



MINIMUM
ESSENTIAL
BUDGET
STANDARDS
RESEARCH CENTRE



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.



Report by VPSJ Research Team:

Dr Bernadette Mac Mahon DC, Director

Hannah Boylan, Researcher

Robert Thornton, Senior Researcher and Policy Officer

CONTENTS

| | |
|--|-----------|
| Foreword | 04 |
| Acknowledgements | 05 |
| Glossary of Terms | 06 |
| Executive Summary | 07 |
| Care at Home: Costs of Care Arising from Disability | 14 |
| 1. Introduction | 14 |
| 2. Summary: Literature Review | 18 |
| Section One | 18 |
| Section Two | 19 |
| 3. Methodology | 19 |
| 4. Statement and Discussion of Results | 23 |
| i. Household Budget Areas | 24 |
| ii. Total Core MESL Cost per week | 34 |
| iii. Discussion of Results | 35 |
| iv. Other Hidden Costs of Caring | 37 |
| 5. Benchmarking Income Adequacy | 39 |
| MESL Expenditure Need by Salary Level | 40 |
| Income Adequacy | 42 |
| 6. Conclusions | 47 |
| Bibliography | 50 |
| Appendix 1 Literature Review | 53 |
| Appendix 2 Net Cost of Housing Adaptation | 64 |
| Appendix 3 MESL Expenditure & Net Household Income Tables | 66 |

FOREWORD

I am very pleased to introduce this *Care at Home: Costs of Care Arising from Disability* report undertaken by the Vincentian Partnership for Social Justice on behalf of Family Carers Ireland, which identifies the additional costs of a Minimum Essential Standard of Living for a household caring for an adolescent child with a profound intellectual disability.

This study is particularly timely, when the contribution made to our society by those involved in unpaid caring is being actively examined in political and policy circles. This can be seen not only in the ongoing discussions regarding the review of Article 41.2 of the Constitution, but also in the context of Government commitments to establish a statutory home support scheme; create a dedicated pension for long-term family carers and better facilitate caring and unpaid work through the reform of parental and carer leave provisions set out in the EU Directive on Work-life Balance for Parents and Carers.

The findings presented in this study are an important contribution to these discussions, and demonstrate not only the additional and often substantial direct costs faced by caring households, but the hidden costs of caring that are often unaccounted for in Government policy, including the opportunity costs of foregone employment and income, and the forced financial costs imposed on families when public services are not available and families have little choice but pay privately.

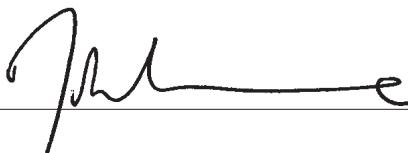
The evidence presented in this report is clear – the cost of achieving a Minimum Essential Standard of Living for a household where care is provided to an adolescent child who has a profound intellectual disability is significantly higher than a similarly composed household without a disability and caring responsibilities. The report also shows that much of the additional costs borne by caring households arise due a denial of what should be publicly-provided services and supports, such as respite, assessments and care equipment, rather

than direct care related costs.

No two caring situations are the same, however in order to develop a MESL for a caring household it was necessary to identify and focus on a specific caring situation. While Family Carers Ireland supports carers of people of all ages and conditions, for the purpose of this study we agreed to focus on a two-parent household with an adolescent child who has a profound intellectual disability. The rationale for choosing this case study was in recognition of the considerable challenges that 'parent carers' may experience. The intensity of their caring role can place significant demands on them, which can make it difficult to combine paid employment with caring and frequently requires regular and significant additional care costs. While Family Carers Ireland provides support to many family carers in a situation similar to the case study described and see the considerable additional costs associated with caring and disability, it is important to stress that many of these additional costs are also borne by other types of caring households.

I would like to convey our thanks to the authors of this report, Dr Bernadette MacMahon DC, Hannah Boylan and Robert Thornton whose work has shone a light into the dark corner of carers' lives, and has helped give an insight into the reality faced by caring families trying to making ends meet.

We hope this study will be a valuable addition to the evidence base underpinning the case for a significant reform of how we recognise, support and financially recognise the unique, yet enormous contribution of family carers.



John Dunne
Chief Executive | Family Carers Ireland

ACKNOWLEDGEMENTS

The VPSJ Research Team acknowledges with warm appreciation the unique contributions of the following ;

The members of the four focus groups to the establishment of the data on the additional needs and costs required for households, with a child who has a profound intellectual disability, to have a minimum essential standard of living. Their day to day experience as carers ensured that the data accurately reflected the lived reality of relevant households. The conscientiousness of the focus groups in implementing the detailed and rigorous demands of the consensual budget standards methodology ensured the required high standard of data collection. Their generosity, love and dedication as carers was inspirational and challenging.

The work of volunteer, Brenda Hunter D.C., in recording the proceedings of the Focus Group meetings, as an independent observer, made an important contribution to the development of the household budgets. The independent account of the discussions and consensus reached by the focus groups augmented the reliability and validity of the contents of the final budgets. We are very grateful to Brenda for her painstaking, detailed and time-consuming work as well as for her commitment to the project.

The willingness of the Principles of Special Schools and the Administrators of Day and Residential Services to respond to queries was much valued and provided knowledge, based on experience, professionalism and commitment. Their patience and expertise provided reliable and valued insights and answers to a number of key questions. Support for the research was also evidenced in the additional time and attention given to consulting their colleagues as the need arose.

The work of previous colleagues of the VPSJ who in the course of 22 years helped to build a solid, reliable and valid bank of data from which to draw, develop and bring to new levels of knowledge.

Their legacy, which is contained in a large number of reports and papers, influenced both the methodology and the documentation and analysis of the data of this study and will continue to enable the MESL work to advance and respond to developing needs.

And finally, the members of the Advisory Group which consisted of Nikki Dunne, Clare Duffy and Catherine Cox. They generously gave of their time and considerable expertise and at all times recognised the independence of the research data, while being ideal collaborators, were a pleasure and privilege with whom to work. In particular we thank Dr Nikki Dunne, who was our liaison person, and was unfailingly available to respond to requests. Through her work of assembling the members of the four focus groups, Nikki made a crucially important contribution to the study. The commitment and professional expertise of Family Carers Ireland is contributing to the greater recognition of the needs and rights of Family Carers and to on-going efforts to ensuring appropriate recognition and support.

The VPSJ is honoured to have been invited to undertake research on the Cost of Care arising from Disability. It is hoped that the data will contribute to a better quality of life for people with disability who face enormous challenges in daily life, to supporting the efforts of family carers to access the goods and services they and their family member need, and to strengthening the voice of Family Carers Ireland in their promotion of greater recognition and more adequate supports. We also hope that the research will give policy makers a clearer understanding of the life changing role of family carers, as well as their needs and rights. Their role has significance and impact beyond the family and reflects our values and commitments as a society.

GLOSSARY OF TERMS

Consensual Budget Standards (CBS) methodology:

This involves facilitating a series of focus group sessions with members of the public who represent the household type under consideration. Through a facilitated, deliberative discussion process focus group members reach a socially negotiated consensus on the goods and services required for a MESL. The methodology enables the development of a consensus within each group and across the groups about the costs faced by the household type under consideration.

Family Carers Ireland:

Family Carers Ireland is the national charity supporting the 500,000+ family carers across the country who care for loved ones such as children or adults with physical or intellectual disabilities, frail older people, those with palliative care needs or those living with chronic illnesses, mental ill-health or addiction.

Gross Salary:

Salary from employment, before the deduction of PAYE (income tax), USC and PRSI

Household Benefits Package (HBP):

Provides a credit towards home energy costs (€35.00 per month) and a Television Licence (€160 per year) to the household.

Marginal Effective Tax Rate (METR):

A measure of the level of taxation and withdrawal of benefits & supports associated with a given increase in gross salary.

Minimum Essential Standard of Living (MESL):

A standard which meets an individual/household's physical, psychological and social needs at a minimum but socially acceptable level. It is one in which the focus is on needs and not on wants and is a standard below which nobody should be expected to live.

Minimum Income Standard (MIS):

This defines the gross income a household needs in order to reach their Minimum Essential Standard of Living.

Net Household Income:

The total income to the household, combining net salary and any applicable social welfare supports

Net MESL Expenditure:

MESL expenditure needs, including housing costs and adjusted for secondary benefits (e.g. Medical Card or level of Housing Adaptation Grant)

Net Salary:

'Take home pay', salary after the deduction of PAYE, USC and PRSI

UN Convention on the Rights of Persons with Disabilities (UNCRPD):

The Convention, adopted by the UN in 2006, aims to ensure that people with a disability enjoy the same human rights as everyone else and is the first international human rights treaty to clearly recognise the rights of all people with disabilities to live in the community as equal citizens

Vincentian Partnership for Social Justice (VPSJ):

Vincentian initiative, established in 1995, to work for change in the social and economic structures which contribute to inequality, poverty and social exclusion.

EXECUTIVE SUMMARY

1. Introduction

This research provides facts and figures on the cost of a Minimum Essential Standard of Living (MESL) for a two parent household caring for an adolescent child who has a profound intellectual disability. This standard is one which meets an individual/household's physical, psychological and social needs at a minimum but socially acceptable level. Since 2006 the Consensual Budget Standards (CBS) methodology has been used by the Vincentian Partnership for Social Justice (VPSJ) to establish the cost of an MESL for households in Ireland. The current study applies the CBS methodology to establish the cost of an MESL for a household caring for an adolescent child who has a profound intellectual disability.

In 2019/2020 Family Carers Ireland undertook Ireland's first national "State of Caring" survey with 1,250 family carer participants. The survey found that for many families, taking on caring responsibilities results in long-term financial hardship, with the loss of income from employment exacerbated by higher household costs. The survey also highlighted the long-term impact of caring, as years spent on a low income or out of the workforce mean carers can't repay debt, build savings or contribute to a pension.¹

Family Carers Ireland's vision is an Ireland in which family carers are properly recognised, supported and empowered and their mission is to highlight the contribution of family carers to Irish society and to improve the lives of family carers throughout the country. They advocate on behalf of family carers at local, regional and national level and they believe that no one should have to care alone.

The UN Convention on the Rights of Persons with Disabilities

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) was adopted by the UN in 2006. The Convention aims to ensure that people with a disability enjoy the same human rights as everyone else and is the first international human rights treaty to clearly recognise the rights of all people with disabilities to live in the community as equal citizens.²

The following Articles from the UNCRPD outline some of the responsibilities of the Irish State in relation to households caring for a child with a disability.³

Article 7 – Children with disabilities, states that;

1. States 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.
2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.

¹ Family Carers Ireland (2020) "State of Caring Survey" available at: <https://familycarers.ie/media/2022/family-carers-ireland-state-of-caring-2020.pdf> accessed October 2021

² Parker, C. (2009) 'An Overview of Article 19 of the UN Convention on the Rights of Persons with Disabilities.' In Bulic et al (eds.) Focus on Article 19 of the UN Convention on the Rights of Persons with Disabilities. Brussels: European Coalition for Community Living, pp. 21-26.

³ UN General Assembly (2006) "Convention on the Rights of Persons with Disabilities" available at: <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf> accessed October 2021

Article 23 – Respect for home and the family, states that;

3. States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.

Ireland was the last EU Member State to ratify the Convention in March 2018, over 10 years after it had initially signed the Convention. However, Ireland is yet to ratify an Optional Protocol of the UNCRPD, which would allow people with disabilities to make complaints to the UN in relation to potential rights violations.

European Pillar of Social Rights – Implications for Family Carers

The EU Pillar of Social Rights was announced by the European Commission in September 2015, and proclaimed by the European Parliament, the Council of the European Union and the European Commission in November 2017. The Pillar of Social Rights contains 20 principles aimed at creating a fairer, more inclusive and just society across Europe. A number of these principles are particularly relevant to improving the lives of family carers, namely:⁴

Principle 9: Work Life Balance

Parents and people with caring responsibilities have the right to suitable leave, flexible working arrangements and access to care services. Women and men shall have equal access to special leaves of absence in order to fulfil their caring responsibilities and be encouraged to use them in a balanced way.

Principle 14: Minimum Income

Everyone lacking sufficient resources has the right to adequate minimum income benefits ensuring a life in dignity at all stages of life, and effective access to enabling goods and services. For those who can work, minimum income benefits should be combined with incentives to (re)integrate into the labour market.

Principle 18: Long-term Care

Everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services.

Minimum Essential Standard of Living

Consensual Budgets Standards (CBS) methodology has been used by the VPSJ since 2006 to establish with members of the public the goods and services required by different household types to achieve an MESL. At present the VPSJ's MESL data covers 90% of household compositions.⁵

A MESL, as already stated, is one which meets an individual/household's physical, psychological and social needs at a minimum but socially acceptable level. It is one in which the focus is on needs and not on wants and is a standard below which nobody should be expected to live. This understanding of an MESL allows for differences in the ways in which needs are met. While there is an acceptance that people with a disability cannot live a life which is identical in all respects to that of people who do not have a disability,

⁴EU Pillar of Social Rights (2015) available online: https://ec.europa.eu/info/strategy/priorities-2019-2024/economy-works-people/jobs-growth-and-investment/european-pillar-social-rights/european-pillar-social-rights-20-principles_en accessed January 2022

⁵The MESL data is focused on single family-unit households, household compositions comprised of either a single adult or a couple, and any dependent children. The remaining 10% not covered by the current MESL dataset, are households with additional adults e.g. a family household with children, parents and grand-parent, and households with more than four children.

there is recognition that they have a right to equivalent/comparable goods, services, activities and opportunities which are needed in order to have an MESL.

The VPSJ's previous study from 2017 which examines the MESL for a single adult with vision impairment, demonstrates that this methodology is effective in establishing the cost of a minimum standard of living for a specific group of people, or households, with a disability. This allows comparisons to be made in identifying additional needs and in providing a benchmark against which to evaluate the adequacy of social transfers and minimum wage rates.

Scope of the Current Study

Understanding the cost of a particular disability is key to the provision of supports which meet the needs of people with a disability and their carers. The current study seeks to establish the additional needs and expenditure required by a specific group of people –households caring for an adolescent child with a profound intellectual disability – in order to have a standard of living which is comparable to that of a household with the same composition without additional caring and disability needs.

The case study used in this research is as follows:

CASE STUDY



The Kelly Family:

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

Underlying assumptions:

- Both parents are in good health.
- Eoin avails of free school transport.
- The Kelly family home was built after 2010.
- The family have the following entitlements:
 - Medical Card for Eoin and Carers GP Visit Card for Audrey
 - Household Benefit Package - free TV licence and contribution towards energy costs (€35 reduction monthly from electricity or oil bill)
 - Disabled Driver and Disabled Passenger Scheme - fuel grant and exemption from motor tax
 - Housing Adaptation Grant Scheme
 - Specialised equipment received from the HSE - changing bench, comfort chair, wheelchair tray.
 - Medical Supports from HSE – incontinence products, medical gloves.

Although this case study is specific to Eoin and his family's experience, the situation and conditions listed in the Case Study, developed by Family Carers Ireland, reflects that of many households caring for a child with a profound intellectual disability.

2. Review of Literature

The review of literature consists of two sections. The first section considers research from Ireland, the UK and other international research into the cost of disability and the impact which this has on family carers. This is not an exhaustive literature review, but instead focuses on research which looks at the cost of a disability, how this cost is measured, the impact which it has on people living with a disability and their families, and the State's support and services in response to these costs.

Section Two looks at the definition of intellectual disability, and the criteria used to identify an intellectual disability. It examines the classifications of intellectual disability: mild, moderate, severe and profound, as well as the characteristics related to, and the additional needs associated with, a profound intellectual disability.

A condensed summary of the literature review is presented in the main report, with the full literature review available in Appendix 1.

