

'KEEPING IT IN THE FAMILY': THE PROPOSED AND REJECTED IRISH CONSTITUTIONAL AMENDMENT ON FAMILY CAREGIVING – INSIGHTS FROM THE IDS-TILDA CARER STUDY



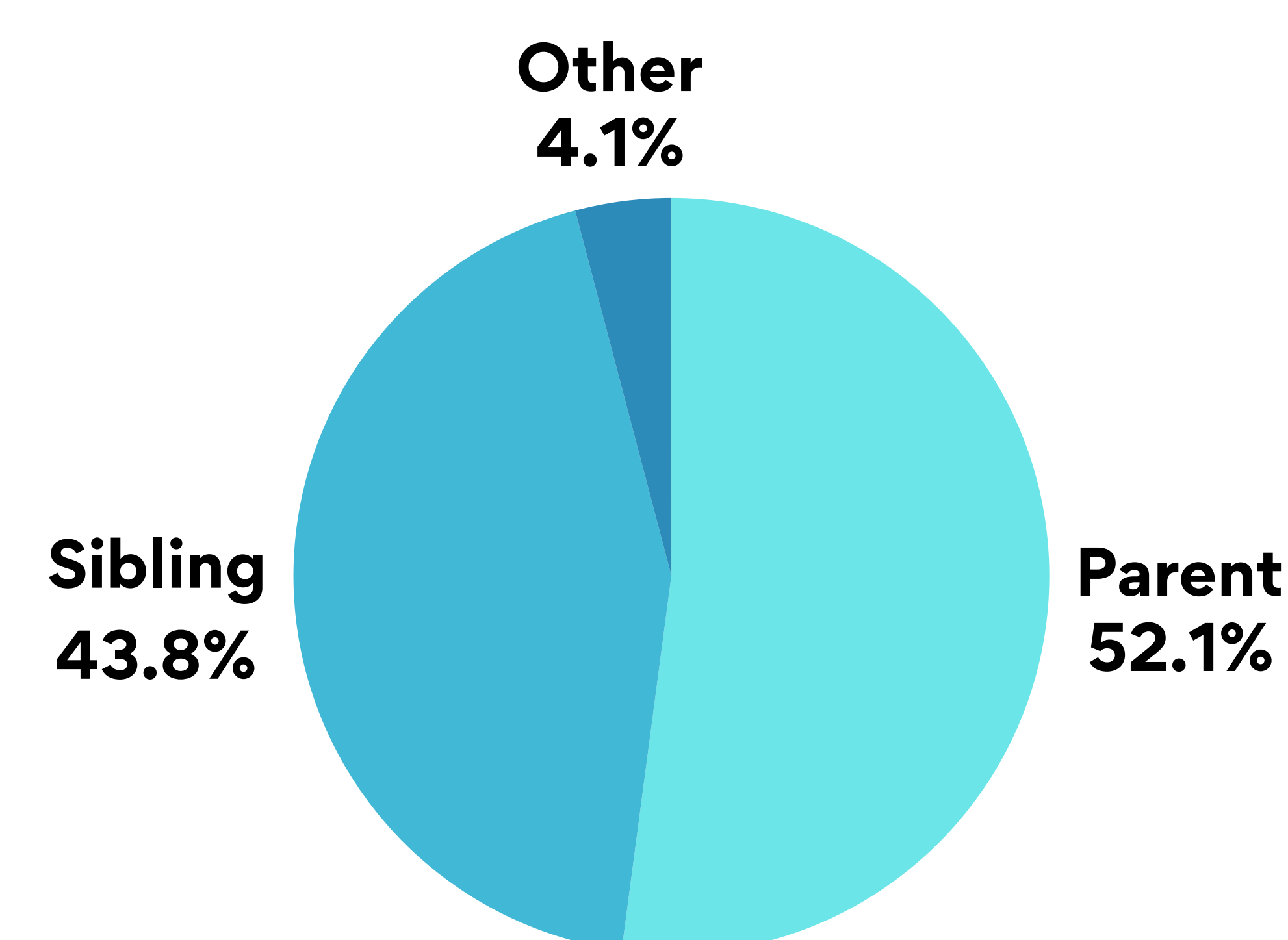
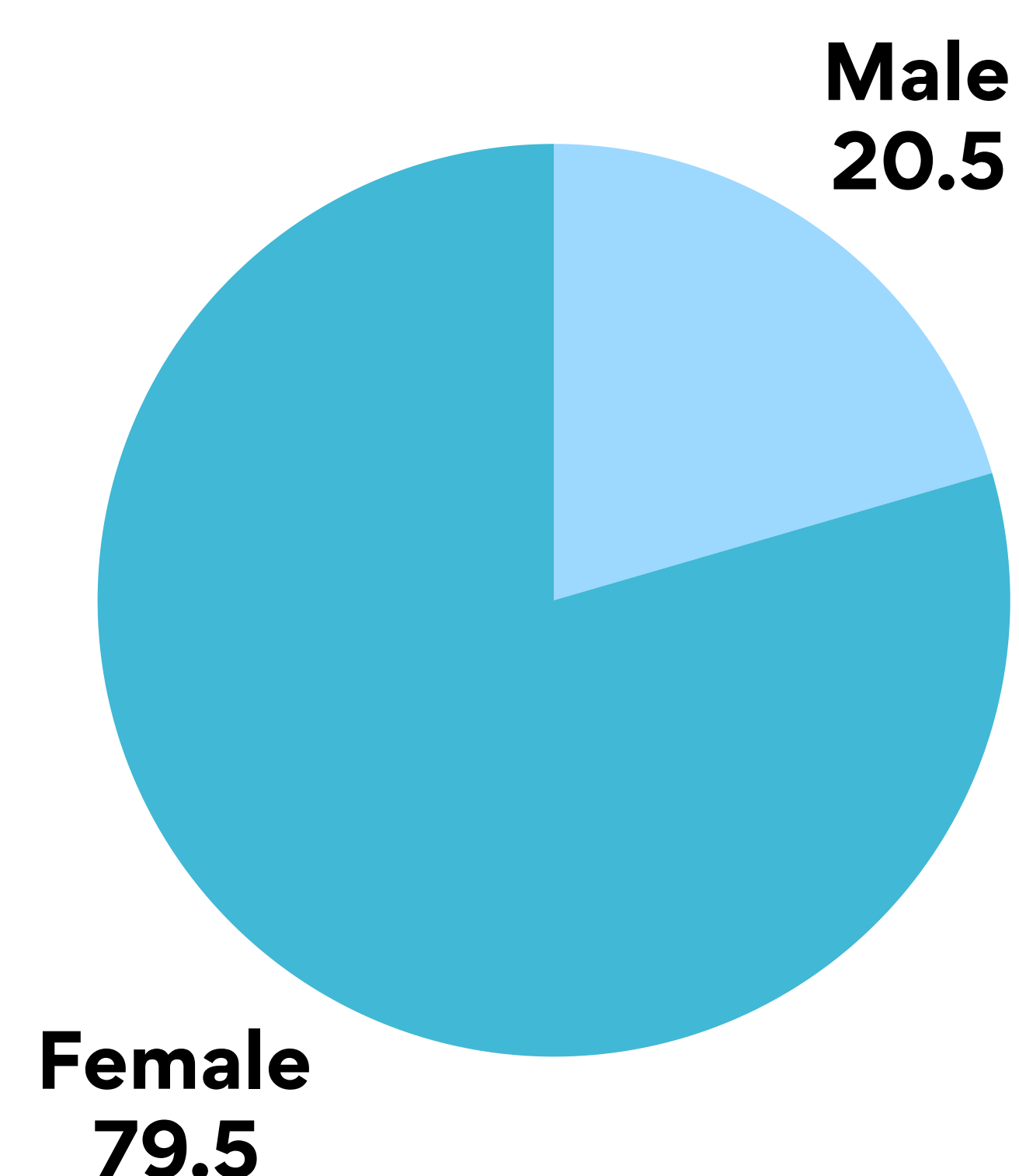
The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)

