

Health and well-being of sibling carers of adults with an intellectual disability in Ireland: Four waves of data

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Abstract

Background: As the life expectancy of people with intellectual disability increases, they may now outlive their parents or their parents' ability to continue to care. Siblings of adults with intellectual disability often succeed their parents as primary carers. Little is known about the health and well-being of this important cohort of carers who will be both caring for and ageing alongside their brother or sister with intellectual disability. The Carer's Study within The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) provides a unique insight into the health and well-being of family carers of older adults with intellectual disability including sibling carers in Ireland. This article reports on the findings from waves 1, 2, 3 and 4 of the IDS-TILDA Carer's Study.

Methods: The IDS-TILDA Carer's Study surveys family carers of older people (aged 40 years and older) with intellectual disability on a 3-yearly cycle. The family carers complete a self-administered, mixed-methods questionnaire. The qualitative data are analysed thematically, and a descriptive analysis of the quantitative data is conducted using SPSS.

Findings: In each wave, sibling carers comprised a significant proportion of the Carer's Study participants: W1 58%; W2: 61.4%; W3: 76.7%; and W4: 45.8%. The siblings were predominantly female, not in paid employment and were caring without the support of a spouse or partner. Across the four waves, siblings reported good general health. However, a high prevalence of particular conditions including back pain, aching joints and stress was also reported, and in each wave, siblings reported feeling completely overwhelmed by their care responsibilities. Although sibling carers reported that they have considered the future, only a minority have progressed to action in this regard.

Conclusions: There is evidence of the strong relational and emotional commitment by the siblings to their brother or sister with intellectual disability. However, through the four waves of data, there was also evidence of physical, mental and financial toll. An urgent need exists to identify and engage with siblings to protect their well-being as they provide care for an increasingly ageing sibling.

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KEYWORDS

family, family support, health and social care policy and practice, intellectual disability

Accessible Summaries

- When the parents of people with intellectual die or can no longer provide care and support, brothers and/or sisters may take over the role.
- Little is known about the lives of these brothers and sisters and whether they need support.
- Our study asks brothers and sisters about their lives, their health and the good and more difficult things about being a carer.
- This paper reports on the results of four surveys over 9 years.
- Most brothers and sisters felt that their health was good but because many reported health problems, more support should be available to brothers and sisters who are carers.

1 | BACKGROUND

The welcome increase in the life expectancy of people with intellectual disability over recent decades has implications for their lifelong care (Brennan et al., 2016; Hayden et al., 2022; Lee & Burke, 2020). As of 2017, 69% of people with intellectual disability in Ireland lived at home with parents, siblings, relatives or foster parents; the Irish Department of Health projects that the number of adults with intellectual disability who are living with family members will be 20% higher by 2032 than it was in 2017 (Department of Health, 2021). It is now probable that people with intellectual disability will outlive their parents or their parents' ability to continue to care and it is likely that many siblings will take over the responsibilities of caregiving (Brennan et al., 2016; Hayden et al., 2022; Kruithof et al., 2021; Lee & Burke, 2020).

Without adequate and appropriate support, informal may carers experience negative physical, psychological and financial impacts (UNECE, 2019). The focus of the literature relating to caregiving and disability has largely been on families with children with disability, with less research focusing on the specific context of caring for adult children with intellectual disability (Cairns et al., 2014; Mahon et al., 2019). However, the extant evidence indicates that carers of adults with intellectual disability experience worse general health than the general population including high blood pressure, greater pain or discomfort and anxiety and depression (Grey et al., 2018; Taggart et al., 2012). Older carers, in particular, may be at increased risk of poor health and well-being outcomes (Namkung et al., 2017; Yamaki et al., 2009). Nevertheless, caregiving is a multidimensional experience and positive and negative impacts of caregiving may coexist and are not mutually exclusive (Beighton & Wills, 2019; Pristavec, 2018). Family carers of people with intellectual disability have reported deriving great satisfaction from their role despite experiencing high levels of depression, anxiety and stress (Rowbotham et al., 2011). Carers of adults with intellectual disability

may enjoy, and even rely on, the companionship and practical and emotional support that they receive from their family member (Truesdale, et al., 2021).