3. Methodology (*Consensual Budget Standards*)

The present study builds on the existing body of research undertaken by the VPSJ into the goods and services, expenditure and adequate income required by households and individuals in order to have a Minimum Essential Standard of Living (MESL). The Consensual Budgets Standards methodology (CBS) involves facilitating a series of focus group sessions with members of the public who represent the household type under consideration. The facilitation process is detailed, time consuming and transparent. Through a facilitated, deliberative discussion process focus group members reach a socially negotiated consensus on the goods and services required for a MESL. "The actual expenditure choices and judgements that are made by people in real life on the ground, as they manage their money, contributes to the final consensus."⁶

The methodology enables the development of a consensus within each group and across the groups about the additional costs of caring for a family member with a profound intellectual disability.

Four different groups of people – all carers of adolescents with a profound intellectual disability - were recruited by Family Carers Ireland and were drawn from counties across Ireland. These carers constituted the membership of the different focus groups. Their life experiences and circumstances were, for the most part, similar to those outlined in the case study.

In keeping with previous studies, the focus was on needs and not wants, only items which are essential to meet physical, psychological and social needs are included in the list of goods and services which are necessary in order to have a MESL. While the facilitation process was similar to that used by members of the public in previous studies, because of Covid-19, the focus group meetings took place virtually. Steps were taken to minimise the limitations of this form of engagement.

⁶ Middleton, S. (2000) "Agreeing Poverty Lines: The Diversity of Consensual Budget Standards Methodology" in Bradshaw, J. and Sainsbury, R. (eds) *Researching Poverty*. Aldershot

4. Statement and Discussion of Results

The cost of an MESL – main areas of household expenditure

The core costs of the MESL⁷ are the sum of 14 household budget areas, namely Food, Clothing, Personal Care, Health, Household Goods, Household Services, Communications, Social Inclusion and Participation, Education, Transport, Household Energy, Savings and Contingencies, Insurance, Personals Costs.

Two additional budgets were added to the 14 core budget areas – Housing Adaptations and Caring Costs, which are specific to the Case Study household type.

The total MESL cost for a two-parent household caring for an adolescent child with a profound intellectual disability amounts to €752.49 a week. This is an additional €243.95 when compared to a two-parent household with an adolescent child without additional caring and disability needs.

The following table shows the results of the changes made to the MESL budget areas from the findings of the Focus Groups.

| MESL Category | No Additional Disability or Caring Needs | Caring for a Child with a Profound Intellectual Disability | Difference |
|--------------------------------------|--|--|-----------------|
| Transport | €70.63 | €144.18 | €73.55 |
| Caring Costs | €0.00 | €61.80 | €61.80 |
| Household Goods | €19.34 | €45.97 | €26.63 |
| Personal Care | €21.26 | €45.07 | €23.81 |
| Health | €15.31 | €34.78 | €19.47 |
| Clothing | €26.86 | €43.47 | €16.61 |
| Housing Adaptation | €0.00 | €13.55 | €13.55 |
| Social Inclusion & Participation | €86.27 | €95.75 | €9.47 |
| Insurance | €41.87 | €48.32 | €6.45 |
| Household Energy | €29.20 | €34.84 | €5.63 |
| Household Services | €6.06 | €8.56 | €2.50 |
| Food | €113.18 | €114.95 | €1.77 |
| Personal Costs ⁸ | €9.13 | € 9.13 | €0.00 |
| Savings & Contingencies ⁹ | €21.36 | €21.36 | €0.00 |
| Communications | €25.74 | €20.23 | - €5.51 |
| Education | €22.34 | €10.55 | - €11.78 |
| Total | € 508.54 | € 752.49 | € 243.95 |

⁷ The core MESL baskets focus on the fixed costs and do not include a housing cost, i.e. rent or mortgage. For the purposes of identifying the additional core MESL costs for a household where care is provided to a child with a profound intellectual disability, the inclusion of a housing cost is not required at this point.

When undertaking an examination of the adequacy of the available services and income supports to a family of this type, an appropriate housing cost will be included in the overall MESL basket for that scenario.

⁸ The Personal Costs budget for the Kelly family remained the same as that of a family without additional caring and disability needs, this budget area includes passport fees, banking fees and trade union fees.

⁹ The Savings and Contingencies budget for the Kelly family also remained the same as that for a household without additional caring and disability needs, this budget includes a weekly savings allocation and the cost of Life Assurance.

These additional costs are the consequences of caring for a child with a profound intellectual disability. The cost of a MESL is significantly higher for the household caring for a child with a profound intellectual disability than for households in the general population which do not have a member with a disability. The household budget areas with the largest additional costs are Transport, Caring Costs, Household Goods, Personal Care, Health, Household Adaptations and Clothing. Two of these areas are specifically related to the disability – Caring Costs and Household Adaptations.

Notable levels of income support are available to households providing care to a child with a profound intellectual disability, relative to the social welfare provisions for other groups. However, strict eligibility criteria attached to these income supports as well as significant challenges in accessing public services which force families to pay privately, impacts negatively on the expenditure patterns of these households.

While the emphasis of this report is on the economic costs of caring, the hidden, and often unquantifiable, costs including the opportunity cost of lost earnings potential are also highlighted.

5. Benchmarking Income Adequacy

Establishing the cost of a MESL for a household with a child with a profound intellectual disability, provides an evidence-based benchmark against which to measure the adequacy of available income supports for this household type.

The range of applicable direct income supports and indirect supports which reduce potential MESL expenditure needs are examined. Notable levels of income support are available to households providing care to a child with a profound disability, relative to the social welfare provision to other groups. For the household type examined here, the full rate of Carer's Allowance, Domiciliary Care Allowance and the Carer's Support Grant, provides up to €361 per week in direct income supports.

Indirect supports also play a significant role in reducing the potential MESL expenditure needs of the household type examined. The combination of a means-tested Medical Card, the Household Benefits Package, and qualifying for the maximum tier of Housing Adaptation Grant, can reduce potential MESL expenditure need by up to €100 per week.

The net 'Additional Costs' required to enable a socially acceptable MESL for a household caring for a child with a profound intellectual disability range from €207 to €308 per week.

Benchmarking the adequacy of net household income, from the combination of salary and social welfare supports, against net MESL expenditure need (including the effect of indirect secondary benefits reducing potential MESL costs), shows that full-time minimum wage employment does not provide the basis of an adequate income.

While the analysis finds that the maximum level of direct income support exceeds the additional net MESL expenditure costs arising from the caring and disability related needs of the household, it is also found that net household income is deeply inadequate with a gross salary below €25,000 per annum and remains inadequate until a gross salary of €32,175 is reached. The maximum level of direct income supports cannot adequately address both low pay and the additional needs arising from caring and disability, to enable an adequate income at lower salary levels.

The analysis in this report finds that, when compared to a household without additional caring and disability needs, the household caring for a child with a profound intellectual disability faces a greater

depth of income inadequacy at low incomes, and the persistence of inadequacy to a higher income point. This differential is indicative of the opportunity cost of one of the parents taking on the full-time family carer role and forgoing the potential of paid employment.

6. Conclusions

There are 13 conclusions from the study. They refer to the following:

- The cost of a MESL for a household with additional caring and disability needs.
- The drivers of additional expenditure required by the household in comparison to a household without additional caring and disability needs.
- The role of income supports.
- The impact of the inadequacy and inequality of access to goods and services.
- Income adequacy.
- The hidden costs of caring.
- The role of family carers.

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

1 Introduction

This report provides an analysis of the additional needs which a household, caring for an adolescent child who has a profound intellectual disability, requires in order for them to have a Minimum Essential Standard of Living (MESL). This standard is one which meets an individual / household's physical, psychological and social needs at a minimum but socially acceptable level. Since 2006 the Consensual Budget Standards (CBS) methodology has been used by the Vincentian Partnership for Social Justice (VPSJ) to establish the cost of a MESL for households in Ireland. This study applies the CBS methodology to establish the cost of a MESL for a household with an adolescent child with a profound intellectual disability.

In 1999 a group of women in Cherry Orchard, Dublin asked the questions, "Will no one show the Government what it is like never to have enough to make ends meet? Will no one show them what it is like to live on social welfare or on the minimum wage? Will no one show them what people need just to have a decent life with dignity?"

This plea from people who struggled to make ends meet led to the work of the VPSJ to establish robust evidence on the expenditure needed for a MESL. At present the VPSJ's MESL data covers 90% of households¹⁰ and is being used increasingly as a reference by policy and decision-makers, statutory groups and NGOs.

The questions which were voiced by the group in Cherry Orchard could very well be those of many

people who have a disability, or those caring for a child with a disability.

The EU Survey on Income and Living Conditions (EU-SILC), 2019, showed that 37.5% of individuals who are not at work due to illness or disability are at risk of poverty, in comparison to 4.6% of individuals who described their economic status as 'at work'. Also, over 4 in 10 of individuals unable to work due to permanent illness or disability are living in enforced deprivation, meaning that they experience two or more of the eleven types of deprivation, which include being unable to afford to replace any worn out furniture, being unable to afford to have family or friends for a drink or a meal once a month, etc. The consistent poverty rate for individuals who cannot work due to illness or disability stands at 18.1%. ¹¹

Equivalent statistics on the experience of households caring for a child with a disability are not available from the EU-SILC, however it could be reasoned that similar experiences would be applicable.

In 2019/2020 Family Carers Ireland undertook Ireland's first national "State of Caring" survey with 1250 family carer participants. The survey found that for many families, taking on caring responsibilities results in long-term financial hardship, with the loss of income from employment exacerbated by higher household costs. The survey also highlighted the long-term impact of caring, as years spent on a low income or out of the workforce mean carers can't repay debt, build savings or contribute to a pension.¹²

¹⁰The MESL data is focused on single family-unit households, household compositions comprised of either a single adult or a couple, and any dependent children. The remaining 10% not covered by the current MESL dataset, are households with additional adults e.g. a family household with children, parents and grand-parent, and households with more than four children.

¹¹ CSO (2019) "EU Survey on Income and Living Conditions 2019" available at: <https://www.cso.ie/en/releasesandpublications/ep/p-silc/surveyonincomeandlivingconditionsilc2019/povertyanddeprivation/> accessed October 2021

¹² Family Carers Ireland (2020) "State of Caring Survey" available at: <https://familycarers.ie/media/2022/family-carers-ireland-state-of-caring-2020.pdf> accessed October 2021

The survey also found that even carers in employment are likely to see their working lives adversely affected by having to reduce their hours of work, accept low-paid, precarious work options or sacrifice promotion and career opportunities as a result of their caring responsibilities.

52% of carers who participated in the survey stated that they live in households with a gross income of less than €30,000 per year, while 29% stated that they live in households with a total income of less than €20,000 per year. In 2016, the CSO reported that the median gross income per household in Ireland was over €45,000, demonstrating that the majority of carers who participated in the FCI's survey receive a considerably lower income than the median income of the general population.¹³

When asked about their ability to cope financially, 70% of survey participants said they find it hard to make ends meet, while 19% said they could only make ends meet with great difficulty. In the European Quality of Life Survey from 2016, only 7% of Irish respondents found it difficult to make ends meet, suggesting that family carers are an at-risk group for poverty and financial instability.¹⁴

The findings of the Family Carers Ireland's survey outline the significant financial hardship and risk of poverty faced by many family carers in Ireland, as well as the need for further research on the costs associated with caring.

This study has been undertaken in collaboration with Family Carers Ireland. Family Carers Ireland is the national charity supporting the 500,000 family carers across the country who care for loved ones such as children or adults with physical or intellectual disabilities, frail older people, those with palliative care needs or those living with chronic illnesses, mental health difficulties or addiction.

Family Carers Ireland's vision is an Ireland in which family carers are properly recognised, supported and empowered and their mission is to highlight the contribution of family carers to Irish society and

to improve the lives of family carers throughout the country. They advocate on behalf of family carers at local, regional and national level and they believe that no one should have to care alone.

The UN Convention on the Rights of Persons with Disabilities

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) was adopted by the UN in 2006. The Convention aims to ensure that people with a disability enjoy the same human rights as everyone else and is the first international human rights treaty to clearly recognise the rights of all people with disabilities to live in the community as equal citizens.¹⁵ Ireland was the last EU Member State to ratify the Convention in March 2018, however is yet to ratify an Optional Protocol of the UNCRPD, which would allow people with disabilities to make complaints to the UN in relation to potential rights violations.

The following Articles from the UNCRPD clearly outline the responsibilities of the Irish State in relation to households caring for a child with a disability:¹⁶

Article 7 – Children with disabilities, states that;

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.
2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.

Article 23 – Respect for home and the family, states that;

3. State's Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, State's Parties shall undertake to provide early and comprehensive information,

¹³ CSO (2016) "Income in Ireland" available at: <https://www.cso.ie/en/releasesandpublications/ep/p-gpii/geographicalprofilesincomeireland2016/incomeinireland/> accessed October 2021

¹⁴ Eurofound (2016) European Quality of Life Survey 2016, https://www.eurofound.europa.eu/sites/default/files/ef_publication/field_ef_document/ef1733en.pdf 6 Ibid.

¹⁵ Parker, C. (2009) 'An Overview of Article 19 of the UN Convention on the Rights of Persons with Disabilities.' In Bulic et al (eds.) Focus on Article 19 of the UN Convention on the Rights of Persons with Disabilities. Brussels: European Coalition for Community Living, pp. 21-26.

¹⁶ UN General Assembly (2006) "Convention on the Rights of Persons with Disabilities" available at: <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf> accessed October 2021

Costs of Care Arising from Disability

services and support to children with disabilities and their families.

Article 28 – Adequate standard of living and social protection, states that;

1. State's Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.

2. State's Parties recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realization of this right, including measures:

(a.) To ensure equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs;

(b.) To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes;

(c.) To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care.

These UNCRPD articles clearly present the responsibilities of the Irish Government to provide adequate services and supports, including social protection supports, to families caring for a child with a disability, in order to ensure that they have an adequate standard of living and that all of their human rights are being met.

European Pillar of Social Rights – Implications for Family Carers

The EU Pillar of Social Rights was announced by the European Commission in September 2015, and proclaimed by the European Parliament, the Council of the European Union and the European Commission in November 2017. The Pillar of Social Rights contains 20 principles aimed at creating a fairer, more inclusive and just society across Europe. A number of these principles are particularly relevant to improving the lives of family carers, namely:¹⁷

Principle 9: Work Life Balance

Parents and people with caring responsibilities have the right to suitable leave, flexible working arrangements and access to care services. Women and men shall have equal access to special leaves of absence in order to fulfil their caring responsibilities and be encouraged to use them in a balanced way.

Principle 14: Minimum Income

Everyone lacking sufficient resources has the right to adequate minimum income benefits ensuring a life in dignity at all stages of life, and effective access to enabling goods and services. For those who can work, minimum income benefits should be combined with incentives to (re)integrate into the labour market.

Principle 18: Long-term Care

Everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services.

Consensual Budgets Standards Methodology

Consensual Budgets Standards (CBS) methodology has been used by the VPSJ since 2006 to establish with members of the public the goods and services required by different household types to achieve a MESL. At present the VPSJ data covers 90% of the population. Groups of people drawn from the general population and from different socio-economic backgrounds in a facilitated deliberative discussion process reach a socially negotiated consensus on the goods and services necessary to achieve this standard of living. Experts are consulted as required e.g. nutritionist, household energy consultants. People with the lived experience of the household type under consideration make the

¹⁷ EU Pillar of Social Rights (2015) available online: https://ec.europa.eu/info/strategy/priorities-2019-2024/economy-works-people/jobs-growth-and-investment/european-pillar-social-rights/european-pillar-social-rights-20-principles_en accessed January 2022

decision about what the household needs in order to have a MESL. The budget standards which are developed in the course of the group meetings provide a baseline against which the adequacy of social welfare transfers and minimum wage rates can be evaluated.

A Minimum Essential Standard of Living (MESL) is one which meets an individual/household's physical, psychological and social needs at a minimum but socially acceptable level. It is one in which the focus is on needs and not on wants and is a standard below which nobody should be expected to live.