INTRODUCTION

The social contract for care: 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.

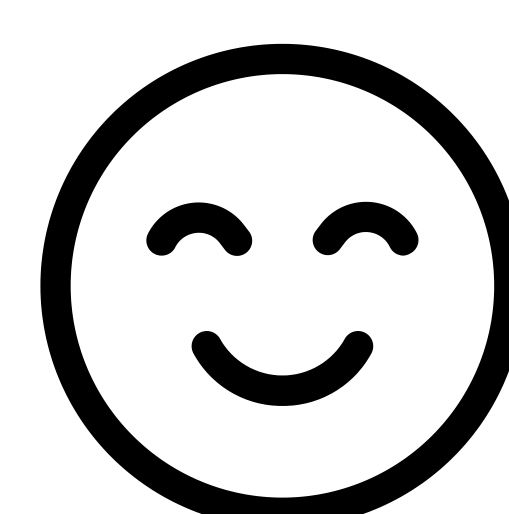
In 2024, 73.93% of the electorate rejected the government's proposed Constitutional changes relating to the definition of a family, and to the interface between state and family with reference to the provision of care. The proposed change would have impacted the legal and social policy balance of responsibility for care provision between the State, the family and citizens in need of care.

IDS-TILDA CARER'S STUDY: WAVE 5

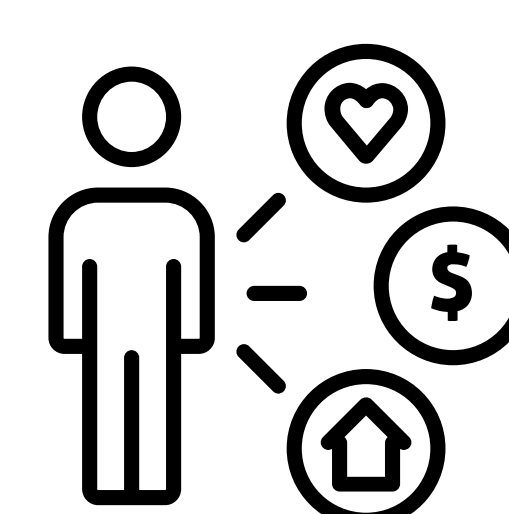


Most siblings were aged between **56 & 65 years**.
All parents were aged over **66 years**, 4 parents (11.4%) aged **86 or over**.

REASONS FOR PROVIDING CARE



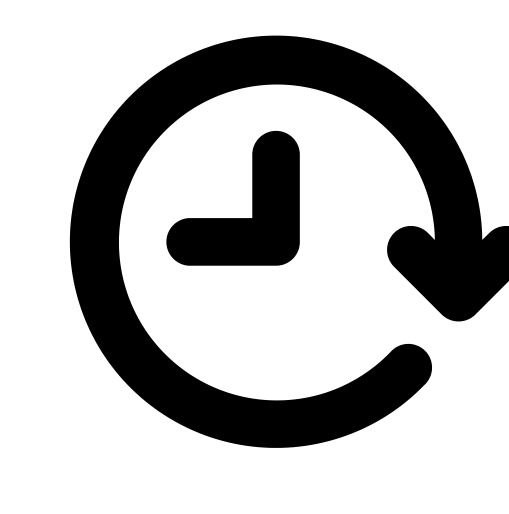
Because I enjoy it: **28.8%**



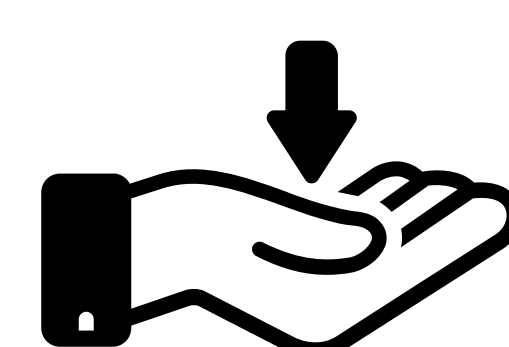
Because I'm needed: **46.6%**



Services not available: **11%**



I've always done so: **42.5%**



Feel obliged: **17.8%**



Because I'm the parent: **49.3%**



The most frequently cited difficulty was that caregiving was **confining** (56.3%, n= 40)

The most difficult aspect was reported to be being **constantly on call** (57.6%, n= 38)



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PROVIDE A TAGLINE OR A SHORT SUMMARY AS YOUR SUBTITLE

ANALYSIS

Future care

84.8% (n=28) of parents, 93.1% (n=29) of siblings and 100% of those in the “other” category expected that they would still be caring for their family member in 5 years’ time.

Most expected to be giving the same 54.5% (n=36) or more 24.2% (n=16) care to their family member in five years’ time

Where lies the responsibility for care of older people with intellectual disabilities?

The participating carer: 66.2% (n=45)

The wider family: 26.5% (n=18)

The State: 7.4% (n=5)

The lack of expectation amongst Irish family carers of a state responsibility for care provision is remarkably low at 7.5%. Carers had no confidence that the state would look after their adult child even when they themselves can no longer do so.

- What will happen when I’m gone (pm870)
- Worry all the time. Sure no future for them. Only put in a home (pm070)

CONCLUSIONS

The positioning of the family as the principal point of care is remarkably robust even in the face of personal challenges experienced by care givers. 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.

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

I am a parent & it is my duty



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



My sister is very important to me & my parents would have wanted me to look after her



To keep [sibling] out of a nursing home

CITE KEY REFERENCES OR ADD YOUR ACKNOWLEDGEMENTS