Sibling relationships have a number of unique characteristics, not least that it is usually the longest-lasting relationship that an individual will experience (Cicirelli, 1995). Although the population trends indicate that siblings of people with intellectual disability will increasingly be involved in caregiving, they are usually not involved in any future planning by their parent(s) (Heller & Arnold, 2010; Leane, 2020; Sonik et al., 2016). Brennan et al. (2016) reported a process of implicit progression from parent to sibling and some siblings being unaware that they had been nominated as the guardian of their sibling until the death of the parent caregiver, precipitating significant upheaval in their own lives.

The spectrum of caregiving to an adult sibling with intellectual disability is broad and encompasses a myriad of tasks and roles including personal and social care, advocacy and guardianship (Heller & Kramer, 2009). Assuming responsibility for a brother or sister with an intellectual disability, and indeed the expectation of a forthcoming care responsibility, may represent a life-changing transition for the adult sibling, and yet, there is little evidence about the dynamics of this transition or even the actual extent to which siblings are assuming primary care of their adult brother or sister who is ageing with intellectual disability. In addition, there is limited research evidence about the factors that support successful intergeneration transfer or about the supports and resources that would facilitate this. Adult siblings may constitute a taken-for-granted backdrop to family care (Tozer & Atkins, 2015). Sciscione (2022) argues that there is no societal model for siblings caring for their adult brother or sister and the extant literature focusses more on siblings' anticipation of caregiving than on their experiences of being carers of their sibling with an intellectual disability (Casale et al., 2021; Doody et al., 2010; Kruithof et al., 2021; Orsmond & Seltzer 2000; Sciscione, 2022). The intention to care at some time in the future may not result in actual

caregiving and the reality of caregiving may differ from the anticipations that siblings had of caregiving (Burke et al., 2016). The limited existing research literature, emanating primarily from North America, Australia and the UK, identifies that siblings need relevant information and support from formal services including for future planning and system navigation (Arnold et al., 2012; Bigby et al., 2015; Cuskelly, 2016; Davys et al., 2010; Heller & Kramer, 2009; Holl & Morano 2014; Redquest et al., 2020; Sciscione, 2022; Taggart et al., 2012). Namkung et al. (2016) theorise that sibling caregivers may be vulnerable to distress for a number of reasons, including that the physical, emotional and financial consequences of taking on additional responsibilities at a time of life when they may have considerable work and family commitments; that providing care to a sibling is nonnormative and therefore more stressful; and also that service providers may not involve or provide information to a sibling caregiver to the extent that they would involve a parent caregiver.

Siblings in Ireland do not have a legal duty or obligation to care for a sibling with a disability; however, there may be strong, implicit familial and societal expectations that they will do so (Leane, 2020). No accurate data exist in Ireland on the number of sibling adults who care for their adult brother or sister with an intellectual disability. The Carer's Study, which is nested in the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA), provides a unique insight into the lives of family carers of older adults with intellectual disability including sibling carers. This paper reports on four waves of data collected over 9 years. The number of participating siblings varied across the waves; therefore, the data represent four point-in-time snapshots and the data may constitute a baseline from which practical and policy initiatives can be developed to support this important cohort of family caregivers.

2 | METHODS

The data presented in this article are from Waves 1, 2, 3 and 4 of the IDS-TILDA Carer's Study. These four waves of the study took place between 2011 and 2020. IDS-TILDA is a nationally representative longitudinal study of people aged 40 years and older with an intellectual disability in Ireland. It was launched in 2008 with the main aim of identifying the principal influences on successful ageing in people with intellectual disability and to determine whether they are the same or different from the influences on successful ageing for the general population. The data from IDS-TILDA are also used to track the impact of key Irish social and health policies (McCarron et al., 2017). Eleven percent (83) of the 753 people with intellectual disability recruited to Wave 1 of IDS-TILDA lived with a family member. Of these, 51 lived with one or both parents, 31 lived with siblings and one lived with another relative. All 83 family members were invited to participate in the Carer's Study and 47 carers took part in Wave 1 of the study, 70 carers participated in Wave 2 and 44 carers participated in Wave 3. To preserve the representativeness of the IDS-TILDA sample, the sample was refreshed before Wave 4 data

collection to replace the age 40–49 years cohort of people with intellectual disabilities, who, by Wave 4, had aged to older than 50 years. The recruitment resulted in 135 new participants in the IDS-TILDA study; 30 parents and 13 siblings joined the Carer's Study as did one nephew, one brother-in-law and one niece. In Wave 4, 29.5% of the sibling participants were new to the study.