In addition to establishing the cost of a MESL for a range of household types in urban areas, the VPSJ has also established the needs of these household types in rural areas. The work in a number of rural locations, with a range of household types, demonstrated the appropriateness of the CBS methodology for use with groups that have needs which are additional to those of other sections of the population. The VPSJ's previous study from 2017, which examines the MESL for a single adult with vision impairment, demonstrates that this methodology is effective in establishing the cost of a minimum standard of living for a specific group of people, or households, with a disability. This allows comparisons to be made in identifying additional needs and in providing a bench mark against which to evaluate the adequacy of social transfers and minimum wage rates.

The MESL allows for differences in the ways in which needs are met. While there is an acceptance that all people with a disability cannot live a life which is identical in all respects to that of people who do not have a disability, there is recognition that they have a right to equivalent/comparable goods, services, activities and opportunities which are needed in order to have a MESL.

Scope of the Study

Previous research in the area of disability and caring for a child with a disability has shown that an additional cost of living clearly exists and differs according to the nature and severity of the disability. Research also shows that those with a disability

and households caring for a child with a disability, experience a lower standard of living compared to those without a disability. Understanding the costs associated with a particular disability and the subsequent provision of care is a critical first step towards ensuring that people with a disability and their carer(s) receive the services and financial supports they need.

A family carer is someone who is providing an ongoing significant level of care to a person who is in need of that care in the home due to illness, disability or frailty.¹⁸

This study seeks to establish the additional needs and expenditure required by a specific group of people – households caring for an adolescent child with a profound intellectual disability – in order to have a standard of living which is comparable to that of households in the general population of the same household composition, that are not caring for an adolescent child with a profound intellectual disability.

The MESL expenditure data in this report is based on costs in 2021, reflecting prices from the specific point in time when this phase of the research was undertaken.¹⁹ While there has been exceptional volatility in prices in the subsequent months, it has not been possible to capture these in this report. The costs included reflect the experience of the Focus Group participants which were discussed during the Focus Group meetings.

Where the various social transfers, supports, and secondary benefits are referenced throughout this report, the 2022 rates are applied. This includes social welfare rates of payment, national minimum wage, personal taxation, and the eligibility thresholds and earnings disregards included in the means tests of any supports under consideration, based on the information available at the time of compilation in January 2022.

The costs of caring for a family member with a profound intellectual disability are not limited to financial costs only. Family carers may also experience emotional, physical, psychological and social costs which can be lessened by the

¹⁸ Department of Health (2012). National Carers' Strategy – Recognised, Supported, Empowered. Department of Health, Dublin.

¹⁹ See 'Costing the goods and services' in the Methodology section for more.

provision of adequate income supports and access to essential services. While the purpose of MESL research is to establish the expenditure necessary to meet physical, psychological and social needs at a minimum but socially acceptable level, there is a need to recognise, understand and respond to the often-hidden costs which are largely unquantifiable but which can be life changing for carers. This study will seek to shine a light on some of these hidden and unquantifiable costs.

2 Summary: Literature Review

The literature review is made up of two sections. The first section considers research from Ireland, the UK and other international research which looks at the cost of disability, how this cost is measured, the impact which it has on people living with a disability and their families/carers, and the State's support and services in response to these costs.

The second section focuses on profound intellectual disability, and the criteria used to identify an intellectual disability, the different classifications of intellectual disability, and the characteristics related to, and additional needs associated with, a profound intellectual disability. The full literature review is included in Appendix 1, this section provides a condensed summary of the literature review.

Section One

Despite differences in methodology and approach, studies from Ireland, the UK and other international research agree that there are considerable additional costs experienced by those living with a disability and their carers, and that these costs vary depending on the severity of the disability or condition, and level of care needs.

The UK literature highlights how additional expenses for people living with a disability and their carers can arise from a wide variety of sources. Those mentioned include transport, food, clothing, personal assistance, home adaptations, essential equipment, hospital visits, energy costs, therapies costs and social inclusion costs.

The research demonstrates that the standard of living for a person with a disability tends to be lower, on average, than someone without a disability with the same income. The majority of studies, from Ireland, the UK and those mentioned in international research, also conclude that the State supports and provisions in place at the time of these studies were inadequate to cover the additional costs incurred by people living with a disability and their carers, and that further practical and financial supports are required in order to cover these costs.

With regards to the current report - the additional costs of a Minimum Essential Standard of Living for a household caring for an adolescent with a profound intellectual disability - the findings are relevant to the situation of parents who are the full-time carers of their child. The additional costs associated with the child's disability become the responsibility of their family, the consequent lower standard of living is experienced by the entire household, and the state supports offered to the child and their carer are not sufficient to enable the household to meet these additional expenses.

The Irish research also highlights the issues being experienced by families caring for a child with a disability in relation to a lack of service provision from the state, as a result, where finances allow, many parents are forced to pay for private services and in doing so experience financial hardship or risk falling into debt. The research also demonstrates the barriers of entry to employment that carers experience, leading to reduced income and poorer standards of living.

Additionally, the UK literature goes further in discussing the experience of parents/guardians caring for a child with a disability and the additional expenses and difficulties arising from these expenses. It highlights struggles relating to receiving inadequate state assistance and service provision. Issues relating to seeking employment, due to the demands of caring for a disabled child when adequate childcare is not easily accessible, therefore impacting the potential income of the household. It also discusses how parents bridge the gap between income and spending in various ways, such as going into debt, spending less on

themselves and other family members and altering their lifestyles and aspirations.

In relation to measurements of poverty, the research also suggests that standard poverty measures underestimate the experience of those living with disabilities and their carers as their standard of living tends to be lower than that of someone without a disability with the same income. Because of this, disability adjusted poverty measures are suggested.

The literature emphasises the need for participatory research, such as the Consensual Budgets Standards approach, for appropriate and accurate research into the cost of a disability.

The considerable use of the Consensual Budget Standards approach - the methodology used in this report - in measuring the additional costs associated with disability in the UK literature demonstrates the appropriateness of this method for research of this type, as well as highlighting the importance of including individuals with disabilities, or their family's/carer's, in the research.

A previous Irish study carried out by the VPSJ with the National Council for the Blind of Ireland, further echoes the success of this methodology in establishing a socially negotiated consensus among the participants. The outcome of this study also supports the value of using this methodology to estimate the cost of a MESL for people with different types of disabilities.

Section Two

Definitions of intellectual disability generally state that there are three criteria required in order for an intellectual disability to be identified. These are:

- **Intellectual impairment** – this is measured using IQ test, however there are issues with using IQ alone, as measurements can vary during a person's growth and development, and many people have individual strengths and abilities that cannot be captured within the confines of these tests.
- **Social or adaptive dysfunction** – social function is difficult to measure, it considers a person's

ability to relate to others, communication skills, eating, drinking, toileting and gross and fine motor skills etc.

- **Early onset** – these impairments must be identified in childhood, and not acquired later in life.

Intellectual disability is classified depending on severity. The four classifications are mild, moderate, severe and profound. This study focuses on individuals with a profound intellectual disability.

A person with a profound intellectual disability is described as having an IQ under 20. People with a profound intellectual disability often have congenital syndromes. They are more likely to have additional associated medical conditions. They need significant support and supervision in their day to day life and often have considerable additional needs. People with profound intellectual disability depend strongly on others to satisfy their basic needs, such as feeding, drinking, toileting, mobility and communication.

3 Methodology

The Consensual Budget Standards (CBS) methodology draws on the real-life experience of people on goods and services that everyone should be able to afford, while at the same time drawing on expert knowledge about basic requirements and expenditure. A Research Advisory Group, consisting of senior members of the staff of Family Carers Ireland was established and regularly consulted. Principals of Special Schools and Managers of Day and Residential Services were also consulted as the need arose. The CBS methodology requires the establishment of focus groups for each household type. The following is an outline of the CBS methodology as used in this study to identify the additional goods and services associated with the main areas of household expenditure.

Areas of Household Expenditure

The core costs of the MESL are the sum of the following 14 household budget areas, which are included in the MESL budgets for every household type. Caring costs and household adaptations are two additional MESL budget areas included in this report which are specific to a household caring for an adolescent child with a profound intellectual disability. The inclusion of both additional expenditure areas was endorsed by each of the focus groups.

Table 1: Core MESL Budget Areas

| | | |
|------------------------------------|------------------------------------|---------------------------|
| Core MESL Budget Areas | Food | Clothing |
| | Household goods | Education |
| | Household services | Transport |
| | Personal care | Communications |
| | Household energy | Health-related costs |
| | Social inclusion and participation | Personal costs |
| | Insurance | Savings and contingencies |
| Carer Specific Budget Areas | Caring costs | Housing adaptation |

Housing Costs

The core MESL baskets do not include a housing cost, i.e. rent or mortgage. Housing costs are variable, differing by tenure (social housing, private rented, owner occupied, etc.) and location, and can also be affected by income level (e.g. a differential rent in social housing or Housing Assistance Payment). The core MESL baskets focus on the fixed costs and exclude variable costs which are scenario dependent.

Appropriate housing is of course required to enable a household to have a socially acceptable minimum standard of living. When assessing the overall minimum income needs of a household the MESL analysis defines scenarios, specifying the employment status, income level and housing cost under consideration. This provides a complete picture of the household's minimum expenditure requirements and provides a benchmark for the assessment of income adequacy.

For the purposes of identifying the additional core MESL costs for a household where care is provided to a child with a profound intellectual disability, the inclusion of a housing cost is not required at this point. However, when undertaking an examination of the adequacy of the available services and income supports to a family of this type, an appropriate housing cost will be included in the overall MESL basket for that scenario.

CASE STUDY



The Kelly Family:

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

Underlying assumptions:

- Both parents are in good health.
- Eoin avails of free school transport.
- The Kelly family home was built after 2010.
- The family have the following entitlements:
 - Medical Card for Eoin and Carers GP Visit Card for Audrey
 - Household Benefit Package - free TV licence and contribution towards energy costs (€35 reduction monthly from electricity or oil bill)
 - Disabled Driver and Disabled Passenger Scheme - fuel grant and exemption from motor tax
 - Housing Adaptation Grant Scheme
 - Specialised equipment received from the HSE - changing bench, comfort chair, wheelchair tray.
 - Medical Supports from HSE – incontinence products, medical gloves.

Case study – The Kelly Family

In order to identify the additional needs associated with a caring household it is necessary to construct a hypothetical case study, defining the family composition and the age and level of disability of the person being cared for. Following consultation with Family Carers Ireland it was agreed that the case study would focus on a two-parent household caring for an adolescent with a profound intellectual disability. National and international definitions of intellectual disability generally share three key criteria. These are:

1. A significant impairment of adaptive behaviour (social functioning);
2. A significant impairment of intellectual functioning, with;
3. Both impairments arising before adulthood.

Intellectual disability (ID) is the presence of a significantly reduced ability to understand new or complex information and to learn new skills, with a reduced ability to cope independently, which starts before childhood and adolescence and has a lasting effect on development. However, the presence of low intelligence (IQ below 70) is not, of itself, a sufficient reason for deciding whether an individual requires health and social care support. An assessment of social and adaptive functioning and communication skills should also be considered when determining need. The terms 'mild', 'moderate', 'severe' and 'profound' are used to describe different levels of intellectual disability. These terms correspond to different IQ levels. This study focuses specifically on profound intellectual disability, where the child or adult typically requires pervasive support in relation to all domains of adaptive functioning.²⁰

During the course of the study it became apparent that many caring households face delays in accessing essential supports and items critical to the care and progression of the cared for person. In many instances' families have little choice but to pay privately for these items in order to minimise the serious implications their denial could have on the development and progression of their child. In recognition of this, it was agreed that a once-off cost for three items would be included in the study, namely the purchase of an adapted wheelchair; a hospital bed and mattress and a ceiling track hoist.

Although this case study is specific to Eoin and his family's experience, the situation and conditions listed in the case study reflect that of many households caring for a child with a profound intellectual disability.

Composition and Preparation of the Focus Groups

Four focus groups involving 32 family carers identified by Family Carers Ireland were convened as a core part of this study. The carers involved were from both urban and rural locations; included people from different socio-economic backgrounds and were familiar with the social, economic and medical circumstances of the Kelly family.

Due to the ongoing COVID-19 restrictions focus group meetings took place virtually, using Zoom. This raised some challenges not associated with the traditional focus group meetings, including creating a comfortable environment conducive to putting carers at ease and creating an engaging discussion. A further challenge was the inability to display posters to illustrate the Kelly family case study and draw attention to key concepts e.g. focus on needs not wants. To minimise these challenges, explanatory materials were sent to focus group participants in advance. Participants were subsequently contacted by a representative from Family Carers Ireland, who coordinated the administration associated with the study. They were also contacted by a member of the research team by phone. These conversations allowed family carers to ask questions about the study, discuss the methodology, build rapport with the research team and helped to create a relaxed, focused and engaged environment at the actual Zoom meeting. A significant advantage of using Zoom as the platform to host focus groups was that it allowed carers from across the country to participate in the study, resulting in a broad representation of family carers. The Zoom platform made it possible for members of the focus groups, who would not have been free to absent themselves from the family home because of caring duties, to participate in and contribute to three-hour focus group sessions.

Stages of the Work of the Focus Groups

The focus groups are described in terms of the sequence in which they met: first, second, third and fourth.

Orientation Stage: The work of each new focus group began with an orientation session - a shared understanding is developed of key concepts and principles e.g. MESL, needs versus wants, and developing a socially negotiated consensus.

Focus Group 1: The task of the first focus group was to study the original budgets for members of the general population (similar in age, accommodation and needs but without disability and caring needs) which were established for each expenditure area. The members of the focus group then identified changes which they agreed as necessary in order to meet the expenditure

²⁰ HSE (2021) "MHID - National Model of Service" Available: <https://www.hse.ie/eng/services/publications/mentalhealth/hse-national-mhid-model-of-service-january-2021.pdf> (accessed February 2022)

needs of family carers in households with disability and caring needs, as described in the Kelly family case study. These changes took the form of the inclusion of additional items or amendments to existing items.

Focus Group 2: Focus Group 2 reviewed the changes proposed by Focus Group 1 and reached a consensus on the recommendations put forward by them and any additional amendments required.

Focus Group 3: Focus Group 3 reviewed the changes proposed by the previous two focus groups and reached a consensus on their recommendations and any further amendments required.

Focus Group 4: The fourth focus group is referred to as 'the check back group'. They reached the 'final consensus' and considered the approximate costs of the changes proposed.

Reaching Consensus

When the focus groups had deliberated on each budget area, the researchers identified the consensus among the four groups regarding the changes that need to be made to the original budgets in order to meet the requirements of households with the specific disability and caring needs. On the rare occasion when a consensus was not evident the researchers identified the most frequently held view.

For the most part, definite levels of consensus emerged from the focus groups regarding the additional needs of households with an adolescent child who has a profound intellectual disability. When there were differences in the specification of additional or different items required to meet these needs the researchers based their decisions on the consensus reached in relation to purpose, function/features and expectations of these items.

Costing the goods and services

During the course of their work, the focus groups in the original core MESL studies for other household types have produced an itemised list of approximately 2000 goods and services which have been individually priced in outlets identified

by the focus groups. The items included in the core MESL budget were those for a household consisting of two parents and an adolescent boy. The costs for each item already in the basket in the core MESL were updated to March 2021 in line with the VPSJ MESL 2021 update which is based on a March-to-March cycle. The additional or newly replaced items for the household caring for an adolescent with a profound intellectual disability were priced in November 2021 online in the stores nominated by the focus group participants. When the quantity of any item included in the core MESL was increased, the price for the item in the original MESL was used.

