

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

Final Report

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**The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing  
(IDS-TILDA)**

*Making Ireland the best place to grow older*

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## **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. They questioned the suitability of such changes for 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 papers were presented at the 2016 IASSIDD 2016 World Congress in Melbourne, Australia and one at the IGS 2016 Annual conference
- **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.

## Introduction

Currently in Ireland, families are the main providers of support for people with Intellectual Disabilities (ID). Sixty seven per cent of those registered on the National Intellectual Disability Database (NIDD) live at home with parents, siblings, relatives or foster parents, with 30% aged 35 years and older with a moderate to profound level of intellectual disability living at home/with family.<sup>1</sup> This situation is forecasted to continue into the future as it aligns with the desire of people with ID and their families to maintain primary support within the home for as long as possible and with Irish public policy which seeks to relocate the care of people with intellectual disabilities from large and socially isolated congregated settings into family homes and communities.<sup>2</sup> It is hoped that in so doing, people with an intellectual disability will experience a full and inclusive life within the community. The care of people with ID in the family home offers advantages, including enhanced quality of life along with major exchequer savings through the reduced reliance on fulltime residential care, and the increased probability of facilitating the desires of people with ID for community living. However, there are a number of challenges to its' successful realisation which require explicit elucidation. For example, it must be acknowledged that the success of such contemporary ID policy is decisively dependent on the capacity of families and family homes to provide care and infrastructure which is conducive to meeting their family member with ID's changing needs across their lifespan.

To date, research evidence explicating successful family strategies that enable long term and sustainable family caregiving capacity to people with ID is demonstrably limited. This study, "*Understanding Family Strategies that Enable Long Term and Sustainable Home Environments for Older People with an Intellectual Disability*", provides pertinent data to redress this evident knowledge deficit. Most pertinently, this study, nestled within its' parent study IDS TILDA (Intellectual Disability Supplement to The Irish Longitudinal Database on Ageing) which is the largest, most comprehensive, and nationally representative longitudinal study of people aged 40 years and over with an ID in Ireland, is strategically placed to expedite our increased and contextual understanding about the challenges, needs, and sustainability of families supporting their family members with ID in the home.<sup>3</sup> Consequently, it will also assist in informing both the feasibility of current, and the development of future, public health policy.

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<sup>1</sup> Kelly, C. (2015), **Health Research Board Statistics Series 28, Annual Report of the National Intellectual Disability Database Committee 2014**. Dublin: Health Research Board.

<sup>2</sup> Health Service Executive (2011), **Time to Move on from Congregated Settings: A Report from the Working Group on Congregated Settings**, Dublin: Health Service Executive.

<sup>3</sup> McCarron, M., Swinburne, J., Burke, E., McGlinchey, E., Mulryan, N., Andrews, V., and McCallion, P. (2011). **Growing Older with an Intellectual Disability in Ireland 2011: Results from the Intellectual Disability Supplement of the Irish Longitudinal Study on Ageing**. Dublin: School of Nursing and Midwifery, Trinity College Dublin.

# Research Approach and Methodology

## Study design and data collection methods

This study is nested within its parent study of the IDS TILDA.<sup>4</sup> The IDS TILDA study is the only, most comprehensive and nationally representative longitudinal study of people aged 40 years and older with an intellectual disability in Ireland. Initiated in 2008, the IDS TILDA study has now completed two waves of longitudinal data collection. Wave 1 in 2010 and Wave 2 in 2013 included a pre-interview questionnaire and an extensive face to face computer assisted interview which comprehensively captured a participant with ID's psychological and physical health, behavioural and lifestyle components, and their health care utilisation. Also included in Wave 1 and Wave 2 of IDS TILDA's data collection methods was a carer's self-completion questionnaire which aimed to garner quantitative data on family carers' experiences of supporting their family member with an ID.

In order to complement and further elucidate the quantitative data garnered from IDS TILDA's carer self-completion questionnaire, a qualitative study design was employed for this nested study. The strengths of qualitative research include its exploratory capacity, flexibility, and emphasis on the subjective experience of the participant, including their interpretation and meaning of events.<sup>5</sup> The qualitative data collection tools of focus groups and semi-structured one to one interviews were utilised. The hallmark of focus groups is their explicit facilitation of group interaction and discussion to produce valuable comparative and contrasting data and insights<sup>6</sup>, in addition to providing rich, concentrated data on a specific topic. In order to respond to family carers articulated difficulties in attending a focus group due to the all-encompassing nature of the caregiving role and/or compromised health status, semi-structured one to one interviews were introduced to the methodology. Like focus groups, one to one interviews facilitate in depth insight into people's unique experiences, and their perceptions, and understandings of same. The focus groups and the one to one interviews were semi-structured in format in order to foster their exploratory capacity and thus allow the emergence of surprising and unanticipated findings, but also to ensure the study aims and objectives were satisfied and to provide a common framework across all data sources. Five focus groups and six supplementary interviews were conducted.

## Study sample and recruitment

Potential participants were recruited from the 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. This pre-existing pool of 62 carers comprised of both sibling and parent carers with diverse socio-demographic backgrounds (i.e. age, gender, socio-economic status) and geographical locations. Of these, 48 had indicated that they would be willing to participate in future research.

Recruitment packs (See Appendix 1, 2, 3) consisting of an invitation letter, information sheet, and consent form were posted to 48 out of the pre-existing pool 62 family carers<sup>7</sup>. The recruitment pack provided comprehensive information about the purpose of the study, data collection

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<sup>4</sup> McCarron, M., Swinburne, J., Burke, E., McGlinchey, E., Mulryan, N., Andrews, V., and McCallion, P. (2011). **Growing Older with an Intellectual Disability in Ireland 2011: Results from the Intellectual Disability Supplement of the Irish Longitudinal Study on Ageing**. Dublin: School of Nursing and Midwifery, Trinity College Dublin.

<sup>5</sup> Sarantakos, S. (2012), **Social Research**, London: Palgrave Macmillan.

<sup>6</sup> Morgan, D.L., (1996), Focus Groups. **Annual Review of Sociology**, 22, 129-152.

<sup>7</sup> 53 of the pre-existing pool of 62 carers had consented to be contacted again. Out of the consenting 53, 1 family carer had passed away, and 4 carers were already taking part in a different IDS TILDA sub-study. The remaining sample from which to recruit from subsequently comprised of 48 carers.

procedures, the potential advantages and disadvantages of their participation, and the ethical issues of voluntary participation, informed consent, and confidentiality. Following the distribution of recruitment packs, family carers were subsequently contacted by telephone, during which the information contained within the recruitment packs was verbally explained and their interest in participation garnered. 17 family carers (15 from pre-existing pool + 2 additional partner/spouses) consented to be interviewed. From the remaining cohort of the pre-existing pool of family carers, 7 were interested but could not attend during the data collection period, 12 were not interested in participating, 11 were uncontactable, and 3 were no longer eligible as their family member with an ID had since moved into residential care.

Rich, in-depth data was gathered from 17 family carers who were currently supporting their family member with an ID in the home environment (See Table 1. for participant and care recipient profiles). In the event, whilst the sample size of focus groups was small (n=2-3), five focus groups and six supplementary one to one semi-structured interviews were conducted, giving a total sample number of 17 family carers (7 sisters, 1 sister in-law, 6 parents, 3 brothers). Focus groups and interviews were conducted in Dublin, Cork, Limerick, Louth, Wexford, Offaly, Laois, and Leitrim.

### **Focus group/interview locations**

Participants were encouraged and facilitated to select a venue and site that was most convenient to them. In the event, focus groups were conducted in Trinity College Dublin (n=1), in an ID service (n=1) or in a local hotel (n=3). The one to one interviews were conducted in participants home (n=5), or in a hotel (n=1).

### **Conduct of focus groups/interviews**

Light refreshments were offered to participants on arrival and they were invited to sit in a circle around the centrally placed dictaphone in order to maximise participation. Immediately prior to the commencement of the focus groups, the researcher provided a brief introduction about the study, its purpose, and the specific topics under discussion, before obtaining written informed consent from all the participants.

The focus group discussions were then initiated by the researcher asking the opening question on the interview guide (Appendix 4). As the discussion continued, the researcher only interjected as and when necessary with topical follow up prompts and/or elaborative questions (e.g. compare/contrast, elicitation of real life examples, and further elaboration or clarification questions). Close attention was given to listening for topics/issues that were not on the interview guide but which the participants instigated discussion on to ensure all emerging findings could be fully elaborated on and investigated thoroughly. In addition, participant body language and non-verbal cues were also closely observed to ascertain participant comfort levels with the topics under discussion and to ensure all of the participants were provided with equal opportunity to share their views and experiences. When all topics on the interview guide were discussed and the participants were content that the discussion had covered all relevant topics and issues, the researcher thanked all the participants for their valuable input and time and drew the focus group session to a close. The duration of focus groups was approximately 90 minutes.

**Table 1. Participant and Care Recipient Profile**

Participant Pseudonym	Gender	Age	Health Conditions		Care recipient (CR)	CR Age	CR Level of ID	CR Health Conditions	Location	Focus Group/ Interview
<b>1 - Rose</b>	Female	66-75	N/A		Sister	50-64	Moderate	Thyroid	Rural	I-I Interview
<b>2 - Patricia</b>	Female	72	N/A		Son	40-49	Moderate	Gastric reflux, Cerebral palsy, Arthritis	Urban	Focus group
<b>3 - Mary</b>	Female	55	Back pain, Anxiety, Depression, Aching Joints, High BP, Headaches, Stress,		Sister	40-49	Moderate	Asthma, Thyroid	Urban	Focus group
<b>4 -Eileen</b>	Female	56-65	Rheumatoid arthritis		Sister	40-49	Mild	N/A	Urban	Focus group
<b>5 - Breda</b>	Female	66-75	N/A		Son	40-49	Moderate	N/A	Rural	Focus group
<b>6 - Martin</b>	Male	76-85	N/A		Son	40-49	Moderate	N/A	Rural	Focus group
<b>7 - Gerard</b>	Male	68	Rheumatoid arthritis, Back pain, Diabetes, Urinary incontinence, Anxiety, Depression, High BP, Stress, Headaches.		Son	40-49	Severe	N/A	Urban	I-I Interview
<b>8 - Tom</b>	Male	79	Aching joints		Daughter	40-49	Moderate	Osteoporosis, Epilepsy	Urban	I-I Interview
<b>9 - Lilian</b>	Female	84	High BP		Daughter	40-49	Moderate	N/A	Rural	I-I Interview
<b>10 - Kathy</b>	Female	56-65	Lymphedema, Anxiety, Depression, Headaches, Stress.		Brother	40-49	Moderate	Schizo-affective disorder	Urban	I-I Interview
<b>11 - James</b>	Male	53	Osteo-arthritis, Stress,		Sister	40-49	Moderate	Query onset dementia, hearing difficulties	Rural	Focus group

Participant	Gender	Age	Health Conditions	Care recipient (CR)	CR Age	CR Level of ID	CR Health Conditions	Location	Focus Group/ Interview
<b>12 - Elaine</b>	Female	46-55	N/A	Sister in Law	40-49	Moderate	Query onset dementia, hearing difficulties	Rural	Focus group
<b>13 - Pat</b>	Male	56	Back pain, Anxiety, Depression, High BP, Stress, Headaches.	Brother	50-64	Mild	N/A	Rural	Focus group
<b>14 - Joe</b>	Male	56-65	N/A	Sister	50-64	Mild	Diabetes	Rural	Focus group
<b>15 - Ann</b>	Female	56-65	High BP	Brother	40-49	Mild	N/A	Rural	I-I Interview
<b>16 - Sheila</b>	Female	50	Headaches, Stress.	Sister	40-49	Mild	N/A	Urban	Focus group
<b>17 - Carol</b>	Female	46-55	N/A	Sister	40-49	Mild	Dementia, Thyroid, Osteoporosis	Urban	Focus group

The conduct of the supplementary one to one interviews followed the same process and format to the focus groups. After a brief summary of the study and obtaining written informed consent, interviews began with the researcher asking the initial question on the interview guide. As the interview continued, the researcher utilised prompt questions to explore participant led topics and to ensure all the topics on the interview guide were discussed in sufficient depth and breadth. At the end of the interviews, the researcher thanked the participants for their valuable contributions. The duration of interviews lasted on average, between 60 and 90 minutes.

## Data analysis

Focus groups and interviews were recorded, transcribed and analysed thematically.<sup>8,9</sup> Individual transcripts were read numerous times, open codes identified, and subsequently condensed into general themes. The next stage of data analysis included an examination of open codes to begin the process of axial coding which assisted in identifying the relationships and connections between themes, as well as the conditions which gave rise to these occurrences including context, interactions and consequences. Once complete, codes for individual transcripts were subsequently compared, with minor modifications made to include data of relevance to the topic, but which was not necessarily discussed by all participants. This process provided repeated opportunities for the research team to cross-check the raw data against emergent themes, thus ensuring analytical

<sup>8</sup> Attride-Stirling, J., (2001), 'Thematic Networks: An Analytic Tool for Qualitative Research', **Qualitative Research**, 1 (3), pp. 385-407

<sup>9</sup> Mason, J. (2002), **Qualitative Researching**. London: Sage.

development was robust, rigorous and trustworthy. Coded transcripts were entered into NVivo and the final stages of thematic analysis, whereby examining associations and discrepancies in the coded data, were completed. The coding system was discussed within the team and subsequent feedback was fed into the data coding structure. Study findings were also subsequently validated by an advocate with an ID.

### **Ethical considerations**

Ethical approval for this study was received from the Research Ethics Committee of the Faculty of Health Sciences in Trinity College Dublin. All participants were provided with both written and verbal information about the study, which specifically outlined study procedures, the risks and benefits to taking part, in addition to the protocols associated with confidentiality, voluntary participation, and the protection of participants' wellbeing. Prior to every focus group and interview, the researcher verbally reiterated to all participants that their participation was voluntary and they could choose not to answer any question if they so wished, or to stop the interview and/or withdraw from the study at any stage. Participants were also verbally assured that their confidentiality was strictly protected at all stages and that all data files were password protected and stored in accordance with the Data Protection (Amendment) Act 2003. During two of the one to one interviews, family carers became visibly upset whilst sharing their experiences. The researcher reminded the participants that their wellbeing was of utmost importance and that they could take a break and recommence the interview at a later stage or withdraw from the study if they so wished. However, both carers decided to continue the interview. At the end of all the interviews and focus groups, the researcher spent time ensuring all the participants felt comfortable with how the discussion went and their participation in it.

# Literature Review

## Introduction

In 2014, 11,504 of the 27,887 people registered on the National Intellectual Disability Database were 35 years of age or more and approximately 30% of this cohort lived at home with family (n=3,451).<sup>10</sup> This most recent report from the NIDD also reveals that people with ID's increased life expectancy has led to an increased demand for full-time residential services, in addition to higher levels of support when attending day services. In fact, the NIDD estimates that 2,168 new residential places will be required during the period 2015-2019; 57% of which are needed by those aged 35 years or over.<sup>11</sup> Whilst it is unclear what exact proportion of this 57% are people currently living at home, this data from the NIDD appears to indicate that family caregiving capacity for the older age cohort is already experiencing a decline. Full implementation of 'Time to Move on from Congregated Settings'<sup>12</sup>, a governmental policy directing the transition of 4,000 people with ID from institutionalised settings into the community, is yet to be achieved and there remains 16% of people with ID living within institutionalised settings.<sup>13</sup> Consequently, it may be particularly astute to ensure that an additional rapid influx of older people with ID also requiring residential placements in the community does not emerge from the cohort currently being supported by their families. To date however, despite family carers providing a level of care that it is estimated would cost the state somewhere in the region of between 2.5 and 4 billion euro annually to replicate in formal settings,<sup>14</sup> references to family caregiving and support for same remain relatively absent from contemporary policy, particularly in the ID sector.

This is, however, with the exemption of the National Carer's Strategy (NCS)<sup>15</sup>, launched in July 2012, which mandated that "Carers will be recognised and respected as key care partners. They will be supported to maintain their own health and well-being and to care with confidence. They will be empowered to participate as fully as possible in economic and social life"<sup>16</sup>. The NCS includes 42 action points inclusive of topics such as better recognition of the carer role and contribution, involving carers as partners in care planning and provision, ensuring adequate and timely monetary support, and the further development of formal support systems for carers. However, recent evaluations monitoring the progress of the strategy have explicitly highlighted that many of the strategy's actions points are barely instigated, much less achieved.<sup>17</sup> Worryingly, the strategy's progress with regards some of its' stated action points, including respite resources, was also deemed

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<sup>10</sup> Kelly, C. (2015), **Health Research Board Statistics Series 28, Annual Report of the National Intellectual Disability Database Committee 2014**. Dublin: Health Research Board.

<sup>11</sup> Kelly, C. (2015), **Health Research Board Statistics Series 28, Annual Report of the National Intellectual Disability Database Committee 2014**. Dublin: Health Research Board.

<sup>12</sup> Health Service Executive (2011), **Time to Move on from Congregated Settings: A Report from the Working Group on Congregated Settings**, Dublin: Health Service Executive.

<sup>13</sup> Kelly, C. (2015), **Health Research Board Statistics Series 28, Annual Report of the National Intellectual Disability Database Committee 2014**. Dublin: Health Research Board.

<sup>14</sup> Care Alliance Ireland (2015) **Family Caring in Ireland**. Retrieved from <http://www.carealliance.ie/userfiles/file/Family%20Caring%20in%20Ireland%20Pdf.pdf>

<sup>15</sup> Department of Health (2012), **'The National Carers' Strategy-Recognised, Supported, Empowered'** Dublin: Brunswick Press LTD.

<sup>16</sup> Department of Health (2012), **'The National Carers' Strategy-Recognised, Supported, Empowered'** Dublin: Brunswick Press LTD, p.9.

<sup>17</sup> Carers Association Ireland (2015), **'Family Carers' Scorecard: What Has the National Carers Strategy Achieved? An Assessment of Progress from the Perspective of Family Carers'**. Retrieved from [http://www.carersireland.com/userfiles/file/Family%20Carers%20Scorecard%20Summary\(4\).pdf](http://www.carersireland.com/userfiles/file/Family%20Carers%20Scorecard%20Summary(4).pdf).

to be regressive. Whilst support for family caregiving appears to be experiencing inertia, the adequate acknowledgment of older people with an ID is also lacking within contemporary policies in the ID sector. For example, 'New Directions; Review of HSE Day Services and Implementation Plan 2012-2016'<sup>18</sup> specifically denotes a transformation of how day services are configured and implemented, yet there is no explicit acknowledgment of how such a transformation may impact on or be tailored to the complex and distinct needs and capacities of the older cohort of people with ID and the implications of this for family caregivers. Similarly, older people with ID are largely absent from policy documentation within the aged sector, with the notable exception of the Irish National Dementia Strategy.<sup>19</sup> Such an arguable invisibility within policy discourse and implementation may severely impinge on the sustainability of family caregiving for older people with an ID as the facilitation to and development of tailored supports and responses to their distinct and complex needs do not appear to be forthcoming in the immediate future.

In light of this Irish context, this literature review aims to provide a comprehensive overview of current research evidence pertaining to family caregiving capacity in the intellectual disability sector, including facilitators and barriers to its sustainability. The search for relevant literature comprised of both formal and informal strategies. The formal search strategy included inserting multiple combinations of MESH keywords such as, but not limited to, 'intellectual disabilities', 'family carer', 'caregiver', 'sibling carer', 'family strategies', 'family resilience', 'future care planning', into electronic databases PUBMED, Academic Search Complete, MEDLINE, and CINAHL. Citations yielded from the formal search strategies were assessed for relevancy to the study topic and full texts retrieved for further examination and inclusion into the literature review. Informal strategies included the identification and retrieval of relevant literature which was cited in the studies yielded from the formal search strategy. In addition, the publication histories of evidently prolific authors in the specific field of inquiry were examined and full texts of the pertinent publications within same were recovered. Grey literature was accessed via google and google scholar utilising the same keywords as previously outlined, along with searches of websites of a broad range of governmental, non-governmental, community, and voluntary organisations.

