



MINIMUM
ESSENTIAL
BUDGET
STANDARDS

RESEARCH CENTRE

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Care at Home - Costs 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

Dr Bernadette Mac Mahon D.C.,
Hannah Boylan and Robert Thornton

Background and Goal

- State of Caring - 2019/2020 Survey - Family Carers Ireland
- UN Convention Rights of Persons with Disabilities
- Minimum Essential Standard of Living (MESL)
- Current Study
 - Additional costs of a MESL for households caring for an adolescent with a profound intellectual disability

State of Caring - Findings

- Caring Responsibilities frequently result in long term financial hardship and in higher household costs.
 - 52% of participants Annual income of less than €30,000
 - 29% of participants Annual income of less than €20,000

UN Convention on the Rights of Persons with Disabilities

Article 7

State's parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

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

Consensual Budget Standards Methodology

Works with members of the public to identify the goods, services, expenditure and income, necessary to meet this standard of living

- 3 - 4 Different focus groups are established which represent the relevant household, with members from different socio-economic backgrounds.
- Through engaging in a deliberative interactive and in depth discussion process, reach a socially negotiated consensus on the necessary goods and services.

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

Case Study

‘The Kelly Family’

- Pat and Audrey Kelly live in a bungalow with their 14-year-old son, Eoin.
- Pat works full-time and Audrey receives the Carer’s Allowance as Eoin requires 24/7 care and supervision.
- Eoin has a profound intellectual disability, is incontinent and is a wheelchair user, he is not independently mobile, cannot sit unaided and has involuntary movement of his arms and legs.
- He attends a special education facility 20km away from the family home.
- Eoin is healthy but is prone to infection so he has a period of time when hospitalisation is necessary (*once or twice yearly*).
- He has a regular sleeping pattern, limited communication skills where he relies on people around him to communicate. Eoin eats a typical diet, which is blended and liquids thickened.

Assumptions

- Parents are in good health.
- Provision of free school transport.
- The Kelly family's house was built after 2010.
- Because of the long waiting times and the negative impact on development and the quality of life, the consensus of the Focus Groups was that the following items would be purchased privately - wheelchair, hospital bed and mattress and ceiling track hoist.

The Family are availing of the following:

- Medical card for Eoin and GP visit card for Carer
- Household Benefit Package - free TV licence and contribution towards energy costs (€35 reduction monthly from electricity)
- Disabled Driver and Passenger Scheme - fuel grant, and exemption from motor tax
- Housing Adaptation Grant
- Specialised equipment received from the HSE - changing bench, comfort chair, wheelchair tray
- Medical Supports from HSE – incontinence products, medical gloves

Results

UNCRPD Article 7 – Children with disabilities



“1. State’s Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.”

- The expenditure needs of the family in the Case Study, The Kelly Family, 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

Unchanged MESL Budget Areas

- Personal Costs
- Savings and Contingencies

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

New Household Budget Areas:

CARING COSTS

€62 weekly

HOUSEHOLD ADAPTATIONS

€14 weekly

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.

Benchmarking Income Adequacy

MESL



Establishing cost of MESL provides an evidence-based benchmark.