4 Statement and Discussion of Results

This chapter presents the following:

- Expenditure on core household budgets
- Discussion on
 - The contribution of income supports
 - The financial implications of inequality and inadequate access to essential services and supports
 - Drivers of costs
- The hidden costs of caring

Expenditure of Core Household Budgets

The UN Convention on the Rights of People with Disabilities aims to ensure that people with a disability enjoy the same human rights as everyone else and live in the community as equal citizens. In this chapter the expenditure needs of the Kelly family are compared to those of a similar family without the disability and caring needs of the Kelly family. Differences in goods and services due to disability and caring are taken into account. Comparison between the expenditure of the two households are made and differences arising due to the disability and subsequent care needs are explained.

The MESL expenditure data in this report is based on costs in 2021, reflecting prices from the specific

point in time when this phase of the research was undertaken.²¹ While there has been exceptional volatility in prices in the subsequent months, it has not been possible to capture these in this report. The costs included reflect the experience of the Focus Group participants which were discussed during the Focus Group meetings.

The tables in this chapter refer to 'MESL – no caring and disability' when discussing the MESL budget of a two-parent household with an adolescent child without additional caring and disability needs; 'MESL – caring and disability' when discussing the MESL of the Kelly Family; and 'Difference' when referring to the increase or decrease in expenditure between the two of these household budgets.

(i.) Household Budget Areas

1. Food

| MESL – no caring and disability | | MESL – caring and disability | | Difference ²² | |
|---------------------------------|---------|------------------------------|---------|--------------------------|---------|
| Total | €113.18 | Total | €114.95 | Total | + €1.77 |

The Kelly family's food budget amounted to €114.95 weekly, an additional €1.77 when compared to the household food budget of two parents and one adolescent child, without additional caring and disability needs.

The case study states that Eoin²³ has a typical diet, with solids blended and liquids thickened. Additional or different items added to the Kelly family's food budget amounted to €9.26, with €7.49 of this being offset by substitutions for items that are not suitable given Eoin's dietary requirements, such as the removal of crisps, biscuits, bread rolls and a deli lunch on a Friday, replaced with additional milk and gravy (for blending) alongside additional yogurts, and the inclusion of pre-prepared soups and custard.

The inclusion of a hospital food allowance accounted for €1.92 of the different items added to the budget. Focus groups agreed that as Eoin would require hospitalisation once or twice a year, the inclusion of a food allowance for carers was necessary. Focus groups agreed on a €20 allowance per day that Eoin spent in hospital, and estimated, given Eoin's condition, that five days of hospitalisation a year would be appropriate at a minimum level.

2. Clothing

| MESL – no caring and disability | | MESL – caring and disability | | Difference | |
|---------------------------------|--------|------------------------------|--------|------------|----------|
| Total | €26.86 | Total | €43.47 | Total | + €16.61 |

The Kelly family's clothing budget amounted to €43.47 weekly, an additional €16.61 when compared to the clothing budget for a household without additional caring and disability needs.

²¹ See 'Costing the goods and services' in the Methodology section for more.

²² All tables present average weekly cost rounded to two decimal places, unrounded data used in all calculations. The totalling of rounded figures may differ slightly from the totalling of the unrounded data.

²³ Any reference within this section to "Eoin" or "Audrey" is in relation to the hypothetical Kelly Family discussed in the Case Study of the report.

Eoin's clothing budget has a higher cost of €13.03 when compared to an adolescent child without additional caring and disability needs, largely due to Eoin's incontinence.

€7.40 of the additional cost in Eoin's clothing budget is accounted for by changes to items that are also included in the adolescent budget without additional caring and disability needs. This includes increasing the frequency that replacement clothing must be purchased, such as tracksuits, t-shirts and pyjamas, to allow for soiling, staining and the increased washing and drying associated with Eoin's incontinence.

€7.78 of the cost in Eoin's clothing budget is due to the need for items specifically related to his disability. These include the addition of a wheelchair blanket, specialised wheelchair mitts instead of gloves, and bibs.

€2.10 of the cost of Eoin's clothing budget was offset through the removal of clothing items that the focus groups agreed were not suitable for Eoin. The items removed include underwear (Eoin would instead wear incontinence pads), a belt, jeans, flipflops etc.

The Kelly parents' clothing budget was €3.58 higher when compared to the two parent clothing budget of a family without additional caring and disability needs. This addition was in Audrey's clothing budget, Eoin's full-time carer, and was due to the need to halve the lifespan of items such as jumpers, trousers, jeans, t-shirts, tracksuit bottoms and coats. Focus group members agreed that this reduction in lifespan was made necessary by the increase in wear and tear associated with caring duties. Thermal gloves, good quality trainers and a rain jacket were also added to Audrey's clothing budget.

3. Personal Care

| MESL – no caring and disability | MESL – caring and disability | Difference |
|---------------------------------|------------------------------|------------|
| Total | Total | Total |
| €21.26 | €45.07 | + €23.81 |

The Kelly family's personal care budget amounted to €45.07 a week, which is €23.81 higher than the comparable budget for the other household, without additional caring and disability needs. This difference is primarily caused by the need for additional products for Eoin, which include Caldesene Powder, Vaseline, Sudocrem, body moisturiser, baby powder, wipes and waste bags for Eoin's nappy disposal. This figure includes items that are already in the adolescent child without additional caring and disability needs budget, such as soap, body wash, shampoo, conditioner, sun cream, shaving cream and deodorant, which need to be replaced with alternatives for sensitive skin.

Focus groups agreed that nappies/incontinence pads and medical gloves are needs for the Kelly household given Eoin's disability and should be accessible through the Public Health Nurse (PHN) free of charge, as it is assumed that Eoin has a full Medical Card. Focus groups did, however, highlight inconsistencies in accessing these items through the PHN, for example some participants mentioned that they could not get enough incontinence pads from the PHN to meet their child's needs and often had to buy their own to compensate for the inadequacy of the allocation. Because of this, it was agreed by the focus group participants that one packet of incontinence pads would be purchased a month, in order to make up for any shortfalls that may be experienced.

4. Health

| MESL – no caring and disability | | MESL – caring and disability | | Difference | |
|---------------------------------|--------|------------------------------|--------|------------|----------|
| Total | €15.31 | Total | €34.78 | Total | + €19.47 |

The Kelly family's Health budget²⁴ amounted to €34.78 a week, €19.47 higher than the comparable for the other household, without additional caring and disability needs.

This addition was offset by €8.08, due to the removal of GP, dentist, optician and prescription costs for Eoin, as it is assumed that he has a Medical Card and therefore would not be charged for these services. The addition was also offset by Audrey's (Eoin's mother) entitlement to a Carer GP Visit Card, which removes the cost of GP visits for the carer. The GP visit card does not, however, cover the cost of prescriptions, which are included in the budget.

The need to access private therapies for Eoin contributed to the higher costs. Focus groups highlighted the need to access private medical therapies, such as Occupational Therapy, Speech and Language Therapy, Physiotherapy, and Psychology, for a child with Eoin's level of disability. Focus groups stated that although these therapies can be accessed publicly, waiting lists are usually very long, and in order to provide their child with a level of care which meets their needs and prevents regression, they have to pay privately to access these services.

Family Carers Ireland also agreed that parents caring for a child with Eoin's needs would likely be paying for private services to supplement inadequate public provision, where financially possible. It was accepted that at a minimum, Eoin would need to access one private therapy session a month (of the four therapies mentioned above) meaning that he would access 12 private sessions a year. The cost included for this therapy in Eoin's Health budget is the average cost of one session of Occupational Therapy, Physiotherapy, Speech and Language Therapy and Psychology, amounting to €93.75 a month, €21.63 a week.

The inclusion of the cost of an Assessment of Needs for Eoin contributes an additional €5.77 a week to the household Health budget. This cost has been included as focus groups and Family Carers Ireland clearly highlighted the need for periodic multidisciplinary assessments of need at the key stages of a child's development. These assessments, however, are not readily accessible through public education/health services and frequently have to be accessed privately. The cost of one assessment of need, averaging at a price of €1,500, has been included with a lifespan of five years to cover the adolescent period in Eoin's life.

5. Household Goods

| MESL – no caring and disability | | MESL – caring and disability | | Difference | |
|---------------------------------|--------|------------------------------|--------|------------|----------|
| Total | €19.34 | Total | €45.97 | Total | + €26.63 |

The Kelly family's household goods budget amounted to €45.97 a week, an additional €26.63 when compared to the household budget without additional caring and disability needs. These additional costs come from a number of changes to the household goods budget.

²⁴ The core MESL budget presents the costs prior to the reduction of means-tested secondary benefits. Therefore, the health costs do not include the effect of a full Medical Card or GP Visit Card, with the exception of the non-means tested Medical Card for a child for whom a household is receiving Domiciliary Care Allowance and the GP Visit Card for a person in receipt Carer's Allowance.

In relation to Eoin's incontinence, there was an increase in the amount of bedding and towels needed in comparison to the household goods budget of an adolescent child without additional caring and disability needs. This increase accounted for €4.66 a week, which included an increase in quantities of items such as sheets, duvets, duvet covers, pillows and towels, as well as the inclusion of a mattress protector and pillow protectors.

Another considerable change made to the budget was the substitution of the flooring included in the household goods budget for a family without additional caring or disability needs, with laminated flooring. As stated in the case study, Eoin is a wheelchair user, and focus groups agreed that there is a need for laminated flooring throughout the Kelly's home in order to ensure accessibility and safety for Eoin.

Specialised items including a hospital bed and mattress, a wheelchair and a wheelchair tray, a ceiling track hoist, a changing bench and a specialised comfortable chair were all agreed by the focus groups to be essential at a minimum level for Eoin given his disability.

These specialised items should be available to the Kelly family without charge through the HSE, however, participants emphasised the difficulty and inconsistencies they experienced when trying to access these items from the HSE. They emphasised long waiting times and that they often had to buy their own specialised items at considerable expense, or rely on fundraising or support from community groups and charities in order to access these items and meet Eoin's needs as a growing adolescent.

Being denied access to these essential items can have serious impacts on the health, safety and development of a child with a profound intellectual disability. Because of this, the cost of the wheelchair, the hospital bed and mattress, and the ceiling track hoist have all been included in the budget. This amounts to an additional €16.44 weekly, which includes the 13.5% VAT reduction available in respect of medical equipment.

The focus groups also highlighted the need for an audio-visual monitor for Eoin, as he requires full-time care and supervision, and such a monitor is needed to check on him while he is sleeping.

There were changes in the Kelly's household goods budget relating to electrical items. This included the shortening of the washing machine's lifespan and the inclusion of a tumble drier, which was deemed necessary due to Eoin's incontinence. The blender originally included in the budget without additional caring and disability needs was substituted for a better-quality blender, as it is required to blend Eoin's food to meet his dietary requirements. Focus groups also agreed that a dishwasher should be included in the household goods budget. Focus groups agreed this was needed to aid the full-time carer and save time that could otherwise be spent caring for their child, rather than manually washing dishes. These changes to electrical items accounted for a €3.76 increase weekly in the Kelly family's household goods budget.

The focus groups made a considerable number of changes to the cleaning materials section of the household goods budget for the Kelly household. Focus groups highlighted the need for larger quantities of cleaning products, such as bleach, disinfectant spray, dish cloths, refuse sacks and clothes washing detergent, as well as the inclusion of kitchen roll, floor wipes and dishwasher tablets. These changes accounted for an additional €6.18 in the Kelly family's cleaning budget, with focus groups agreeing that it was the consequence of Eoin's disability (e.g. incontinence and the involuntary movements of his limbs) that these additional cleaning products were needed. Participants also highlighted the need to protect Eoin from infection, and that cleaning products were essential for this.

€4.57 of the changes made to the Kelly's household goods budget was offset by the substitution of the flooring type for the Kelly's home, as well as the removal of certain household items that are included in the adolescent child without additional caring and disability needs budget. These include a single bed, a mattress, a

Costs of Care Arising from Disability

study desk and a study chair. Focus groups agreed that these items would not be required given Eoin's disability.

6. Household Services

| MESL – no caring and disability | MESL – caring and disability | Difference |
|---------------------------------|------------------------------|---------------|
| Total €6.06 | Total €8.56 | Total + €2.50 |

The Kelly family's household services budget amounted to €8.56 a week, which is €2.50 higher when compared to the household services budget of a family without additional caring and disability needs.

Focus groups agreed that a household caring for a child with Eoin's level of need would produce a considerably more waste, e.g. disposal of Eoin's incontinence products and a large amount of packaging for items such as incontinence pads, wipes, medications, etc. The Kelly's household services budget includes the cost of an additional general waste bin to account for this need.²⁵

7. Communications

| MESL – no caring and disability | MESL – caring and disability | Difference |
|---------------------------------|------------------------------|---------------|
| Total €25.74 | Total €20.23 | Total - €5.51 |

The Kelly family's communications budget amounted to €20.23 a week, which is €5.51 less when compared to the communications budget of the other household. This is due to the removal of a mobile phone and credit allowance for Eoin. Focus groups agreed that given Eoin's disability a phone would not be suitable for him. However, there are alternative electronic devices included in Eoin's social inclusion budget.

8. Social Inclusion

| MESL – no caring and disability | MESL – caring and disability | Difference |
|---------------------------------|------------------------------|---------------|
| Total €86.27 | Total €95.75 | Total + €9.47 |

The Kelly family's social inclusion budget amounted to €95.75, which is €9.47 higher when compared to the household social inclusion budget for a family without additional caring and disability needs.

²⁵ In 2017 Government secured funding towards the cost of a €75 waste rebate for households who would be affected by higher waste collection charges due to the disposal of incontinence products, however the rebate did not materialize due to administration difficulties in identifying eligible households.

The Kelly family's social inclusion budget is considerably different from that of a household who do not have additional caring and disability needs. Their social inclusion budget contains sporting activities including football, swimming and basketball/ dance classes. Family outings include going to the cinema, a concert and discos. The toy section includes a bike, helmet, and football. Focus groups agreed that the majority of these items would not be suitable for Eoin and as such the Kelly family's social inclusion budget has been amended to reflect Eoin's needs.

Eoin's budget includes swimming once a week. Focus groups highlighted how important swimming is for a child with Eoin's needs, not only as a form of exercise and activity, but also as a form of physical therapy. Eoin cannot go swimming by himself given his need for full-time care and supervision, and focus groups stated that both parents would need to go with him to provide adequate care for Eoin. Focus groups agreed that swimming can only be done in wheelchair accessible pools, that have a hoist/access to allow Eoin to get into the pool, as well as adequate changing facilities for Eoin. Focus groups also stated that Eoin needs swimming nappies and a specialist incontinence swim costume.

Family outings identified by focus groups as suitable for the Kelly family include; going to the cinema, bowling, an annual visit to the zoo and an annual attendance at a pantomime. Again, as Eoin requires full-time care and supervision, at least one parent would be with Eoin at all of these outings. Focus groups also highlighted the importance of wheelchair accessibility and adequate changing facilities when planning any family outing for Eoin, and how this can greatly impact the options available to a family caring for a child with Eoin's needs.

The 'toy' budget for Eoin is considerably more important than it would be to an adolescent child without a disability. Because of Eoin's disability, he is not able to simply go outside or to entertain himself. Focus groups emphasised the importance of appropriate toys to entertain a child with Eoin's needs and to keep him occupied and engaged.

Focus groups noted the need for an additional TV for Eoin, as well as a tablet. They noted that this tablet could act as Eoin's communication device through apps.

Focus groups agreed on the inclusion of a 'sensory toy allowance' of €20 for parents to be able to update Eoin's toy supply every 6 months, alongside the inclusion of sensory lights, and beanbags. These are toys that focus groups identified as suitable to meet Eoin's sensory needs.

Focus groups noted that toys and electronic devices are frequently broken, due to the involuntary movement of the child. Because of this, the budget includes the cost of instant replacement insurance for Eoin's tablet, as well as a protective case.