The literature review revealed that to date research efforts have primarily focused on the stresses and strain that family carers' experience. Consequently, there is a commensurate deficit of available evidence 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. Nevertheless, there is a vast amount of applicable evidence which will assist to contextualise and thus inform the development of this specific research topic. In this light, this literature review presents relevant literature within three themes;

- The family carer experience
- Factors mediating family caregiving capacity, and
- Future care planning

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<sup>18</sup> Health Service Executive (2012) '**New Directions Review of HSE Day Services and Implementation Plan 2012-2016**'. Retrieved from <http://www.hse.ie/newdirections/>.

<sup>19</sup> Department of Health (2014), '**The Irish Dementia Strategy**'. Retrieved from <http://health.gov.ie/wp-content/uploads/2014/12/30115-National-Dementia-Strategy-Eng.pdf>

## The family carer experience

Older people with an ID are often considered ‘family-less elderly’,<sup>20</sup> in that they rarely marry or have children.<sup>21</sup> McCarron et al. (2011)<sup>22</sup> identified that 99% of their Irish sample population of older people with an ID were not married and had no children. As a result, older people with intellectual disabilities often rely on their ageing parents and/or midlife siblings for support across their increased lifespan. This can mean that families’ active caregiving, once limited in duration, can now span up to six or seven decades.<sup>23,24</sup> Over the last forty years, research efforts to understand the family carer experience have consistently focused on the challenges and detrimental outcomes of supporting a family member with ID over a prolonged period of time.<sup>25</sup> Often referred to as ‘carer burden’ or ‘carer strain’, innumerable studies have documented that due to the demands and duration of the caregiving role, family carers of older people with ID experience higher rates of social and economic disadvantage,<sup>26,27</sup> in addition to compromised physical and mental wellbeing.<sup>28</sup> The onset of carer strain is by no means inevitable and is now understood to be mediated by a diverse number and types of psychosocial factors, as well as care-recipient characteristics.<sup>29,30,31,32,33</sup> However, it remains noteworthy to acknowledge that carer strain is understood to be a contributing factor informing family carers’ decision to relinquish the caring role and to establish

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<sup>20</sup> Bigby, C. (1997), ‘When Parents Relinquish Care: Informal Support Networks of Older People with Intellectual Disability’, **Journal of Applied Research in Intellectual Disabilities**, 10 (4), pp. 333-344.

<sup>21</sup> Mc Conkey, R., Kelly F, Mannan, H., and Craig, S. (2010), ‘Inequalities in Respite Service Provision; Insights from the National, Longitudinal Study of People with Intellectual Disabilities’, **Journal of Applied Research in Intellectual Disabilities**, 23 (1), pp. 85-94.

<sup>22</sup> McCarron et al. (2011), op.cit

<sup>23</sup> Braddock D., Emerson E., Felce, D. and Stancliffe, R. (2001), ‘Living Circumstances of Children and Adults with Mental Retardation or Developmental Disabilities in the United States, Canada, England and Wales, and Australia’, **Mental Retardation and Developmental Disabilities Research Reviews**, 7 (2), pp. 115–121.

<sup>24</sup> Mulvany F., Barron S., and McConkey, R. (2007), ‘Residential Provision for Adult Persons with Intellectual Disabilities in Ireland’, **Journal of Applied Research in Intellectual Disabilities** 20 (2), pp. 70–76.

<sup>25</sup> Janicki, M., Seltzer, M., and Krauss, M. (1987), ‘Contemporary Issues in the Aging of Persons with Mental Retardation and other Developmental Disabilities’ in **Rehabilitation Research Review**, Washington, DC: DATA Institute, pp., 1-43.

<sup>26</sup> McConkey, R. (2005) ‘Fair Shares? Supporting Families Caring for Adult Persons with Intellectual Disabilities’, **Journal of Intellectual Disability Research**, 49 (8), pp. 600-612.

<sup>27</sup> Black, L and McKendrick, V. (2010), ‘Careful Plans Report’. **Positive Futures Report**, Lisburn. Retrieved from <http://www.positive-futures.net/cmsfiles/downloads/research/Careful-Plans-Report-May-2010.pdf>

<sup>28</sup> Foundation for People with Learning Disabilities (2003), **Planning for Tomorrow**. London: Foundation for People with Learning Disabilities.

<sup>29</sup> Hayden M., and Heller, T. (1997), ‘Support, Problem Solving/Coping Ability, and the Personal Burden of Younger and Older Caregivers of Adults with Mental Retardation’, **Mental Retardation**, 35 (5), pp. 264–372.

<sup>30</sup> Irazabal, M., Marsa, F., Garcia, M., Gutierrez-Recacha, P., Martorell, A., Salvador-Carulla, L., and Ochoa, S. (2012), ‘Family Burden Related to Clinical and Functional Variables of People with Intellectual Disability with and without Mental Disorder’, **Research in Developmental Disabilities**, 33 (3), pp. 796-803.

<sup>31</sup> Maes, B., Broekman, T. G., Došen, A., and Nauts, J. (2003), ‘Caregiving Burden of Families Looking after Persons with Intellectual Disability and Behavioural or Psychiatric Problems’, **Journal of Intellectual Disability Research**, 47(6), pp. 447-455.

<sup>32</sup> Magaña, S., Schwartz, S. J., Rubert, M. P., and Szapocznik, J. (2006), ‘Hispanic Caregivers of Adults with Mental Retardation: Importance of Family Functioning’, **American Journal on Mental Retardation**, 111 (4), pp. 250-262.

<sup>33</sup> Minnes, P., Woodford, L., and Passey, J. (2007), ‘Mediators of Well-being in Ageing Family Carers of Adults with Intellectual Disabilities’, **Journal of Applied Research in Intellectual Disabilities**, 20 (6), pp. 539-552.

crisis respite placement.<sup>34</sup> Such an outcome can evidently result in increased levels of stress for all the family, but specifically for the family member with an ID.<sup>35</sup>

Nevertheless, the strong emphasis that international research has placed on the described detrimental outcomes and challenges of the carer role is being contested. Emerging evidence suggests that despite the challenges of caregiving, families with ID still report comparatively typical levels of wellbeing,<sup>36,37,38</sup> in addition to demonstrating positive perceptions about supporting a family member with an ID.<sup>39,40,41</sup> Consequently, it is now increasingly understood that negative and positive outcomes of caregiving for a family member with an ID can co-exist relatively independently of each other.

## **Factors mediating family caregiving capacity**

This growing evidence illuminating the dual nature of the caregiver experience supports the two-factor model of care giving,<sup>42</sup> which postulates that there are two partially independent pathways to carer outcomes; one challenging pathway and one beneficial pathway. Each pathway is thought to be informed by a variety of push-pull factors, which in turn may facilitate or hinder family capacity to support their family member with ID in the home. In the following section, a number of these push-pull factors will be further examined.

## **Formal supports for families**

Research evidence has reached a general consensus that formal supports, such as day centres, supported employment, education, respite care, domiciliary support, and financial support are pertinently central to facilitating family functioning<sup>43</sup> and thus family capacity to support their family member with ID.<sup>44</sup> Despite this, research also suggests that older people with intellectual disabilities

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<sup>34</sup> Nankervis, K., Rosewarne, A., and Vassos, M. (2011), 'Why do Families Relinquish Care? An Investigation of the Factors that Lead to Relinquishment into Out-of-Home Respite Care', **Journal of Intellectual Disability Research**, 55 (4), pp. 422-43.

<sup>35</sup> MENCAP, (2002), **The Housing Time-bomb: The Housing Crisis Facing People with a Learning Disability and their Older Parents**. London: MENCAP.

<sup>36</sup> Smith, G., and Tobin S., (1993), 'Practice with Older Parents of Developmentally Disabled Adults', **Clinical Gerontologist**, 14 (1), pp. 59-77.

<sup>37</sup> Tobin S., (1996), 'A Non-Normative Age Contrast: Elderly Parents Caring for Offspring with Mental Retardation' in **Adulthood and Aging: Research on Continuities and Discontinuities**, Bengston, V. Ed, Berlin: Springer-Verlag, pp.124-142.

<sup>38</sup> Hayden M., and Heller, T. (1997), 'Support, Problem Solving/Coping Ability, and the Personal Burden of Younger and Older Caregivers of Adults with Mental Retardation', **Mental Retardation**, 35 (5), pp. 264-372.

<sup>39</sup> Grant, G., and Ramcharan, P. (2001), 'Views and Experiences of People with Intellectual Disabilities and their Families (2), the Family Perspective', **Journal of Applied Research in Intellectual Disabilities**, 14 (4), pp. 364-380.

<sup>40</sup> Grant, G. and Whittell, B. (2000), 'Differentiated Coping Strategies in Families with Children and Adults with Intellectual Disabilities: The Influence of Gender, Family Composition and the Lifespan', **Journal of Applied Research in Intellectual Disabilities** 13 (4), pp. 256-275.

<sup>41</sup> Kim, H., Greenberg, J., Seltzer, M., and Krauss, M. (2003), 'The Role of Coping in Maintaining the Psychological Well-being of Mothers of Adults with Intellectual Disability and Mental Illness', **Journal of Intellectual Disability Research**, 47 (4-5), pp.313-327.

<sup>42</sup> Lawton, M., Moss, M., Kleban, M., Glicksman, A., and Ravine, M. (1991), 'A Two-factor Model of Caregiving Appraisal and Psychological Well-being', **Journal of Gerontology: Psychological Sciences**, 46 (4), pp.181-189.

<sup>43</sup> Merriman, B. and Canavan, J. (2007), **Towards Best Practice in the Provision of Respite Services for People with Intellectual Disabilities and Autism**. Galway, Ireland: HSE/NUI Galway/National Parents and Siblings Alliance/Daisychain Foundation.

<sup>44</sup> Ansello, E. and Janicki, M. (2000) 'The Aging of Nations: Impact on the Community, the Family, and the Individual', in **Community Supports for Aging Adults with Lifelong Disabilities**, Janicki, M and Ansello, E, eds. Baltimore: Brookes Publishing, pp. 3-18.

are the recipients of less day care, respite care, social and domiciliary support, and also less input from most health services.<sup>45</sup> Such findings may, in part, be due to the reluctance of ageing family carers to utilise formal services or psychosocial interventions as a result of previous negative encounters, lower expectations of such services and fear that their son/daughter would be removed from their family home.<sup>46</sup> Research in the Irish context confirms that families of people with intellectual disabilities experience many disappointments and struggles with services.<sup>47,48,49,50</sup> In fact, research evidence suggests that the relationship between families and formal ID services can be tenuous. Chadwick *et al.* (2013) stated in their 2013 study<sup>51</sup> that previous research studies<sup>52,53,54,55,56</sup> have frequently reported that families feel that ID services;

- do not receive an adequate amount or quality of services
- do not get sufficient information about and from services
- are constantly fighting for better services
- are not adequately listened to, respected or involved by services
- ignore their expertise as carers for their family members
- are primarily reactive rather than proactive; and
- are uncoordinated, inflexible and unresponsive.

It is perhaps inevitable that such disappointment with, and fighting for services, is considered to have a detrimental impact on a family's ability to support their family member with an ID.

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<sup>45</sup> McConkey, R. and Adams, L. (2001), 'Matching Short Break Services for Children with Learning Disabilities to Family Needs and Preferences', **Child Care, Health and Development**, 26 (5), pp. 429–444.

<sup>46</sup> Ryan, A., Taggart, L., Truesdale-Kennedy, M., and Slevin, E. (2014), 'Issues in Caregiving for Older People with Intellectual Disabilities and their Ageing Family Carers: a Review and Commentary', **International Journal of older people nursing**, 9 (3), pp. 217-226.

<sup>47</sup> Kenny K. and McGilloway S. (2007), 'Caring for Children with Learning Disabilities: An Exploratory Study of Parental Strain and Coping', **British Journal of Learning Disabilities**, 35 (4), pp. 221–228.

<sup>48</sup> McConkey, R. (2005) 'Fair Shares? Supporting Families Caring for Adult Persons with Intellectual Disabilities', **Journal of Intellectual Disability Research**, 49 (8), pp. 600-612.

<sup>49</sup> McConkey, R., Kelly F, Mannan, H., and Craig, S. (2010), 'Inequalities in Respite Service Provision; Insights from the National, Longitudinal Study of People with Intellectual Disabilities', **Journal of Applied Research in Intellectual Disabilities**, 23 (1), pp. 85-94.

<sup>50</sup> Power, A. (2008), 'It's the System Working for the System': Carers' Experiences of Learning Disability Services in Ireland', **Health and Social care in the Community**, 17 (1), pp. 92–98.

<sup>51</sup> Chadwick, D., Mannan, H., Garcia Iriarte, E., McConkey, R., O'Brien, P., Finlay, F., and Harrington, G. (2013), 'Family Voices: Life for Family Carers of People with Intellectual Disabilities in Ireland', **Journal of Applied Research in Intellectual Disabilities**, 26 (2), pp. 119-132.

<sup>52</sup> Dobson B., Middleton, S. and Beardsworth, A. (2001), **The Impact of Childhood Disability on Family Life**. York: Joseph Rowntree Foundation.

<sup>53</sup> Sardi I., Northway R., Jenkins R., Davies R. and Mansell, I. (2008), 'Family Carers' Opinions on Learning Disability Services', **Nursing Times**, 104 (March), pp. 30–31.

<sup>54</sup> Shearn, J. and Todd, S. (1997), 'Parental Work: An Account of the Day to Day Activities of Parents of Adults with Learning Disabilities', **Journal of Intellectual Disability Research**, 41 (4), pp. 285–301.

<sup>55</sup> Summers J., Marquis J., Mannan, H., Turnbull A., Fleming, K., Poston D., Wang, M. and Kupzyk, K. (2007), 'Relationship of Perceived Adequacy of Services, Family-Professional Partnerships, and Family Quality of Life in Early Childhood Service Programmes', **International Journal of Disability, Development & Education**, 54 (3), pp. 319–338.

<sup>56</sup> Yannamani, N., Zia, A. and Khalil N. (2009), 'Family Carers of People with Learning Disabilities: Common Themes across Caring', **Psychiatry**, 8 (11), pp. 441–444.

## Relational caregiving

In much of the research which examines caregiving within the family, the caregiving relationship is narrowly depicted in dyadic terms. Knox (2007, p.289)<sup>57</sup>, drawing upon Lloyds work,<sup>58</sup> argues that such a “categorical distinction between carer and care recipient can distort the relationship between these two parties and work against the interests of both”. Thus, it is argued that focusing on caring dyads detracts from the family system, wherein all family members’ roles and tasks are negotiated, including the roles of both the caregiver and the care recipient. Caregiving in the family is now increasingly considered in relational terms which acknowledge the dynamic nature, mutuality, and interdependence of the family system.<sup>59</sup> Knox and Bigby (2007)<sup>60</sup> describe midlife care of a person with an ID as ‘a negotiated business’ wherein families ‘just get along with their lives together.’ In their study, each member of the family had their roles and certain rules were established in order to conduct ‘family business’. Similarly, Hines *et al.* (2014)<sup>61</sup> refer to a balancing act whereby the ‘pulls’ in terms of the needs of the adult child with autism in this case are balanced with the ‘pulls’ from the rest of the family, as well as the needs of the carer. The traditional carer/care recipient dyadic is also challenged by increasing evidence of the positive contribution that an older family member with an ID offers to the family system.<sup>62</sup> A study by Williams and Robinson (2001)<sup>63</sup>, in addition to others<sup>64,65,66</sup>, revealed that older people with an ID, including those with high support needs themselves, perform practical care tasks, provide emotional support, and are a strong source of companionship for elderly parents. Kramer *et al.* (2013)<sup>67</sup> propose, such reciprocity of caregiving is also evident between older people with an ID and their sibling carers.

## Family adaptation and coping skills

Similar to the evident perceptual shift from the carer/care recipient dyadic to relational and reciprocal caregiving, research evidence now suggests that the once perceived inevitability of carer strain must be challenged. Contemporary research argues that carers’ demonstrate potential to

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<sup>57</sup> Knox, M., and Bigby, C. (2007), ‘Moving towards Midlife Care as Negotiated Family Business: Account of people with intellectual disabilities and their families ‘Just getting along with their Lives together’, **International Journal of Disability, Development and Education**, 54(3), pp. 287-304.

<sup>58</sup> Lloyd, L. (2003), ‘Caring Relationships: Looking beyond Welfare Categories of “Carers” and “Service Users” in Stalker, K ed, **Reconceptualising Work with Carers. New directions for Policy and Practice**, London: Jessica Kingsley, pp.17-55.

<sup>59</sup> Jokinen, N. (2006), ‘Family Quality of Life and Older Families’, **Journal of Policy and Practice in Intellectual Disabilities**, 3 (4), pp.246-252.

<sup>60</sup> Knox, M., and Bigby, C. (2007), ‘Moving towards Midlife Care as Negotiated Family Business: Account of people with intellectual disabilities and their families ‘Just getting along with their Lives together’, **International Journal of Disability, Development and Education**, 54(3), pp. 287-304.

<sup>61</sup> Hines, M., Balandin, S., and Togher, L. (2014), ‘The Stories of Older Parents of Adult Sons and Daughters with Autism: A Balancing Act’, **Journal of Applied Research in Intellectual Disabilities**, 27(2), pp. 163-173.

<sup>62</sup> Williams, V., and Robinson, C. (2002), ‘He Will Finish up Caring for Me’: People with Learning Disabilities and Mutual Care’, **British Journal of Learning Disabilities**, 29 (2), pp. 56-62.

<sup>63</sup> Williams, V., and Robinson, C. (2002), ‘He Will Finish up Caring for Me’: People with Learning Disabilities and Mutual Care’, **British Journal of Learning Disabilities**, 29 (2), pp. 56-62.

<sup>64</sup> Hayley, W., and Perkins, E. (2004), ‘Current Status and Future Directions in Family Caregiving and Aging People with Intellectual Disabilities’, **Journal of Policy and Practice in Intellectual Disabilities**, 1(1), pp. 24-30.

<sup>65</sup> Bibby, R. (2013), ‘I Hope He Goes First’: Exploring Determinants of Engagement in Future Planning for Adults with a Learning Disability Living with Ageing Parents. What are the Issues? **British Journal of Learning Disabilities**, 41(2), pp. 94-105.

<sup>66</sup> Taggart, L., Truesdale-Kennedy, M., Ryan, A., and McConkey, R. (2012), ‘Examining the Support Needs of Ageing Family Carers in Developing Future Plans for a Relative with an Intellectual Disability. **Journal of Intellectual Disabilities**, 16 (3), pp. 217-234.

<sup>67</sup> Kramer, J., Hall, A., & Heller, T. (2013), ‘Reciprocity and Social Capital in Sibling Relationships of People with Disabilities’, **Mental Retardation**, 51(6), pp. 482-495.

adapt and develop resilience to negative physical and mental wellbeing outcomes. Habitually, the 'wear and tear' hypothesis<sup>68</sup> suggests that carer's levels of tiredness and ability to cope is commensurate to the duration of the carer role. Research also suggests that this 'wear and tear' process is further exacerbated by the need to consistently and tirelessly advocate for services and supports for their family member. Conversely, the adaptation hypothesis argues that carers actually learn to progressively adapt over time. This adaptation process is facilitated by their learning of new skills, and the development of expertise which in turn enable carers to cope better.<sup>69,70</sup> Previous research evidence provides support for the adaptation hypothesis by reporting that older parents of adult children with an ID tend to report greater satisfaction and less stress than their younger peers.<sup>71,72, 73</sup> Older caregivers are also proven to be more accepting of their situation and skilful at reframing the meaning of their situation and the challenges they confront than their younger counterparts.<sup>74,75,76</sup>

There is of course, large variation in the coping styles that families develop and employ and not all coping styles are conducive to positive wellbeing. Recently, Piazza *et al.* (2014)<sup>77</sup> argued that strategies to reduce carer strain such as disengagement, distraction, emotion focused coping, cognitive and/or behavioural therapy may provide short term relief, but in the long term offer little contribution in terms of building sustainable resilience within the carer role. Conversely, the use of accommodative coping, whereby a carer adjusts ones goals flexibly in response to a persistent problem, in addition to active 'problem focused' coping strategies, which include planning, positive reinterpretation and growth as well as suppression of competing activities, are respectively associated with positive well-being<sup>78</sup> and lower depressive symptoms.<sup>79</sup> Older carers in Llewelyn *et*

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<sup>68</sup> Johnson, C., and Catalano. (1983), 'A Longitudinal Study of Family Supports to Impaired Elderly,' **The Gerontologist**, 23 (6), pp. 612-618.

