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Keeping It in the Family: The Proposed and Rejected Irish Constitutional Amendment on Family Caregiving—Insights From the IDS-TILDA Carer Study

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ABSTRACT

Background: In 2024, Irish people rejected their government's proposed Constitutional changes relating to the definition of a family, and the interface between state and family with reference to the provision of care. Using data from a Carer's Study, this paper reflects on the defeated Care Amendment with reference to current and historic social policy that mediates, shapes and informs family and the state's responsibility for care provision for people with intellectual disability.

Methods: Family carers of older people with intellectual disability completed a self-administered, mixed methods questionnaire. Qualitative data were analysed thematically, and a descriptive analysis of the quantitative data was conducted using SPSS.

Findings: The positioning of the family as the principal point of care is remarkably robust even in the face of personal challenges experienced by caregivers. Within the reality of limited formal services, it would appear that family-based care continues to be constructed as the natural and neutral form of care provision, relieving the state of obligations to care for citizens with disabilities.

Conclusions: An urgent exploration of the social contract for care is required to address the fundamental question as to where the responsibility for the long-term care of people with intellectual disability resides.

1 | Introduction

Having achieved independence in 1921, the Constitution of the Irish Free State was adopted by the Irish parliament in December 1922. During the early decades of independence, Irish governments sought to administer a fledgling state while also shaping a distinctive Irish identity and shared set of values. This was set against a backdrop of enduring poverty, chronic outward migration and a pervasive influence of religious institutions in shaping Irish society. Within this early formation of nationhood, a new Constitution of Ireland was drafted by the government and ratified by the Irish people in 1937. This Constitution formalises and gives power to the various branches of government and courts and sets out how those institutions should function. The Constitution also addresses the fundamental rights of every Irish citizen and requires all laws to be consistent with the provisions of the Constitution. This Constitution is only amendable through a referendum of the Irish people.

Since 2012, Ireland has engaged in exercises in deliberative democracy to consider and make recommendations on key issues of concern in society. A Constitutional Convention sat between 2013 and 2014 and addressed issues including electoral

Summary

- In 2024, Irish people were asked to vote to change what the Constitution says about care. The Irish people did not agree with the proposal and voted against it.
- One of the reasons that people voted against it was because they thought that it was putting all the responsibility to provide care on families and no responsibility on the State.
- The Carer's Study explores the health and well-being of the family carers of older people with intellectual disability.
- This paper considers the result of the Irish referendum alongside the data from a national study of family carers of older people with intellectual disabilities. Family carers reported that they believed that care was their responsibility and that they would still be caring in 5 years time.
- It is important to explore how the responsibility for care is shared between the State and families, so people with intellectual disabilities can be supported to live their best lives.

reform, blasphemy and same sex marriage. Since 2016, a series of Citizen's Assemblies have been established bringing together randomly selected citizens, elected representatives, civil society groups and subject area experts to discuss and consider legal and policy issues in Ireland. Areas explored by the Citizens' Assemblies include ageing, drug services, abortion, the environment, fixed term sentencing and gender equality. The Assembly makes recommendations and reports back to the Irish government, including recommendations regarding constitutional change.

The Citizens' Assembly on Gender Equality, which was established in 2019, reported in 2021 and made a number of recommendations for constitutional change, including to Articles 40 and 41 of the Constitution (The Citizen's Assembly on Gender Equality 2024). Subsequently, the Irish Government put forward the "family referendum" (39th amendment) in 2024, which sought to expand the definition of family, thereby extending constitutional protection beyond those traditionally founded on marriage. This "family referendum" relates to Articles 41.1.1 and 41.3.1 of the Constitution. Article 41.1.1 identifies the family "as the natural primary and fundamental unit group of society, and as a moral institution possessing inalienable and imprescriptible rights, antecedent and superior to all positive law". The referendum proposed to amend this Article by identifying that a family could be "founded on marriage or on other durable relationships". Article 41.3.1 pledges to "guard with special care the institution of Marriage, on which the Family is founded, and to protect it against attack". The referendum proposed to remove the words "on which the family is founded" to be consistent with the changes proposed for Article 41.1.1. The term "durable relationship" was left undefined, which was a point of contention and controversy throughout the campaign. The proposed changes were rejected by the Irish people; 67.69% of the electorate voted against it with just 32.31% voting for the change. It should be noted that while the Citizen's Assembly had recommended that the definition of the family should be extended beyond a marital family, it had not made reference to durable relationships.