Eoin's social inclusion budget also includes a pocket money allowance of €10 a week, the same allowance which is included in the social inclusion budget for an adolescent child without additional caring and disability needs. Focus groups participants agreed that this was needed for Eoin's societal integration whilst on outings with his family or others e.g. bowling, the pantomime, the zoo.

The Kelly parent's social inclusion budget is not significantly different from that of the social inclusion budget of a household without additional caring and disability needs.

One difference is the removal of the television license cost. As Eoin's mother is his full-time carer and receives Carer's Allowance, she is entitled to the Household Benefits Package, which provides an exemption to the television license fee.

Another area that differed for the Kelly family was the family 'holiday'. Focus groups agreed that the holiday accommodation included in the budget for a household without caring responsibilities, which was the rental of a mobile home for a week, would not be suitable for Eoin given his accessibility needs. Instead, the inclusion of a weekly rental in a wheelchair accessible / disability friendly cottage is included in the budget. This was an addition

Costs of Care Arising from Disability

of €3.65 weekly for accommodation, however choice of accommodation is greatly limited due to Eoin's needs.

Also, in relation to the holiday, the inclusion of a travel allowance for fuel (diesel) is included. In the household social inclusion budget without additional caring and disability needs it is assumed that the family use public transport when going on their holiday, however, given Eoin's needs, focus group participants agreed that public transport would not be suitable. The inclusion of an additional 21 litres of fuel is included in the budget, allowing for 200km for the trip to and from the holiday, and an additional week's worth of fuel for during the holiday. This adds an additional €0.32 on a weekly basis to the budget; this price also takes account for the Fuel Grant that the Kelly Family would receive through the Disabled Drivers and Disabled Passengers Scheme (discussed in the transport budget section.)

Focus groups agreed that the 'night out' allowance for the Kelly parents should remain the same as those included in the budget without additional caring and disability needs, however they did note that going out or socialising together, without their child, was something that they virtually never did. This is due to Eoin's need for full-time care and supervision, and the expense that comes with getting professional nurses/carers to care for Eoin if they were to go out for a few hours. The cost of this care is included and further discussed in the Caring Costs budget section.

9. Education

| MESL – no caring and disability | MESL – caring and disability | Difference |
|---------------------------------|--------------------------------|----------------------------------|
| Total €22.34 | Total €10.55 | Total - €11.78 |

The Kelly family's education budget amounted to €10.55 weekly, €11.78 less than the education budget for a two parent and adolescent child household without additional caring and disability needs.

Focus groups agreed that Eoin's education budget would differ considerably from that of an adolescent child without a profound intellectual disability who attends mainstream secondary school. Items such as school books, stationary and State exam fees were not included in Eoin's education budget, as agreed by the focus group participants. Eoin's education budget includes his uniform, with four tracksuit sets per year included due to Eoin's incontinence and changing needs. It also contains the cost of a school bag and lunch box, as well as a school contribution of €100 a year, which is a figure agreed on by the focus group participants.

10. Transport

| MESL – no caring and disability | MESL – caring and disability | Difference |
|---------------------------------|---------------------------------|----------------------------------|
| Total €70.63 | Total €144.18 | Total + €73.55 |

The Kelly family's transport budget amounted to €144.18 a week, which is an additional €73.55 when compared to the household's transport budget without additional caring and disability needs.

Focus group participants agreed that the Kelly family would require two cars, a wheelchair accessible car for Eoin and a standard car. Focus groups highlighted that the wheelchair accessible car would need to be permanently available to Eoin and his mother to allow for him to attend medical appointments, therapy sessions etc. The cost of public transport for Eoin's mother is not included in the budget as she is entitled to a Free Travel Pass. However, the focus groups noted that it would be unlikely given Eoin's needs, that the Kelly Family would not use public transport while with Eoin.

The additional cost of €73.55 a week comes from the inclusion of an adapted car and includes the cost of the car itself, NCT costs, maintenance and servicing costs, disability parking permit cost (€35 every two years) and the weekly cost of diesel.

This budget also takes into consideration deductions in line with the Disabled Drivers and Disabled Passengers Scheme that is provided by the State. As it is assumed the Kelly's 2018 car was adapted by a previous owner, they do not receive any VAT back on the cost of the car. However, they do qualify for the Fuel Grant which provides for a €0.495 rebate per litre up to 2730 litres a year, as well as Motor Tax exemption. These reductions offset the additional transport costs by €9.84 a week.

Focus groups agreed on the need for a second car for the Kelly family, with an accessible car required to meet Eoin's transport needs and a second vehicle to allow Eoin's dad to commute to work.

Focus groups therefore agreed that the car costs included in the budget of a household without additional care and disability needs should remain in the Kelly family's transport budget.

11. Household Energy

| MESL – no caring and disability | MESL – caring and disability | Difference |
|---------------------------------|------------------------------|------------|
| Total | Total | Total |
| €29.20 | €34.84 | + €5.63 |

The Kelly family's household energy budget amounted to €34.84 per week, €5.63 higher than the household energy budget of the other household, without additional caring and disability needs.

This additional cost is due to greater demands on the household's heating and electricity, arising from Eoin's disability.

With regards to household energy, focus groups agreed that the Kelly family would have the heating on for 12 hours a day during the winter and would allow for five hours of heating a week during the summer; this accounts for an additional €5.45 weekly on the household's heating expenditure. Focus groups stated that children who use a wheelchair often experience circulation problems and can become cold more quickly as they are not moving around as often as a child without a disability.

The Kelly family's weekly electricity expenditure was €8.26 higher than that of the comparable budget for the other household. This is caused by the additional use of electrical items, such as increased washing of clothes and blending of food, the use of a night light and extra showers for Eoin due to his incontinence. It was also caused by the use of extra electrical items, such as a tumble drier, a dishwasher, an audio-visual monitor, an additional TV for Eoin, charging of his tablet and use of his sensory light, as well as the charging of his wheelchair and hoist.

Costs of Care Arising from Disability

The addition to the Kelly family's electricity cost was offset by €8.08 weekly, due to their entitlement to the Household Benefits Package, as they receive Carer's Allowance. This package allows for a €35 deduction in electricity costs monthly.

12. Insurance

| MESL – no caring and disability | | MESL – caring and disability | | Difference | |
|---------------------------------|--------|------------------------------|--------|------------|---------|
| Total | €41.87 | Total | €48.32 | Total | + €6.45 |

The Kelly family's Insurance budget amounted to €48.31 per week, €6.45 higher than that of the insurance budget for a household without additional caring and disability needs.

The increase is due to the second car insurance policy needed for the Kelly family's wheelchair adapted car. However, the entitlement to a full Medical Card for Eoin and Carer's GP Visit Card for Eoin's mum, reduce the cost of the basic private health insurance included in the MESL basket. This offset a proportion of the additional car insurance cost.

13. Household Adaptations

| MESL – no caring and disability | | MESL – caring and disability | | Difference | |
|---------------------------------|-------|------------------------------|--------|------------|----------|
| Total | €0.00 | Total | €13.55 | Total | + €13.55 |

Household adaptations is a new budget area which focus groups agreed was necessary for the Kelly family. The Kelly family's household adaptations budget amounted to €13.55 a week.

This includes the cost of adapting the family home in order for it to be fully accessible and safe for Eoin. As stated in the case study, the Kelly family home is a bungalow, and is assumed to have been built subsequent to 2010, when building regulations stated that doors had to be wide enough to be accessed by wheelchairs.

The adaptation costs included in the budget are the building of a ramp at the front door, the building of a wet room that is accessible to Eoin, and the installation of a ceiling track hoist which goes between Eoin's bedroom and the wet room. Focus group participants agreed that at a minimum level, these are the adaptations that would need to be made to the house. Focus group members who had recently had these adaptation works completed in their own homes, or had recently obtained estimates of the costs of these adaptations, agreed on the figure of €43,000 as the total expenditure.

The net cost of the housing adaptations included in the MESL basket is comprised of:

- The gross cost of the adaptations
- Less the VAT refund of 13.5%

- Less the Housing Adaptation Grant (*eligibility and level payable based on a means test*)
- Plus the cost of a home improvement loan to meet the proportion outstanding.

The Housing Adaptation Grant pays up to 95% of the cost, to a maximum of €30,000. The final net cost of the works to the household ranges from €10,567 to €54,626, depending on the level of grant applicable²⁶. In the core basket discussed here, the net costs are based on the household qualifying for the maximum rate of the grant, that being €30,000.

14. Caring Costs

| MESL – no caring and disability | MESL – caring and disability | Difference |
|---------------------------------|------------------------------|------------|
| Total | €0.00 | Total |
| | | |
| Total | €61.80 | + €61.80 |

Caring costs is also a new budget area which focus groups agreed is necessary for the Kelly family. It includes the cost of six physiotherapy sessions a year for Eoin's full-time carer. Focus groups agreed that due to the physical toll that caring for a child with Eoin's needs takes on a carer's health, they would need at minimum one block of physiotherapy a year, which they stated generally consists of six sessions. This contributed €6.92 weekly to the caring costs budget.

The budget also allows for eight counselling sessions over a four-year period for Eoin's carer. Focus groups discussed the emotional toll that caring full-time for a child with Eoin's needs has on a carer's mental health, and that access to counselling is essential. The inclusion of counselling added €2.40 weekly onto the caring costs budget.

This budget also includes the expense of legal fees. Focus groups highlighted the importance of planning for the future when caring for a child with a profound intellectual disability. The budget allows for three one-hour meetings with a solicitor, at €250 per hour, in relation to the writing of wills, the establishment of trust funds, advice on the Assisted Decision-Making Capacity Act, power of attorney etc. These legal fees are included with a lifespan of four years as Eoin is 14 currently, according to the case study, and these legal matters would require to be addressed prior to Eoin turning 18 years old.

Respite care should be provided for free to a family caring for a child with a profound intellectual disability by the State. Family Carers Ireland campaign for a minimum of 20 days respite a year in order to offer family carers an adequate break from caring. Focus group participants made it very clear that it would be most unlikely that the Kelly family would receive even a small proportion of the number of respite care days that are seen as crucial for families to continue caring for their family member. In reality, for many in the focus groups respite was not available at all; to a small number, respite was available to a limited degree. All focus group participants were adamant that without access to adequate respite, families, like the Kelly family, are left mentally and physically exhausted and struggling to cope.

Because of this, the inclusion of six nights of over-night respite in the family home per year are included in the budget. Although six nights of at home respite is considerably less than the 20 days of public respite that Family Carers Ireland campaign for, it was agreed that six nights of private respite would be the minimum first step towards ensuring the provision of adequate respite services.

Eleven hours of overnight care from a Health Care Assistant amounts to €423.49, the total cost of six

²⁶ For further information on the Housing Adaptation Grant for People with a Disability, its various rates and the impact it would have depending on the income of the household, see Appendix 2.

nights private at home respite care contributes an additional €48.86 a week to the caring costs budget for a two-parent family caring for an adolescent child with a profound intellectual disability.

(ii.) Total Core MESL Cost per week:

| MESL Category | No Additional Disability or Caring Needs | Caring for a Child with a Profound Intellectual Disability | Difference |
|---------------------------------------|--|--|----------------|
| Transport | €70.63 | €144.18 | €73.55 |
| Caring Costs | €0.00 | €61.80 | €61.80 |
| Household Goods | €19.34 | €45.97 | €26.63 |
| Personal Care | €21.26 | €45.07 | €23.81 |
| Health | €15.31 | €34.78 | €19.47 |
| Clothing | €26.86 | €43.47 | €16.61 |
| Housing Adaptation | €0.00 | €13.55 | €13.55 |
| Social Inclusion & Participation | €86.27 | €95.75 | €9.47 |
| Insurance | €41.87 | €48.32 | €6.45 |
| Household Energy | €29.20 | €34.84 | €5.63 |
| Household Services | €6.06 | €8.56 | €2.50 |
| Food | €113.18 | €114.95 | €1.77 |
| Personal Costs ²⁷ | €9.13 | €9.13 | €0.00 |
| Savings & Contingencies ²⁸ | €21.36 | €21.36 | €0.00 |
| Communications | €25.74 | €20.23 | - €5.51 |
| Education | €22.34 | €10.55 | - €11.78 |
| Total | €508.54 | €752.49 | €243.95 |

The total core MESL cost for a two-parent household caring for an adolescent child with a profound intellectual disability amounts to €752.49 a week. This is an additional €243.95 when compared to a two-parent household with an adolescent child without additional caring and disability needs.

Of all core budget areas (included in all MESL household budgets) transport has the largest additional cost for the family caring for an adolescent child with a profound intellectual disability, with an additional €73.55 weekly.

²⁷ The Personal Costs budget for the Kelly family remained the same as that of a family without additional caring and disability needs. This budget area includes passport fees, banking fees and trade union fees.

²⁸ The Savings and Contingencies budget for the Kelly family also remained the same as that for a household without additional caring and disability needs. This budget includes a weekly savings allocation and the cost of Life Assurance.

Following this, the core budget areas of household goods (€26.63), personal care (€23.81), health (€19.47) and clothing (€16.61) all make a considerable contribution to the additional weekly MESL expenditure need of a two-parent household caring for an adolescent child with a profound intellectual disability.

The core budget areas of social inclusion (€9.47), insurance (€6.45), household energy (€5.63), household services (€2.50) and food (€1.77) contributed to a lesser extent to the additional weekly MESL expenditure cost of the family caring for a child with a profound intellectual disability.

The core budget areas of personal costs and savings and contingencies had no change, and the areas of education (-€11.78) and communications (-€5.51) saw a reduction in the weekly MESL expenditure cost for a two-parent household caring for a child with a profound intellectual disability.

The two new budget areas added to the MESL budget for a two-parent family caring for an adolescent child with a profound intellectual disability, housing adaptions (€13.55) and caring costs (€61.80), both considerably contributed to the additional weekly MESL expenditure need of this household, as they are expenses not incurred by the two-parent household without additional caring and disability needs.

(iii.) Discussion of Results

Contribution of State Supports

Because Eoin has a profound intellectual disability and his mother is his full-time carer, the family receive a number of State supports which help mitigate household expenditure.

These include:

- Eoin has a Medical Card and his mother receives a Carer's GP Visit Card, which offsets a proportion of the cost of the health, insurance and personal care budget.
- The Kelly family are entitled to the Disabled Drivers and Disabled Passengers Scheme, which offsets a proportion of the transport budget.
- Entitlement to the Household Benefits Package, which offsets a proportion of the household energy and social inclusion budget.
- Entitlement to the Household Adaptations Grant, offsetting a proportion of the household adaptations budget.
- Domiciliary Care Allowance also received which could be regarded as offsetting some of the therapy costs for Eoin.
- Eoin's mother receives Carer's Allowance and the annual Carer's Support Grant and is entitled to a Free Travel Pass.

Financial implications of inadequate access to essential services and supports

Paying Privately for Assessment of Need

The Ombudsman for Children in 2020 stated ‘Many parents of a child with a disability have been on a waiting list for years to access assessment of need for their child. Many have found that once their child is assessed they struggle to get all or any of the services recommended to help their child talk, move, learn, grow’.²⁹ Roddy makes a similar statement when she points out that policies from the 2005 Disability Act refer to the rights of children with a disability to have their needs assessed and based on that assessment to receive special health and publicly funded education services. She notes that due to the lack of service provision, children with disabilities do not necessarily receive these services, which can lead to parents paying for private services, which may result in financial hardship and debt.³⁰

The need for periodic updated assessments of progress is also recognised as necessary at educational and health service levels. While it is provided by some services it is not available to all children and at significant stages in their development and education, for this reason the cost of a multi-disciplinary assessment is included in the budget.

Provision of supports and services

When the Government launched the National Disability Strategy (NDS) in 2004, it was recognised that ‘there was a lack of uniformity in the provision of disability services nationally, inconsistent approaches developed between geographical locations, the type of service (statutory or non-statutory) and the type of disability’.³¹ This point was frequently reiterated 17 years later by members of the focus groups who participated in this study.