<sup>69</sup> Hayden M., and Heller, T. (1997), 'Support, Problem Solving/Coping Ability, and the Personal Burden of Younger and Older Caregivers of Adults with Mental Retardation', **Mental Retardation**, 35 (5), pp. 264–372.

<sup>70</sup> Krauss, M., & Seltzer, M., (1993), 'Current Well-being and Future Plans of Older Caregiving Mothers', **The Irish Journal of Psychology**, 14 (1), pp. 48-63.

<sup>71</sup> Smith, G., and Tobin S., (1993), 'Practice with Older Parents of Developmentally Disabled Adults', **Clinical Gerontologist**, 14 (1), pp. 59–77.

<sup>72</sup> Tobin S., (1996), 'A Non-Normative Age Contrast: Elderly Parents Caring for Offspring with Mental Retardation' in **Adulthood and Aging: Research on Continuities and Discontinuities**, Bengston, V. Ed, Berlin: Springer-Verlag, pp.124-142.

<sup>73</sup> Hayden M., and Heller, T. (1997), 'Support, Problem Solving/Coping Ability, and the Personal Burden of Younger and Older Caregivers of Adults with Mental Retardation', **Mental Retardation**, 35 (5), pp. 264–372.

<sup>74</sup> Grant, G., and Ramcharan, P. (2001), 'Views and Experiences of People with Intellectual Disabilities and their Families (2), the Family Perspective', **Journal of Applied Research in Intellectual Disabilities**, 14 (4), pp. 364-380.

<sup>75</sup> Grant, G. and Whittell, B. (2000), 'Differentiated Coping Strategies in Families with Children and Adults with Intellectual Disabilities: The Influence of Gender, Family Composition and the Lifespan', **Journal of Applied Research in Intellectual Disabilities** 13 (4), pp. 256–275.

<sup>76</sup> Kim, H., Greenberg, J., Seltzer, M., and Krauss, M. (2003), 'The Role of Coping in Maintaining the Psychological Well-being of Mothers of Adults with Intellectual Disability and Mental Illness', **Journal of Intellectual Disability Research**, 47 (4-5), pp.313-327.

<sup>77</sup> Piazza, V., Floyd, F., Mailick, M., and Greenberg, J. (2014), 'Coping and Psychological Health of Aging Parents of Adult Children with Developmental Disabilities', **American Journal on Intellectual and Developmental Disabilities**, 119 (2), pp.186-198.

<sup>78</sup> Seltzer, M., Greenberg, J., Floyd, F., and Hong, J. (2004), 'Accommodative Coping and Well-being of Midlife Parents of Children with Mental Health Problems or Developmental Disabilities', **American Journal of Orthopsychiatry**, 74 (2), 187.

<sup>79</sup> Seltzer, M., Greenburg, J., and Krauss, M. (1995), 'A Comparison of Coping Strategies of Aging Mothers of Adults with Mental Illness or Mental Retardation', **Psychology and Aging**, 10 (1), 64-75.

al's (2010)<sup>80</sup> study appeared to be utilising such accommodative and problem focused coping strategies when they described a number of beneficial practical coping strategies that they utilised to overcome the challenges of the caring role including 'relying on experience, finding out as much information as you can about a problem, establishing a regular routine and sticking to it, and thinking about a problem and a way to overcome it'. Further to families' practical coping strategies, a family's attitudinal outlook is also believed to influence their appraisal of the caregiving experience. For example, Blacher and Baker (2007)<sup>81</sup> argue that positive personality dispositions (e.g. optimism, empowerment, perceived competence, self-mastery) may minimise the detrimental effect of carer challenges on carer's physical and mental wellbeing, and thus sustain family capacity to remain supporting their family member with an ID in the family home.

### **Compound caregiving**

Lastly, the newly recognised scenario of compound family caregiving also appears to have the potential to influence families' capacity to support their family member with an ID. In the context of intellectual disabilities, compound caregiving can refer to the experience of elderly parents who are already providing support to their older son/daughter with ID, and who subsequently become caregivers for an additional family member.<sup>82</sup> Parents in this position are already lifelong caregivers to their adult child with intellectual disabilities when they adopt an additional caregiving role to, for example, a spouse. The potential outcome of compound caregiving can be role overload, with detrimental implications on caregiver's quality of life and wellbeing. However, to date, there is currently limited evidence to confirm this as Perkins *et al.* (2010)<sup>83</sup> demonstrated in their 2010 comparative study between compound and non-compound carers. Perkins *et al.* (2010) did identify however that in comparison with the non-compound caregivers, the compound caregivers had increased desire to place their son/daughter into residential care, indicating perhaps increased levels of stress and compromised well-being. However, no differences were apparent between the two groups in relation to life satisfaction, depressive symptomatology, physical health, or mental health. Despite these findings, compound caregiving is likely to be an increasingly common scenario in forthcoming years, and may be especially pertinent for the sibling caregivers of adults with an ID, who may potentially experience simultaneously caregiving for elderly parents, their sibling with an ID, and their own children.

### **Future care planning**

The future care plans for a family member with an ID can be a highly anxiety-provoking and emotive issue.<sup>84,85,86,87</sup> As a result, available international evidence suggests that families will avoid making

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<sup>80</sup> Llewelyn, G., McConnell, D., Gething, L., Cant, R., and Kendig, H. (2010), 'Health Status and Coping Strategies among Older Parent-carers of Adults with Intellectual Disabilities in Australia', **Research in Developmental Disabilities**, 31(6), pp. 1176-1186.

<sup>81</sup> Blacher, J. and Baker, B. (2007), 'Positive Impact of Intellectual Disability on Families', **American Journal on Mental Retardation**, 112 (5), pp. 330-348.

<sup>82</sup> Perkins, E. A., and Haley, W. E. (2010), 'Compound caregiving: When Lifelong Caregivers Undertake Additional Caregiving Roles', **Rehabilitation Psychology**, 55 (4), pp. 409-417.

<sup>83</sup> Perkins, E. A., and Haley, W. E. (2010), 'Compound caregiving: When Lifelong Caregivers Undertake Additional Caregiving Roles', **Rehabilitation Psychology**, 55 (4), pp. 409-417.

<sup>84</sup> Bowey, L and McGlaughlin, A (2007), 'Older Carers of Adults with a Learning Disability Confront the Future: Issues and Preferences in Planning', **British Journal of Social Work**, 37(1), pp. 39-54.

<sup>85</sup> Chou, Y., Lee, Y., Lin, L., Kroger, L. and Chang, A. (2009). 'Older and Younger Family Caregivers of Adults with Intellectual Disability: Factors Associated with Future Plans', **Intellectual and Developmental Disabilities**, 47(4), pp. 282-294.

future plans until it becomes unavoidable or will articulate non-definitive aspirational plans (what they would like to happen).<sup>88,89,90</sup> In fact, evidence of families engaging with definitive long-term and emergency planning with their family member with an ID and other family members appears limited.<sup>91</sup> The reasons for families' reluctance in this regard are considered to be complex and multi-factorial. Taggart *et al.* (2012) identified numerable reasons for families' lack of future care plan activity including carer avoidance, carer denial about the inevitability of their own mortality, insufficient support and guidance from service providers, a lack of appropriate residential options, and a worry regarding the quality of out of home placements.<sup>92</sup> In addition, Gilbert *et al.* (2008) and Bowey and McGlaughlin (2007) found that carers were sceptical of services' abilities to provide the same quality of care that their family member received at home, and feared that their family member with an ID would be unable to make their needs known to a staff member with whom they were unfamiliar.<sup>93, 94</sup> Ryan *et al.* (2014) also found that ageing carers believed there was 'plenty of time'.<sup>95</sup> The authors concluded that carers' perception of 'plenty of time' may have been fuelled by their lack of awareness about the considerable duration of time required to secure alternative care options and support outside of the home.

However, it must be acknowledged that one of the strongest reasons for parents' reluctance to make future plans for their adult child with an ID is their expectation or 'hope' that a non-disabled sibling would eventually assume the carer role.<sup>96,97</sup> Such parental expectations are often unexpressed and subsequently parents risk their adult child with an ID receiving inadequate or inappropriate support when they can no longer care for them.<sup>98, 99,100</sup> This is not always the case however as prior

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<sup>86</sup> McConkey R, McConaghie J, Barr, O., and Roberts, P. (2006), 'Views of Family Carers to the Future Accommodation and Support Needs of their Relatives with Intellectual Disabilities', **Irish Journal of Psychological Medicine**, 23 (4), pp.140–144.

<sup>87</sup> Prosser, H. (1997), 'The Future Care Plans of Older Adults with Intellectual Disabilities Living at Home with Family Carers', **Journal of Applied Research in Intellectual Disabilities**, 10 (1), pp. 15–32.

<sup>88</sup> Black, L and McKendrick, V. (2010), 'Careful Plans Report'. **Positive Futures Report**, Lisburn. Retrieved from <http://www.positive-futures.net/cmsfiles/downloads/research/Careful-Plans-Report-May-2010.pdf>

<sup>89</sup> Ryan, A., Taggart, L., Truesdale-Kennedy, M., and Slevin, E. (2014), 'Issues in Caregiving for Older People with Intellectual Disabilities and their Ageing Family Carers: a Review and Commentary. **International Journal of older people nursing**, 9 (3), pp. 217-226.

<sup>90</sup> Taggart, L., Truesdale-Kennedy, M., Ryan, A., and McConkey, R. (2012), 'Examining the Support Needs of Ageing Family Carers in Developing Future Plans for a Relative with an Intellectual Disability. **Journal of Intellectual Disabilities**, 16 (3), pp. 217-234.

<sup>91</sup> Bowey, L and McGlaughlin, A (2007), 'Older Carers of Adults with a Learning Disability Confront the Future: Issues and Preferences in Planning', **British Journal of Social Work**, 37(1), pp. 39–54.

<sup>92</sup> Taggart, L., Truesdale-Kennedy, M., Ryan, A., and McConkey, R. (2012), 'Examining the Support Needs of Ageing Family Carers in Developing Future Plans for a Relative with an Intellectual Disability. **Journal of Intellectual Disabilities**, 16 (3), pp. 217-234.

<sup>93</sup> Gilbert, A., Lankshear, G., and Petersen, A. (2008), 'Older Family Carers' Views on the Future Accommodation Needs of Relatives who have an Intellectual Disability', **International Journal of Social Welfare**, 17 (1), pp. 54-64.

<sup>94</sup> Bowey, L and McGlaughlin, A (2007), 'Older Carers of Adults with a Learning Disability Confront the Future: Issues and Preferences in Planning', **British Journal of Social Work**, 37(1), pp. 39–54.

<sup>95</sup> Ryan, A., Taggart, L., Truesdale-Kennedy, M., and Slevin, E. (2014), 'Issues in Caregiving for Older People with Intellectual Disabilities and their Ageing Family Carers: a Review and Commentary. **International Journal of older people nursing**, 9 (3), pp. 217-226.

<sup>96</sup> Dillenburger, K., and McKerr, L. (2012), 'How Long are We Able to Go On?' Issues Faced by Older Family Caregivers of Adults with Disabilities', **British Journal of Learning Disabilities**, 39(1), pp. 29-38.

<sup>97</sup> Ryan, A., Taggart, L., Truesdale-Kennedy, M., and Slevin, E. (2014), 'Issues in Caregiving for Older People with Intellectual Disabilities and their Ageing Family Carers: a Review and Commentary. **International Journal of older people nursing**, 9 (3), pp. 217-226.

<sup>98</sup> Heller, T., and Kramer, J. (2009), 'Involvement of Adult Siblings of People with Developmental Disabilities in Future Planning', **Intellectual and Developmental Disabilities**, 47 (3), pp.208–219.

studies have suggested that between a third and a half of siblings share their parents' expectation that they will support their sibling with ID in the future.<sup>101,102</sup> In fact, in many cases adult siblings frequently demonstrate positive relationships with their siblings with an ID, including regular contact, a strong emotional connection, and shared activities.<sup>103,104,105,106,107</sup> Nascent research is also highlighting that adult siblings are progressively displaying increased participation in the caring activities necessary to support their sibling with an ID.<sup>108</sup> Siblings' carer roles may range from becoming the primary caregiver for their sibling with an ID including co-residence, to providing their sibling with an ID regular respite from their residential placement, or to overseeing their receipt of services, finances, and other life decisions.<sup>109</sup> There are however a number of factors which may influence whether a sibling will fulfil such carer roles. Burke (2012)<sup>110</sup>, amongst others<sup>111,112</sup>, reports that siblings expected and therefore were most likely to assume greater caregiving responsibility for their brother or sister with an ID if they were;

- female,
- had a close relationship with their sibling with ID,
- lived closer to their sibling with ID, and
- the lone sibling without a disability.

In addition, as previously discussed, the demands of non-disabled siblings' lives, such as work, spouses, children, and/or grandchildren, are also likely to influence the extent to which non-disabled

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<sup>99</sup> Freedman, R., Krauss, M., and Seltzer, M. (1997), 'Aging Parents' Residential Plans for Adults with Mental Retardation', **Mental Retardation**, 35 (2), pp. 114–123.

<sup>100</sup> Heller, T., and Factor, A. (1993), 'Aging Family Caregivers: Support Resources and Changes in Burden and Placement Desire', **American Journal on Mental Retardation**, 98 (3), pp. 417–426.

<sup>101</sup> Davys, D., Mitchell, D., and Haigh, C. (2014), 'Futures Planning - Adult Sibling Perspectives', **British Journal of Learning Disabilities**, 43 (3), pp. 219-226.

<sup>102</sup> Heller, T., and Arnold, C. (2010), 'Siblings of Adults with Developmental Disabilities and Psychosocial Outcomes, Relationships and Future Planning', **Journal of Policy and Practice in Intellectual Disabilities**, 7(1), pp. 16-25.

<sup>103</sup> Bigby, C., Webber, R., and Bowers, B. (2015), 'Sibling Roles in the Lives of Older Group Home Residents with Intellectual Disability: Working with Staff to Safeguard Wellbeing', **Australian Social Work**, 68 (4), pp. 453-468.

<sup>104</sup> Bigby, C. (1998), 'Parental Substitutes: The Role of Siblings in the Lives of Older People with Intellectual Disability', **Journal of Gerontological Social Work**, 29(1), pp. 3-21.

<sup>105</sup> Greenberg, J.S., Seltzer, M.M, Orsmond, G.I. and Wyngaarden Krauss, M. (2014), 'Siblings of Adults with Mental Illness or Mental Retardation: Current Involvement and Expectation of Future Caregiving', **Psychiatric Services**, 50 (9), pp. 1214-1219.

<sup>106</sup> Heller, T., and Arnold, C. (2010), 'Siblings of Adults with Developmental Disabilities and Psychosocial Outcomes, Relationships and Future Planning', **Journal of Policy and Practice in Intellectual Disabilities**, 7(1), pp. 16-25.

<sup>107</sup> Hodapp, R. M., Urbano, R. C., and Burke, M. M. (2010), 'Adult Female and Male Siblings of Persons with Disabilities: Findings from a National Survey', **Journal Information**, 48 (1), pp. 52-62.

<sup>108</sup> Bigby, C., Webber, R., and Bowers, B. (2015), 'Sibling Roles in the Lives of Older Group Home Residents with Intellectual Disability: Working with Staff to Safeguard Wellbeing', **Australian Social Work**, 68 (4), pp. 453-468.

<sup>109</sup> Bigby, C., Webber, R., and Bowers, B. (2015), 'Sibling Roles in the Lives of Older Group Home Residents with Intellectual Disability: Working with Staff to Safeguard Wellbeing', **Australian Social Work**, 68 (4), pp. 453-468.

<sup>110</sup> Burke, M., Taylor, L., Urbano, R., and Hodapp, R. (2012), 'Predictors of Future Caregiving by Adult Siblings of Individuals with Intellectual and Developmental Disabilities', **American Journal on Intellectual and Developmental Disabilities**, 117(1), pp. 33-47.

<sup>111</sup> Seltzer, M., Greenberg, J., Floyd, F., and Hong, J. (2004), 'Accommodative Coping and Well-being of Midlife Parents of Children with Mental Health Problems or Developmental Disabilities', **American Journal of Orthopsychiatry**, 74 (2), 187.

<sup>112</sup> Heller, T., and Arnold, C. (2010), 'Siblings of Adults with Developmental Disabilities and Psychosocial Outcomes, Relationships and Future Planning', **Journal of Policy and Practice in Intellectual Disabilities**, 7(1), pp. 16-25.

siblings become involved in supporting their sibling with an ID.<sup>113</sup> Hodapp and Urbano (2007), report that this cohort of the population is likely to be the first generation of people with an intellectual disability to reach their 50s and 60s and consequently there also exists a first generation of sibling caregivers.<sup>114</sup> This increase in intergenerational transfer of caregiving must be recognised and adequate supports developed for this new familial dynamic of caregiving for people with an ID.

The consequences of families' reluctance to make definitive future plans for the care of their family members with an ID can be considerable, as it may lead to crises and emotional trauma for all concerned.<sup>115</sup> Absence of future plans can also induce inappropriate placement for the family member with an ID and can prompt unexpected dilemmas for siblings or extended families.<sup>116,117</sup> In order to avoid such detrimental circumstances, a number of authors argue that the role of service providers is integral and that they must facilitate families' early formation of future care plans as early as possible by sensitively instigating the conversation with families, offering support, and providing accessible information on the available services.<sup>118,119,120,121</sup> Magrill (2005) argues that conversations about future planning should be inclusive of the current needs of families.<sup>122</sup> Service providers must therefore facilitate the process of families' future care planning whilst also providing support to assist them in sustaining their present caregiving role for as long as is feasible. Such a dual approach is however relatively absent from the currently available research evidence.<sup>123</sup>

## Summary

- Traditionally, international research predominantly focused on the detrimental outcomes and challenges of the family caregiving experience. However, more nuanced contemporary research suggests that negative and positive outcomes of family caregiving can exist concurrently and independently of one another.

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<sup>113</sup> Dew, A., Llewellyn, G., and Baladin, S. (2004), 'Post-parental Care: A New Generation of Sibling-Carers', **Journal of Intellectual and Developmental Disability**, 29 (2), pp. 176-179

<sup>114</sup>Hodapp, R., and Urbano, R. (2007), 'Adult Siblings of Individuals with Down syndrome Versus with Autism; Findings from a Large-Scale US Survey', **Journal of Intellectual Disability Research**, 51(12), pp. 1018-1029.

<sup>115</sup> Taggart, L., Truesdale-Kennedy, M., Ryan, A., and McConkey, R. (2012), 'Examining the Support Needs of Ageing Family Carers in Developing Future Plans for a Relative with an Intellectual Disability. **Journal of Intellectual Disabilities**, 16 (3), pp. 217-234.

<sup>116</sup> Thompson, D and Wright, S., (2001), **Misplaced and Forgotten: People with Learning Disabilities in Residential Services for Older People**. London: The Foundation for People with Learning Disabilities.