Core questions have remained consistent across all waves of the IDS-TILDA Carer's Study, although the questionnaire has evolved with a small number of questions omitted and others added in subsequent waves. The wave 4 questionnaire comprised 65 questions within seven sections: about yourself; support you provide; understanding your experience of caregiving; family and social networks; your health; health services for the person you support; and future planning. The questionnaire comprises both structured and unstructured questions and participants are encouraged to elaborate on the responses to many of the questions.

At the start of each wave of the study, a field researcher makes telephone contact with the carers to confirm their interest in participating in the study. Wave 1, 3 and 4 carer participants received a Carer's Study questionnaire though the post. When completed by the carer, the questionnaire was either returned by post or collected by the field researcher, who conducted the IDS-TILDA interview with the person for whom they care. All wave 2 carer questionnaires were administered by a researcher.

The qualitative data were analysed thematically, and a descriptive analysis of the quantitative data was conducted using SPSS v27.

2.1 | Ethics

Ethical approval for the IDS-TILDA study was granted by the Trinity College Dublin Faculty of Health Sciences Research Ethics Committee, following intensive piloting of the measures and the data collection approach. Ethical approval was also sought and granted by the 138 service providers who support the participants with intellectual disability in the study.

3 | FINDINGS

This section will first outline the demographic characteristics of the sibling carers in Waves 1, 2, 3 and 4 of the study, focussing on gender, marital and employment status and their perception of financial well-being. The carer's reasons for providing care to their family member will then be presented, followed by the data on their health status and on their engagement with future planning.

3.1 | Demographics

Table 1 presents details of the sibling carer's demographics below.

Between Waves 1 and 3, a clear generational transfer of care from parent to sibling can be noted. The percentage of sibling carers

TABLE 1 Sibling carer demographics.

	Wave 1	Wave 2	Wave 3	Wave 4
% Sibling carers	58% (n = 26)	61.4% (n = 43)	76.7% (n = 33)	45.8% (n = 33)
Male	25% (n = 6)	11.6% (n = 5)	15.9% (n = 7)	25% (n = 8)
Female	75% (n = 18)	88.4% (n = 38)	84.1% (n = 37)	75% (n = 24)
Age group				
36–45 years	4.2% (n = 1)	9.3% (n = 4)	3% (n = 1)	3% (n = 1)
46–55 years	54.2% (n = 13)	34.9% (n = 15)	36.4% (n = 12)	24.2% (n = 8)
56–65 years	29.2% (n = 7)	37.2% (n = 16)	42.4% (n = 14)	57.6% (n = 19)
66+ years	12.5% (n = 3)	18.8% (n = 8)	18.2% (n = 6)	15.2% (n = 5)
Married/living with partner	69.6% (n = 16)	72.1% (n = 31)	54.5% (n = 18)	42.4% (n = 14)
Single/never married/ separated/divorced/ widow	30.4% (n = 7)	27.9% (n = 12)	45.5% (n = 15)	57.6% (n = 19)
Employed/self-employed	36% (n = 9)	54.8% (n = 23)	33.4% (n = 11)	42.4% (n = 14)
Gave up/cut down paid employment	30.3% (n = 4)	34.2% (n = 13)	47.6% (n = 10)	27.3% (n = 9)

increased from 58% ($n = 26$) in Wave 1 to 76.7% ($n = 33$) in Wave 3. Following the refreshing of the sample to reinstate the 40–50-year cohort, the percentage of sibling carers in Wave 4 was 45.8% ($n = 33$).

Across the waves, most of the sibling carers were female (W1: 75%; W2: 88.4%; W3: 84.1%; W4: 75%). More than half the siblings in Wave 4 (57.6%) were aged between 56 and 65 years and a further 24.2% were aged between 46 and 55 years. In Waves 3 and 4, siblings were asked how long they had been a carer for their sibling. A small number of siblings had been caring for more than 30 years (W3: 10%, $n = 3$; W4: 3.1%, $n = 1$). In Wave 4, the highest percentage had been caring for up to 10 years (46.9%, $n = 15$); 31.3% ($n = 10$) had been caring for between 11 and 20 years; and 18.7% ($n = 6$) had been caring for between 21 and 30 years. The years caring as reported by the siblings are presented in Table 2 below.

The data suggest that sibling carers are increasingly providing care without the support of a partner. In Wave 1, less than one-third (30.4%) of the sibling carers were single, separated/divorced or widowed; this percentage increased to 45.4% in Wave 3 and in Wave 4, 57.6% of the sibling carers were caring without the support of a partner.