The "Care Referendum" (40th Amendment) sought to remove what was considered to be outdated references to women's and mothers' duties within the home, and to acknowledge the State's recognition and support for care provision within a family. The existing Article 41.2 of the Constitution pledges not to force women to take up paid work outside the home, thereby neglecting their duties in the home. While acknowledging the vital role of unpaid care, Article 41.2 ascribes the responsibility for such care exclusively to women:

> *The State recognises that by her life within the home, woman gives to the State a support without which the common good cannot be achieved.*
>
> (Bunreacht na hÉireann 1937, Article 41.2)

The Article has long been criticised, and the Citizens' Assembly recommended its deletion. However, the referendum in 2024 proposed not to simply delete the Article but to replace the Article with the less gendered wording of:

> *The State recognises that the provision of care, by members of a family to one another by reason of the bonds that exist among them, gives to Society a support without which the common good cannot be achieved, and shall strive to support such provision.*
>
> (FLAC 2024)

If adopted, this change would have emphasised the primacy of family care provision, with the state recognising the contribution to society from such family-based care and "striving" to support such care provision. As such, this proposed change would have had a significant long-term impact on defining and shaping the legal and social policy balance of responsibility for care provision between the State, the family and citizens in need of care within Ireland, with the constitution requiring all laws to be consistent with its provisions. The outcome of the referendum saw almost three-quarters (73.93%) of the electorate voting against this proposed amendment, with 26.07% voting for the proposal. This proposed and defeated "care referendum" is the central focus of this paper, specifically as it relates to the relationship between the State and Family and the "social contract" of care for people with an intellectual disability.

The social contract for care operates within a complex and dynamic social process influenced by the social welfare orientation of the state, national social policy, the demographic profile and the cultural expectations of families (Brennan et al. 2022). Attitudes to care reflect family, cultural and sociostructural circumstances and are subject to change (Wittenberg et al. 2024). Care services in Ireland developed under the strong influence of the Catholic Church, whose social thinking was underpinned by the "fundamental", "unshaken" and "unchangeable" principle of subsidiarity, which demands that care should be given by those closest to the individual who needed that care (Timonen 2008). In practice, Irish family members have historically held the principal responsibility for

care, and such care was situated as a private matter and as one that was not the concern of the State (Smith 2012). Although family members in Ireland have never had a formal legal obligation to provide care, such family-based care has culturally been assumed to be natural.

In parallel to family-based care, Ireland also experienced large-scale institutional confinement of those whose needs fell outside the perceived norms, including those with mental illnesses or intellectual disability (Brennan 2014). The approach to care for people with an intellectual disability in Ireland has seen a paradigm shift over the past 50 years, underpinned by a social policy reorientation in Ireland (Brennan and D'Eath 2023) which mirrors that of many other countries, with a shift away from large built environments to community settings based on policies of de-congregation and de-institutionalisation (Brennan et al. 2022). This policy reorientation places an increased emphasis on care within community and family home settings, which has occurred when wider sociological and economic dynamics have fundamentally changed the capacity of families to provide care within the homeplace. For example, the previously taken-for-granted assumption of a pool of women available to care in the home and the community is no longer valid. Wide scale sociological dynamics, such as greater gender equality; increased control of fertility; increased participation of women within the formal labour market; emigration, migration and labour mobility; and macro-economic factors such as decreased affordability of living spaces, have all impacted on the role, function and makeup of family units and women's perceived and socially constructed roles with families.