<sup>117</sup> Ryan, A., Taggart, L., Truesdale-Kennedy, M., and Slevin, E. (2014), 'Issues in Caregiving for Older People with Intellectual Disabilities and their Ageing Family Carers: a Review and Commentary. **International Journal of older people nursing**,9 (3), pp. 217-226.

<sup>118</sup> Bowey, L and McGlaughlin, A (2007), 'Older Carers of Adults with a Learning Disability Confront the Future: Issues and Preferences in Planning', **British Journal of Social Work**, 37(1), pp. 39–54.

<sup>119</sup> Dillenburger, K., and McKerr, L. (2012), 'How Long are We Able to Go On?' Issues Faced by Older Family Caregivers of Adults with Disabilities', **British Journal of Learning Disabilities**, 39(1), pp. 29-38.

<sup>120</sup> Gilbert, A., Lankshear, G., and Petersen, A. (2008), 'Older Family Carers' Views on the Future Accommodation Needs of Relatives who have an Intellectual Disability', **International Journal of Social Welfare**, 17 (1), pp. 54-64.

<sup>121</sup> Taggart, L., Truesdale-Kennedy, M., Ryan, A., and McConkey, R. (2012), 'Examining the Support Needs of Ageing Family Carers in Developing Future Plans for a Relative with an Intellectual Disability. **Journal of Intellectual Disabilities**, 16 (3), pp. 217-234.

<sup>122</sup> Magrill, D (2005), **Supporting Older Families: Making a Real Difference**. London: Mental Health Foundation.

<sup>123</sup> Heller, T., Caldwell, J., & Factor, A. (2007), 'Aging Family Caregivers: Policies and Practices. **Mental Retardation and Developmental Disabilities Research Reviews**, 13(2), pp. 136-142.

- Currently available literature has identified a number of factors which may inform and mediate the family caregiving experience including, but not limited to, socio-demographic indices, the accessibility of and satisfaction with formal services, the incidence of compound caregiving, family coping mechanisms, and the degree of relational caregiving.
- Nevertheless, research evidence examining the explicit strategies families' utilise to enable current and sustainable future supports for their family member with an ID in the home is limited in Ireland and internationally.
- Similarly, whilst evidence suggests that families' future care planning is non-definitive and aspirational in nature, further elucidation of this research evidence is required, especially in relation to the experiences and perceptions of sibling caregivers.

# Study Results

## Introduction

Study findings are divided into two sections; Section A explores the present sustainability of family caregiving capacity, whilst Section B elucidates the potential for future family caregiver capacity. The number of participants who contributed to each theme is stated within each section and selected quotes are provided to illustrate the breadth of opinions articulated within each theme.

In Section A, the present sustainability of family caregiving, the study findings suggest that the sustainability of family caregiving capacity is influenced by numerous systemic, socio-demographic and psychosocial variables which impacted on their capacity to sustain family caregiving presently and into the future. From the outset, the presence of certain sociodemographic variables, such as life stage and financial capacity, appeared to enable carers' capacity to firstly undertake and secondly subsequently sustain family caregiving in the home. Further, systemic variables originating from the receipt and adequacy of formal support services, in addition to the impact of broader policy initiatives, were deemed to impact on and conflict with the family caregiving experience and thus in turn families' capacity to adequately support their family member with ID in the home. Lastly, family carers appraised numerous psychosocial indices including the all-encompassing nature of the caregiver role and the accessibility of informal supports, to be integral to determining their mental and physical health outcomes and thus their consequential ability to continue caregiving in the home. Notably however, study findings also suggest that underpinning the influential systemic, socio-demographic, and psychosocial components to family caregiving capacity was families' fundamental love for and commitment to their family members with ID. It was from this familial connection which many of the family carers derived the strength to sustain family caregiving in the home. In Section A, the three capacity themes of 1) socio-demographic, 2) systemic, and 3) psychosocial will be further elucidated upon.

In Section B, the future sustainability of family caregiving, family's decision making process and opinions about the future care of their family member with ID are comprehensively explored. In the first instance, the majority of family's demonstrated limited definitive planning as any future plans that were considered remained evidently aspirational in nature. Whilst some family's had at a minimal openly discussed the future with other family members, others had never broached the subject. That being said there was a number of parent carers in particular who had inserted instructions regarding future care of their adult child with an ID into the will. Whilst a number of families described that future family caregiving would continue into the future, primarily through transition of care from parents to siblings or sibling to sibling, the vast majority of family carers articulated that they represented the last remnant of family caregiving capacity within their families and as a result, residential services would be pertinently required in the future.

## Section A: Present sustainability of family caregiving

*“There is no point in pretending it is easy and it’s fine, it is not. You are trying to juggle everything and it is juggling it and you are just managing to keep it all up and that is it” (Carol, Urban FG)*

### Socio-demographic components of family caregiving capacity

#### Life stage

Participant’s narratives suggest that there are particular life stages which may be specifically conducive to the initiation of family caregiving, especially for sibling caregivers, but also its continued sustainability. In particular sibling caregivers described that it was precisely because they, in comparison to their other siblings, were at a stage of their lives which was perceived to be more suitable to caring for their sibling with ID that they became primary caregiver. In most cases (n=8), this conducive life stage was associated with the socio-demographic variables of being single, having no or adult children, in the 30-45 year age-group, and not working;

*So I was the single one out of the other 10 we’ll say the ten of us leaving [brother’s name] outside of that. So they were all married and had children had families and had a life going on as the saying goes. So like I said well he has to be looked after someone has to look after him. Someone has to care for him I didn’t see the option of putting him anywhere, I didn’t see that. It wouldn’t be what I would of wanted for him and it’s easy to say your parents wouldn’t have wanted but they’re gone so they didn’t have a say or a choice then. It was the people who were left behind had to make that decision (Kathy, Sibling, Urban I-I interview)*

Notably, like the family carer described in the above quotation, a number of the sibling caregivers (n=5) also began firstly caring for their parents before subsequently continuing on in that role for their sibling with ID. In particular, it was being single in addition to the absence of young children and work which participants appraised to influence their comparative capacity to undertake the carer role;

*Well I came over here, my mum died of cancer and my father had Parkinson’s. [...] So I come over and stayed with my father and [sister’s name], so ehm dad lived for another 6 years then. I’ve been with [sisters name] ever since [...] I wasn’t doing much over in England anyway so (James, Sibling, Urban/Rural FG)*

*I was never asked, my mother never asked me, like, will you mind us or anything like that it was just my kids had grown up, [...] they grew up and they have their own children now and they’re living their own lives and I had nobody in my own house, [...] so that’s how I was the one to take over. My oldest sister now, she minds kids going to school and come back from school and things like that so it was all her life so she wouldn’t change it [...] (Eileen, Sibling, Urban FG)*

Conversely to the other sibling carer participants who had mostly finished rearing their children or who had never started a family, two of the sibling caregivers had only recently been married, were in their twenties, and were in the process of rearing their young children when they began family caregiving. However, in comparison to the life stages of their other siblings’ lives, their life stages were deemed comparatively more ‘settled’ and therefore more suited to undertaking the family caregiving role;

*We didn’t have a, we didn’t have an option, my two, the other two siblings, there’s five of us in the family; my older sister was absolutely useless, absolutely didn’t want to know once everything*

*transpired the way it did. My brother wasn't married, was still playing the field, happy out so he was no use and then my younger sister was the same, she wasn't married, she was working, she had a different life. I was the only one that had a settled. [...] I had just been married a year, two years, and had my first child and I kind of figured I'll be looking after him for twentyish years so I kind of thought I can do, I can do that, I can do [sisters name]. (Carol, Sibling, Urban FG)*

*So as I say there was nothing planned so I being the only girl, you know there was two girls and three boys but I being the only one who was married none of them were married so I just took on the challenge (Rose, Sibling, Rural I-I Interview)*

As previously referred to, the absence of a working career outside of the home did seem to pertinently inform participants' capacity to initiate and sustain family caregiving. This was particularly identified in the narratives of the family carers who at the time of initiating caregiving were working outside of the home but who had to subsequently withdraw from that part of their working lives over time. These participants (n=4) noted that the all-encompassing nature of the caregiver role within the home, due to their sibling with ID's deteriorating health and thus increasing needs depleted their time and energy resources to such an extent that there were little resources left to direct into their working career;

*We were both working full time, my husband and myself, with our one year old and ehm I gave up my job because I kind of felt it was too big for me, it was overwhelming the whole situation [...] I couldn't cope with work, the baby, [sister's name], the renovations, so I thought I'll stop for a few years and start again in another few years when it is all settled so that is what we did [...] (Carol, Sibling, Urban FG)*

*it has taken 10 years now and I have been doing all the caring for them [...] we had been trudging along [...], we've been trudging along, trudging along, and there has been a lot of very dangerous situations where their vulnerability has really scared the bejesus out of us so three years ago I decided to go part-time and then two years ago, I had done one year part-time and it was just getting too much because they are getting older there is a lot of other little things coming, uh it is so vast and wide now, that two years ago I had given up work altogether, so I am now their full time carer (Sheila, Sibling, Urban FG)*

## **Financial Capacity**

The additional socio-demographic variable which was deemed integral to the sustainability of family caregiving was carer's financial capacity. In many respects the caregiving experience was mediated by families' financial resources. The family carers (n=11) who were in receipt of the carer's allowance and/or were financially comfortable rarely cited financial components as a barrier to family caring sustainability. Conversely however, those who did not qualify for the carer's allowance (n=6), despite giving up work and caring full time for their family member with ID cited this as one of the principal mediators which informed the sustainability of the caregiving experience;

*[...] we've been managing, we've been okay but for the last two years that I have had to give up employment and having to deal with this we are slowly going under debt wise. We are okay, we eat, we have a car, we can do that but we've given up so much and we have sacrificed so much and now we are really in a lot of debt (Sheila, Sibling, Urban FG)*

Like the above citation alludes to, many of the participants' in this cohort believed that the family member's disability allowances were insufficient to cover both their daily living costs and any additional costs incurred as a result of their required ID care;

**Participant A:** *she gets disability allowance and the state have worked it so that they have pulled all resources from her day service so that her disability allowance goes on her daily day service in that she needs a tenner for this, she needs 20 for that, she needs her hair done, she needs this, she needs that, she needs 15 euro for a blood test. I mean that is \*\*\*\*ing ridiculous [...] she is on a medical card for most of her medical needs and she needs 15 euro for a blood test I just think it is crazy*

**Participant B:** *so if she was to live independently there wouldn't be enough money in that to be paying a rent to feed her, electricity bills, yea its crazy*

**Participant A:** *no, no there wouldn't be, there wouldn't be (Carol & Sheila, Siblings, Urban FG)*

*So the money she gets now doesn't keep her, you see we gave her, her own house because I felt she always needed her own independence because she never had that in her life so we gave her house but the money she gets doesn't keep her because there's an awful lot of maintenance [to the house] [...] and ehm the oil bill alone is 1500, the insurance alone is 1000 a year so there is no way what she gets can keep her (Joe, Sibling, Rural FG)*

A number of the family carers (n=3) also cited other perhaps comparatively 'invisible' costs to caring for their family member at home including house renovations. The renovations completed were required not only in order to create space but also to promote independence for their family member with ID and to ensure their positive caregiving experience and health outcomes;

*There is plans in motion, we're selling the family home, sold just now. We've plans to build two independent living little apartments units on our house but it all has to be connected, interconnected so that is where we are at the minute. So we will probably go into a little bit more debt but I am kind of hoping that without the travelling and with them on site [...] it will ease the worry but financially it is not going to ease up but I don't know what we are going to do but we have to do something, at the minute we have to do something for my health to continue looking after them (Sheila, Sibling, Urban FG)*

As a result of insufficient financial capacity to meet the considerable costs to family caregiving, family carers often assumed the financial deficit and subsequently the consequential psychological stress originating from same;

*I'm in the same boat. I mean this year now our boiler blew up and it cost a thousand and 50cent for the boiler and that was the fuel money for this winter. I've had to go to the credit union now and borrow a thousand euros for the fuel for the winter, you know so that fuel allowance that my brother should be getting would be hugely beneficial if we could get that but we can't get anything off them so if anything goes wrong, anything like that puts me under huge pressure (Pat, Sibling, Rural FG)*

## Systemic components of family caregiving capacity

### Qualifying for carer's allowance

As discussed in the previous section on financial capacity, a number of the carers, sibling carers specifically, were experiencing financial restraints as a result of the cost of family caregiving. The majority of the sibling carers were unable to work due to their perceived need to support their family member with ID full-time. Yet despite their full-time carer role, many of them (n=6) did not qualify for the carer's allowance. Participants felt that there were systemic issues associated with the eligibility criteria of the carer's allowance and its subsequent distribution to the carers. They identified these systemic issues with the carer's allowance as a barrier to them fulfilling the carer role without undue financial stress and strain. Whilst participants perceived that their family member with ID required their full time support, their family member was often deemed by the system as not sufficiently disabled so as to qualify their family carer's for the allowance;

*I'm not getting paid for my brother because he is not deemed as sufficiently handicapped even though he's fairly bad and people in the centre tell me there are other people as official carers and the people they are caring for are not half as bad as my brother (Pat, Sibling, Urban FG)*

In other cases, participants felt that the emphasis in the assessment of their family members' was on physical disability and as a result the support needs required for intellectual disabilities were not adequately considered and/or assessed;

*We are fighting now for carers allowance at the minute [...] it keeps coming back this is the fourth time going for it now and because of [psychologists name] pushing this, he has met the girls he is the one that assess them, he has reassessed them, he is helping me a lot. It keeps coming back saying physically 'yes your sisters obviously do need a little bit of care but not enough to warrant this' and I have now asked for an oral hearing because they have no provision even in paper work for intellectually vulnerabilities (Sheila, Sibling, Urban FG)*

For others, it was their assets or spouse's income which resulted in their not qualifying for the carers' allowance. This was despite their inability to work in order to continue to care for their family member with ID and their subsequent loss of individual income either outside the home or from their alleged assets;

*He told me to sell the land and spend the money, he told me to sell the land, spend the money and then apply. He said I've a great chance of getting it then (laughs) (Joe, Sibling, Rural FG)*

A couple of the female sibling carers found this extremely frustrating as although their families' income was above the threshold, they felt that that income was to be prioritised for their children or that their spouse shouldn't be expected to financially support their sibling in-law;

*no because it is means tested and I have three children, my husband works, I work now so they just think she is in a home where there is money but there is not [...] that is not for [sister's name] that is for my boys like that's what we're earning money for, the kids to put them through college (Carol, Sibling, Urban FG)*

*I do know it's very hard to get a penny out of them, I get nothing, absolutely nothing because we are means tested and as I said they expect my husband to support not only me but my sister, I mean it's atrocious (Mary, Sibling, Urban FG)*

In one case, specific systemic anomalies resulted in a sibling with ID receiving less financial support now than he did before his brother came to live with him and support him full time;

*The only thing as well is I am caring for my brother but I am probably costing him money because if he was on his own he would be entitled to all these allowances but he is not entitled with me being in the house but he can't live on his own [...] I mean I am on a fixed income as well like, but he's not entitled to any allowance because I'm living in the house with him and that's ridiculous, I think that is absolutely ridiculous. I mean it would be different if I was working, I certainly would have no problem at all, it wouldn't bother me whatsoever but since I'm on a fixed income I am struggling. I just feel it is unfair (Pat, Sibling, Rural FG).*

The resulting outcome for a number of the family carers denied carer's allowance was a lengthy appeals process to prove the needs of their family member with ID and thus to validate their role as their carer. This protracted process added further psychological stress and strain onto carers, not least because they struggled to understand the logic of the state's willingness to financially support their family member in a nursing home rather than facilitating their living at home through the adequate distribution of the carer's allowance;

*They turned me down twice and I appealed it and it is still going on like. I called him but there recently [...] you know what he told me to do 'send us in a letter saying you don't want to look after her anymore and we will put her in a nursing home', yea they are prepared to pay for a nursing home but you want give me the carers allowance to keep her at home, it doesn't make sense 20% of what they are prepared to pay would keep her at home permanently [...] (Joe, Sibling, Rural FG)*

The participants (n=6) felt that the carer's allowance system needed to be reviewed in order to adequately capture and validate the needs of people with ID as well as the support their family carers provide to them. One of the participants proffered the recommendation that the distribution of the carers allowance should be points based with different levels of need being connected to different amounts of financial assistance. In this way he felt the role of all carers would be validated and all would receive a degree of financial support rather than the all or nothing system he perceived to be currently in operation;

*I think things need to be on a points system, when you're looking for an emigration visa to Australia there's points, are you a doctor 20 points, are you a nurse 5 points, you know but we need a points systems where you'd qualify to give you part of the carer's allowances. If I earn ten thousand a year and you earn 15, well we both shouldn't be told well you don't qualify because you're earning over 9 thousand, why not give me a 100 and you 60, break it down like, give everyone a little few bob rather than saying if you get (inaudible 1.52.37), you get nothing (Joe, Sibling, Rural FG)*

## **The role of formal supports**

Formal support services, in the form of day/training centres or respite, were perceived by all of the family carers (n=17) to be integral to sustaining their capacity to continue caregiving within the home. Daily services in particular were held in extremely high regard by family carers, not least because it provided them with daily respite from their caregiving role. The vast majority of family carers reported that their family members had been attending their day services from 9am to 5pm

for four or five days a week for a considerable length of time, some for up to thirty years. As a result, family carers often appraised that the day service, its' staff members, and their peers there cumulatively represented a large component of their family members' lives as it provided them with a consistency of daily routine, comfort, enjoyment, quality of life, and a sense of purpose;

*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 (Mary, Sibling, Urban FG)*

*He gets that five days a week which is fantastic for him, absolutely fantastic. They pick him up and drop him home about 3:30pm in the evening and they are absolutely brilliant with him, really are lovely people. He lives for that, when he is there in the morning [...] has a path beat worn from the front door out to the kitchen window and back again and he just keeps going all the time. From the minute they are supposed to arrive he just keeps going in and out until they arrive (Pat, Sibling, Rural, FG)*

Family carers consequently noted that their family members would be distressed if their access to these day services were to be reduced or terminated;

*No, no I couldn't, I'd say he'd die (Eileen, Sibling, Urban FG)*

*If she didn't have the workshop, I think she would just crack up you know, she would be impossible because as a I say it is her life, no matter how sick she was she would be, or if myself and [partner's name] could be here, we could be dying, even when she was in her best state she'd climb over us to get to the workshop and she'd climb us to get to her friends [name] you know (Elaine, Sibling, Urban/Rural FG)*

Equally, many of the family carers felt that their capacity to support their family member with ID within the home would be compromised without such formal support;

*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 (Mary. Sibling, Urban FG)*

**Participant A:** *no I mean I couldn't [...] I mean he's no trouble but I still would think we would have gone crazy if...*

**Participant B:** *even when he's on holidays, ye know*

**Participant A:** *he gets bored, we get bored, but I mean they're are only 3 weeks, 2-3 weeks summer holidays and generally we're down in the mobile so I mean that doesn't even, but I mean if we had him, I'd have him killed or he'd have me, you know (Breda & Martin, Parents, Rural FG)*

Similarly respite was also seen as both a facilitator to strengthening family caregiving capacity but also as an additional source of pleasure and quality of life for their family member with ID. Conversely however, there was a notable divergence in family caregivers' experiences of the availability and flexibility of respite services. Some of the families (n=3) appeared to be able to avail of regularly scheduled as well as flexible, emergency scheduled respite for their family member with ID;

*she goes every weekend now, but she loves it, she never complains, she goes off out the door [...] she comes back Monday evening, they take her to the workshop yea, and if we wanted a Thursday like if we needed they would try and fit us in for you know (Elaine, Sibling, Urban FG)*