“We try to give our children a reasonable standard of life and to do this you have to fight every step of the way. Nothing comes easily. We are sent around in circles. All this fighting for what our child needs is draining on the carer. The supports are not just there and the system is always working against you.”

(FOCUS GROUP MEMBER)

The term ‘postcode lottery’ was frequently used in the course of the focus group sessions. While the majority of the family carers participating in the focus groups had very limited access to adequate services and supports, a small number were fortunate to have had a very positive experience in accessing supports. Nonetheless, as set out above, long waiting times and uncertainty led to consensus amongst focus group members that the costs of essential equipment, vital therapies and respite be included in the Kelly family’s budget.

“Some counties have very good services. People are lucky there. Why can’t there be good services in all counties?”

(FOCUS GROUP MEMBER)

²⁹ Ombudsman for Children (2020) “Unmet Needs – a report by the Ombudsman for Children’s Office on the challenges faced by children in Ireland who require an assessment of their needs.” available at: <https://www.oco.ie/library/ombudsman-for-children-launches-unmet-needs-a-report-on-the-challenges-faced-by-children-in-ireland-who-require-an-assessment-of-their-needs/> (Accessed December 2021)

³⁰ Roddy, A., (2021) “Income and conversion handicaps: estimating the impact of child chronic illness/disability on family income and the extra cost of child chronic illness/child disability in Ireland using a standard of living approach” The European Journal of Health Economics (2021) available at: <https://doi.org/10.1007/s10198-021-01371-4> (Accessed September 2021)

³¹ Ombudsman for Children (2020) “Unmet Needs – a report by the Ombudsman for Children’s Office on the challenges faced by children in Ireland who require an assessment of their needs.” available at: <https://www.oco.ie/library/ombudsman-for-children-launches-unmet-needs-a-report-on-the-challenges-faced-by-children-in-ireland-who-require-an-assessment-of-their-needs/> (Accessed December 2021)

Drivers of Household Budget Costs

A number of researchers examining the additional cost of disability have identified goods and services similar to those presented in the current study.³²

The more recent studies illustrate how the additional costs can arise from a wide variety of sources, some of which reflect advances in science, technology, health care, holistic care and education. The findings by Scope are consistent with the findings in this study with regards to the key areas of additional expenditure facing families with a disability and caring needs, namely transport, toys, clothing, energy, therapy and home adaptation costs.³³

(iv.) Other Hidden Costs of Caring

While acknowledging that the emphasis of the study is on the economic costs of caring, the focus groups were unanimous in requesting that consideration would be given to the hidden, often unquantifiable, costs of caring.

The focus group members had but one goal in life, to ensure that their child knew that he or she was loved and that their child received the necessary care. While their love and care were deep and unconditional, they were very aware of the different costs of caring which impacted on their lives and on those of the other members of the family.

The following are among the hidden costs many full-time family carers experience:

- The impact of caring on physical and mental health.
- Reduction in the standard and quality of living due to the loss of income when the carer is obliged to withdraw from full or part-time employment because of caring duties.
- The possibility of having to live with long-term debt and poverty.
- The experience of social isolation because of the difficulty in maintaining social contacts.
- The strain on family and marriage relationships.
- The constant anxiety about the future, which impacts on personal wellbeing and which can lead to depression.
- The stress of always having to fight for the rights and needs of the child with a profound intellectual disability, caused by inadequacy in the provision of services and equipment and the inequality in distribution across counties.
- The lack of understanding of the role of a full-time family carer, the failure to recognise its similarity with that of the carer employed in the health care system, and to fund accordingly.
- The life-changing consequences of being a full-time carer of a child with profound intellectual disability, which are sometimes referred to as opportunity costs.

"When a person becomes the carer of an elderly parent, they usually do so having had a different life, including a career. When a person learns that their child has a profound disability and they become their carer, their whole life changes and their hopes and dreams for their own career and future are shattered."

(FOCUS GROUP MEMBER)

³² These researchers include Berthoud, R. 1991, Dobson, B and Middleton, S. 1998, Smith, N et al. 2004, Hill, K et al. 2015 and 2017, and Scope, 2019 – all discussed within the full Literature Review in Appendix 1.

³³ Scope (2019) "The Disability Price tag 2019" available at: <https://www.scope.org.uk/campaigns/extra-costs/disability-price-tag/> (Accessed September 2021)

In relation to their own health and the need to keep well for the sake of their child, carers spoke of the difficulty in being able to make and keep doctor and dentist appointments. Many found it almost impossible to get a replacement carer for even a short time. The knowledge of the consequences of taking risks with one's health, regular back pain because of heavy lifting and frequent anxiety induced headaches all impact on personal wellbeing.

The consequences for the household's financial situation are acutely experienced when the second adult is no longer free to remain in paid employment. The responsibility of caring frequently leads to the complete withdrawal from employment or to a significant reduction in working hours, and to the impossibility of career advancement. The loss of the second salary usually leads to a major reduction in living standards. This decrease in the household's financial situation can have negative consequences for the education and development of other children in the family and is a source of considerable sorrow or guilt for parents.

"Siblings lose out because of the inadequate services. They suffer and have to do without. They have to compromise. They are young and they pay a mental and physical cost when the family is not supported."

(FOCUS GROUP MEMBER)

The demands of caring can make it difficult to maintain family and other relationships, to go out for an evening and socialise, all leading to the eventual feeling of being less a part of the community with the consequent sense of loneliness. The strain on marriage and family relationships caused by the never-ending demands of caring and the lack of opportunity to be 'off duty together' were apparent. It was noteworthy that approximately a third of focus group members had broken marriages.

Many family carers in the focus groups referenced to the constant battle they face each day and having to fight to ensure their child's needs were being met and their rights realised. This often leads to sleepless nights worrying about the future of their child as well as worrying about debt. Some focus group members described how their lives changed when they learned that their child had a profound intellectual disability. Their hopes for their career were no longer relevant, their lives narrowed and they began a life of fighting on behalf of their child.

"While the costs of raising a child with a disability today is significantly higher for families as the research clearly shows evidence of, let's also remember it does not just include financial costs and the results of the financial implications on the family. It also includes many more equally significant costs. The costs of health and well-being on each of the family members, the costs of the family's integrity, dignity, respect and sense of belonging in their community. The social and emotional costs, psychological and mental well-being costs are equally higher for families with children with disabilities. My son is now almost 20 years old and as a highly qualified successful health professional I incur many personal costs including my place in the community, my personal identity upon giving up my successful career because of the needs of my child. Following this we start to question who we are and have many unanswered questions. We, as carers, have rights just like our family members that we care for, and it's about our inclusivity in the community and our rights to equality and equal opportunities. Life as a family carer can be a very isolating trajectory and it is in the best interest of all members of our local communities to ensure that the costs we as carers incur at more than just a financial level are addressed and good support is provided. Community matters. We matter too."

(FOCUS GROUP MEMBER)

Lone Parent Households

The situation was more acute for lone parent households who could be confined to the house for days because there was no one to replace them when their child could not attend school or was ill. Many experienced being forgotten by their neighbours and no longer a part of the community. Feeling trapped was a familiar occurrence when there was no other adult with whom to communicate, to share concerns and decision making, to find support and companionship, to free them to do the shopping, or to take time with friends. They experience all of the hidden costs experienced by two parent families, but without the support of another adult family member and usually with greater financial restrictions. Feeling guilty about the possibility that other children in the household could feel neglected when priority was frequently given to the child with a disability, and finally, the need to be always on the defensive and always fighting for their child's entitlements, take a toll on wellbeing.

The current study has focused on the expenditure and income needs of the two-parent household. However, the contributions of the members of the focus groups underlined the need to research the expenditure and income needs of the one parent household where the income associated with the single adult is the basis of the family income. The more limited income aggravated the impact of the hidden costs.

Members of the focus groups saw the alleviation of these hidden costs to comprise of a more adequate provision of accessible services, increased income supports and recognition of their role as family carers as equivalent to that of their counterparts in the public service, with the associated renumeration based on employment instead of a social welfare payment.

5 Benchmarking Income Adequacy

Establishing the cost of a Minimum Essential Standard of Living (MESL) for a household undertaking family caring for a child with a profound intellectual disability, provides an evidence-based benchmark against which to measure the adequacy of available income supports for this household type.

In this section, the range of applicable income supports are examined, the structure and tapering of supports is assessed, and the minimum gross salary required to enable a household to afford their MESL requirements is identified. In addition to the supports available to all households with children (e.g. Child Benefit), the further direct income supports relevant to this household type are:

| | | |
|-----------------------------------|-----------------------------|---|
| Carer's Allowance | Means tested & taxable | Rate payable tapers with household income |
| Domiciliary Care Allowance | Not means tested or taxable | Standard monthly payment |
| Carer's Support Grant | Not means tested or taxable | Standard annual payment |

In addition to the above direct income supports, the Incapacitated Child Tax Credit also applies. Furthermore, as discussed above, secondary benefits which reduce the potential cost of household needs are reflected in the net MESL cost for the household. For example, final home energy costs include the contribution from the Household Benefits Package, and health costs take account of Medical Card or GP Visit Card as applicable.³⁴

The discussion below presents an analysis of the MESL expenditure need and total household income at a range of salary levels, examining earnings from full-time National Minimum Wage employment up to an annual gross salary of €75,000.

The income calculations for the household with a family carer and adolescent child with a profound intellectual disability are based on one adult in full-time employment and one adult a full-time family carer. Net household income is presented for each increment in gross salary, comprised of net salary and applicable social welfare payments.

The net salary (after PAYE, PRSI and USC) is calculated, taking account of the additional PAYE arising from taxable social welfare payments (Carer's Allowance) and relevant tax credits (including the Incapacitated Child Tax Credit). At each income level the rate of Carer's Allowance payable is calculated, and the average weekly value of the Domiciliary Care Allowance and Carer's Support Grant are also included. The average weekly value of the Christmas Bonus is also included, where eligible long-term social welfare supports form part of the household income.

For comparison purposes, the position of a household of the same composition (but without additional caring and disability needs) is also presented. In this case the net income is calculated on the basis of one adult engaged in full-time employment and one in half-time employment, i.e. the household's combined gross salary is one and a half full-time salaries.

MESL Expenditure Need by Salary Level

The salary level of a household influences the net MESL expenditure need of the household, this is due to changing eligibility to means tested supports which can reduce living costs and the net MESL expenditure requirements of a household.

Medical Card

At lower income levels the household can be entitled to a means tested Medical Card (and at slightly higher levels a GP Visit Card), this has the effect of reducing health related costs. In the case of a household with a family carer and adolescent child with a profound intellectual disability, the recipient of the Carer's Allowance is entitled to a non-means tested GP Visit Card, and the child is entitled to a non-means tested Medical Card. In this context, means based household eligibility for a Medical Card will reduce the health-related costs for both adults in the household, while means based eligibility for a GP Visit Card will have a lesser impact reducing costs for the adult in employment only.

For the household scenario examined here the Medical Card reduces the net MESL expenditure by an average of €32.60 per week (the means tested GP Visit Card reduces net MESL expenditure by €1.14).

Household Benefits Package

The Household Benefits Package (HBP) provides a credit towards home energy costs (€35.00 per month) and a Television Licence (€160 per year) to the household³⁵. In the context of the household situation examined in this report, receipt of the HBP is contingent on being eligible for the Carer's Allowance.

The HPB reduces the net MESL expenditure by an average of €11.15 per week.

Housing Adaptation Grant

The Housing Adaptation Grant is a means tested support which contributes up to 95% (to a maximum of €30,000) of the cost of adaptations required to make the home suitable for a person

³⁴ Where the various social transfers, supports, and secondary benefits are referenced throughout this report, the 2022 rates are applied. This includes social welfare rates of payment, national minimum wage, personal taxation, and the eligibility thresholds and earnings disregards included in the means tests of any supports under consideration, based on the information available at the time of compilation in January 2022.

³⁵ See sections 8 and 11 under 'Household Budget Areas'.

with a disability. The level of grant payable is tiered, reducing over five tranches in line with assessable household income.

At the maximum level the grant contributes an average of €56.49 per week, reducing the net adaptation costs to an average of €13.55, when there is no entitlement to the grant the net adaptation cost in the MESL basket is €70.33.³⁶

Range of Net MESL Expenditure Need

A two parent household with a full-time family carer and adolescent child with a profound intellectual disability, adjusted for secondary benefits (as detailed above) and based on living in an urban area (but requiring private transport), with a housing cost (mortgage) of €955 per month, will have an average weekly net MESL expenditure need of €940 to €1,040.

Table 1: MESL Expenditure, per week, by annual gross salary³⁷

| MESL | €20,475 | €30,000 | €35,000 | €40,000 | €45,000 | €50,000 | €55,000 | €60,000 | €65,000 | €70,000 | €75,000 |
|------------------------------------|---------|---------|---------|---------|---------|---------|-----------|-----------|-----------|-----------|-----------|
| Caring & Disability | €940.28 | €940.28 | €971.74 | €971.74 | €981.15 | €987.00 | €1,001.12 | €1,001.12 | €1,012.42 | €1,023.57 | €1,040.52 |
| No Additional Caring or Disability | €726.09 | €732.93 | €732.93 | €732.93 | €732.93 | €732.93 | €732.93 | €732.93 | €732.93 | €732.93 | €732.93 |
| Additional Costs | €214.19 | €207.35 | €238.81 | €238.81 | €248.22 | €254.07 | €268.19 | €268.19 | €279.49 | €290.64 | €307.59 |

The net MESL expenditure need changes at key gross salary points³⁸ due to changes in entitlement to secondary benefits which reduce potential MESL costs.

- At a gross salary level equivalent to full-time national minimum wage (NMW) employment through to an annual gross salary of €30,000, the MESL costs are at the lowest. At this level the household is eligible for the full suite of direct and indirect supports, including a means tested Medical Card and the maximum rate of Housing Adaptation Grant.
- When gross salary exceeds €30,000 the household is not eligible for a means tested Medical Card. While a GP Visit Card is retained for both adults (and the non-means tested Medical Card for a child with a profound disability), health related expenditure needs for the household increase. The adult in paid employment is not eligible for a means-tested GP Visit Card when the gross salary reaches €46,000.
- The Housing Adaptation Grant is paid at five levels. For the household type examined the level payable reduces to the second tier when gross salary exceeds €40,000, with an associated increase in net MESL expenditure need.

³⁶ For further detail of the Household Adaptation costs see section 13 under 'Household Budget Areas' and for the calculation of the net cost see Appendix 2 Net Cost of Housing Adaptation

³⁷ In the labelling of graphs and tables in this section, full-time gross salary bands are utilised, it should be noted that in the dual income scenario examined (when there are no additional caring and disability needs) the gross salary earned in the household will be 1.5 times the salary band label.

³⁸ These salary points are specific to the scenario examined and would vary with the composition of the household (e.g. number of children in the household) and scenario examined (e.g. housing cost).

Costs of Care Arising from Disability

- The level of Housing Adaptation Grant subsequently reduces at gross salary levels in excess of €45,000, €50,000 and €60,000. Finally, a gross salary of over €70,000 will exceed the eligibility threshold for the Housing Adaptation Grant.
- A gross annual salary of €67,000 exceeds the means test limit for the Carer's Allowance. Eligibility for the HBP is linked to receipt of the Carer's Allowance, therefore at this salary level the net MESL expenditure need is €11.15 per week higher due to not qualifying for the HBP.