The resounding defeat of the proposed constitutional changes was described by the then Irish Taoiseach (Prime Minister) Leo Varadkar, who was a key advocate for a "yes, yes vote", as "two wallops to the government" (Irish Catholic Bishops Conference 2024). The suggestion that people used the opportunity that the referenda presented to send a message to the government was one of several that were mooted in the aftermath of the defeat. However, opposition to the referendum came from disparate sources spanning the progressive and the conservative and included those focussing on carers' rights and the rights of people with disabilities. Hence, the causal factors underlying the "no, no" referendum result are multiple, complex and divergent, and this paper does not attempt to provide a unifying explanation for this referendum result. Rather the findings of the IDS-TILDA Carer's Study, which was completed in the 2 years preceding the referenda, are explored within the context of the failed attempt to pass the 40th "Care" Amendment. The Carer's Study specifically explores care provision for older people with an intellectual disability, which has a number of unique and defining features including the longevity of the caring relationship, the impact of the concurrent ageing of the family carer and the person with intellectual disability, concerns about the future when the family carer is no longer able to provide care and the intergenerational nature of the care (Wormald et al. 2023; Marsack-Topolewski and Graves 2020; Brennan et al. 2018; Baumbusch et al. 2017). Drawing from the carers' studies data, this paper engages with the concept of the social contract for care (Brennan et al. 2022) with specific reference to the rejected 2024 "Care" amendment to the Irish constitution. Ireland is far from unique in experiencing uncertainty about the social contract for the care of people with intellectual disability in this postinstitutional era. The data emanating from the IDS-TILDA Carers' Study, set against the course and outcome of the defeated reference, offers a timely and unique insight into the Irish experience of engaging with this universal question of care capacity within society.

2 | Methods

Giving a unique insight into the experiences of providing care to an older adult with intellectual disabilities, the Carer's Study forms an inherent part of the IDS-TILDA. which is now entering its sixth wave, in Ireland. It was launched in 2008 with the main aim to identify 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 are also used to track the impact of key Irish social and health policies. The IDS-TILDA has received full ethical approval from Trinity College Dublin.

The Carer's Study surveys the family carers of the IDS-TILDA participants on a 3-yearly cycle. The questionnaire used in the study contains approximately 75 questions within the 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. Although the core questions remain consistent across the waves, a number of questions were added to the Wave 5 survey to specifically explore the carers' opinions on where the responsibility lies for the care of their family member with intellectual disabilities.

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. When completed by the carer, the questionnaire is either returned by post or collected by the field researcher who conducted the (anonymised) interview with the person for whom they care.

The qualitative data are analysed thematically, and a descriptive analysis of the quantitative data is conducted using SPSS v27. Relevant data to this paper is set out in Section 3, which is then contextualised and explored in the discussion section with reference specifically to proposed and rejected 40th "Care" Amendment of the Irish constitution in 2024.

3 | Findings

Data collection for Wave 5 of the study took place in 2022 and 2023, preceding the announcement of the constitutional referendum on care. This data provides some very timely insights into key characteristics and dynamics that are directly relevant to the issues pertinent to the proposed family Carer amendment, specifically Demographic Profile, Rationale for Choosing to Care, Health and Well-Being of Caregivers, Future Expectations and Perceived Responsibility for Care Giving. Text responses are provided throughout the presentation of the findings to include the direct voice of the carers. The ID coding system used is as follows: pm = mother, pf = father, ss = sister, sb = brother, of = other female relationship and om = other male relationship.

3.1 | Demographics

Most of the participating carers were female (79.5%, $n = 58$). Just over half (52.1%, $n = 38$) were the parent of an older person with intellectual disability; 43.8% ($n = 32$) were a sibling of the older person; 4.1% ($n = 3$) were categorised as "other" and comprised one niece, one sister-in-law and one participant who was not related to the older person.

The majority of carers (55.5%, $n = 40$) were married or living with a partner, whereas 44.5% ($n = 32$) were single, separated, divorced or widowed. Thirteen (36.1%) of parent carers were widowed; one sibling carer and one "other" were widowed. The characteristics of the carers is presented in Table 1.

TABLE 1 | Characteristics of carers.

Gender	
Male	20.5% ($n = 15$)
Female	79.5% ($n = 58$)
Relationship to care recipient	
Parent	52.1% ($n = 38$)
Sibling	43.8% ($n = 32$)
Other 1 each: Niece, sister-in-law, no relation	4.1% ($n = 3$)
Marital status	
Married/partnered	55.5% ($n = 40$)
Parent	55.6% ($n = 20$)
Sibling	57.6% ($n = 19$)
Other	66.6% ($n = 2$)
Single/never married	12.5% ($n = 9$)
Parent	0%
Sibling	24.2% ($n = 8$)
Other	33.3% ($n = 1$)
Separated/divorced	11.1% ($n = 8$)
Parent	8.3% ($n = 3$)
Sibling	15.2% ($n = 5$)
Other	0%
Widowed	20.8% ($n = 15$)
Parent	36.1% ($n = 13$)
Sibling	2.9% ($n = 1$)
Other	33.3% ($n = 1$)

Two features above are of particular interest, first most carers are in fact female, so while the proposed referendum sought to remove the outdated gendered expectations of "women's role with the home", the reality on the ground was that care responsibility continued to be primarily the responsibility of women within the home place. Second family relationship, through marriage or reproduction, continued to overwhelmingly determine who engages with caring roles for older people with an ID, with only one carer identifying as "no relation".