*he has to have so many days in respite between the year so every so often you'll get a letter saying he can come in for two nights and he is grand, loves it, [...] he even does say did the letter come today, you know, waiting on it like and he only just back from it (giggles) and you'd have to say 'no, you're not getting it for another two weeks now (Eileen, Sibling, Urban FG)*

Whilst the availability of respite was appraised by some participants as very good, others (n=10) noticed a cut back in its availability since the economic recession in Ireland in 2008/2009. From family narratives, it appears that both the amount of respite and its reliability has respectively become reduced and compromised in the last ten years;

*Well it all depends. It used to be [son's name] would go up there about once a month. That's drifted off to once every two months, once every two and a half months. And it's a case of, of also there's been emergencies and if an emergency crops up he doesn't get it. And you could be told that on the day that he's supposed to go. So things have altered quite a bit recently (Gerard, Parent, Urban I-I Interview)*

Whilst for some families, respite was reduced; other families (n=4) have received little or no respite for the entire duration of the year;

*Now talking of which this year I had got no respite at all until august weekend. I had a son home from Australia and got no offer of respite. But I rang up and I asked them for a few days so she got four days respite in [organisation] which is one of the residential places belonging to [organisation]. Now in previous years and I hadn't had any respite since the previous September, that's September 2014 (Tom, Parent, Urban I-I Interview)*

Such a reduction in respite had an impact on familial caregiving capacity, with family members recounting that during the now protracted time in between respite visits, they often reached emotional and psychological points of exhaustion;

*We get the respite, but like we could get chunks of it and then we could go four months with nothing and I'm ready then to (exasperated face) (Mary, Sibling, Urban FG)*

In addition to the psychosocial impact on families, the reduction of respite services also inhibited the steady progression and transition to independent living for their family members with ID. It appeared many families were utilising respite services as a tool to familiarise and slowly transition their family member with ID to either living independently or to the community group setting in the future;

**Participant:** *like that, [son's name] never liked respite like, I was trying to get him used to it but it was stopped them so that was like, to me like I was defeated then you know*

**Interviewer:** *So has he not gone, hasn't had the opportunity to go back since?*

**Participant:** *no he hasn't had respite now, God it is probably, it's probably about 4 years. (Patricia, Parent, Urban FG)*

## **Policy in reality**

The narratives of a number of participants (n=6) also demonstrated discontent with contemporary Irish policy on ID and ID services. These families felt that whilst the ethos of current policy may be theoretically preferable, its' implementation and feasibility in reality was questionable. In the first instance, families' rationale in this regard originated from their belief that the fiscal and community

infrastructure needed to implement policy, specifically community inclusion, was currently not available. One carer recounted that whilst he supported the idea of increased community inclusion for people with ID, he felt that the necessary financial resources to successfully and adequately implement such an initiative were not forthcoming;

*The government came up with this idea of taking people out of the institutions and put them into local communities which is grand, great idea, but you have to follow it up with backup and with money and they haven't they have just withdrawn them all and just left them people go and sort of have forgotten about them, they are the forgotten of Ireland (Pat, Sibling, Rural FG)*

Other family carers, specifically in rural areas, questioned the feasibility of 'community inclusion' in geographically isolated locations where the essential components of community infrastructure (e.g. public transport, footpaths, street lights, shops, coffee shops, restaurants, community groups) needed for its safe and adequate implementation were limited. One carer poignantly articulated that the automatic assumption that 'community' existed universally across each town and village in Ireland needed to be rectified. He believed that the economic recession and consequential emigration of young people in recent years has resulted in the reduction of 'communities' within which people with ID can be included;

*You see when you're living and working in Dublin, you might forget what it is to be living in a rural part of the country, you can't just put on a pair of shoes and walk down to the local shops [...] come down to my local town sure you could fire a shot at any time of the day and wouldn't hit anybody, completely different, shops are all closed now (Joe, Sibling, Rural FG)*

Such a perception regarding the limitations of community infrastructure were not however limited to the rural areas. A number of the family carers situated in urban areas (n=3) also noted that community inclusion not only required the utilisation of the person with ID's disability allowance, an added expense not previously required and which impacted once again on families financial capacity to sustain family caregiving, but also that its feasibility was compromised by growing closures of community facilities;

*[service name] did that, decided to make all the centres local to their communities so they access the community for what they needed so this and this is where the disability allowance gets spent in the community which is fine but if there is nothing left for the person themselves, then they start to pull back on the services in the community, they start to close libraries that the people access and use computers in [...] so it's like they give with one hand and pull back with the other (Carol, Sibling, Urban FG)*

Aside from questioning the fiscal and community infrastructure needed to implement current policy, families (n=6) also perceived policy in relation to independent living and community inclusion to be ideological in nature as it did not adequately reflect or address the contextual realities of their and their family members' lives;

*If only it was like how they envisaged it in real life (Tom, Parent, Urban I-I Interview)*

*[sister's name] was brought to a certain level with [service's name] where she believed she could work at anything, she could buy a house and actually it was me that was holding her back and we would drive by new houses and she would go 'I want to buy one of them, I want to get one of them'. She has no money, she has nothing. She is not part of the deeds of the house even but she was elevated to a point that [...] it is unrealistic. I hope those come to match their [...] idea and that they*

*don't give them the ethos before they have the supports and they don't expect us to do the job of 20 people, we can't do it (Carol, Sibling, Urban FG)*

In particular, the family carers felt that although the premise of independent living for people with ID was theoretically preferable, it was inappropriate and impractical for their family members;

*They don't want people in care service in a way that they all live in the one place, and go to bed at the same time, they want them to be self-sufficient, independent living is the big word now, I mean it's alright but for some people independent living is not the thing for them at all (Rose, Parent, Rural I-I Interview)*

Equally, a number of the family carers (n=2) felt that policies which emphasised community participation for people with ID did not take on board their perception of the potential risk factors which may arise for their family member with ID from the implementation of same. Two of the female siblings in particular felt that ID services were instigating social inclusion in the community without due consideration as to which activities were appropriate and/or safe for their family members with ID;

*When [sister's name] joined [service's name] they signed her up for a computer course at the adult education centre, this is over a year ago, I knew she was in the early stages of dementia, it's just such a disconnect, and I know why they do it, I know it looks good on paper work and it's all about that (Carol, Sibling, Urban FG)*

*but they have a programme running at the minute that they are trying to include them back into society in that they want them to go for coffee morning, we want them to go for their lunch, we want them to be able to go down to the library and I'm going 'no, no, no. no, no I need [sister's name] to be clawed back in from there', because she is going out and thinking I have all of this freedom, I am so independent, I can just pick up anybody. [...] and if I meet anybody that says hello to me, I think they are my best friend so I will tell you all about my bank account and all about where I live and I will invite them for tea. The centre themselves don't get it because they think they know her of old which was years ago and here they have this little woman who I want to put a leash on sometimes and say 'stop I understand where you are coming from with some of your clients but this programme is not suiting this client that I know. I have dug her out of a hole that was so dangerous for her so please don't be doing this' (Sheila, Sibling, Urban FG)*

Consequently, some of the family carers felt that current policy appeared to be designed for and directed towards younger people with ID or people with mild/moderate ID. As a result, they were of the opinion that the needs of the older age cohort and those with severe/profound ID, of which their son/daughter/sibling was a member of, were predominantly unacknowledged within such policy documents and governmental strategies;

*The level that [sister's name] is at now, there is nothing for her. There is nothing beyond this vocational, this kind of aspiring. I went to a meeting in [service name] in the local hotel and the walls were filled with the courses they could do, this, that, achievements, these who went to some place and achieved that or the other and I left. I said 'there is nothing here that reflects [sister's name] nothing, nothing' and I said I am tired of going to meetings where that its 'oh we have X amount of clients out in the workplace with the supports, with this, with that, with the other'. [sister's name] is not one of them and that is all I care about (Carol, Sibling, Urban FG)*

Families also recounted that their family members, unlike younger people with ID, had been attending their ID services for decades and so to disrupt that consistency of routine by

reformulating how and where ID services were to operate would result in detrimental outcomes for their family members;

*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 and then they present with challenging behaviour (Rose, Sibling, Rural I-I Interview)*

The consequential outcome arising from contemporary policies' disconnect with families' realities was that many of the caregivers perceived current policy to actually work against families and induce increased strain and stress onto them. In many cases families had to financially support their family members' community activities, had to emotionally and psychologically negotiate their family members with IDs perceived to be unrealistic expectations about their capabilities in life, and worried that their family member with ID was involved in inappropriate and/or unsupervised activities in the community. Rather than working collaboratively, 2 of the family carers perceived services to prioritise client based initiatives to such an extent that it served to undermine families' valuable input and apprehension. One participant recalled how often she felt services treated her as the 'enemy' when she tried to articulate her concerns about her sisters' participation in community inclusion;

*I understand that where [sister's name] goes is client based so their loyalty is with [sister's name], I get that. They have known me for 25 years. I just wish that you were included within that same respect kind of thing, if you know what I mean, that you are not the enemy, you are not fighting, and there is nothing being done on-towards. So I wish that relationship was a bit more giving and a bit more honest (Carol, Sibling, Urban FG)*

## **Psychosocial components of family caregiving capacity**

### **The all-encompassing carer role**

The vast majority of family carers' narratives (n=14) emphasised the overwhelming nature of the carer role which was perceived to challenge the sustainability of their caregiving capacity. The types and levels of support their family member required were perceived by most of the family carers to be extensive. Family carers, especially those caring for family members with severe/profound ID, dual ID and mental health diagnoses, or those with advancing health difficulties like dementia, described having to continually attend to every aspect of their family members' physical, emotional, and psychological needs at all times of the day and night;

*You know his body gets deprived of oxygen and his body reacts. It's pretty violent and at the same time he's spluttering, it's everywhere and recently he's been wetting himself. We've had months of you know where he's been pooing in his underpants, in his pyjamas. Again these are all things which are part of his condition (Gerard, Parent, Urban I-I Interview)*

Many of the family members reported that whilst in the past their family member with ID had had a degree of independence, as old age advanced they were now noticeably more, if not completely, dependent on them. The outcome of this change in support needs was that family carers, who had previously been fulfilling the role of carer with a certain level of comfort, were now adjusting to the new, heightened level of care which was required from them;

*but what has happened now he was never solely independent, but what has happened now is he is completely dependent on me, this is what where the whole cycle has come back to that he has*

*become completely dependent on me, what I mean by that now is he wants to know where I am, and where I'm going and if I do, if I am going somewhere he wants to be with me and comes with me [...] we go to the market and we get the few vegetables and the bit of fruit and things like that [...] And he would bring his key with him before the house key and he would come home and I might, he might bring home the bag and I might just browse around the shops like or something like that but now he won't bring the key at all. This has went on now for about two years because that means I have to come home because he's got no key to come in you know (Kathy, Sibling, Urban I- I Interview)*

Such a high level of dependency was often reported to be, at times, suffocating and draining by many of the family carers as it meant that their family member with ID was constantly at their side. One carer noted how her sisters' dependency on her had increased to such an extent that she mimicked her movement and even her emotions;

*[...] she'd ehm shadow me a lot so if I was in the sitting room she would be in the sitting room, if I went into the kitchen she'd be pottering around beside me. She thinks she is independent of you but she is just mimicking kind of what you are doing if you know what I mean [...] she is very full on, she is right beside me, to the point where she would mimic your emotions [...] I was on the phone, [...] she was like that end of the table and I was this end, she had just gotten up she was eating her porridge and she was eating away and I was on the phone to my sister and my nephew had passed and anyway [...] I just started crying and I said 'oh my God', I was just taking it all in and she had no idea what the phone call was about and she was crying eating her breakfast; isn't that so sad (Carol, Sibling, Urban FG)*

In addition to their family members' overwhelming physical and emotional dependency on them, a number of the carers (n=2) also recounted that wherever they went or whatever they did with their family member, their cognition was always on high-alert; assessing potential external dangers or risks to their family members and consequently adapting their behaviour or movements. This was particularly when they were in public spaces that they had never or rarely visited;

*yea I mean I can take him places but it is tough on me, if I take him say up to Dublin, it is a scary place for me because I am watching him all the time, and handicapped people have this habit of walking a little bit behind you, just a step but it's enough to sort of take them out if your vision so if you're looking around at them all the time so it's hard to believe it horrible [...] especially with people around and that, you don't know who bump into them or get lost so that's a constant (Pat, Sibling, Rural FG)*

*I do have to treat [son's name] day and night as a blind person when we are out because you see when I'm on holidays and you might be in some place that you'd be wanting to look at the buildings, I would have to look at the cracks in the ground coming along (Patricia, Parent, Urban FG)*

The all-encompassing nature of the caregiving role had negatively impacted on the quality of family carers' lives and their familial relationships. The requirement to constantly attend to and prioritise their family member with ID's needs resulted in some of the family carers even making health care decisions which ensured minimal disruption to their family member with ID and their own caregiving capacity;

*I had to go in for a hysterectomy. I didn't in the end but that is what I was thinking 'I can't, I have no time for a hysterectomy [...] can't do it, no' so I did a stopgap thing that will keep me going for a little while [...] because I don't have the time and she has got dementia so she is so dependent on me now that if you take out the routine it can set her so far back (Carol, Sibling, Urban FG)*

The high level dependency of their family member with ID also appeared to result in carers' feeling physically, psychologically, and intellectually restricted. Family carers often reported that when formal supports could not be secured, their ability to leave the house to go anywhere or do anything without their family member with ID was severely curtailed;

*He wasn't well but I have actually got him back [attending day service] since Monday, you see I wanted to try get him back because we were going away, I wanted to see how he was, and Sunday like my son said 'mam I think you better leave [son's name] at home'. Now talk about, what am I going to do? Can ye imagine me telling [son's name] that he is not going?, and us going? I mean this is where I kind of feel I should of taken up respite years ago (Patrica, Parent, Urban FG)*

In fact, one participant noted that he and his wife hadn't been on a holiday together in over 17 years;

*Ah no I don't go away, I've never been away for a weekend since we came here to live, no, no, its 17 years, we don't go anywhere. As a couple we never went anywhere cos eh well we had four children and where would you go with [sister's name] as well, it just wouldn't work (Joe, Sibling, Rural FG)*

This reported lack of respite away from their home environment and without their family member with ID was a recurrent theme in many of the family carer's narratives. Many of them, like the participant described in the above quotation, could not easily recall when they had last been away for a weekend or a holiday with just their spouse;

*The last time myself and [husband's name] went away? I can't remember honestly (Sheila, Sibling, Urban FG)*

In some cases, this lack of respite was to such an extent that to participate in this research study by attending the focus group in the evening, outside of their home, was considered a 'break' by one of the family carers because she wasn't cognitively 'on-call' for her sisters' needs;

*this is a night out [...] going off in the car, the girls know if they need me now they have to ring [husband's name] and I'm going (relief expression). Sounds ridiculous like but you know it is a long time like since we had it like that (Sheila, Sibling, Urban FG)*

Family carers also reported a psychological implication as a result of their requirement to fulfil an all-encompassing carer role; that of lost dreams and goals. Sibling caregivers in particular noted how they often wondered what their life would have been like had they not become their family member with ID's primary carer;

*I think I would have made different decisions throughout my life, do you know what I mean had [sister's name] had not been there. We would have moved from where we are, years ago when the boys were kind of growing up, all of those things, it does affect your life enormously, like enormously (Carol, Sibling, Urban FG)*

For some, it was difficult to live a life not of their choosing, that of a primary carer, whilst also grieving for a life that they much desired but which was deemed unobtainable to them;

*I suppose for me I would just like the idea that I could have a bit of my own freedom, my own personal freedom, I mean if I was to think about it or if I was a worrier that I think that I would be in a worse state, yea, if I thought this is going to be my life, this is it and I never asked for it and I often think she's not my daughter you know, I have my own four children who have also had lots of difficulties, so she's not my daughter (Mary, Sibling, Urban FG)*

Given the pressures that many of the family carers were under, it was not surprising that many of them felt overwhelmed and exhausted at some stage in their carer career. One participant's narrative in this regard was particularly pertinent. Still reeling from the death of his wife 9 months prior and with his own physical and psychological difficulties, this male participant was struggling to adjust to his new life as the primary caregiver of his son with severe/profound ID. He describes how one day, the mounting pressures engulfed him;

*You know I used to think 'are you doing this on purpose to upset me or whatever?' cause I tried for nine months to do everything on my own and, it was a steep learning curve I can tell ya [...] I actually broke down myself. I was passing [son's name] his dinner, [...] I passed him his plate and he dropped his plate and you know it was an accident. However, it was, I was at the end of my tether then [...] so I picked up my plate and just with the dinner on it and I just thrown, smashed it on the floor [...] it exploded into bits and it was everywhere. You know I then realised I had to clean up. So I you know, I got on to the floor and I'm sitting there amongst everything trying to get everything in. [son's name] could do nothing and you know I'm sort of brushing with the hand brush trying to get everything in and looking at it, it's everywhere and I just stopped and I cried then, I must of cried for about six hours without moving. [...] (Gerard, Parent, Urban I-I Interview)*

### **The accessibility of informal supports**

As discussed in 'The role of formal supports', family carers demonstrated dependency on formal supports for daily and period respite. This level of dependency may be, at least in part, as a result of the evidentially limited informal supports available to many of the family carers. A proportion of the sibling carers (n=6) in particular articulated that they garnered minimal supports (e.g. practical, emotional, and financial) from other siblings, extended family members, friends, or neighbours. In some cases informal supports from these sources were perceived by participants to be non-existent;

*None of her family have any interest. I have three sisters, counting [sister's name], four brothers and none of them, they're gone, [sister's name] doesn't exist as far as their concerned. Some of them don't come 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 (Joe, Sibling, Rural FG)*

*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 (Mary, Sibling, Urban FG)*

In many cases, it appeared that the lack of informal supports from other siblings was as a result of acrimonious and tenuous interactions in the past, particularly during the time their parents had passed away and ensuing discussions commenced regarding caregiving transition for their family member with ID. Frequently, the decision to continue family caregiving in the home in favour of transitioning to residential care was an unfavourable one amongst many of the other siblings and therefore no emotional, psychological or support to sustain and continue the implementation of this decision was forthcoming from them;

*So as time went on, when we took her over the family all fell out with us, even to get her own television out of the house was a problem. We couldn't even get her own television. There was an argument to get everything, she could take nothing out of the house even though her mother left her everything in her will, so that was a great problem. But ehm over the years we have [sister's name] now 15 years and it has after taking a long time for the sisters to even come round to the idea that she is not in a home, that she's with us and she's still, they still say that she would be better off in a*

nursing home. But she was far too young for a nursing home, she wasn't even 40 years of age (Joe, Sibling, Rural FG)

Although periodically, other siblings perhaps may have tried to offer support, from the perspective of the primary caregiving sibling, it was not the type of support they desired or felt appropriate;

*[...] but this was when they [...] flew in [...] to sort out the problem and they wouldn't contribute any money but yet they'd put her in a nursing home, like that was their way of sorting it out. So they had it sorted out so when I objected to it, her going to [service name] to stay there, they all washed their hands of her, no one wanted to know anything about her as if she disappeared (Joe, Sibling, Rural FG)*

*[...] they can't see any problem with bringing the two girls out to the pub and let them have a drink and letting them have this and oh sure let them go out and let them do that [...] they actually do not understand the needs of these two girls so (Sheila, Sibling, Urban FG)*

However, notably a number of the sibling family carers (n=3) did appear to have strong informal networks of supports and as a result demonstrated higher levels of caregiving capacity and satisfaction in their caregiving role. For example, in the case of some of the sibling carers, other family siblings provided them with ad hoc respite by caring for their sibling with an ID one evening a week, or every second weekend and, in some cases, taking them away on a holiday for a week;

*I mean it's brilliant now as I say that my sister and I are friendly again and he goes up to her every other weekend, yeah she'll pick him up on a Friday here and leave him back Sunday evening he loves that (Ann, Sibling, Rural I-I Interview)*

*They'd collect her maybe 6 o'clock and she mightn't be home until half ten, quarter to eleven o'clock, they're actually absolutely brilliant with her and they might take her to [location] they have a holiday home in [location], like mobile home] and they'd always yea they'd take her one weekend every year back there and on St. Stephen's night, say on Stephen's day they'd come and collect her, they go down, she sleeps overnight, they're fantastic (Elaine, Sibling, Urban/Rural FG)*

Similarly, parent carers also noted that their other adult children sometimes facilitated respite in comparable ways to those described;

*[son's name] has such a full life like there football fanatics in our house, so I have grandchildren and you know so its football, football, football so [son's name] would have been at Dublin Saturday night and then Sunday he was going out early Sunday morning with the other nephews, he is the water boy, so he has a full life (Patricia, Parent, Urban FG)*

This ad hoc respite appeared to reduce the all-encompassing nature of caregiving by providing family carers with periods of rest, as well as facilitating an increased independence and flexibility to satisfy their interests, hobbies, and life goals which existed outside of their caregiving role. In addition, these family carers appeared to feel more psychologically supported in their role as primary caregiver and thus comparatively less isolated and alone to the family carers who did not experience commensurate levels of informal supports.