Can measure adequacy of available incomes supports

NET HOUSEHOLD INCOME



The total income to the household: net salary + social welfare supports

Analysis at range of salary levels, from full-time NMW to €75,000 per annum

NET MESL EXPENDITURE



MESL cost varies by salary level

Means-tested secondary supports

Net MESL €940 to €1,040 per week

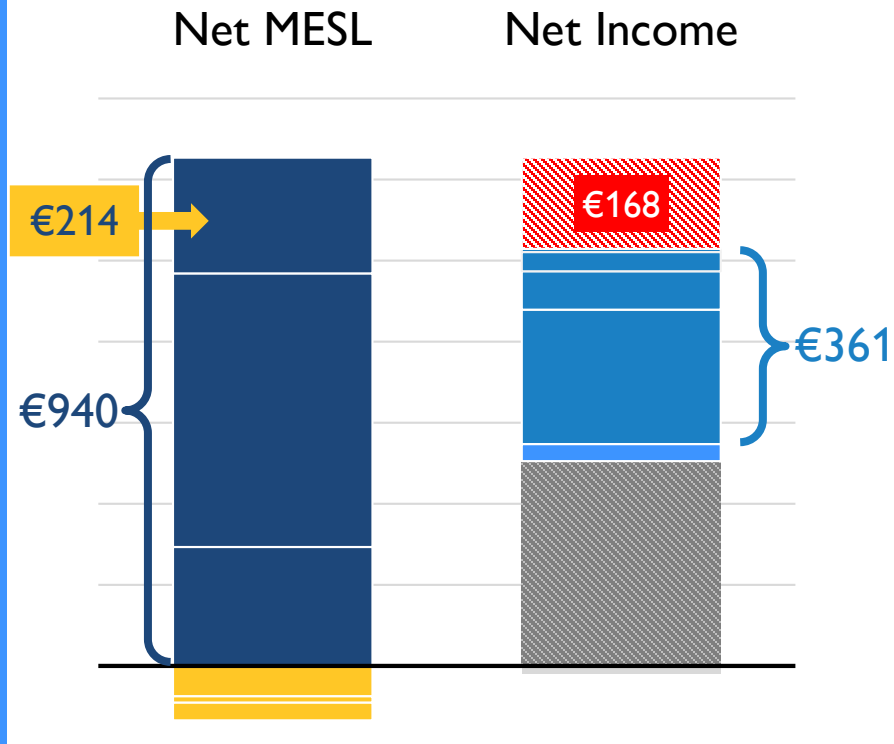
STRUCTURE OF SUPPORTS



Examine structure and tapering of support.

Compare to position of household without additional needs.

Benchmarking Income Adequacy



Two Parents, one in full-time employment, one a full-time family carer

National Minimum Wage Employment

- Net MESL Expenditure €940 per week
- Net household Income €772 per week
 - Net Salary €379 per week
 - Caring & Disability Supports €361 per week
 - Child Benefit €32 per week
- Net household income meets only 82% of MESL need, €168 shortfall
- Minimum Income Standard – Gross salary of €32,175 per annum

Summary of Conclusions

Conclusions

Additional Core Costs

- €752 per week
core MESL for a two-parent household, caring for an adolescent child with a profound intellectual disability
- €244 higher
than the MESL for a two-parent household with an adolescent child without additional caring and disability needs

Conclusions

LARGEST AREAS OF DIFFERENCE

- Transport
- Caring costs
- Household goods
- Personal care
- Health
- Clothing
- Household adaptation

INCOME SUPPORTS

- Notable levels of income support available
- Carer's Allowance, Domiciliary Care Allowance and Carer's Support Grant, provide up to €361 per week

Conclusions

INCOME ADEQUACY

- Maximum social welfare income supports exceed additional caring & disability MESL costs
- But, net household income is inadequate until a gross salary of €32,175 is reached.
- The income supports cannot address both low pay and the additional needs arising from caring & disability, to enable an adequate income at lower salary levels.

OPPORTUNITY COST

- Compared to a household without caring and disability needs, the household caring for a child with a profound disability faces a greater depth of income inadequacy at low incomes, and the persistence of inadequacy to a higher income point.

Conclusions

INEQUALITY

- The inequality and inadequacy in the provision of services and supports impacts on the expenditure patterns of households.
- Many parents meet these costs themselves.
- Consequences include: lower standard of living, long term loans and possibility of living with debt

UNQUANTIFIABLE

- 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

Conclusions

LONE PARENT

- Current study focused on two-parent household.
- The contribution of the focus group members underlined the need to undertake similar research for the one-parent household.
- One income
- All hidden costs

ROLE OF FAMILY CARERS

- Role of family carers needs to be clearly understood and supported through awareness of the 24/7 nature of its demands, its hidden costs, and its equivalence to the similar role of paid employment in the public service.

Conclusions

Hill, K. et al (2017)

THIS STUDY

Studies of the additional cost of disability will never capture every case, and this is not their intention

- Establishes the cost of a MESL for households caring for an adolescent child with a profound intellectual disability, grounded in the lived experience of such households.
- It provides an important indication of the cost required to meet the needs of an individual with different levels and forms of disability, and their carers'.



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