With reference to age, whereas three siblings (9.4%) were in the youngest (36–45 years) age group, siblings were mostly in the 56–65-year-age bracket. All parents were aged over 66 years with four of the parents (11.4%) aged 86 years or over. Table 2 presents the age groups of the carers.

The above data are interesting in that it suggests that a pattern of intrafamily and an intergenerational shift of care provision only occurs when parent carers reach later life.

3.2 | Choosing to Care

Despite that, fewer than 30% of carers reported that they provide support to their family member because they "enjoy and want to", more than three-quarters (77.1%, $n = 54$) reported that they chose to take on the care responsibility. The detail of these responses is presented in Table 3.

Interestingly, a higher percentage of siblings (80.6%, $n = 25$) than parents (72.2%, $n = 26$) reported that they chose to take on the role of carer. All three participants in the "other" category chose the role. When asked to elaborate on the reasons for providing care, participants consistently indicated a view that care provision was a "natural" or "assumed" responsibility within currently existing Irish family structure. However, this needs to be situated within the context of limited alternatives with regard to state-provided services. The quotes presented below give an overview of the perspectives of the carers.

3.2.1 | Parents Elaboration

- Automatic/duty/what a parent does:

TABLE 2 | Age group.

Age group (years)	All (%)	Parent (%)	Sibling (%)	Other (%)
36–45	4.3	0	9.4 ($n = 3$)	0
46–55	10	0	18.8 ($n = 6$)	25
56–65	22.9	0	46.9 ($n = 15$)	25
66–75	34.3	48.6 ($n = 17$)	18.8 ($n = 6$)	50
76–85	22.9	40 ($n = 14$)	6.3 ($n = 2$)	
86+	5.7	11.4 ($n = 4$)		

TABLE 3 | Reason for providing care.

	All (%)	Parents (%)	Siblings (%)	Other (%)
Because I am the parent	49.3 ($n = 36$)	94.7 ($n = 36$)	n/a	n/a
Because I have always done so	42.4 ($n = 31$)	52.6 ($n = 20$)	34.4 ($n = 11$	0 ($n = 0$)
Because I am needed	46.6 ($n = 34$)	42.1 ($n = 16$)	53.1 ($n = 17$)	33.3 ($n = 1$)
Because I feel obliged to	17.8 ($n = 13$)	15.8 ($n = 6$)	21.9 ($n = 7$)	0 ($n = 0$)
Because services are not available	11 ($n = 8$)	10.5 ($n = 4$)	12.5 ($n = 4$)	0 ($n = 0$)
Because I enjoy and want to	28.8 ($n = 21$)	21.1 ($n = 8$)	34.4 ($n = 11$)	66.7 ($n = 2$)

Automatic requirement of parent.

(pf674)

I'm his mother.

(pm777)

Automatically as a loving parent.

(pm872)

Because he is my son. He needed to be cared for.

(pm678)

I am a parent and it's my duty.

(pm272)

- Positive:

I love being a carer and bring her to all her hospital appointments and get her medication.

(pm276)

Participant is my daughter and I wouldn't have it any other way.

(pm870)

We want our daughter to remain in her home as long as possible.

(pf977)

- Lack of alternative:
  - o There is no one else. I don't have a choice.

(pm376)

3.2.2 | Siblings' Elaboration

- Expectation:

As an unmarried sibling living at home following the death of my parents it was expected of me.

(ss176)

I promised my mother and father I would take care of my sister for the rest of her life or mine! I looked after all three of them at the start of 2006.

(sb474)

- Organic outcome

I live in same house so it happened organically.

(ss975)

I live in home place and I have always actively been involved along side my mother.

(ss579)

- Consequence of the relationship

He is my brother.

(sb12)

[He] is my brother. Both of our parents are dead.