## **Family resilience**

All of the family carer narratives (n=17) also provide demonstrable evidence that counteracting the described systemic and psychosocial inhibitors to families' caregiving capacity was a stalwart family resilience and positive attitudinal perspective. On numerous occasions, the vast majority of family

carers noted that despite the many challenges which they confronted, they always felt and believed that they would somehow overcome them;

*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 (Pat, Sibling, Rural FG)*

However, the mechanisms or strategies through which they prevailed over challenges appeared to be unconsciously performed as consistently participants articulated that they weren't sure how or indeed what they did, but that they just got on with it;

*Take everything as it comes, what can you do (Patricia, Parent, Urban FG)*

*As the fella said, carry on and do the best you can (Tom, Parent, Urban I-I Interview)*

*oh gosh I haven't a clue would you believe I think it's just getting up every day and dealing with what comes in front of you other than that I don't know what where I get whatever bit of strength I might have I don't know where it comes from just me I suppose (Kathy, Sibling, Urban I-I Interview)*

Despite this unconscious ability to prevail over innumerable challenges, some of the carers did feel that their caregiving capacity was aided by an inherent predisposition to care for others above all else. Family carers articulated that even from childhood they were always denoted within the family as 'the strong one', the second mother, and thus the one who others went to for love and support. It was this personality disposition and caring nature which informed and facilitated their caregiving sustainability;

*you know so I'll go up and I'll do some of her a bit of cleaning and I do the ironing I do all the ironing for her [...] yeah I'm still doing that but that's my nature, that's my nature. And I remember somebody saying to me one time you can't save the world [participant's name] (Kathy, Sibling, Urban I-I Interview)*

*I think I was meant to be a carer, because even when I was in my teens I was looking after my grandmother, and then my late wife, as I said, she got a transplant 21 years before she died, before that she was in hospital several times, on dialysis and all this kind of thing [...], so obviously I was caring for her at home and then the children when she was in the hospital, so basically what I'm saying is I was a carer, story of my life I suppose (Tom, Parent, Urban I-I Interview)*

Such psychological and attitudinal resilience to caregiving challenges may have been informed, at least in part, by family carers' explicit unconditional love for and commitment to their family member with ID; a factor which was reported within participants narratives. In many cases it appeared that their love for their family member with ID was the bedrock bolstering their capacity to fulfil their caregiving role in the home. Whilst all other external factors, such as formal and informal support networks, may have mediated their caregiving experience, participants felt that it was their caring nature and love for their family member which fundamentally promoted their ability to support their family member in the home;

*We would be miserable without him (Breda, Parent, Rural FG)*

*I'm not sure what my coping skills are, I know I'm sort of more in touch with my feelings regarding my brother, I really have a love for him (Pat, Sibling, Rural FG)*

Evidently, the love and commitment which family carers described was reciprocal in nature. Family carers passionately recounted the love and companionship they received from their family member with ID and the benefits it afforded not only them but the holistic family unit;

*I absolutely adore her, I love her and she is the grandparent that they didn't have, that the kids didn't have (Carol, Sibling, Urban FG)*

*He brings, he brings he unites the family [...] they're all very close. [son's name] was the glue that kept them together, you know they'd look after him [...] you know he's moulded the family. Really he's like the queen bee you know she moulds all the workers around but that's [son's name] he's the centre of everything (Gerard, Parent, Urban I-I Interview)*

## Section B: Future sustainability of family caregiving

### Discussing the future

Interestingly, study findings suggest that the majority of family carer's future care plans (n=15) were demonstrably aspirational in content with few definitive future care plans confirmed for their family members with ID. However, whilst family carers appeared to aspire for certain care infrastructure occurring in the future, they differed as to the extent to which they had discussed their aspirational care plans with other members of the family. For example, a number of the parent participants (n=4) articulated that, to some degree, discussions about the future care options of their adult child with ID had occurred with their other children. However, these discussions appeared to be often ad hoc, informal, and with not all family members present. Consequently, family carers seemed unsure whether their aspirational plans would actually eventuate when the time came and yet no definitive plans appeared to be agreed with residential services, no official agreements amongst all family members were evident, and no reference to future care planning had been inserted into their wills;

**Participant:** *Yer man there [son's name] he's now at the moment seems to be the most likely candidate*

**Interviewer:** *yeah but you haven't had a conversation with him about that*

**Participant:** *[...] I haven't actually [...] but maybe I should over a pint when we're having a pint up there on Thursday nights (Tom, Parent, Urban FG)*

*What the future will hold I don't know, I used to worry about it, I'm a bit of a worrier and I used to worry about it a lot. My boys kind of say not to worry they'll kind of look after him but like...you kind of feel like they have a life, do you know what I mean, my boys they don't even want to talk about it, they're no no, we're here and all that kind of thing (Patricia, Parent, Urban FG)*

Similarly, the majority of sibling carers, who also had predominantly aspirational future care plans, had not discussed these hopes with other family members. In fact in many of the sibling carer families, they had taken the step to discuss future plans with residential services but appeared to have no intention to do the same with other members of the family;

**Participant:** *Well I didn't actually go that far, it's probably I haven't really thought it through as regards that. I just presume like there's, I've got my sister in England and my brother here and my younger brother and my sister here. I'm just thinking like if [service name] came round and said well we told [participant's name] that we are prepared to take, then they would sooner let that happen than put him into a home [...], I feel that they'd say well that's okay with them, takes the pressure off them*

**Interviewer:** *and is that a conversation that you have had with them*

**Participant:** *I haven't actually talked to them about it, no (Pat, Siblings, Rural FG)*

In contrast, two of the six parent carers had either inserted into their will and/or discussed with all their families their future care preferences for their family member with an ID. In the case of parents, these discussions and definitive plans included leaving the family home to their adult child with ID, and stating their preferences for them to be supported within the family home by their siblings, and/or other (paid for) carers;

*The idea is that she stays here, with help if it is needed, [...] the boys will look after it and whatever way this little place would be settled and sorted for her [...] I'd be happy with that you know she'd be in her own environment all the time we'd have a carer I think to come in because we wouldn't, the boys will have done their bit, they will keep an eye they will always keep an eye and make sure that's she's happy and that life goes on for her as best they can you know that kind of situation [...] [daughter's name] will be here anyway and they're all in agreement with that (Lilian, Parent, Rural I-I Interview).*

*I don't you know, what I suspect would happen is if I kicked it, kicked it, I suspect that he probably lock stock and barrel probably would come to live here [...] that's written in that [daughter's name] whoever comes into look after her well that's fine but this is her house so she's in my will. I have stated that she has this is her house and if somebody wants to come in here and look after her from the family that's fine but it's her house (Tom, Parent, Urban I-I Interview)*

## **The potential diminishment of family capacity**

Regardless of whether aspirational or definitive future plans had been made, the content of the majority of families' future plans appeared to question the future sustainability of family caregiving capacity. This was not however the case for all families. As described in the above section, for some families, particularly the parent caregivers, there remained a possibility that a transition of caregiving within the family could occur, primarily from parents to siblings. There were just two of the sibling carers who envisaged a continuing of the caregiving role within the family after they had gone. One of these sibling carers was confident a lateral transition of caregiving from one sibling to another sibling would occur. The second sibling carer was the exception to the rule in that she envisioned and planned for a transition of care to her own children (their sibling with ID's nephews or nieces) when she and her husband had passed away;

*Oh I mean if anything happened to me he'd move up to [sister's name] and that's it. I have no doubt about that, she'd be the best place for him like, oh yeah, yeah and as I say her kids are all grown up now and you know more space and a bit quieter (Ann, Sibling, Rural I-I Interview)*

*We have been open and honest about everything. I have said look if you don't want to do this they will have to go somewhere, if anything happens to myself or [husband's name] and you's just sell up, we won't think anything of you, [...] my daughter in law has said 'we are here for the long haul, the two boys are going to be going to school here so from what we can see, sure'. She seems as easy-going as my husband is and yet she is feisty, she has a fight in her that I have, even though she is my daughter-in-law she has that fight (Sheila, Sibling, Urban FG)*

However for others, siblings and parents alike, the capacity within the family to continue appeared limited. Parents described how their remaining adult children did not satisfy the socio-demographic variables, discussed at the beginning of this study results section in 'Life-stage', considered essential to facilitating family caregiving; they did not live close and they were married with their own children. It was these determinants that appeared to inform parent carer decisions that they would need to seek alternative care outside of the home for their adult child with ID in the future;

*What's going to happen when we're gone? Now the girls idolise him but it...it no way first of all would I think that they should have to have him but anyway [...] I mean for example he has no business living in Clare, no business living in Belfast, England or Germany so and none of those they're*

*all settled with their own families they're not going to...return to cork so that really is our biggest problem really isn't it (Breda, Parent, Rural FG)*

In other cases however, particularly the sibling carers but also a minimal number of the parent carers, caregiving within the family home of their family member with an ID would most certainly be discontinued on their death as they neither expected nor wished their offspring (their sibling with ID's nephews or nieces) to continue the caregiving role. Family carers' perceptions appeared to be informed by their experience of the caregiving role as all-encompassing and therefore extremely challenging, and stressful;

*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 (Gerard, Parent, I-I Interview, Urban)*

Similarly, not only did sibling carers report that there would be no future transition of care to their children but that there would also be no expectation that their spouse was to continue on family caregiving for any amount of time after their passing;

*I think it is amazing that we even have to ask the question now because I assumed that once I made their decision to look after [sister's name] that would be the end of the line. I never thought that there, that you know there might be another handover situation and I am in no doubt that [husband's name], if something happened to me he is not to continue doing what we are doing because it is too hard, he needs to just hand it over to the HSE once I am gone out of the equation (Carol, Sibling, Urban FG)*

*Well I suppose she will require full time respite [...] I think it's happening, if she carries on the way she is now [...] I suppose it'll have to come sooner or later. If I wasn't here, we would have to put her somewhere because it is not [spouse's name] responsibility (James, Sibling, Rural/Urban FG)*

## **A resurgent need for residential care**

As indicated in the above quotations, the outcome of the demonstrable future diminishment of family capacity in many of the families will perhaps be a dependency on state run residential services. The number of family carers (n=10) indicated that residential services will have to be utilised in the future. As discussed, the predominant rationale for this decision was that there simply wasn't any other family member who was either in a suitable socio-demographic life stage or who was willing to continue the family caregiving role. Whilst for many this was a regrettable situation, they could see no feasible alternative within the family;

*I had to do something extraordinary with my, with [service name]. I went into [service name] and said to them 'I am not sure that my family will look after my brother if anything happened to me so I am worried about that' so they said to me 'well we'll be able to look after him in a residential way if anything happened to you' and that gave me a huge peace of mind. I thought to myself that is an awful thing to have to do. I have two brothers and two sisters and his mother is still alive and I couldn't be sure that they would look after him. Isn't that extraordinary, I mean it's just terrible in this day and age (Pat, Sibling, Rural FG)*

**Participant A:** *I would, we want him to stay with [service name], that would be our [preference] we've discussed with [service name] and everything but of course they can't give you any guarantee*

*that they will, [...]It'd be what he stays in now for respite, they have these houses with house mothers and they are brilliant and they are lovely. So that's what we would hope but with the four girls coming very, very regularly and they've all*

**Participant B:** *and bring him out at weekends and ideally if we could keep the house, he could come out every weekend, you know, if it's possible to keep the house (Breda & Martin, Parents, Rural FG)*

In addition to the lack of family capacity, families also perceived the need for residential care due to the advancing age and associated health difficulties of the individual with ID. Like other families of ageing parents or family members, they desired to support their family member for as long as they could but inevitably they could foresee a time that as their family member aged, they would not be able to provide the level of care that they needed;

*yea and as well as that they told us, the two social workers that came that day, told us like, because we put down you know when they send us out a form, will we need full time respite, and we put down maybe 2 or 3 years in the future because we didn't think it would progress as quickly as it did, so they said to us no, ring now and put her name down for full time because they said like you said It will escalate very fast, they said her dementia will come on rapidly (Elaine, Sibling, Rural/Urban FG)*

*I don't know what's going to happen him if anything happens to me because there's no one else to take him. I do know what's going to happen to him. I'm saying that there and I shouldn't have had. He's going to go to a community house and [brother's name] being [brother's name] his coping of that will be very, very hard on him, very, very difficult now I hope to be able to continue doing this for as long as I can you know but I'll do it until I suppose the day the man above wants to take me and I'll try and keep doing it until then but I do see that as he's getting older and as I'm getting older it's probably going to get a little harder because like it is even hard now (Kathy, Sibling, Urban I-I Interview)*

## **Conclusion**

Study findings suggest that whilst family caregiving within the home offers people with an ID an invaluable, immeasurable, and economically preferable support system, its present and future sustainability may be dependent on the adequate availability of numerous interrelated socio-demographic, systemic and psychosocial indices. Of particular concern to present sustainable caregiving capacity are the demonstrable financial pressures that families are enduring, in addition to the overwhelming physical and emotional toll that the all-encompassing carer role appears to entail for families. Both of these inhibitors are of course exacerbated by the limited availability of respite and the lack of informal support from extended family networks. To some degree, the study findings presented imply a questionable future for family caregiving capacity within the home. Whilst a small number of parents and siblings envisaged and planned for future family caregiving capacity after their death, the majority of family carers demonstrated a future dependency on residential services. Whilst this was perceived to be regrettable, family carers believed that the facilitators needed to continue family caregiving simply would not exist after they passed away, and consequently they could see no alternative for their family member with an ID but to utilise residential services.

## Validation of study findings

In order to contextualise and validate the study findings, a proposed seventh focus group was to be conducted with some of the family carers' family members with an ID. However during data collection, family carers' articulated a number of concerns with this proposal including anonymity, accessibility and scheduling issues. It was subsequently hoped that a focus group could be conducted with people with an ID from one or more of the various advocacy groups already established and currently in operation in either ID services or advocate organisations. However, this also proved difficult as many of the individuals involved in such advocacy groups neither lived with nor had frequent contact with their families. It was surmised that the depth of feedback that people with an ID who had little or no experience of living at home with their family could provide may be limited. In addition, from an ethical stance, it was also felt that it may not be appropriate to discuss family caregiving with this specific cohort of people with an ID.

A consultation regarding the findings was facilitated with an advocate who has been involved in a consultancy capacity with this study's parent study of IDS TILDA since its inception and who lives independently with frequent contact and support from family members. The core study findings and relevant questions were constructed into easy-read format and informally discussed with the study advocate. Field notes were written down throughout this informal discussion. During our discussion, the study advocate reiterated two primary themes which validated the data garnered from family carers; 1) the importance of systemic supports and; 2) the mediating role of care recipients' needs.

The study advocate felt that systemic supports (monetary remuneration, day services, and respite) were vital to facilitating and sustaining family caregiving capacity. Whilst she was now proficient in budgeting her allowances, she still felt that the ever increasing cost of living was making family living progressively difficult. Pertinently, she acknowledged the value of the living alone allowance and also the recently proposed increase in the fuel allowance announced in Budget 2016 but yet still recounted that she often worried about meeting the cost of her utility bills. The study advocate's narratives in this regard reflect those of the family carers who, as described in Section A of the study findings, also identified the financial stressors associated with caregiving as an inhibitor to sustaining family caregiving capacity. The study advocate also reiterated family carer's experiences regarding the integral role formal services such as day services and respite played in supporting family caregiving. She felt that some people with an ID required a lot of care and in these cases families would really struggle without the support of formal services. Astutely, the study advocate also noted that families' require the support of an ID specialised social worker to help them negotiate all the different services their family member with ID required, in addition to being there as a confidant to talk to families if they were under stress or upset.

In addition to the important role of systemic support, the study advocate also consistently reiterated the heterogeneity of people with ID's capacities and support requirements. She felt that this was a major mediating factor informing family caregiving experiences and thus capacity to provide prolonged support. In particular, she noted that it would be difficult for families to sustain support in the home for people who had severe or profound ID and/or those who had mobility problems as they aged. Interestingly, the study advocate highlighted that care recipients' needs also determined the extent to which they could perform community inclusion. She felt that some people with ID did not have the skills required to either live independently or be involved in activities in the community and so services would have to acknowledge this and adapt their service accordingly by providing extra supports to this distinct cohort. Once again, this is an informed opinion which was also identified amongst family carers and described in Section A of the study findings wherein families

articulated their concerns regarding the appropriateness and generic implementation of contemporary policy with their family member with an ID.

The study advocate's insights and feedback regarding the study findings was invaluable as it validated the narratives provided by family carers but moreover it also reiterated that the stressors family carers' feel may also be identified and felt by their care recipients. It may therefore be deemed even more pertinent that family caregiving be adequately acknowledged, valued and supported for the health and wellbeing of both family carers and their family members with an ID.

## Discussion

In light of the study findings, there are a number of pertinent issues which require further elucidation and discussion within the context of current policy and previous academic endeavours. This discussion will firstly reiterate the vital role family carer's love and personal commitment for their family member with an ID played in bolstering their capacity to sustain family caregiving. Subsequently, a number of the identified inhibitors to family caregiving capacity are explored, particularly in relation to the various relevant policies currently in operation in Ireland. Lastly, family carers' future care succession planning and the potential implications arising from same are examined.

### Love Labour: The Bedrock of Family Caregiving Capacity

Whilst many inhibitors of family caregiving were identified in this study, one of the strongest facilitators was an evident degree of resilience that all of the family carer's demonstrated. Despite experiencing the psychological and physical stressors associated with the all-encompassing carer role, in addition to enduring financial hardship, the family carers articulated that they would nevertheless find a way as best they could to continue to support their family members with an ID for as long as was feasibly possible. The resilience of family carers to continue caregiving for their adult child with an ID despite the challenges is a nascent area of scholarship<sup>124,125</sup> In this study, families' resilience appeared to be informed by their love for and commitment to their family members with an ID. It was this loyalty to their family member which families identified as transcending all other challenges and consequently acting as a bedrock bolstering their capacity to "keep on keeping on" whilst also counteracting the detrimental physical and psychological effects of caregiving. This form of support is described by Lynch and McLaughlin (1995)<sup>126</sup> as 'Love Labour' which entails "not only to a set of tasks but to a set of perspectives and orientations integrated with tasks [...] the very real activities of looking out for, and looking after, the other; and that includes the management of the tensions and conflict which are an integral part of solidary relations". To the best of our knowledge, no work has previously explored the potentially facilitating relationship between love (i.e. love between care provider and care recipient) and prolonged family caregiving capacity amongst family carers of older people with ID. However there are tentative musings from prior work in a related area which suggests that compassionate love may have a mediating affect in reducing carer burden and informing more positive appraisals of the caregiving experience.<sup>127</sup> Given that love labour is predicated upon the existence of mutuality, trust, commitment, and responsibility between two individuals (care provider and care recipient), it may be difficult to measure and thus replicate in formal care settings. Although, emerging evidence from end of life care would suggest that replication in formal care settings is possible, especially within a relationship-centred care

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<sup>124</sup> Grant, G., Ramcharan, P., and Flynn, M. (2007), 'Resilience in Families with Children and Adult Members with Intellectual Disabilities; Tracing Elements of A Psycho-Social Model', **Journal of Applied Research in Intellectual Disabilities**, 20 (6), pp. 563-575.