The majority of sibling carers in all four waves were of working age—between 18 and 65 years (W1: 87.5%, $n = 21$; W2: 81.2%, $n = 35$; W3: 81.8%, $n = 27$; W4: 84.8%, $n = 28$). Just over 40% (42.4%, $n = 14$) of Wave 4 siblings were in paid employment or were self-employed, an increase from Waves 1 and 3 (W1: 36% $n = 9$; W3:

TABLE 2 Number of years caring.

	Wave 3	Wave 4
1–5 years	20% ($n = 6$)	18.8% ($n = 6$)
6–10 years	16.7% ($n = 5$)	28.1% ($n = 9$)
11–15	13.3% ($n = 4$)	9.4% ($n = 3$)
16–20	20% ($n = 6$)	21.9% ($n = 7$)
21–25	3.3% ($n = 1$)	15.6% ($n = 5$)
26–30	16.7% ($n = 5$)	3.1% ($n = 1$)
31–more	10% ($n = 3$)	3.1% ($n = 1$)

33.4% $n = 11$) and a decrease from wave 2 (W2: 54.8% $n = 23$). Just under 30% of wave 4 of responding siblings (27.3%; $n = 9$) reported that they had given up or cut down on work, a similar percentage to Wave 1 (30.3%, $n = 4$) and a lower percentage than Waves 2 and 3 (W2: 36.4%, $n = 13$; W3: 47.6%, $n = 10$). One carer outlined the dilemma faced by carers with regard to paid employment:

One of the reasons for cutting down on work is that it would be impossible to be a full-time carer and work full-time. Also part-time work is vital to survive financially. It would be very difficult to survive on a carers wage. Full-time work and being a full-time carer would mean no life for a carer.

Twelve Wave 4 sibling carers (36.4%) were in receipt of the Carer's Allowance, which is Ireland's means-tested, main direct income support for carers. A further 5 (15.2%) received the Half Carer's Allowance, which is also means-tested and may be paid to qualifying carers who are receiving another social welfare payment. This represented a decrease in the percentage of the siblings in Wave 3 receiving the Carer's Allowance (48.5%, $n = 16$) and an increase in the percentage of those receiving the Half Carer's Allowance (14.7%, $n = 4$). Wave 3 and Wave 4 carers were asked about their income range and about how well they had managed financially in the previous 12 months. More than half the siblings in both waves had incomes of less than €30,000 and around 40% had incomes of less than €20,000. More Wave 4 siblings than Wave 3 siblings earned over €40,000 ($n = 10$; 33% vs. $n = 2$; 6.1%). Wave 4 sibling carers more frequently reported that they were "living comfortably" or "doing alright" on their income (W4: 84.2% $n = 25$ vs. Wave 3: 54.6%, $n = 18$) and less frequently reported that they were "just about getting by", "finding it quite difficult" or "finding it very difficult" (W4: 24.3%, $n = 8$ vs. W3: 45.4% $n = 15$). The income range reported by the siblings (W3: $n = 26$; W4: $n = 30$) is presented in Table 3 below.

3.2 | Reasons for providing care

In Wave 3 and Wave 4, carers were asked about the reasons why they provide care to their family member with intellectual disability.

TABLE 3 Income range.

	Wave 3	Wave 4
9999 or less	7.7% (n = 2)	10% (n = 3)
€ 10,000 to € 14,999	15.4% (n = 4)	10% (n = 3)
€ 15,000 to € 19,999	26.9% (n = 7)	23.3% (n = 7)
€ 20,000 to € 29,999	23.1% (n = 6)	10% (n = 3)
€ 30,000 to € 39,999	19.2% (n = 5)	13.3% (n = 4)
€ 40,000 to € 49,000	0%	16.7% (n = 5)
€ 50,000 or more	7.7% (n = 2)	16.7% (n = 5)

Whereas just 15.2% (n = 5) of Wave 3 siblings reported that they care because they enjoy and want to do so, almost 30% (27.3%, n = 9) of Wave 4 siblings did so. Almost half 48.5% (n = 16) of wave 4 siblings care because they are needed (W3 42.4%, n = 14); almost one quarter (24.2%, n = 8) because they feel obliged to (W3 15.2%, n = 5); and 15.2% (n = 5) of Wave 4 siblings care because of a lack of services (W3 12.1%, n = 4). In both waves, a number of carers added a comment that they provide care because they love their sibling and because they want to do their best for them:

Because the person I support has expressed the wish to remain at home and I am trying to make this a reality for as long as I can. I also feel it is often the best place to be for anyone at home. Because I love and want the person to be happy (W3).