(ss779)

[She] is my sister and I am living local to her.

(ss672)

- Active choice

Chose to support my sister as no one else available or living in the country.

(ss975)

My sister is very important to me and my parent would have wanted me to look after her.

(sb175)

My father had dementia and my sister had an intellectual disability and it wasn't possible to leave them on their own. I offered to be their full time carer.

(ss673)

- Not an active choice

My sister with the disability lives with my 81 year old mother. My mother got sick and as I am the only family member around I took carers role.

(ss879)

Other family members backed away.

(sb379)

Not a conscious decision. Stepped into the lore when parents became ill/aged.

(sb478)

- Death/incapacity of a parent

Mam is getting older, as time is going on I'm doing more caring for my mam and brother.

(ss271)

'Mother passed away' My mother was [sibling's] primary carer all his life. When she died in 2013, my dad became primary carer until his sudden death in 2015 and then I moved home to take care of [sibling].

(ss270)

My mother-in-law died, who I was a care for, in lockdown whom my brother-in-law lived with. He had nobody else nearby so we (family) decided I would be his carer.

(of276)

Our mother passed away and my brother went into [service provider in the UK] but we had many problems with his care, he came to live with me in Ireland.

(ss870)

- To avoid the alternative

To keep [sibling] out of a nursing home.

(ss170)

Due to the health of my grandparents and didn't want my aunt to be put into care.

(of174)

It is interesting to note the gendered nature of many of the above carers study extracts. This pattern of assumed female care giving within family structures is consistent with patterns demonstrated in data, for example, intergenerational transfer of care responsibility from "mothers" to sibling carers was predominantly (75%) to sister siblings.

3.3 | Health and Well-Being

3.3.1 | Difficulties and Benefits Associated With Providing Care

Carers were asked whether they experienced any of a range of difficulties that have been associated with caregiving and were also asked to identify the most difficult aspects of providing care. The most frequently cited difficulty was that caregiving was confining (56.3%, $n = 40$), and the most difficult aspect was reported to be being constantly on call (57.6%, $n = 38$). More than 60% (61.5%, $n = 32$) of carers reported stress as a difficulty of providing care and just under 60% (56.9%, $n = 33$) reported emotional strain. Siblings (65.6%, $n = 21$) more frequently cited changes in personal plans than did the parent carers (36.1%, $n = 13$). The responses are presented in Table 4.

It is interesting to note that over 65% of sibling carers reported difficulties associated with changes in personal plan, as such there is a personal "cost" associated with the care of an adult sibling. This suggests that for sibling caregivers the perceived social contract for care is strong and is situated within the family, rather than being a matter between the adult citizen in need of care and the state.

3.3.2 | Benefits Associated With Providing Care

When asked to consider the benefits which they derive from providing care, carers most frequently strongly agreed or agreed that providing care: "makes me feel needed" (56.5%, $n = 39$), "makes me feel useful" (50.1%, $n = 35$), "enables me to appreciate life more" (53.6%, $n = 37$) and makes me feel good about myself 49.3% ($n = 34$). The responses of the parents and siblings to most of the statements were largely similar; however, parents were less inclined to report that providing care "makes me feel good about myself". The responses are presented in Table 5.

3.4 | Expectations

The overwhelming majority of responding carers expect that they will still be caring for their family member in 5 years time: 84.8% ($n = 28$) of parents, 93.1% ($n = 29$) of siblings and 100% of

TABLE 4 | Difficulties associated with providing care.

Difficulty	All (%)	Parents (%)	Siblings (%)	Other (%)
It is confining	56.3 ($n = 40$)	55.6 ($n = 20$)	62.5 ($n = 20$)	0
Being constantly on call	57.6 ($n = 38$)	51.4 ($n = 18$)	51.4 ($n = 18$)	66.7 ($n = 2$)
Stress	61.5 ($n = 32$)	47.1 ($n = 17$)	57.7 ($n = 15$)	33.3 ($n = 1$)
Emotional strain	56.9 ($n = 33$)	52.9 ($n = 18$)	50 ($n = 14$)	33.3 ($n = 1$)
Changes in personal plans	49.3 ($n = 35$)	36.1 ($n = 13$)	65.6 ($n = 21$)	33.3 ($n = 1$)
Feeling completely overwhelmed	37.7 ($n = 26$)	34.3 ($n = 12$)	38.7 ($n = 2$)	66.7 ($n = 2$)

TABLE 5 | Benefits associated with providing care.

