



Family  
Carers  
Ireland

No one should have to care alone

# Overview of Ongoing Research Activities

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# THE STATE OF CARING | 2022



# About the Research



Survey of the membership and network reach of Family Carers Ireland



2022 – 2<sup>nd</sup> March 2022



1,484 family carers



Combination of online/postal distribution

Average Age 49yrs

88% women, 11% men

79% caring over 90hrs p/w

27% caring for 2 or more

44% caring for a child U18 with additional needs

## Caring, Loneliness and Social Exclusion

- Increase from 22% to 51% of carers who were severely lonely since the onset of the pandemic
- 83% moderate to severely lonely
- 80% of those with very bad health were severely lonely.

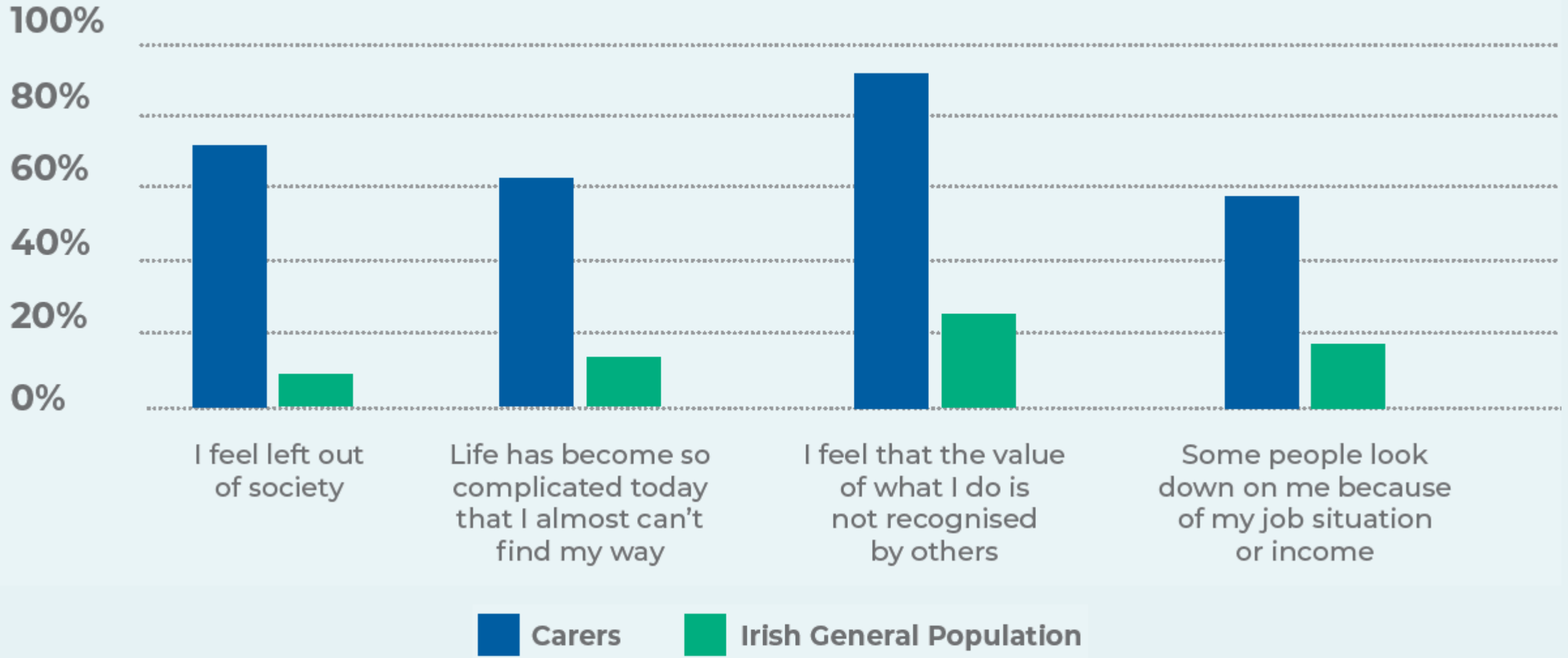


“

I'm alone. No-one understands unless they are in this position. Friends don't fully understand or you don't want to burden them. You lose yourself in so many ways. You become isolated, you stop going out because your family's needs become so overwhelming that you don't have time or money for yourself.