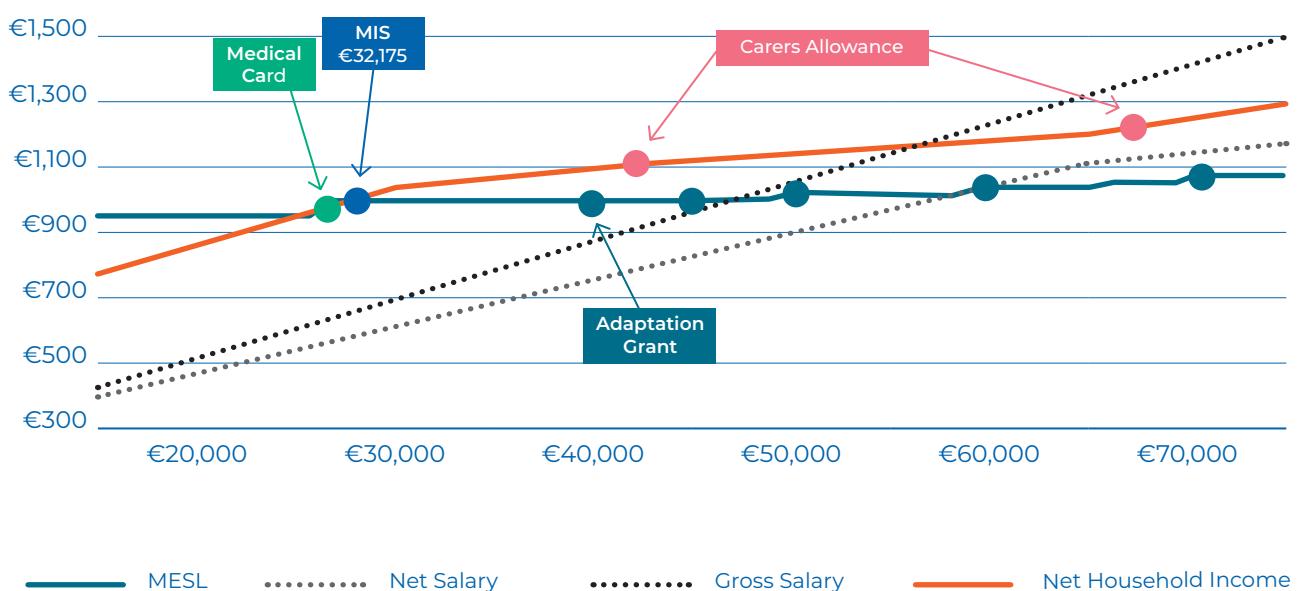
The net MESL expenditure need of a household of the same composition, where the child does not have a disability and there are no additional caring needs, are also presented above. The 'Additional Costs' required to enable a socially acceptable MESL for a household caring for a child with a profound intellectual disability are then identified. The additional costs range from €207 to €308 per week.

Income Adequacy

Benchmarking the adequacy of net household income³⁹, from the combination of salary and social welfare supports, against net MESL expenditure need (including the effect of secondary benefits reducing potential MESL costs), shows that full-time minimum wage employment does not provide the basis of an adequate income. In full-time minimum wage employment:

- Net household income is an average of €772 per week;
 - comprised of a net salary of €379 per week and
 - social welfare supports of €393 per week
- Net MESL expenditure need is €940 per week;
- Net household income falls €168 short of net MESL expenditure need per week.

Graph 1: Benchmarking adequacy of net household income € per week MESL expenditure & net income, by gross annual salary



³⁹ A detailed breakdown of net household income at each salary point is provided in Appendix 3 MESL Expenditure & Net Household Income Tables.

Graph 1 illustrates the assessment of income adequacy, charting the net MESL expenditure need and net household income by the level of gross salary. Income inadequacy is shown where net household income is below net MESL expenditure need, the left portion of the graph. The deep inadequacy of net household income when in full-time minimum wage employment is evident, with net household income providing for only 82% of MESL needs. At each subsequent higher gross salary point examined the depth of inadequacy decreases, with a gross annual salary of €25,000 providing the basis of a net household income which meets 90% of net MESL expenditure need.

Minimum Income Standard

For a two parent household with a full-time family carer and adolescent child with a profound intellectual disability, in the scenario examined, an annual gross salary of €32,175 is required to provide the basis of a net household income which will adequately meet the cost of the household's net MESL expenditure needs. This represents the household's Minimum Income Standard (MIS), at this salary level the household:

- Qualifies for the highest rate of Housing Adaptation Grant
- Is eligible for a means-tested GP Visit Card for the employed adult, in addition to the carers GP Visit Card and child's Medical Card
- Receives the Household Benefits Package
- Is below the threshold for PAYE income tax liability
- Retains eligibility for the full rate of Carer's Allowance.

Table 2: Net MESL Expenditure & Net Household Income, by gross annual salary band

| | €20,475 | €30,000 | €35,000 | €40,000 | €45,000 | €50,000 | €55,000 | €60,000 | €65,000 | €70,000 | €75,000 |
|----------------|-------------------------|-----------------------|--------------------|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|
| Net MESL Exp | €940.28 | €940.28 | €971.74 | €971.74 | €981.15 | €987.00 | €1,001.12 | €1,001.12 | €1,012.42 | €1,023.57 | €1,040.52 |
| Net Salary | €378.63 | €545.77 | €629.57 | €679.12 | €736.64 | €805.16 | €872.68 | €941.20 | €1,008.71 | €1,075.43 | €1,121.62 |
| Social Welfare | €393.45 | €393.45 | €393.45 | €393.45 | €373.07 | €324.65 | €278.79 | €230.37 | €184.51 | €140.68 | €140.68 |
| Net Income | €772.08 | €939.22 | €1,023.02 | €1,072.57 | €1,109.70 | €1,129.81 | €1,151.46 | €1,171.57 | €1,193.22 | €1,216.11 | €1,262.30 |
| Adequacy | Inadequate - €168.19 | Inadequate - €1.05 | Adequate €51.28 | Adequate €100.83 | Adequate €128.55 | Adequate €142.81 | Adequate €150.34 | Adequate €170.45 | Adequate €180.81 | Adequate €192.55 | Adequate €221.78 |
| METR | ... | 6% | 46% | 48% | 71% | 85% | 92% | 79% | 89% | 88% | 70% |

Income Progression

The marginal effective tax rate (METR) is a measure of the level of taxation and withdrawal of benefits & supports associated with a given increase in gross salary. For example, comparing the net household incomes when earning €25,000 to €30,000, shows a METR of 6%; i.e. while gross salary increases by €5,000, net household income increases by €4,700 per annum due to the tax payable on the additional salary. At higher income levels, the METR can be greater due to both the tapering of direct income supports (Carer's Allowance) and reduction in indirect supports (e.g. Housing Adaptation Grant).

The points where changes to entitlements to supports impacts net MESL expenditure need and net household income are also highlighted in Graph 1.

- PAYE income tax is payable on salary earnings and Carer's Allowance, the liability comes into effect from a gross annual salary of €36,000 and upwards.
- The Carer's Allowance is payable at the full rate until an annual gross salary of €43,000 is reached. From this point the rate payable is tapered, the section highlighted in the graph above.
- A partial Carer's Allowance payment is retained until the annual gross salary exceeds €66,710.
- When gross salary exceeds €30,000 the household is not eligible for a means tested Medical Card.
- The points where support from the Housing Adaptation Grant reduces are also indicated.

Combined tapering of Carer's Allowance and reduced eligibility for Housing Adaptation Grant can result in significant METR on changes in gross salary. Examining the effect of €5,000

increments in gross annual salary, reveals an METR of at least 70% (rising to 92% in one instance) on salary changes from €40,000 to €70,000, as summarised in Table 2.

Effectiveness of Social Welfare Income Supports

The social welfare component of net household income is primarily comprised of three supports targeted to those with additional needs due to disability and providing care, these are Carer's Allowance, Domiciliary Care Allowance and Carer's Support Grant. Child Benefit, a universal social welfare payment, also contributes to the net household income.

In the context of the household type examined here, direct social welfare income supports provide up to €393.45 per week (on average). This maximum level of direct income support is retained until the point where the Carer's Allowance taper comes into effect, a gross salary above €43,000 per annum. The total contribution of direct social welfare income supports progressively tapers as gross salary increases, tapering to €140.68 when gross salary exceeds the means test for Carer's Allowance (in this case a gross salary above €66,710 per annum).

This level of income support is notable, particularly at salaries below €43,000. The direct income support at these lower salary levels also exceeds the additional MESL expenditure costs identified as arising from the additional caring and disability related needs of the household. Nevertheless, net household income is deeply inadequate with a gross salary below €25,000 per annum and remains inadequate until a gross salary of €32,175 is reached.

This demonstrates that the maximum level of direct income supports cannot

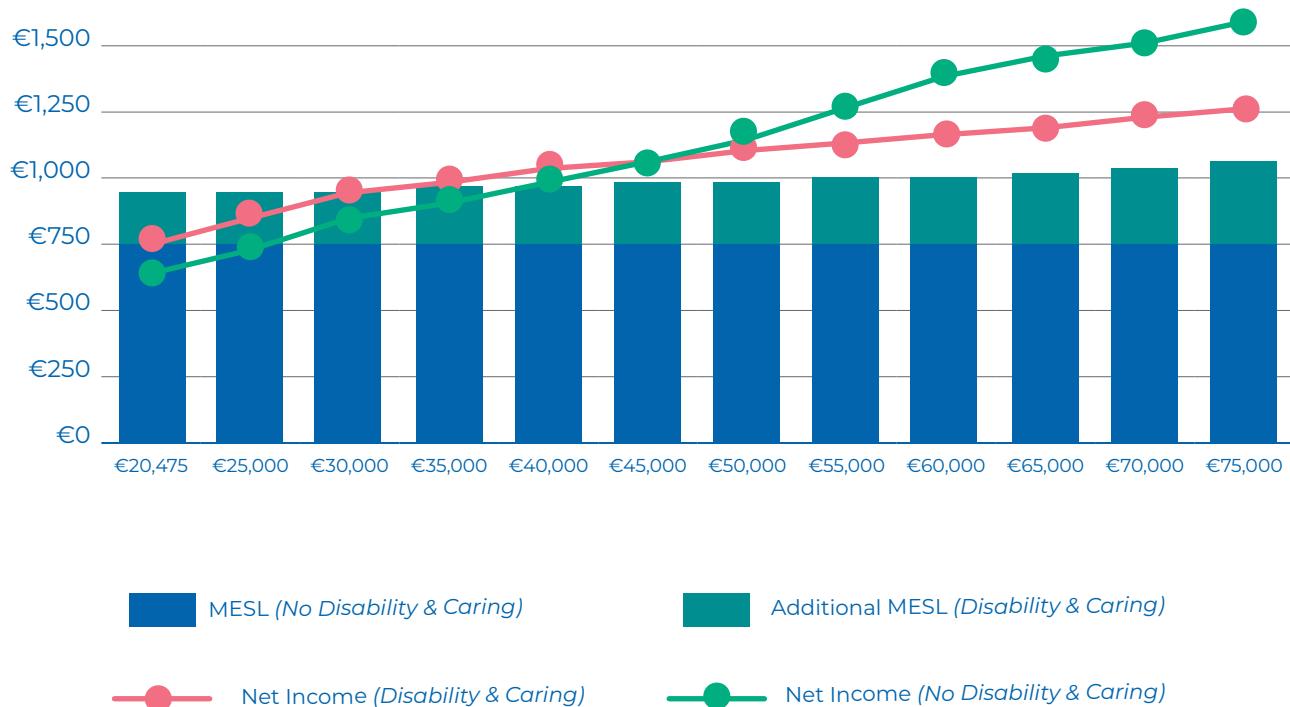
adequately address both low pay⁴⁰ and the additional needs arising from caring and disability, to enable an adequate income at lower salary levels.

Comparison

A comparison of the position of a household with a full-time family carer and adolescent child with a profound intellectual disability, with that of a household of the same composition but without additional caring and disability needs, is informative. Graph 2 illustrates the net MESL expenditure need for a two parent household with an adolescent child, and the additional caring and disability related net MESL expenditure are highlighted⁴¹. The net MESL expenditure need is benchmarked against net household income at each level. The net household income is calculated on the basis of the scenarios stated at the start of this section. In both cases a two parent household with an adolescent child is examined, with the same assumptions regarding location and housing costs.

For the household without additional caring and disability related needs, minimum wage employment does not provide the basis of an adequate income, as is the case for the household with caring and disability needs. This is despite a dual earning scenario based on 1.5 salaries, as opposed to a single earning scenario. Net household income is also deeply inadequate, meeting 84% of net MESL expenditure need.

Graph 2: Comparison of MESL Expenditure Need and Net Household Income, € per week MESL expenditure & net income, by gross annual salary.



⁴⁰ Low pay is defined as earning below two-thirds of median earnings. Median full-time earnings are €40,074 (Eurostat, 2021), giving a low pay threshold of €26,450.

⁴¹ In the labelling of graphs and tables, full-time gross salary bands are utilised, it should be noted that in the dual income scenario examined (no additional caring and disability needs) the gross salary earned in the household will be 1.5 times the salary band label. For example, in the €40,000 column, the combined gross salary of the earners is €60,000.

Costs of Care Arising from Disability

While minimum wage employment results in a deeply inadequate income in both cases, it is notable that the depth of inadequacy is more severe for the household with caring and disability related needs. Despite a notably higher net household income, due to direct social welfare income supports, the inadequacy is €50 per week deeper than that faced by the household without additional caring and disability needs.

- A household with a full-time family carer and adolescent child with a profound intellectual disability, requires a gross salary of at least €32,175 per annum. At this MIS salary point the household will have a minimally adequate income, meeting the net MESL expenditure need.
- The MIS salary point for the household without additional caring and disability needs, is notably lower. An adequate net household income would be achieved at 1.5 full-time salaries at the level of €25,740.

Table 3: Comparison of MESL Expenditure Need and Net Household Income, € per week MESL expenditure & net income, by gross annual salary.

DISABILITY & CARING

| | €20,475 | €25,000 | €30,000 | €35,000 | €40,000 | €45,000 | €50,000 | €55,000 | €60,000 | €65,000 | €70,000 | €75,000 |
|-----------------|------------|------------|------------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|
| Net MESL Exp | €940.28 | €940.28 | €940.28 | €971.74 | €971.74 | €981.15 | €987.00 | €1,001.12 | €1,001.12 | €1,012.42 | €1,023.57 | €1,040.52 |
| Net Income | €772.08 | €848.84 | €939.22 | €1,023.02 | €1,072.57 | €1,109.70 | €1,129.81 | €1,151.46 | €1,171.57 | €1,193.22 | €1,216.11 | €1,262.30 |
| Income Adequacy | Inadequate | Inadequate | Inadequate | Adequate |
| Income MESL | - €168.19 | - €91.44 | - €1.05 | €51.28 | €100.83 | €128.55 | €142.81 | €150.34 | €170.45 | €180.81 | €192.55 | €221.78 |

NO DISABILITY & CARING

| | €20,475 | €25,000 | €30,000 | €35,000 | €40,000 | €45,000 | €50,000 | €55,000 | €60,000 | €65,000 | €70,000 | €75,000 |
|-----------------|------------|------------|----------|----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|
| Net MESL Exp | €726.09 | €726.09 | €732.93 | €732.93 | €732.93 | €732.93 | €732.93 | €732.93 | €732.93 | €732.93 | €732.93 | €732.93 |
| Net Income | €607.81 | €712.84 | €817.74 | €923.99 | €1,021.42 | €1,118.61 | €1,216.35 | €1,290.63 | €1,364.91 | €1,439.18 | €1,513.46 | €1,584.41 |
| Income Adequacy | Inadequate | Inadequate | Adequate | Adequate | Adequate | Adequate | Adequate | Adequate | Adequate | Adequate | Adequate | Adequate |
| Income MESL | - €118.27 | - €13.25 | €84.82 | €191.07 | €288.49 | €385.68 | €483.42 | €557.70 | €631.98 | €706.26 | €780.53 | €851.48 |

The net household income to the household with caring and disability needs, from one full-time salary and direct social welfare income supports, is higher than the net household income to a household without additional caring and disability needs in a dual income (1.5 full-time salaries) scenario, for gross salaries up to €40,000 per annum. Despite this, the overall position of the household with disability and caring needs is worse at each level examined.