Benefit	All (%)	Parents (%)	Siblings (%)	Other (%)
Makes me feel useful				
Agree/strongly agree	50.1 ($n = 35$)	47.2 ($n = 17$)	50 ($n = 15$)	100 ($n = 3$)
Makes me feel good about myself				
Agree/strongly agree	49.3 ($n = 34$)	41.7 ($n = 15$)	56.7 ($n = 17$)	66.7 ($n = 2$)
Makes me feel needed				
Agree/strongly agree	56.5 ($n = 39$)	55.6 ($n = 20$)	56.7 ($n = 17$)	66.7 ($n = 2$)
Enabled me to appreciate life more				
Agree/strongly agree	53.6 ($n = 37$)	52.3 ($n = 19$)	53.3 ($n = 16$)	66.7 ($n = 2$)

TABLE 6 | Anticipated level of care in 5 years time.

Relationship	All (%)	Parent (%)	Sibling (%)	Other (%)
Same amount of care	54.5 ($n = 36$)	54.5 ($n = 18$)	56.7 ($n = 17$)	33.3 ($n = 1$)
Less care	21.2 ($n = 14$)	36.4 ($n = 12$)	6.7 ($n = 2$)	0
More care	24.2 ($n = 16$)	9.1 ($n = 3$)	36.7 ($n = 11$)	66.7 ($n = 2$)

TABLE 7 | Where the responsibility for care lies.

Responsibility	All (%)	Parents (%)	Siblings (%)	Other (%)
My responsibility	66.2 ($n = 45$)	71.4 ($n = 25$)	58.1 ($n = 18$)	66.7
Wider family's responsibility	26.5 ($n = 18$)	14.3 ($n = 5$)	41.9 ($n = 13$)	0
The State's responsibility	7.4 ($n = 5$)	14.3 ($n = 5$)	0	

those in the "other" category. Likewise, most expected to be giving the same or more care to their family member in 5 years time, as seen in Table 6.

A number of parents elaborated that their response was contingent on them still be able to care or even be alive in 5 years time:

> *If God leaves me my health and mind.*
>
> (pm870)

> *At 80 years of age now I will probably be dead.*
>
> (pf778)

> *Yes if I am still around due to my age. I have a good outlook on life.*
>
> (pm276)

Others reported that they did not have a choice about whether or not to still be providing care:

> *I would love to see him settled in a forever home, but think it is highly unlikely. The services are forced to wait for a crisis- Presently not getting funding which allows them to plan for the future.*
>
> (pm376)

> *[family member] is on 4 housing lists- each list he [is on] is just under 3000.*
>
> (pm175)

> *I'm the only one she has and this country is not working or planning hard enough or*
>
> *quick enough for people like my daughter.*
>
> (pm177)

Siblings were more inclined to comment that they did not know what the near future held. Some were positive about the prospect of continuing to care:

> *Hopefully this will be possible.*
>
> (sm976)

> *I will care for my sister as long as is required.*
>
> (sm879)

Others were simply resigned to the prospect:

> *Intellectual disability does not disappear with age.*
>
> (sm672)

> *I don't expect the situation to change.*
>
> (sm176)

3.5 | Responsibility for Care

New questions were introduced in Wave 5 to explore the carers' perceptions about where the responsibility for the care of adults with intellectual disability lies and whether others shared this responsibility. The responses to these questions are presented in Table 7.

Three-quarters (66.2%, $n = 45$) of the respondents identified the responsibility as theirs, with parents (71.4%, $n = 25$) more frequently doing so than siblings (58.1%, $n = 18$). Over 60% (62.5%, $n = 40$) of responding participants reported that, although care was primarily their responsibility, others also shared the responsibility. Parents were more inclined to report that others shared the responsibility than were siblings (parents, 68.6%, $n = 24$ vs. siblings, 66.6%, $n = 15$). One parent considered that a disability service shared the responsibility, and two parents identified that the State shared the responsibility. All other parents who commented located this responsibility within the family:

- "My husband to a degree". (pm574)
- "Her sister on a very limited basis. Her brother also re decisions". (pm677)
- "My other adult children". (pm975)
- "My daughters". (pm071)