3.3 | Health

Almost 70% (69.7%, n = 23) of the siblings who participated in Wave 4 rated their quality of life as good or very good, which is similar to the percentage reported in Wave 1 (69.2%, n = 18) and less than that reported in Wave 2 (78.6%, n = 18). The lowest level of quality of life was reported by the Wave 3 siblings (57.6%, n = 19). Likewise, a smaller percentage of Wave 3 siblings reported being satisfied or very satisfied with their own health than in the other waves (W1: 73.1%, n = 19; W2: 83.7%, n = 36; W3: 60.6%, n = 20; W4: 78.8% n = 26). Four siblings (12.5%) in Wave 4 reported that their health has suffered because of their care responsibilities, which, while similar to the response in Wave 2 (11.9%, n = 5), was a lower percentage than that reported by the siblings in Waves 1 (30.8%, n = 8) and 3 (29%, n = 9). However, almost one quarter (24.3%, n = 8) of Wave 4 siblings reported experiencing severe or moderate levels of pain over the previous 4 weeks and 30.3% (n = 10) experienced moderate or quite a lot of emotional pain over the same time period. One sibling highlighted the impact of the emotional pain that they experience.

Suffer a lot more stress + anxiety. Get angry + resentful. Do not sleep as well. Self-medicate a lot more.

TABLE 4 Health conditions.

Condition	Wave 1	Wave 2	Wave 3	Wave 4
Osteoarthritis	19.2% (n = 5)	4.7% (n = 2)	18.2% (n = 6)	18.2% (n = 6)
Back pain	42.3% (n = 11)	18.6% (n = 8)	48.5% (n = 16)	18.2% (n = 6)
Aching joints	57.7% (n = 15)	27.9% (n = 12)	45.5% (n = 15)	30.3% (n = 10)
Headaches	34.6% (n = 9)	23.3% (n = 12)	36.4% (n = 12)	18.2% (n = 6)
High blood pressure	23.1% (n = 6)	11.6% (n = 5)	24.2% (n = 8)	21.2% (n = 7)
Stress	34.6% (n = 9)	34.9% (n = 15)	24.2% (n = 8)	21.2% (n = 7)
Anxiety	34.6% (n = 9)	9.3% (n = 4)	30.3% (n = 10)	18.2% (n = 6)

Despite the overall positive rating of their own health, siblings also reported experiencing certain health conditions including back pain, aching joints and stress as presented in Table 4 below.

Caregivers were asked about the difficult and the most difficult things about being a carer. Almost 40% (38.7%, n = 12) of Wave 4 siblings experienced difficulty because of the upsetting nature of some of the care recipient's behaviour. The impact of care recipient behaviour changes was identified by one Wave 4 sibling.

Since [participant's] change in behaviour it put a lot of strain on my relationship with my partner and problems with the [service provider] caused us severe anxiety

More than 40% of Wave 4 siblings (W4: 45.2%, n = 14; W3: 51.9%, n = 14; W2: 51.2%, n = 22; W1: 56%, n = 14) cited the confining nature of caring and the need to make family adjustments (W4: 40.6%, n = 13) as difficulties. Just over one-third (38.7%, n = 12) of Wave 4 siblings reported feeling completely overwhelmed by their care responsibilities (W1: 48%, n = 12; W2: 34.1%, n = 14; W3: 51.7%, n = 15). When asked to identify the most difficult things about being a carer, 51.5% (n = 17) endorsed being constantly on call (W1: 48%, n = 12; W2: 46.3%, n = 19; W3: 71%, n = 22); over 40% identified frustration as a difficulty (W1: 32%, n = 8; W3: 38.7%, n = 12); and just under 40% (39.4%, n = 13) identified emotional strain (W1: 48%, n = 12; W2: 17.1%, n = 7; W3: 54.8%, n = 17). The reported impacts are presented in Table 5 below.

Carers were also asked about the benefits that they derive from providing care. The Wave 4 siblings most frequently agreed a little or a lot that caring made them feel useful (63.3%, n = 18), feel good about themselves (55.2%, n = 16) and appreciate life (55.2%, n = 16), and these scores were consistent with those of previous waves. Wave 4 siblings least frequently endorsed feeling appreciated (24.1%, n = 7) and strengthened relationships (30%, n = 9). A Wave

TABLE 5 Impacts of caregiving.