<sup>125</sup> Seltzer, M. M., Floyd, F., Song, J., Greenberg, J., and Hong, J. (2011), 'Midlife and Aging Parents of Adults with Intellectual and Developmental Disabilities: Impacts of Lifelong Parenting', **American Journal on Intellectual and Developmental Disabilities**, 116 (6), pp. 479-499.

<sup>126</sup> Lynch, K. and McLaughlin, E. (1995) 'Caring Labour and Love Labour' in Clancy, P., Drudy, S., Lynch, K., and O'Dowd, L. (eds) **Irish Society: Sociological Perspectives**, Dublin: Institute of Public Administration.

<sup>127</sup> Monin, J. K., Schulz, R., and Feeney, B. C. (2014), 'Compassionate Love in Individuals with Alzheimer's Disease and their Spousal Caregivers: Associations with Caregivers' Psychological Health'. **The Gerontologist**, 55 (6), pp.981-989.

model<sup>128</sup>, it nevertheless incurs an economic cost. Therefore, the evident existence and mediating impact of love labour amongst the study sample, which in many ways may exceed the quality, level and type of other forms of care labour, poses interesting questions and underlies the importance of sustaining such an economically efficient form of care within the family for as long as possible. While this particular aspect of caring labour within the family home setting is difficult to audit or account for in pure economic terms, it appears to be a core facilitator of longevity in care provision within family settings, the absence of which has a direct economic impact in terms of the cost of care provision within residential services. Further research into this underexplored aspect of care provision in the Irish ID sector would appear warranted.

## **Family Caregiving Capacity in Danger**

Although study findings suggest that family caregiving capacity is underpinned by a resilient love, loyalty, and commitment to their family member, family carers' narratives in this study also reveal that this resilience was consistently challenged. Families honestly recounted that they often felt physically, emotionally, and psychologically overwhelmed by the all-encompassing nature of the carer role. Families recounted the physical, emotional and intellectual strain that providing 24 hour care created. In this regards, family's narratives support the vast body of previous work conducted which consistently reiterates the detrimental physical and mental health implications that providing high dependency support to a person with an ID can extend to family carers. However, this study's findings also explicitly reiterate previous research which suggests that the outcome and level of carer strain and thus caregiving capacity is influenced by innumerable mediating factors which inform the evident heterogeneity in the caregiving experience. In this study, the strongest mediating factors which appeared to have the potential to threaten the sustainability of family's caregiving capacity were the; 1) extent and type of care recipients' needs; 2) financial pressures, and 3) strong dependency on formal support services.

### **1) Extent and type of care recipients' needs**

Firstly, family carers in this study noted the mediating impact of their care-recipients' support needs upon their current caregiving experience and their future caregiving ability. They often noted that the level of their caregiving capacity was more cumbersome now than it was in the past as their family member with ID aged and their support needs advanced. In particular, a number of the sibling carers whose family members had also developed dementia noted that they increasingly felt that the care their family member required was exceeding that which they could provide. Equally, the narratives of the two carers in the study sample whose family members had severe/profound ID or had ID with an additional diagnosis of mental health difficulties were distinctly different to those of the family carers with family members with mild or moderate ID. The detrimental implications on their physical and mental health alongside the level of physical and intellectual curtailment to the carer role appeared to comparatively exceed those with family members with mild or moderate ID. Further, a number of the carers of people with mild/moderate ID explicitly acknowledged that their experience was different to those whom were caring for severe/profound ID and hypothetically questioned their own ability to sustain caregiving should their family members' level of ID be more profound or their health deteriorate. This qualitative evidence reiterates previous evidence which suggests that the level of care recipients needs may powerfully mediate the sustainability of family

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<sup>128</sup> McCarron, M., McCallion, P., Fahey-McCarthy, E., and Connaire, K. (2010), 'Staff Perceptions of Essential Prerequisites Underpinning End-of-Life Care for Persons with Intellectual Disability and Advanced Dementia', *Journal of Policy and Practice in Intellectual Disabilities*, 7(2), pp. 143-152.

caregiver capacity.<sup>129</sup> Consequently, present and future initiatives and policies which aim to strengthen family caregiving capacity must move away from conceptually generic, homogenous, 'one size fits all' approaches and instead transition towards implementing innovative and tailored supports which are reflective of the heterogeneous realities and distinct needs of each individual family.

## 2) Financial pressures

One of the strongest factors which appeared to severely impinge on and notably test family's caregiving capacity was the financial implications of fulfilling a full-time carer role. This was most pertinently the case for the carers who did not qualify for the carer's allowance or any other supplementary allowances and so were receiving little or no financial remuneration for their providing care to their family member with an ID. Families noted that they often worried about their ability to meet the cost of basic living expenses such as electricity and heating bills. This worry impacted on their caregiving experience and the level of stress they experienced. Financial remuneration is a factor which is consistently identified and highlighted as central to facilitating the sustainability of family caregiving whilst also adequately recognising the value and worth of caregiving within the family home. However, whilst the National Carer's Strategy does include five action points in relation to income support, it fails to guarantee its full protection. To date, the National Carer Strategy (NCS)<sup>130</sup> has also demonstrated relative inertia with regards to the aforementioned action points in relation to income support which include information, timely access to income supports, reduction in waiting times, highlighting the potential to share an allowance, and a review of transition arrangements post-caring. In 2015, the Carers Association published the Family Carer's Scorecard<sup>131</sup>; an assessment of the NCS's progress of the NCS since its inception in 2012. The Family Carer's Scorecard highlighted that in a number of areas, action to date was deemed regressive. Particularly noteworthy in relation to monetary supports was the 19% cut to the respite care grant in budget 2012, and the halving of funding for Housing Grant Schemes from €79 million in 2011 to €38 million in 2014. Whilst Budget 2016 appears to offer some progressive action, particularly in relation to the restoration of the Respite Care Grant, now renamed the Carers Support Grant, to the 2012 rate of €1,700, the majority of Budget 2016's initiatives offer little consolation to the many full time carers who do not qualify for carer's allowances and yet still endure monetary restrictions. Considering the consensus view that family caregiving is an economically preferential model of caregiving, (Care Alliance Ireland estimate that the cost to the State for providing the same level of care as Family Carers would be between €2.5- €4 billion annually<sup>132</sup>), it is deemed pertinent that all family carers should be provided with some level of financial support which is commensurate to their needs and means.

## 3) Strong dependency on formal support services

An equally strong mediating factor of families' ability to sustain caregiving from families' perspectives was their strong reliance on formal supports, specifically day and respite services. Families noted that day services offered dual benefits; providing them with daily respite whilst also facilitating their family member with ID's access to purposeful, worthy and valuable endeavours and relationships

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<sup>129</sup> Irazabal, M., Marsa, F., Garcia, M., Gutierrez-Recacha, P., Martorell, A., Salvador-Carulla, L., and Ochoa, S. (2012), 'Family Burden Related to Clinical and Functional Variables of People with Intellectual Disability with and without Mental Disorder', **Research in Developmental Disabilities**, 33 (3), pp. 796-803.

<sup>130</sup> Department of Health (2012), **'The National Carers' Strategy-Recognised, Supported, Empowered'** Dublin: Brunswick Press LTD.

<sup>131</sup> Carers Association Ireland (2015), **'Family Carers' Scorecard: What Has the National Carers Strategy Achieved? An Assessment of Progress from the Perspective of Family Carers'**. Retrieved from [http://www.carersireland.com/userfiles/file/Family%20Carers%20Scorecard%20Summary\(4\).pdf](http://www.carersireland.com/userfiles/file/Family%20Carers%20Scorecard%20Summary(4).pdf).

<sup>132</sup> Care Alliance Ireland (2015) **Family Caring in Ireland**. Retrieved from <http://www.carealliance.ie/userfiles/file/Family%20Caring%20in%20Ireland%20Pdf.pdf>.

outside of the familial context. Their family members' with ID strong emotional connection to their day service, its' staff and their peers was particularly noted by families; so much so that they hypothesised that any sudden withdrawal or configuration changes of day services would induce stress and worry. Most pertinently, they also questioned their ability to continue caregiving should any changes occur within services or if services were reduced or withdrawn. This is concerning evidence in the light of recent policy implementation in this regards. *New Directions; Review of HSE Day Services and Implementation Plan 2012-2016*<sup>133</sup> specifically denotes a transformation of how day services are configured and implemented. Anecdotally, the implementation of this policy has supposedly prompted the closure of a number of day services country-wide. Families were extremely conscious of the changes occurring in day services and expressed their worry about the appropriateness of such changes for their ageing family member. Specifically, many of the family carers felt that the implementation of increased community inclusion and participation was not inclusive to the needs of their aging family members, specifically those with dementia and/or those with severe or profound ID.

Families' concerns in this regards may be valid. The required changes espoused in *New Directions* are largely conceptual in nature with minimal practical direction provided as to how current day services should interpret and consequently implement the policy's directives, especially with regards to older people with an ID and those with severe or profound ID. Throughout *New Directions'* policy documentation, the only guidance with regards to the implementation of the policy with those with severe or profound ID is the simple assertion that "For people with severe and profound disabilities, the scope for community inclusion may be limited but the scope for a meaningful form of inclusion that is respectful of their needs should be part of the person-centred plan".<sup>134</sup> Even more perturbing is the fact that there are no explicit references as to how the directives may need to be tailored for the older cohort of people with an ID. Families were therefore worried that services were either implementing the new directions policy in a 'one size fits all' approach or only appeared to be interested in providing a day service to clients who were perceived to be 'more capable' of fulfilling the policy directives outlined in *New Directions*. The resulting outcome was that families felt their family members were being forgotten. Such an outcome, which may be a real and distinct possibility if governmental policies continue to lack clear and explicit guidelines for service implementation with all cohorts of the ID population, would have a negative impact on the sustainability of family caregiving as families made it clear that without the availability of daily respite of reliable, regular and quality day services they could not foresee their continuance of the carer role into the future.

Families expressed similar concerns regarding the reduction and in some cases complete withdrawal of respite services. The flexible availability of quality respite care is consistently identified as an important facilitator of continued family caregiving capacity. However, this is yet another area in which the National Carer's Strategy has under-performed. Action points 4.1.2 and 4.1.3 of the strategy refer to the promotion of person centred, flexible respite care options in addition to the identification of existing service gaps and the development of service performance indicators. To date however, the Family Scorecard report<sup>135</sup> indicates that vital respite hours have been cut and the number of respite and long stay beds reduced. Some practice changes may have impacted on this reduction in respite, for example the welcome improved standards for accommodation required for

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<sup>133</sup> Health Service Executive (2012) '**New Directions Review of HSE Day Services and Implementation Plan 2012-2016**'. Retrieved from <http://www.hse.ie/newdirections/>.

<sup>134</sup> Health Service Executive (2012) '**New Directions Review of HSE Day Services and Implementation Plan 2012-2016**', p.73. Retrieved from <http://www.hse.ie/newdirections/>.

<sup>135</sup> Carers Association Ireland (2015), '**Family Carers' Scorecard: What Has the National Carers Strategy Achieved? An Assessment of Progress from the Perspective of Family Carers**'. Retrieved from [http://www.carersireland.com/userfiles/file/Family%20Carers%20Scorecard%20Summary\(4\).pdf](http://www.carersireland.com/userfiles/file/Family%20Carers%20Scorecard%20Summary(4).pdf).

respite may have impacted on the overall level of respite availability. The Family Scorecard report also highlights anecdotal accounts of reductions in in-home respite services. However, limited national data is available regarding all types of respite services and so ambiguity remains as to the scale and extent of reductions and/or withdrawals of these services. Most perturbing is a statement published in the HSE service plan<sup>136</sup> which states that;

“The 2015 Social Care Operational Plan will include an expanded range of KPIs which include non-overnight respite and no. of people in receipt of more than 30 overnights continuous respite. It is anticipated that there will be a reduction in overnight respite as services more in line with person centred models are delivered. Data validation will be carried out as transition is made to the new KPIs”.

Such an anticipated reduction in overnight respite services may already be occurring. Data released in the HSE National Service Delivery Plan 2015<sup>137</sup> highlighted that delivered respite services, measured as number of overnights, fell short of NSP’s 2014 expected activity/target (182,887 Vs. 243,260 respectively). Such evident reductions in respite availability are not anticipated to abate in the future as the expected activity/target for 2015 for the same indicator has been reduced to 190,000 respite overnight stays.<sup>138</sup> This study’s findings suggest that such reductions are currently having and will continue to have in the future a detrimental impact on families’ caregiving capacity. In order to ensure sustainable family caregiving capacity, it is vital that the evident plan to reduce the availability of respite is reconsidered with a focus on increased bolstering of respite services availability, flexibility and responsiveness to the complex and multi-factorial needs of carers and their family members with ID.

## **Questioning the Feasibility of Future Family Caregiving Capacity**

Family carers identified numerous factors which are debilitating to their caregiving capacity, which raises questions regarding the feasibility of sustaining family caregiving into the future. Although many of the family carers described their caregiving capacity as being under pressure and consequently questioning how long they could feasibly continue, study findings also demonstrate that many of the families appeared to rarely plan for the day where they may no longer be able to continue providing support for their family member with an ID. For most families, their decision making processes with regards to supporting their family member with an ID in the future appeared to be predominantly aspirational in nature and often were not definitely decided until the family had reached crisis point. This was demonstrated by family carers’ narratives in relation to both past transitions of care and also the evident absence of future definitive plans in their narratives. In hindsight, a number of the sibling carers described the circumstances through which they became primary caregivers of their sibling with ID as occurring within an emergency context after the death of their parents. Despite this prior experience of emergency planning, which for many resulted in a legacy of acrimonious relationships with other family members, a number of the siblings revealed that they themselves had not definitively planned for a second transition of care for their sibling with an ID should it be needed into the future. Equally, a number of the parent carer narratives suggest that they were also unsure of the future care plans for their adult child with an ID. Although some parent carers expressed hopes that non-disabled siblings would assume the caregiving role and/or

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<sup>136</sup> Health Service Executive (2014), ‘**National Service Delivery Plan 2015**’, p. 55. Retrieved from <http://www.hse.ie/eng/services/publications/corporate/sp2015.pdf>

<sup>137</sup> Health Service Executive (2014), ‘**National Service Delivery Plan 2015**’, p. 55. Retrieved from <http://www.hse.ie/eng/services/publications/corporate/sp2015.pdf>

<sup>138</sup> Carers Association Ireland (2015), ‘**Family Carers’ Scorecard: What Has the National Carers Strategy Achieved? An Assessment of Progress from the Perspective of Family Carers**’. Retrieved from [http://www.carersireland.com/userfiles/file/Family%20Carers%20Scorecard%20Summary\(4\).pdf](http://www.carersireland.com/userfiles/file/Family%20Carers%20Scorecard%20Summary(4).pdf).

that out-of-home residential services would be utilised, very few had inserted these hopes into their wills or formally discussed and agreed them with their family members. However, many of the families did make concerted efforts to definitively plan and thus discuss with services their hopes that an out of home placement would be made available for their family member in the future but were left disappointed and frustrated in their efforts to do so when services could not guarantee that a residential place would be available in the future.

Such circumstances are reflective of the issues already identified by previous research. Taggart et al.<sup>139</sup> outlines that although failing to adequately construct future plans and support systems may induce inappropriate out-of-home placements, emotional trauma, and unexpected dilemmas for siblings and extended family members, it appears families are often reluctant to proactively and definitively make future plans. Instead, Bowey and McGlaughlin<sup>140</sup> as well as others<sup>141,142</sup> found that families' frequently avoid making future plans until it is unavoidable or they describe future plans which are predominantly aspirational in nature. Whilst some studies suggest that families' relative inactivity in this regards can be explained by factors such as carer avoidance, carer denial about the inevitability of their own mortality, and worry about the quality of out-of-home placements, our study findings lend support to previous work that identifies insufficient support and guidance from service providers, a lack of appropriate residential options, and hope that a non-disabled sibling will assume primary caregiving responsibility as the primary factors informing family carers' struggle to construct definitive future plans.<sup>143</sup>

Conceivably, it was the limited caregiving options available within their own families that also explained family carers' limited capacity to make definitive future plans. Many of the carers, both parents and siblings alike, articulated their perception that they represented the last remnant of family caregiving capacity available within their familial context. Parent and sibling carers explicitly stated that family caregiving capacity was reaching its conclusion. Parent carers noted that their other non-disabled sons/daughters were all working full-time, had small children, and were geographically dispersed. Similarly, sibling carers also noted that their other non-disabled siblings would be unable to initiate primary caregiving responsibilities for the exact same reasons as those articulated by the parent carers and also that they would be in no way allowing or facilitating a future transition of care to their children (sibling with an ID's nieces/nephews). Therefore, many of the family carers appeared to believe that because of the perceived reduction in the traditional facilitators to family caregiving, and in the absence of alternative options, there was little need for familial discussions on the matter as future plans would inevitably involve the utilisation of residential services. This is an important finding, as it demonstrates a perceived future need for residential accommodation for older people with an ID, which is juxtaposed to the scaling down of such accommodation pursued by contemporary Irish ID social policy.

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<sup>139</sup> Taggart, L., Truesdale-Kennedy, M., Ryan, A., and McConkey, R. (2012), 'Examining the Support Needs of Ageing Family Carers in Developing Future Plans for a Relative with an Intellectual Disability. **Journal of Intellectual Disabilities**, 16 (3), pp. 217-234.

<sup>140</sup> Bowey, L and McGlaughlin, A (2007), 'Older Carers of Adults with a Learning Disability Confront the Future: Issues and Preferences in Planning', **British Journal of Social Work**, 37(1), pp. 39–54.

<sup>141</sup> Ryan, A., Taggart, L., Truesdale-Kennedy, M., and Slevin, E. (2014), 'Issues in Caregiving for Older People with Intellectual Disabilities and their Ageing Family Carers: a Review and Commentary. **International Journal of older people nursing**, 9 (3), pp. 217-226.

<sup>142</sup> Black, L and McKendrick, V. (2010), 'Careful Plans Report'. **Positive Futures Report**, Lisburn. Retrieved from <http://www.positive-futures.net/cmsfiles/downloads/research/Careful-Plans-Report-May-2010.pdf>.

<sup>143</sup> Taggart, L., Truesdale-Kennedy, M., Ryan, A., and McConkey, R. (2012), 'Examining the Support Needs of Ageing Family Carers in Developing Future Plans for a Relative with an Intellectual Disability. **Journal of Intellectual Disabilities**, 16 (3), pp. 217-234.

This identified reduction in the traditional facilitators of family caregiving capacity within the domestic space is not new. It is now recognised that with the increased participation of women in the labour force, the reduction in family sizes, and the increased geographical dispersal of family networks, the capacity of families to sustain support for their family member with an ID over a prolonged period of time is reduced. However, this previous evidence alongside this study's tentative finding that there may be an influx of emergency out-of-home placements of older people with an ID in the immediate future is not currently reflected in any national governmental policy to date. Whilst the need to transition the care of 4,000 people with an ID from congregated settings into the community has attracted policy directives and resources for implementation of same, the potential future transition that this study has attentively identified from family home to out-of-home placements of approximately 3,451 people with ID aged over 35 years of age who currently live at home<sup>144</sup> remains comparatively absent from public discourse and governmental planning. However, the potential transition of older people with an ID from each direction into residential care (i.e. family to community and congregating settings to community), if not adequately identified, evaluated and responded to, may result in a bottleneck of limited community care capacity and resources. The detrimental outcome of such a bottleneck of resources within the community could be the resurgent need for larger scale residential services. Given the historical legacy of people with an ID in congregated settings, this outcome is to be avoided.