One sibling reported that the responsibility should be shared between herself and the State. The other siblings, like the parents, located this responsibility within the family:

- "My own family and our brothers". (ss174)
- "His sisters". (ss779)
- "My other 2 brothers". (ss271)

The lack of expectation amongst Irish family carers of a state responsibility for care provision is remarkably low at 7.5%. Those five carers who assigned responsibility to the state were all parent carers and reported that they had been providing care for between 42 and 63 years. Despite the longevity of their caring and their increasing age, these carers had no confidence that the state would look after their adult child even when they themselves can no longer do so. A selection of these comments is presented below:

- Where will she go and how will she be cared for. (pm175)
- We are increasingly worried about our son's life without us. He is not at all prepared for the mental and physical trauma he would experience through the demise of one or both of us. (pm674)
- To get full-time care before I drop off. (pm072)
- I worry about everything, my brain doesn't stop. (pm275)
- What will happen when I'm gone. (pm870)
- Worry all the time. Sure no future for them. Only put in a home. (pm070)

This is interesting from an Irish cultural perspective, and how this sharply contrasts with other jurisdictions where care provision for adult citizens is situated as a social policy issue and state responsibility, rather than a private family matter.

4 | Discussion

The Irish Constitution asserts the vital role of care by women within society but, in doing so, reflects the patriarchal society of 1937 in which women were firmly subordinated to men (Brady 2012). In particular, Article 41.2 of the Constitution recognised "that by her life within the home, woman gives to the State a support without which the common good cannot be achieved". Some 84 years later, the Irish Catholic bishops issued a statement that was read at Sunday masses in the weeks before the referenda advocating a "No, No" vote and support for the existing article.

> *In an age when people, and especially women, often emphasise the desirability of balancing work and domestic commitments, it is noteworthy that the Constitution already recognises and seeks to facilitate the choice of mothers who wish especially to care for the needs of the family and the home.*
>
> (Irish Catholic Bishops Conference 2024)

While the provisions of Article 41.2, and the rationale of the Irish bishops for its retention, are clearly open to critique from a gender equality perspective, the reality on the ground is that care responsibility for adults with an intellectual disability in Ireland continues to be highly gendered with care overwhelming being provided by women within the home place. The data from the IDS-TILDA Carer Study identifies that 79.5% ($n = 58$) of carers are women with 20.5% ($n = 15$) being men; women are disproportionally represented in this data compared to the Irish Census 2022, which reported that 61% of carers were female and 39% were male.

Furthermore, as explored in the introduction, the proposed Care Amendment sought to insert a new article which emphasises the State's regeneration of "family care" and gives a commitment that the State will "strive" to support such care provision. However, this proposed new Constitutional provision did not oblige the State to support carers, it would simply "strive" to do so, without explicating what the State's role would be beyond this vague pledge. This was criticised for granting no rights to people with disabilities or carers and, indeed, it was suggested that the proposed article was carefully worded to avoid any legal obligation on the state to provide supports to carers or to people needing care. Free Legal Advice Centres (FLAC) argued against giving "constitutional expression to harmful stereotypes" (Healy 2024, npn) and reinforcing the notion that it is the responsibility of family members to provide care to adults with disabilities. The proposed changes to the Constitution restricted consideration of care to within the home, expanding that responsibility from women to the whole family, but conspicuously failing to explicate the state's role. This narrow and restricted conceptualisation of state

responsibility for care is consistent with the Carers' Study data which demonstrates an exceptionally low expectation amongst family carers that the state will provide care in the near future with only 7.4% locating the responsibility with the state. The low expectation is further evidenced by the belief of four of these five carers that they would still be providing care in 5 years time.