Condition	Wave 1	Wave 2	Wave 3	Wave 4
Confining	56% (n = 14)	51.2% (n = 22)	51.9% (n = 14)	45.2% (n = 14)
Completely overwhelmed	48% (n = 12)	34.1% (n = 14)	51.7% (n = 15)	38.7% (n = 12)
Family adjustments needed	56% (n = 14)	37.2% (n = 16)	50% (n = 14)	40.6% (n = 13)
Frustration	32% (n = 8)	12.2% (n = 5)	38.7% (n = 12)	42.4% (n = 14)
Constantly on call	48% (n = 12)	46.3% (n = 19)	71% (n = 22)	51.5% (n = 17)
Emotional strain	48% (n = 12)	17.1% (n = 7)	58.4% (n = 17)	39.4% (n = 13)
Upsetting care recipient behaviour	28% (n = 7)	37.2% (n = 16)	42.9% (n = 12)	38.7% (n = 12)

4 sibling emphasised the positive and reciprocal nature of her experience of caring.

I don't see it as a chore/problem to be [participant's] carer. She has enriched my life immensely, and our lives are so much better with having her in our family. We love her dearly, and she gives love to us all and all she meets. (W4)

A smaller percentage of Wave 4 siblings (40.6%, $n = 13$) reported that they received a lot or some support from close relatives (other than parents or children) than in previous waves (W1 60.2%, $n = 18$; W2 49.7% $n = 19$; W3 46.7% $n = 14$). Likewise, a decreasing percentage of siblings reported that they received support from friends (W1: 53.8% $n = 14$; W2: 29.7% $n = 11$; W3: 27.6% $n = 8$; W4: 22.6% $n = 7$). Nevertheless, talking to friends is the most commonly cited coping strategies across the waves (W1: 53.8%, $n = 14$; W2: 52.4%, $n = 22$; Wave 3: 61.3%, $n = 19$; W4: 63.6%, $n = 21$). Few siblings used support groups as a coping strategy; indeed, only two reported doing so in Waves 1 and 2 and none did so in Waves 3 and 4.

More than half the siblings in Wave 4 (57.6%, $n = 19$) used exercise as a coping strategy; 39.4% ($n = 13$) watched TV to help them cope. Just under one quarter of the siblings (24.2%, $n = 8$) used prayer or faith as a coping strategy, and 21.2% ($n = 7$) used respite. The importance of respite was outlined by one Wave 4 sibling.

Respite for the person is wonderful - means one weekend per month is free for me to do what I wish (Wave 4)

The percentage of responding carers who reported having unmet service needs was the highest in Wave 1 and the lowest in Wave 4; the percent and numbers are presented in Table 6 below.

TABLE 6 Unmet service needs.

Wave 1	Wave 2	Wave 3	Wave 4
Unmet service needs for carer			
45.8% ($n = 11$)	34.9% ($n = 15$)	39.4% ($n = 13$)	32.3% ($n = 10$)
Unmet service needs for family member			
48% ($n = 12$)	39.5% ($n = 17$)	30.3% ($n = 10$)	30% ($n = 9$)

However, in each wave, lack of respite and in-home support was consistently identified as a key unmet service need in respect of both the carers themselves and the family members. Carers reported a reduction in, or complete lack of, regular respite and respite that was not structured to benefit the carer.

Would love to be able to go out for an occasion-respite offer her dates that suit them not other way around (Wave 2)

I should be able to call up home help or someone if I needed to go somewhere important or short notice. There should be a good back up/stand-by if I got ill (Wave 1)

4 | FUTURE PLANNING

Approximately 60% of the siblings in all waves reported that they had considered the issue of future planning. A small number gave details of the concrete arrangements that have been put in place including ensuring financial security.

In my will, our solicitor has instructions for her care should I die before her and she should be financially sound (W1)

Some were confident that another family member would take over the care of the person with intellectual disability.

Family will take SR and she can move around between them (W2)

Have arranged for him to live with son and daughter in law who live nearby. (W3)

Sister in UK would take her (W2)

Others indicated that they did not perceive a need for future planning at this stage as they expected that the status quo would prevail for some time.

Hope to have him around as long as possible (W2)

He will stay in family home. As long as they all continue in good health this is fine (W2)

However, many carers who elaborated on their response to the question about future planning were pessimistic about the options for their sibling's future and lacked confidence that satisfactory alternatives would be available.

