomalies in the systemic carer support system, namely the efficient administration and equitable dissemination of the carer's allowance, and the reduced and varied availability of respite care.
- The current direction and 'one size fits all' approach of contemporary ID policy was deemed by many families to be incongruous with the needs of the older age cohort of people with an ID, including individuals with dementia, and/or severe and profound ID. As a result, many of the family carers argued that ID policy and its subsequent implementation required adequate revision to ensure the needs of the aforementioned groups were explicitly addressed.
- Many of the family carers desired increased recognition from the government and ID services of the integral, economically efficient role they played in supporting their family member with an ID by ensuring that families are perceived and treated as equal working partners in the formation and implementation of present and future care plans of their family member with an ID.
- Sibling caregivers in particular felt physically, psychologically, and intellectually restricted and unsupported in their primary carer role.
- Daily ID services (e.g. day services, workshops, training centres) were perceived by family carers to play an integral role in maintaining family caregiving capacity. However, recent policy-driven changes to the location, format, and operation of day services were raising concerns for many of the family carers as they questioned the suitability of such changes to the older cohort of people with ID, of who garnered great solace in a consistent, familiar, and long-established routine.

Future sustainability of family caregiving

- Many of the families' future care plans were not discussed between family members and were demonstrably aspirational in nature. In many cases, this eventually led to acrimonious family relations, in addition to emergency and crisis care planning for their family members with an ID.
- While for some families the future sustainability of family caregiving was deemed to be possible, the majority of families articulated that they represented the last remnant of family caregiving capacity existing within the family. As a result, they felt their family member with an ID would require residential services in the future.
- The future need for amplified tailored residential service provision for the older cohort of people with an ID, who bestride both the older age and ID sectors, necessitates clarification as to which governmental department bears responsibility for ensuring the described needs of an ageing population of people with ID are satisfied.
- The current deficit of research exploring family caregiving capacity in Ireland, particularly within the ID sector, needs to be addressed. Study findings suggest that pertinent future research endeavours should include;
 - Comprehensive elucidation of how family caregiving capacity and its subsequent sustainability may differ in accordance with the evident heterogeneity of carer recipients' needs
 - Further exploration of the mediating role fundamental love and devotion between family members may play in prolonging the longevity of family caregiving capacity.
 - The development, implementation, and evaluation of pilot interventions pertaining to families' future care planning and service innovations to support older people with ID to age in place.

Dissemination Plan

- **Report Publication:** A Full Report and an Accessible Easy-read Version will be published in 2016 and circulated to key policy makers, including the Department of Health and Children, the Health Service Executive, NGO's service Providers, Carers and People with an ID.
- **Conference Presentation:** Emerging study findings have been presented at the Care Alliance Ireland November 2015 conference. Two additional papers

will be presented at the upcoming 2016 IASSIDD 2016 World Congress in Melbourne, Australia.

- **Journal Publications:** Three articles have been drafted and will be submitted for peer review in 2016.
 - Questioning the feasibility of ID policy; the narratives of family caregivers supporting older people with an Intellectual Disability.
 - 'Love labour' and caring for older people with an Intellectual Disability within the family home environment.
 - The diminishment of family caregiving capacity for older people with an intellectual disability.

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TILDA)

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