The positioning of the family as the principal point of care is remarkably robust even in the face of personal challenges experienced by caregivers. For example, over 65% of sibling carers reported difficulties associated with changes in personal plans, but the vast majority of them anticipated that they will continue in this caring role. This enduring assumed or constructed family-based responsibility for care is consistent with research emanating from other jurisdictions. For example, in the context of rural Australia, Garnham et al. (2019) argue that when social policy normalises life-long family care and supports caregivers to sustain caregiving for as long as possible this, coupled with the inadequacy of formal services, "ensures self-sufficiency emerges as the only reasonable life strategy" (p. 838). From an economic perspective, Ireland has a relatively low level of expenditure on care services in general with a continued heavy dependency on family members as unpaid caregivers (Neller et al. 2024). The carers in this study, who construct the responsibility for care to themselves and who see no change in scale of their caregiving over the next 5 years, may be reflecting and projecting on the low level of stated backed services received to date. While the extent to which the outcome of the care referendum was influenced by the electorate's desire for the state to more actively supportive both carers and those who receive care cannot be quantified, in a recent study on dementia care by Teahan et al. (2021) reported that the Irish public were not only in favour of greater support for carers but were also willing to pay more tax to fund this.

5 | Conclusion

Daly (2024) argues that whereas Irish referenda in the early decades of constitutional change, represented procedural requirements in advance of some legal change, they later became a way of making collective statements and "asserting a new national identity and values". Both the "family" and "care" referenda were lost by a margin that was unprecedented in the history of Irish constitutional reform, despite being supported by all parties in the coalition government, the major parties in opposition and most of the civil society groups that advocate on behalf of women and of family carers. While the proposed referenda engaged ideas about family and care, they failed to directly address the social contract for care in Irish society, specifically the balancing of rights for people with disabilities as citizens of the state, the responsibility of the state in light of those rights, and the ambitions of families with regard to their role in long term care provision.

Notable critical voices of the proposed changes included The Irish FLAC who characterised the Care Amendment as "ineffective", "implicitly sexist" and potentially compromising of the rights of people with disabilities (Carolan 2024). The planned changes were also actively opposed by some people with disabilities and carers who eschewed the endorsements of the proposals and who shifted the narrative towards their own real world, lived experiences (O'Dwyer 2024). This perspective saw the proposed Care Amendment as characterised as abliest, deliberately excluding people with disabilities from independent life and enshrining care as a family concern. Thus, people with disabilities were not portrayed as citizens with equality of rights but as objects of care if, in their position statement on the amendment, FLAC (2024) argued that, if passed, it "would give constitutional expression to harmful stereotypes such as the concept that the provision of care .... is the private responsibility of unpaid family members without any guarantee of State support." Likewise, Independent Living Movement Ireland withdrew from the Equality Commission refusing to support as "yes, yes" vote on the basis that is was inconsistent with the United Nations Convention on the Rights of Persons with Disabilities and with their understanding of "care" as "system that empowers disabled people, older people, and anyone who needs support to live and be included in their communities" (Carolan 2024).

Todd and Shearn (1996) in their research with parents of adults with intellectual disability distinguished between "captive" and "captivated" parents. Captivated parents are committed to their enduring caring role on which they base their self-identity and do not attach a significant value on maintaining a substantial "self" outside the family. Captive parents had envisaged an alternate lifestyle to the ones they were living and keenly felt the loss of opportunity and freedom that was a consequence of their enduring role. The data from (anonymised) suggests that Irish family carers of adults with an intellectual disability exist within this captivated/captive dichotomy. Within the reality of an absence of formal services, it would appear that family-based care (particularly by women) continues to be constructed, as the natural and neutral form of care provision, which relieves the state of obligations it has for the care of citizens who are living with disabilities. In the wake of the resounding defeat of the proposed amendments, a citizen's assembly specifically, thoroughly and directly addressing the social contract for care is warranted. Central to this should be an exploration of the rights, hopes and aspirations of people with disabilities, the responsibilities and capacity of the State to vindicate these rights, hopes and aspirations, and the potential role of the family in care provision.

This study is specifically focussed on the Irish context and assumptions around family orientated care. It also considers the interface of such care with social policies that have shifted from historically expansive institutional provision to contemporary aspiration towards care within family settings. As such, it can serve as a good illustration of the social contract of care and the dynamic between the individual, the family and the State in one jurisdiction at a particular moment in time, which was punctuated by a national constitutional referendum on care. Further research in this field would appear warranted, in particular, a multijurisdiction comparative exploration would provide a better understanding regarding the similarities and differences that exist in how carers understand their role with regard to the social contract for care.

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Ethics Statement

Ethical approval for the study was given by the Faculty of Health Sciences at Trinity College Dublin. Participants provide informed consent and are advised of their right to withdraw from the study. Rigid data protection and confidentiality protocols are adhered to by researchers and data mangers.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

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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