The place where I would like to see her go does not exist. I thought by the time she reached 50 she would have it. (Wave 3)

No point in long-term planning because services aren't there (W2)

Spoke to my sister's service provider but funding and red tape seem to be always in the way of realising this (w1)

Feel as if there is nothing out there. Things will get worse not better. (W2)

The siblings responses to the questions about future planning are presented in Table 7 below.

5 | DISCUSSION

The IDS-TILDA Carer's Study provides important insights into the health and well-being of sibling carers of older adults with an intellectual disability in Ireland, a cohort of carers who have received little policy or research attention to date. The Irish Department of Health projects increases both in the population of older people with an intellectual disability and in the number of adults with an intellectual disability living with family members (Department of Health, 2021). These population increases are happening in a social policy and service context of deinstitutionalisation, community living

and limited/inadequate residential service provision. Ireland's health and social care services are highly dependent on family carers and the estimated value of informal care in Ireland dwarfs the State's expenditure on home-based long-term care or long-term residential facilities (Hanly & Sheerin, 2017).

However, changes in family structure and size, the increased participation of women in the paid workforce, an increase in the age of retirement, greater geographical distances between family members and an ageing population all contribute to a declining pool from which family carers have traditionally been drawn (Broese van Groenou et al., 2013; Marking, 2017). Murphy and Turner (2017) suggest that a number of demographic factors render Ireland particularly challenged in the provision of sustainable long-term care including the rate of population ageing and a predominantly rural population. It is within this context that siblings are increasingly taking on the responsibility of caring for their adult brother or sister with intellectual disability. Across all four waves reported in this article, there is evidence of the strong relational and emotional commitment by the siblings to their brother or sister with intellectual disability, a finding consistent with previous research (Heller & Arnold, 2010; Leane, 2020; Orsmond & Seltzer, 2000). However, a greater percentage of siblings in each wave identified that they provided care because they were needed than those who reported providing care because they enjoyed and wanted to care. In each wave, a number of carers were providing care because they felt obliged to do so or because of lack of services. These carers may be particularly vulnerable as research indicates that carers who did not choose to take on the caregiving role had worse psychological outcomes than those carers who had a choice whether or not to care (Li & Lee, 2020).

The discrepancy between the carers', overall very positive, perception of their own general health and quality of life and the reported extent of health conditions and difficulties associated with caregiving should give rise to some concern. In particular, the prevalence of back pain ranged, across the waves, between almost 20% and almost 50% and the prevalence of aching joints ranged between 28% and almost 58%. The frequency with which the carers, across all the waves, reported the difficulty of being constantly on call, feelings of confinement and of being completely overwhelmed indicates how oppressive the relentless nature of caring can be when the carer is not supported to ensure that s/he has time away from the responsibility to pursue some interests of her/his own, to recharge batteries and to focus on their own health and well-being.

More than three-quarters (76%) of the participants in O'Brien's large-scale survey of Irish family carers were married or living with a partner (O'Brien, 2009) and similarly, 53% of family carers of people with intellectual disability in the Lafferty et al. (2016) study. However, most of the wave 4 siblings in this study were caring without the support of a partner and only a minority of the Wave 3 and Wave 4 participants receive regular support from close relatives or from friends. Importantly, lone carers of people with intellectual disability have been identified as particularly vulnerable to the negative impacts of caregiving (McConkey, 2005). The issue of parents ageing

TABLE 7 Future plans.

Future planning				
	Wave 1	Wave 2	Wave 3	Wave 4
Has carer considered long-term planning for their sibling? (Wave 1 & Wave 2)				
	57.7% (n = 15)	58.1% (n = 25)		
Have you thought about where you see your family member with ID living in 5 years? (Wave 3 & Wave 4)				
			57.6% (n = 19)	62.5% (n = 20)
Have you discussed long-term planning with any professional or group? (All Waves)				
	75% (n = 12)	41.9% (n = 18)	24.2% (n = 8)	31% (n = 9)