”

# Social Exclusion Index: Carers & Irish General Population



# The Financial Impact of Caring

**47% in households with gross income less than €30,000 p/a**

**68% of carers find it hard to make ends meet**

**13% in arrears with rent or mortgage.**

**16% in arrears with utility bills**

**16% can only make ends meet with great difficulty**



**8% of general population in arrears with utility bills in 2020**

**7% of general population in arrears with rent/mortgage**

“

*I have never been so poor in my life and struggle to make ends meet. This, on top of caring for someone else, makes life quite hard at times. I feel burnt out.*

”



# Care at Home – Costs of Care Arising from Disability

The additional costs of a Minimum Essential Standard of Living for a household caring for an adolescent with a profound intellectual disability.





# MESL

Minimum Essential Standard of  
Living

- A Standard of Living which meets Physical, Psychological and Social needs at a minimum but socially acceptable level
- The focus is on needs not wants
- A standard below which nobody should be expected to live

# Current Study

## Four different Focus Groups

- Members from across Ireland, using zoom,
- Reach a socially negotiated consensus on the goods and services required by the household in the Case Study to have a MESL

## Worked from MESL budgets for households without a disability

- Made necessary changes, additions and subtractions,
- Produced budgets (14+2) for households with a member with a profound intellectual disability

## Each group met for three hours

- Focused on a different phase of the process, and reached a consensus
- Final group reached the final consensus

- The expenditure needs of the family in the Case Study are compared to those of a similar family, without additional caring and disability needs.
- Differences in goods and services due to disability are taken into account.
- Comparison between the expenditure of the two households are made and differences due to the disability explained.

# Increases in the MESL expenditure need are seen in the budget areas of:

- Food
- Clothing
- Health
- Personal Care
- Household Goods
- Household Services
- Social Inclusion
- Transport
- Insurance
- Household Energy

# The largest increase in Expenditure Need are in the Core Budget Areas of:

## 1. TRANSPORT



|                                   |       |
|-----------------------------------|-------|
| Household w/o disability/caring:  | €70   |
| Household with disability/caring: | €144  |
| Difference:                       | + €74 |

## 2. HOUSEHOLD GOODS



|                                   |       |
|-----------------------------------|-------|
| Household w/o disability/caring:  | €19   |
| Household with disability/caring: | €46   |
| Difference:                       | + €27 |

## 3. PERSONAL CARE



|                                   |       |
|-----------------------------------|-------|
| Household w/o disability/caring:  | €21   |
| Household with disability/caring: | €45   |
| Difference:                       | + €24 |

## 4. HEALTH



|                                   |       |
|-----------------------------------|-------|
| Household w/o disability/caring:  | €15   |
| Household with disability/caring: | €34   |
| Difference:                       | + €19 |

# Decreases in the MESL expenditure need are seen in the budget areas of:

## EDUCATION

|                                   |       |
|-----------------------------------|-------|
| Household w/o disability/caring:  | €22   |
| Household with disability/caring: | €11   |
| Difference:                       | - €11 |

## COMMUNICATIONS

|                                   |      |
|-----------------------------------|------|
| Household w/o disability/caring:  | €26  |
| Household with disability/caring: | €20  |
| Difference:                       | - €6 |

# Total Core MESL Expenditure Need – Weekly Comparison

2 PARENT & ADOLESCENT HOUSEHOLD –  
WITHOUT DISABILITY / CARING

€ 509

2 PARENT & ADOLESCENT HOUSEHOLD –WITH  
PROFOUND INTELLECTUAL DISABILITY / CARING

€ 752

**€244**

When all adjustments are made to the MESL budgets areas for the household caring for an adolescent with a profound intellectual disability their MESL expenditure need is an additional €244 weekly.



# Conclusions

- The inequality and inadequacy in the provision of services and supports impacts on the expenditure patterns of households.
- Families routinely subsidizing public services
- Transport, Caring Costs and Household Goods are the three largest expenditure items for the caring household
- Caring households disadvantaged in multiple ways
- Research undertaken at a point in time
- Report focuses on economic costs, but there are hidden, often unquantifiable, costs:
  - Impact on mental and physical health
  - Loss of income because of inability to work
  - Potential of living in debt or poverty
  - Social isolation, strain on relationships
  - Anxiety about the future and other life changing consequences

# Other Research Activities

- Health Research Board-Health Research Charities funding - *Counting the cost: The contribution of older carers in Ireland and impact of caring on mental health and wellbeing of carers*
- HRB-funded CAREWELL project with UCD
- Irish Research Council New Foundations Grants Scheme
  - CarerHarm
  - Young carer project
- Income support reform
- Building carer involvement and stakeholder engagement
- State of Caring additional analysis
- Research governance