This study suggests that initiatives to ensure adequate, sustainable support in the community for people with ID throughout their lifetime should be two-pronged. Firstly families must be proactively supported and resourced to sustain a positive and quality caregiving experience for as long as possible. This requires renewed concerted efforts to fulfil the aims and objectives of the National Carer's Strategy in a timely and efficient manner but it must also include the formation of innovative ways to support people with ID to age in place within their family home. One such innovative strategy would be to consider the development of in-home support which would comprise of a paid carer to be employed within the family home and supplement or replace, depending on the circumstances of each family, the care currently provided by the family carer. Such a strategy could be facilitated through the establishment of a consumer-directed payments model, sometimes referred to as 'money follows the person' which involves providing people with ID and their families with a bursary of funds to freely choose and subsequently purchase the services and individualised supports that they require. This is a model of state monetary remuneration which was promised in the Programme of Government 2011-2016<sup>145</sup> but yet to date has not been actioned upon. In light of evidence from the UK and the US which suggests the widespread success of such schemes<sup>146,147,148,149,150</sup>, a pilot scheme adapted to the Irish context may be an important and integral step to consider.

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<sup>144</sup> Kelly, C. (2015), **Health Research Board Statistics Series 28, Annual Report of the National Intellectual Disability Database Committee 2014**. Dublin: Health Research Board.

<sup>145</sup> Programme for Government 2011-2016, Retrieved on 19<sup>th</sup> December 2015 from [http://www.taoiseach.gov.ie/eng/Work\\_Of\\_The\\_Department/Programme\\_for\\_Government/Programme\\_for\\_Government\\_2011-2016.pdf](http://www.taoiseach.gov.ie/eng/Work_Of_The_Department/Programme_for_Government/Programme_for_Government_2011-2016.pdf)

<sup>146</sup> Caldwell, J. (2008), 'Health and Access to Health Care of Female Family Caregivers of Adults with Developmental Disabilities', **Journal of Disability Policy Studies**, 19(2), pp. 68–79.

<sup>147</sup> Caldwell, J. and Heller, T., (2007), 'Longitudinal Outcomes of a Consumer Directed Programme Supporting Adults with Developmental Disabilities and their Families', **Intellectual and Developmental Disabilities**, 45(3), pp. 161–173.

<sup>148</sup> Heller, T. and Caldwell, J. (2006), 'Supporting Aging Caregivers and Adults with Developmental Disabilities in Future Planning', **Mental Retardation**, 44 (3), pp.189–202.

<sup>149</sup> Stainton, T. (2002), 'Taking Rights Structurally: Rights, Disability and Social Worker Responses to Direct Payments', **British Journal of Social Work**, 32(6), pp. 751–763.

Secondly, for people for whom ageing in place within the family home is not possible, resources must be directed towards identifying and implementing alternatives to congregated residential care for an ageing ID population. Given that many of the families identified that it was their family members with ID's increasingly high physical and mental health support needs which were impacting upon their ability to sustain family caregiving, such alternatives to congregated residential care must be informed by and designed for the complex needs of an ageing ID population. However, it must be acknowledged that this is easier said than done, indeed international evidence addressing appropriate models of residential care for older people with an ID is relatively limited<sup>151,152</sup> and thus potential for the timely replication in the Irish context is restricted. Further, it remains relatively ambiguous as to whether the 'Disability' or 'Aged' care sector should assume responsibility for resourcing and implementing appropriate models of care for this overlapping cohort of the aged population. This ambiguity of responsibility, and thus allocation and dissemination of funds, creates numerable difficulties in facilitating and supporting people with ID to age in place. Nevertheless, failure to rectify this ambiguity and establish specialised out-of-home placements which are adaptive to the high support needs of the ageing ID populations could lead to an increased incidence of inappropriately placing older people with ID into mainstream aged care settings; exacerbating a nursing home sector which is already overextended but which may also be unable to cater to the complex and unique needs of older people with ID.<sup>153</sup>

Given the described study's findings, alongside the evidently limited resources in long term residential care, the increased life expectancy of the population, and the diminution of traditional facilitators to family caregiving, it is proposed that in addition to adequately resourcing family caregiving and initiating high support community options, it also may be necessary to establish future planning programmes with families to instigate and facilitate the early formation of future care plans. Such an initiative, which has been recommended by a number of authors<sup>154,155</sup>, may assist in reducing families' worries for the future, and potentially avoid emergency out of home placement which may be inappropriate. In particular a number of education packages providing families with information and guidance on the services and supports available to them, and the processes and time involved in accessing such supports have been successfully developed<sup>156,157</sup> and have been proven to encourage families to definitely organise their wishes and intents regarding future succession planning.<sup>158</sup>

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<sup>150</sup> Stainton, T. and Boyce, S. (2004) 'I Have Got My Life Back: User's Experiences of Direct Payments', **Disability and Society**, 19(5), pp. 443–454

<sup>151</sup> Bigby, C. (2008), 'Beset by Obstacles: A Review of Australian Policy Development to Support Ageing in Place for People with Intellectual Disability', **Journal of Intellectual and Developmental Disability**, 33(1), pp. 76-86.

<sup>152</sup> Webber, R., Bowers, B., and Bigby, C. (2014), 'Residential Aged Care for People with Intellectual Disability: A Matter of Perspective', **Australasian Journal on Ageing**, 33(4), pp. E36-E40.

<sup>153</sup> Thompson, D. J., Ryrie, I., and Wright, S. (2004) 'People with Intellectual Disabilities Living in Generic Residential Services for Older People in the UK', **Journal of Applied Research in Intellectual Disabilities**, 17(2), pp.101-108.

<sup>154</sup> Taggart, L., Truesdale-Kennedy, M., Ryan, A., and McConkey, R. (2012), 'Examining the Support Needs of Ageing Family Carers in Developing Future Plans for a Relative with an Intellectual Disability', **Journal of Intellectual Disabilities**, 16 (3), pp. 217-234.

<sup>155</sup> Heller, T. and Caldwell, J. (2006), 'Supporting Aging Caregivers and Adults with Developmental Disabilities in Future Planning', **Mental Retardation**, 44 (3), pp.189–202.

<sup>156</sup> Planned Lifetime Advocacy Network (PLAN), (2008) Workshops and seminars. Retrieved from [http://www.plan.ca.resources\\_workshop2.php](http://www.plan.ca.resources_workshop2.php)

<sup>157</sup> Etmanski, A., Collins, J., and Cammack, V. (2011), 'Safe and Secure: Six Steps to Creating a Good Life for People with Disabilities'. Vancouver: PLAN Life Advocacy Network.

<sup>158</sup> Heller, T. and Caldwell, J. (2006), 'Supporting Aging Caregivers and Adults with Developmental Disabilities in Future Planning', **Mental Retardation**, 44 (3), pp.189–202.

Further research into this area, with a view to developing systems of long term care planning and care transitions, would appear to be prudent.

## **Dissemination Plan**

A number of strategies will be employed to ensure adequate dissemination of this study and its findings. On finalisation of this report, it is the intention of the study team to publish this report and an accessible easy-read version of it in conjunction with the National Disability Authority. It is hoped that the launch of the publication will coincide with the hosting of a one day symposium which will present the study findings and be attended by participants, academics, advocates, NGOs and policy makers. Following on from this event, the published report will be circulated to key policy makers, including the Department of Health and the Health Service Executive. In addition, the study findings will also be presented at various conferences. To date, the study team have already presented emerging study findings at Care Alliance Ireland's November 2015 conference entitled '20 years in Family Carer Research' and have presented two papers at the 2016 IASSIDD 2016 World Congress in Melbourne, Australia and another at the 2016 IGS conference in Killarney. A minimum of three academic articles will be submitted for publication to academic journals in 2016. The focus of these articles will be;

- 1) Questioning the feasibility of ID policy; the narratives of family caregivers supporting older people with an intellectual disability.
- 2) 'Love labour' and caring for older people with an Intellectual Disability within the family home environment.
- 3) The diminishment of family caregiving capacity for older people with an intellectual disability.

## **Future Plans for Research Field**

Study findings suggest a number of areas which require further exploration in future research endeavours. As described, family caregiving capacity was heterogeneous in accordance with the care recipient's levels of need. Therefore, in order to adequately inform future policy and service initiatives, it is deemed necessary to further extrapolate the distinct experiences, needs and potential for caregiving sustainability of family carers across the spectrum of ID. Similarly, fundamental love and devotion to family members with ID was identified to be a strong mediating factor informing family caregiving capacity. However, the origins, components, and implementations of such love labour are minimally understood and so further research is required, particularly if we are to avoid its future depletion which could in turn induce economic costs in the form of increased residential service requirements. The researching of 'love labour' is challenging but such research could include qualitative studies with carers focused on 'love, resilience and care', coupled with daily /weekly quantifying and costing of 'non task-orientated care' including activities such as company, conversation, empathy, solidarity and community making. Finally, study findings also suggest that many families may require assistance in constructing definitive future plans that facilitate their family member with ID to age in place within the family home and community. It is suggested that the most necessary and practicable response to such findings may be to develop and pilot targeted inter-agency interventions within an evaluative research framework. Such interventions may be in the form of an educational package designed to instigate and facilitate family discussions regarding future care-plans, alongside the potential development of innovative service provision to assist people with an ID to age in place with the tailored supports they and their families require. The funding of such

timely, practical and translatable research endeavours would, it is argued, instigate the required discourse to inform pre-emptive action regarding the future care needs of older people with an ID and their families.

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## Appendix I- Participant Invitation Letter

Dear Carer,

As you are aware, Trinity College Dublin is carrying out a research study, called IDS TILDA, about the health and well-being of people with intellectual disabilities as they grow older in Ireland. You and your family member with intellectual disability have kindly supported and participated in this study over the last few years. You may remember that last year you completed a carer questionnaire about your experiences of supporting an older adult with intellectual disability, and about your own health and well-being. At that time, you confirmed that you may be interested in taking part in future IDS TILDA research about the carer experience.

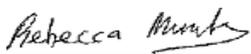
We would therefore like to invite you to take part in a new research strand of the IDS TILDA Study, which aims to understand in depth your experience of supporting an older person with an Intellectual Disability, the potential challenges and benefits of caregiving in the home, and the formal and informal supports that you currently access or hope to access in the future. The research involves a number of focus groups (discussion groups) with carers across Ireland who support a family member with intellectual disability. The focus groups will include approximately 6 family carers, and will be approximately 1 hour in duration. We would like you to consider participating in one of these focus groups. You are however under no obligation to be involved in this research. Your participation is completely voluntary.

We have attached a participant information leaflet with this letter, which we hope will answer some of the questions you may have about this research. Also included for your information is a participant consent form. If you decide to participate, you will be asked to sign this form on the day you attend the focus group.

Please take some time to read these documents. In a week or so, our researcher Rebecca Murphy will telephone you to discuss the study and answer any questions you may have. In the meantime, if you have any questions or require further clarification about the study, please do not hesitate to call Rebecca directly on 087 4349546 or email her on [murphr30@tcd.ie](mailto:murphr30@tcd.ie).

We would like to take this opportunity to thank you sincerely for your continued support of the IDS TILDA study.

Yours sincerely,

  
Rebecca Murphy  
Researcher  
IDS TILDA Family Carer Study

  
Dr. Damien Brennan  
Principal Investigator  
IDS TILDA Family Carer Study

  
Professor Mary McCarron  
Principal Investigator  
Intellectual Disability Supplement to TILDA

## **Appendix 2 – Participant Information Leaflet**

### **‘Understanding family strategies that enable long term and sustainable home environments for older people with an Intellectual Disability’**

We would like to invite you to take part in this new research strand of the IDS TILDA study. This new study aims to understand the strategies families use to support their family member with intellectual disabilities at home. In the following sections of this information leaflet, detailed information about participating in this study is provided.

#### **What has this got to do with me?**

You have received this information leaflet because you care for a family member with intellectual disabilities in the family home and have a vast amount of knowledge and expertise which would contribute to the research. The aim of the research is to help us understand in depth your experience of supporting an older person with an Intellectual Disability, the potential challenges and benefits of caregiving in the home, and the formal and informal supports that you currently access or hope to access in the future. We would also like to ask you to share your thoughts, opinions, or any concerns that you may have about future care plans for your family member with an intellectual disability.

#### **Can anyone participate in this research?**

To be involved you must be a carer for a family member with intellectual disabilities, be over 18 years old, willing to provide informed consent, and willing to have the focus group audio recorded.

#### **If I agree to participate, what will be involved?**

You would join a number of people (around 6) for a group discussion in a place and at a time of convenience to all participating. The discussion will take approximately 60 minutes of your time. We will talk about the challenging and beneficial aspects of supporting family members with intellectual disabilities in the home, the current supports and strategies that help families and also families' concerns and worries about future care plans for their loved ones with intellectual disabilities. I will not ask you to talk about anything you are uncomfortable talking about. The discussion will be tape recorded so that we can listen to it after the focus group is finished and make sure we understand everything you said.

#### **Do you I have to be involved?**

Participation in this research is completely voluntary; you do not have to participate. If you decide to volunteer to participate in this study, you may withdraw at any time. If you decide not to participate, or if you withdraw at any time, you will not be penalised and will not give up any benefits or services that you had before entering the study.

#### **Will everyone know I spoke to you?**

No, your identity will remain confidential. Your name will not be published and will not be disclosed to anyone outside of the IDS TILDA research team.

## **Are there any benefits to being involved?**

This research may not provide any direct benefits to you. It does not provide any financial compensation. However, it provides you with the opportunity to voice your personal views and concerns in relation to your caregiving role presently and into the future. It is hoped that the knowledge you and the other participants provide will contribute to the development of public policy and guidelines to better assist caregivers support their family member with intellectual disabilities in the family home.

## **What are the risks?**

There is a small risk that you may become distressed or upset whilst participating in the discussion. In these instances, we will stop the discussion and provide you with an opportunity to take a break or to talk through your feelings. If after a break you are happy to continue, we will do so. However, if you still feel distressed, you can decide to withdraw from the study. In addition, should any unprofessional practice be disclosed during the interview we are obliged to report this to the relevant authorities.

## **What will happen with the information?**

The information you provide will be written up as a report and may be submitted for publication to academic journals and/or presentations at conferences. It is hoped that the findings of this research study will also inform future policy developments to better assist families to support their family member with intellectual disabilities. If you would like a copy of the focus group discussion and/or the final report, let us know and we will send it to you.

## **What happens next?**

Take as much time as you need to read through this information and consider any personal advantages and/or disadvantages to you participating. Rebecca will ring you in a week or so and ask if you have any questions about the research. Rebecca will then ask you if you would/would not like to participate, or if you need some more time to think it over.

**Compensation:** This study is covered by standard institutional indemnity insurance. Nothing in this document restricts or curtails your rights.

**Permission:** This research has been granted ethical approval from the Faculty of Health Sciences, Trinity College, Dublin.

**Further information:** You can get more information or answers to your questions about the study, your participation in the study, and your rights, from Rebecca Murphy who can be telephoned at 087 4349546 or emailed on [murphr30@tcd.ie](mailto:murphr30@tcd.ie).

**We would like to thank you for taking the time to read this information and for your continued support of the IDS TILDA study.**

## **Appendix 3 – Participant Informed Consent Form**

### **Understanding family strategies that enable long term and sustainable home environments for older people with an Intellectual Disability**

#### **Researcher Contact Information**

Rebecca Murphy, Telephone: 087 4349546, Email: murphr30@tcd.ie

#### **Background**

The purpose of this study is to describe family strategies that enable long term and sustainable home environments for older people with an intellectual disability. We would like to better understand your experience of supporting an older person with an intellectual disability, the potential challenges and benefits of caregiving in the home, and the formal and informal supports that you currently access or hope to access in the future. We would like to ask you to share your thoughts, opinions, or any concerns that you may have about future care plans for your family member with an intellectual disability.

#### **Study Procedures**

Participation in this study will involve voluntarily attending one focus group discussion. The focus group will be approximately 60 minutes in duration, will be conducted in English, and will be audio recorded. It will consist of approximately 6 participants, all of whom are carers to a family member with intellectual disabilities, and will be held in a place of convenience and privacy. During the focus group, you will be asked to share your knowledge on caring for a family member with an intellectual disability at home. After the focus group, the recording will be transcribed and analysed. Your confidentiality will be protected at all stages of the research. Your name will not be used in written transcriptions or in any written material on the study. The findings of this research will be written up as a report and may be submitted for publication to academic journals and/or presentations at conferences.

#### **Declaration**

I have read, or had read to me, the information leaflet for this project and I understand the contents.

I have had the opportunity to ask questions and all my questions have been answered to my satisfaction.

I understand that all information collected in this study will be treated as confidential and that my identity will remain confidential

I understand that the focus group will be conducted in English and audio taped

I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights.

I understand that I may withdraw from the study at any time and I have received a copy of this agreement.

I understand that if instances of alleged professional misconduct be disclosed, that the researcher is obliged to report this to the authorities.

I understand that the information I provide will not be used in future unrelated studies without further specific permission being obtained.

**PARTICIPANT'S NAME:** .....

**CONTACT DETAILS:** .....

**PARTICIPANT'S SIGNATURE:** .....

**Date:**.....

**Statement of investigator's responsibility:** I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

**INVESTIGATOR'S SIGNATURE:**.....

**Date:**.....

## Appendix 4 – Interview Guide

**ICE BREAKER:** Would you like to tell me a bit about yourself and also about your family member with ID?

1. Your family member with ID lives at home for at least 2 days per week, can you tell me about your families' decision to support your family member with ID at home?

**Elaboration/Prompts:** What factors informed your decision?

2. Could you tell me about the positive, beneficial aspects of supporting your family member at home, for your family member with ID?, for you? and for your family as a whole?
3. Overall, how would you currently describe your experience to date of supporting your family member with ID at home?

**Elaboration/Prompts:** (a) Has your experience changed over time? (b) What has influenced/instigated change?

4. What helps you to be able to support your family member at home?

**Elaboration/Prompts:** (a) Does your family member with ID access formal supports (e.g. day services, residential, respite, supported employment programmes, therapeutic services, domiciliary, financial) and how have they helped? (b) Do you and your family members' informal supports (e.g. families, neighbours, friends, hobbies) help? (c) Does your family member with ID help? (provide emotional, psychological support to you, provide practical support around the house)

5. Could you tell me if there are any challenges in supporting your family member at home?

**Elaboration/Prompts:** (a) how do you and families responds to these challenges? (b) Have your responses changed over time? (c) Do you think your appraisal (i.e. attitudes towards/psychological response) of challenges has changed over time? (d) Have these challenges ever made you reconsider your family's decision to support your family member at home?

6. Do you feel like you and your family member with ID require additional support?

**Elaborations/prompts:** (a) What do you think this support should be/look like? (b) How do you think that would help?

7. Do you think your family will require additional and/or different types of supports into the future?

8. Have you and your family thought about and/or discussed what the future might hold for your family member with ID?

**Elaboration/Prompts:** **(a)** Have you made any plans (definitive or aspirational) for the future support needs of your family member with ID? **(b)** Do they involve other members of the family (e.g. your children) becoming more involved in supporting your family member? **(c)** If yes, have you discussed this with them? **(d)** What factors (family, financial, environmental, social, emotional) are informing your thoughts/choices/decisions about the future?

9. Has it been difficult to think and make plans for the future needs of your family member? Do you think you would have/would still benefit from some type of support to help your family through this decision making process?

10. The 'Time to Move on from Congregated Settings report' recommends the movement of all people with ID into more independent settings in ordinary housing dispersed amongst the general population; do you agree/disagree with this policy? If you could design a model of support for other families in the future, what would it be?

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