concurrently with their adult child with intellectual disability has become an issue of concern and in 2000, the WHO has characterised older people with intellectual disability and their ageing family carers as two joint vulnerable groups as they age together. Sibling carers are of an age cohort with the brother or sister for whom they provide care and will also be ageing in parallel with them. The needs of older carers may often go unrecognised and therefore unaddressed particularly when the roles of the designated caregiver and care recipient become blurred (Manthorpe et al., 2015). Caregiving is dynamic rather than static and seemingly small changes in the lives of either the care recipient or carer may threaten the sustainability of the care arrangement. Carers, particularly as they age, may have support needs, notwithstanding that their experience of caregiving is a positive one (Gant & Bates 2019). The UK's Care Act (2014) is a clear legal framework that explicitly locates the responsibilities for addressing the needs of caregivers and their quality of life with the local authorities. However, Irish carers are not entitled to an assessment of their own needs, as distinct from those to whom they give care (Courtin et al., 2014), and yet, without an assessment of need, it is difficult to appropriately meet needs (Henwood et al., 2017).

The great majority of the sibling carers (82.4%) were aged between 36 and 65 years of age in all waves and were, therefore, of working age. Whereas it was reported in 2019 that 55% of informal carers in Ireland were also in paid employment (Russell et al., 2019), this level of employment among the carers of older adults with intellectual disability in this study was only reached in Wave 2; in the other waves, employment levels ranged between 33.4% and 44.4%. In all four waves, carers reported that they gave up or cut down on paid employment because of their care responsibilities. Employment outside the home may have a protective effect on a carer's well-being, easing financial pressures and enhancing self-esteem; the social interaction that employment may provide may represent essential support to sustain the carer's capacity to care and be a significant contributor to well-being (Hoff et al., 2014; Joseph & Joseph, 2019; Lafferty et al., 2022). The disproportionately low level of engagement in the paid workforce requires exploration to investigate whether there are particular barriers to employment for carers of older people with intellectual disability and the supports required to overcome any such barriers.

Many parents of persons with intellectual disability have concerns about the future care of their adult child, even to the extent of hoping that their child dies before their parents (Bibby, 2013). Research has also identified the reluctance of many parents of adults with intellectual disability to pass the caregiving responsibility to their other children (Heller & Kramer, 2009; Kruithof et al., 2021; Lee & Burke, 2020; Brennan et al., 2018), notwithstanding evidence about siblings' expectations that they will be involved in the future care of their brother or sister (Heller & Arnold, 2010; Leane, 2020). Where the responsibility for care passes from the parent to the sibling of the person with intellectual disability, so too does the issue of future planning. Most Wave 3 and 4 participants had thought about where their family member with intellectual disability would be in 5 years' time; however, only a minority had

discussed this with a professional. Irish carers of people with intellectual disability have limited opportunities to choose between alternatives either in respect of supports to themselves as carers or in respect of the services received by the care recipient. The increase in the lifespan of people with intellectual disability and the very significant policy shift in Ireland away from deinstitutionalisation and towards decongregation and community living is highly positive. However, these changes have been taking place alongside a social and economic transformation in Ireland and without a fundamental consideration where the social contract for care provision lies within contemporary Irish society (Brennan et al., 2022). The paradigm shift in care provision is predicated on an assumption of the availability of family carers able and willing to provide an unbounded level of care and support to their family member and within a policy context where the state explicitly frames extended family caregiving as normative. Sibling carers are becoming an increasingly significant part of care provision for adults with intellectual disability in the context of a system that is underpinned by, and highly dependent on, family carers. It is important to understand their experiences to provide them with the support that they need and that may enhance both their lives and the lives of those for whom the care.

In terms of recommendations, the results reported in this article indicate a need to engage with siblings to protect their well-being as they provide care for an increasingly ageing sibling. With reference to practice, there is a specific need for formalised engagement between service management and professional staff and sibling carers. A model for such engagement to support future planning by family members has been proposed by McCausland et al. (2019). It is also recommended that such structured modes of future planning are included in the curriculum for nurses, social care workers, social workers and others working in the area of intellectual disability. Policy makers and services need to pay attention to the needs of these sibling carers or the whole edifice of family care of older people with intellectual disability may collapse.

6 | STRENGTHS AND LIMITATIONS

The main limitation of the study is that the findings are based on sibling carers of those older people with intellectual disability who opted-in to the IDS-TILDA Carer's study and may not be generalisable to other carers. The data are not from the same sibling each wave; however, the repetitive nature of the study adds strength to the findings and provides a unique insight into this important but unresearched cohort of family carers.

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CONFLICT OF INTEREST STATEMENT

All the authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions. IDS-TILDA is committed to open-access data. Anonymised data and study documentation for these can be accessed through the Irish Social Science Data Archive (ISSDA).

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