For the household with disability and caring needs, income inadequacy persists until a higher salary level is reached. Furthermore, the degree of discretionary income which remains available after the MESL needs are met, is significantly lower for the household with additional caring and disability needs. This becomes particularly evident at salary levels of €45,000 and above. At this point the dual income scenario examined provides a higher net household income, than the combination of a single salary and direct social welfare income supports. The net income differential grows as the Carer's Allowance continues to taper and is compounded as the withdrawal of indirect supports increases the net MESL expenditure need of the household with additional caring and disability needs.

This differential is indicative of the opportunity cost of one of the parents taking on the full-time family carer role and forgoing the potential of paid employment. Furthermore, it demonstrates that while the social welfare supports provided may meet the additional MESL costs of caring & disability (in the context examined), the supports do not adequately address the opportunity cost of lost earnings potential. This is all the more acute at salary levels of €55,000 and above, as the tapered supports no longer meet the additional net MESL expenditure needs arising from caring and disability.

6 Conclusions

1. The cost of a MESL for a two-parent household caring for an adolescent child who has a profound intellectual disability is significantly higher than that for the household without additional caring responsibilities and disability.
2. Based on this study, the case study, and the associated assumptions, the weekly core MESL for a two-parent household, caring for an adolescent child with a profound intellectual disability is €752 a week. This is €244 higher than the MESL for a two-parent household with an adolescent child without additional caring and disability needs.

3. When this additional expenditure need is considered in relation to the household having a gross income of €30,000 a year, the annual additional expenditure need for the household caring for an adolescent child with a profound intellectual disability amounts to €10,782.⁴²
4. The additional cost of caring arises from needs for goods and services specific to the disability. This report finds that the household budget areas with the largest additional disability related costs are; Transport, Caring Costs, Household Goods, Personal Care, Health, Clothing and Household Adaptations.
5. Notable levels of income support are available to households providing care to a child with a profound intellectual disability, relative to the social welfare provision to other groups. For the household type examined here, the full rate of Carer's Allowance, Domiciliary Care Allowance and the Carer's Support Grant, provides up to €361 per week in direct income supports.

Despite these relatively high social welfare rates the analysis finds that a minimum annual gross salary of €32,175 is required to provide the basis of a net household income which will meet the MESL expenditure needs of a household with a full-time family carer and adolescent child with a profound intellectual disability.

6. The maximum level of direct income support also exceeds the additional net MESL expenditure costs identified as arising from the caring and disability related needs of the household. However, net household income is deeply inadequate with a gross salary below €25,000 per annum and remains inadequate until a gross salary of €32,175 is reached.

The maximum level of direct income supports cannot adequately address both low pay and the additional needs arising from caring and disability, to enable an adequate income at lower salary levels.

7. Indirect supports can play a significant role in reducing the potential MESL expenditure needs of the household type examined. A means-tested Medical Card reduces the net MESL

⁴² The additional MESL cost increases with gross salary, primarily due to the tapering of the Housing Adaptation Grant. The additional MESL need reaches a maximum of €15,590 per annum, when the household is not eligible for the adaptation grant.

expenditure by an average of €32.60 per week. Receipt of the Household Benefits Package (which is contingent on qualifying for Carer's Allowance) reduces the net MESL expenditure by an average of €11.15 per week. The Housing Adaptation Grant is a means tested and tiered support, at the maximum tier it contributes an average of €56.49 per week, reducing the net adaptation costs to an average of €13.55.

Combined these three supports reduced potential MESL expenditure need by up to €100 per week.

8. In addition to the direct costs arising from caring and disability needs, as identified in this research, undertaking a full-time family caring role also presents an opportunity cost in the form of forgoing the potential for paid employment. The analysis presented here finds that, when compared to a household without caring and disability needs, the household caring for a child with a profound intellectual disability faces a greater depth of income inadequacy at low incomes, and the persistence of inadequacy to a higher income point.

This demonstrates that while social welfare supports may meet the additional MESL costs associated with caring and disability, the supports do not adequately address the opportunity cost of lost earnings potential.

9. The inequality and inadequacy in the provision of services and supports to households caring for a member with a disability impacts on the expenditure patterns of these households. The term "postcode lottery" is frequently used to describe the adequacy and accessibility of services across the country. These services are recognised as essential in ensuring the rights, development, quality of life and wellbeing of children with a profound intellectual disability. Aware of the regression and harm caused by delay in accessing these services, many parents believe they have no alternative but to meet the relevant costs themselves. The consequences for the majority of those who do so include a lower standard of living for all the family, long term loans and the possibility of living with

debt. Other consequences include relying on charitable organisations or fundraising to access these services and supports. There is a long standing and urgent need to address at national level the current situation of inequality in access to adequate services and equipment.

Many parents experience the huge emotional costs of having to fight every step of the way to access the services and supports to which their child is entitled. The current situation of inequality and inadequacy in the access of supports and services constitutes a principle source of stress and anxiety for parents of children with intellectual disability.

10. Although the emphasis of this report is on the economic costs of caring, it is necessary to also acknowledge the hidden, often unquantifiable, costs experienced by parent's caring for a child with a profound intellectual disability. These include the impact on physical and mental health, the loss of income caused by inability to work because of caring duties, the potential of living in debt or poverty, social isolation, strain on relationships, the constant stress of "always having to fight," because of inadequacy in the provision of services and supports, to which their child is entitled.
11. The role of the family carer needs to be more clearly understood, recognised and supported through greater awareness of the nature of its demands, which for many carers means around the clock presence. Recognition is also needed of the similarity between the role and service of the carer in the family setting and those of the carer employed in the health service. The former receives a social welfare payment, and the later receives a salary.
12. The current study has focused on the expenditure and income needs of the two-parent household. However, the contributions of the members of the focus groups underlined the need to research the expenditure and income needs of the one parent household, in which the income associated with the single adult is the basis of the family income.

13. As Hill, K. et al states “studies of the additional cost of disability will never capture every case, and this is not their intention. Rather, they have set out to create greater understanding of where costs tend to be the greatest, and how this can vary as people’s circumstances change.”⁴³ Indecon concurs that a base standard income for all individuals with a disability is unlikely to address costs incurred by those most severely limited by disability.⁴⁴

This study establishes the cost of a minimum socially acceptable standard of living, a MESL, for households caring for an adolescent child with a profound intellectual disability, grounded in the lived experience of such households. It, thereby, provides an important indicator of the costs required in order to meet the physical, psychological and social needs of individuals with different levels of intellectual disability, different forms of disability, and their carers’.

⁴³HILL, K. ... et al, (2017) “Sight loss and Minimum Income Standards: the additional costs of severity and age.” Loughborough: Centre for Research in Social Policy, Loughborough University. Available at: https://repository.lboro.ac.uk/articles/report/Sight_loss_and_Minimum_Income_Standards_the_additional_costs_of_severity_and_age/9471134 (Accessed September 2021)

⁴⁴Indecon (2021) “The Cost of Disability in Ireland” Available at: <https://www.gov.ie/en/publication/1d84e-the-cost-of-disability-in-ireland-research-report/> (Accessed December 2021)

BIBLIOGRAPHY

- Berthoud, R. (1991). Meeting the costs of disability. In G. Dalley (Ed.), *Disability and social policy*. London: Policy Studies Institute. Available at: <https://www.guerillapolicy.org/publications/archivepdfs/Disability%20and%20social/BERTHOUD.pdf> (Accessed September 2021)
- Boat, TF, Wu JT. (2015) "Committee to Evaluate the Supplemental Security Income Disability Program for Children with Mental Disorders." Institute of Medicine; Division of Behavioural and Social Sciences and Education; The National Academies of Sciences, Engineering, and Medicine. Washington (DC): National Academies Press (US) Available at: <https://www.ncbi.nlm.nih.gov/books/NBK332877/> (Accessed September 2021)
- CSO (2016) "Income in Ireland" available at: <https://www.cso.ie/en/releasesandpublications/ep/p-gpii/geographicalprofilesofincomeinireland2016/incomeinireland/> accessed October 2021
- CSO (2019) "EU Survey on Income and Living Conditions 2019" available at: <https://www.cso.ie/en/releasesandpublications/ep/p-silc/surveyonincomeandlivingconditionssilc2019/povertyanddeprivation/> accessed October 2021
- Cullinan, J., Gannon, B. Lyons, S. (2011) "Estimating the extra cost of living for people with disabilities." *Health Economics*, 20 (5), pp. 582-599. Available at: (Accessed September 2021) https://aran.library.nuigalway.ie/bitstream/handle/10379/942/paper_0134.pdf?sequence=1&isAllowed=y (Accessed September 2021)
- Department of Health (2012). National Carers' Strategy – Recognised, Supported, Empowered. Department of Health, Dublin.
- Department of Social Protections (2019) "National Carers' Strategy" available at: <https://www.gov.ie/en/publication/a1e44e-national-carers-strategy/> accessed October 2021
- Dobson, B. and Middleton, S. (1998) Paying to care: The cost of childhood disability York: Joseph Rowntree Foundation (748). Available at: <https://www.jrf.org.uk/report/paying-care-cost-childhood-disability> (Accessed September 2021)
- Enable Ireland () "Learning Disability – Information for Parents" available at: <https://www.enableireland.ie/sites/default/files/publication/Learning%20Disability-R4%20final%20NE.pdf> (Accessed September 2021)
- EU Pillar of Social Rights (2015) available online: https://ec.europa.eu/info/strategy/priorities-2019-2024/economy-works-people/jobs-growth-and-investment/european-pillar-social-rights/european-pillar-social-rights-20-principles_en accessed January 2022
- Eurofound (2016) European Quality of Life Survey 2016, https://www.eurofound.europa.eu/sites/default/files/ef_publication/field_ef_document/ef1733en.pdf 6 Ibid.
- Eurostat (2021) Structure of earnings survey: annual earnings. Online database (accessed 14/12/2021): https://ec.europa.eu/eurostat/databrowser/view/EARN_SES_ANNUAL/default/table?lang=en

- Family Carers Ireland (2020) "State of Caring Survey" available at: <https://familycarers.ie/media/2022/family-carers-ireland-state-of-caring-2020.pdf> accessed October 2021
- Family Carers Ireland (2021) "Who We Are" (website) available at: <https://familycarers.ie/about-us/who-we-are> accessed October 2021
- Hill, K., Davis, A., Hirsch, D., Padley, M., Smith, N. (2015) "Disability and Minimum Living Standards: The additional costs of living for people who are sight impaired and people who are Deaf" Loughborough: Centre for Research in Social Policy, Loughborough University
- HILL, K. ... et al, (2017) "Sight loss and Minimum Income Standards: the additional costs of severity and age." Loughborough: Centre for Research in Social Policy, Loughborough University. Available at: https://repository.lboro.ac.uk/articles/report/Sight_loss_and_Minimum_Income_Standards_the_additional_costs_of_severity_and_age/9471134 (Accessed September 2021)
- HSE (2021) "MHID - National Model of Service" Available: <https://www.hse.ie/eng/services/publications/mentalhealth/hse-national-mhid-model-of-service-january-2021.pdf> (accessed February 2022)
- Indecon (2004) "The Cost of Disability" Available at: <http://nda.ie/File-upload/Indecon-Report-on-the-Cost-of-Disability.pdf> (Accessed September 2021)
- Indecon (2021) "The Cost of Disability in Ireland" Available at: <https://www.gov.ie/en/publication/1d84e-the-cost-of-disability-in-ireland-research-report/> (Accessed December 2021)
- Loughborough University (2021) "Our Students – Chloe Blackwell" available at: <https://www.lboro.ac.uk/subjects/social-policy-studies/students/chloe-blackwell/> (Accessed September 2021)
- MacMahon, B., Moloney N. (2017) "A minimum essential standard of living for a single adult with vision impairment" Available at: https://www.budgeting.ie/download/pdf/full_report_vpsj_ncbi_2017_a_mesl_for_a_single_adult_with_vision_impairment.pdf (Accessed September 2021)
- Middleton, S. (2000) "Agreeing Poverty Lines: The Diversity of Consensual Budget Standards Methodology" in Bradshaw, J. and Sainsbury, R. (eds) Researching Poverty. Aldershot
- Mitra, S., Palmer, M., Kim, H., Mont, D. and Groce, N. (2017) "Extra costs of living with a disability: A review and agenda for research." Disability and Health Journal 10 (4) pp. 475-484 available at: https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2967775 (Accessed September 2021)
- National Council for Special Education (2021) "Severe/Profound General Learning Disability" available at: <https://www.sess.ie/categories/general-learning-disabilities/severeprofound-general-learning-disability> (Accessed September 2021)
- Ombudsman for Children (2020) "Unmet Needs – a report by the Ombudsman for Children's Office on the challenges faced by children in Ireland who require an assessment of their needs." available at: <https://www.oco.ie/library/ombudsman-for-children-launches-unmet-needs-a-report-on-the-challenges-faced-by-children-in-ireland-who-require-an-assessment-of-their-needs/> (Accessed December 2021)
- Parker, C. (2009) 'An Overview of Article 19 of the UN Convention on the Rights of Persons with Disabilities.' In Bulic et al (eds.) Focus on Article 19 of the UN Convention on the Rights of Persons with Disabilities. Brussels: European Coalition for Community Living, pp. 21-26.
- Roddy, A., (2021) "Income and conversion handicaps: estimating the impact of child chronic illness/disability on

family income and the extra cost of child chronic illness/child disability in Ireland using a standard of living approach" The European Journal of Health Economics (2021) available at: <https://doi.org/10.1007/s10198-021-01371-4> (Accessed September 2021)

- Scope (2019) "The Disability Price tag 2019" available at: file:///C:/Users/Hannah%20Boylan/Downloads/disability-price-tag-technical-report-2019%20(3).pdf (Accessed September 2021)
- Smith, Noel; Middleton, Sue; Ashton-Brooks, Kate; Cox, Lynne; Dobson, Barbara M.; Reith, Lorna (2004) "Disabled people's costs of living: more than you would think." Loughborough University. Available at: https://repository.lboro.ac.uk/articles/online_resource/Disabled_people_s_costs_of_living_more_than_you_would_think/9598310 (Accessed September 2021)
- UN General Assembly (2006) "Convention on the Rights of Persons with Disabilities" available at: <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf> accessed October 2021

APPENDIX 1 LITERATURE REVIEW

This literature review consists of two sections.

The first section considers research from Ireland, the UK and other international research into the cost of disability. This is not an exhaustive account, however focuses on research which looks at the cost of a disability, how this cost is measured, the impact which it has on people living with a disability and their families/carers, and the State's support and services in response to these costs.

The second section focuses on profound intellectual disability.

(i.) Irish Literature:

In 2004, Indecon International Economic Consultants submitted a report to the National Disability Authority (NDA) which represented an independent review of the cost of disability in Ireland. The purpose of the research was to advise an established working group, via the NDA, of the additional costs experienced by people with disabilities, looking specifically at the direct or indirect costs of the disability, and to evaluate the appropriateness of mechanisms, policies or instruments used to address the identified additional costs.⁴⁵

The study implemented the standard of living approach alongside other approaches (direct survey approaches, expenditure diary approaches, budget standards cost estimation approaches, and an approach based on the adjustment of international cost estimates) in order to estimate the cost of disability in Ireland.

In relation to the Consensual Budget Standards methodology, Indecon's study states that because people with disabilities may be so different in their needs, it is harder to design a model budget which might get widespread agreement. They state that drawing up a "typical" budget for people

with disabilities is not easy, because individuals' circumstances are so different from one another. Due to this, the researchers view their budget standards exercise as indicative only, but states that it is useful as a technique that directly presents examples of the specific costs faced by a disabled person.

The study's results suggest that costs of disability can be significant and vary with severity of disability, and that the types of extra costs incurred tend to differ across persons with different disabilities/conditions.

Overall, Indecon's assessment was that the living standards of a disabled person tend to be lower on average than a non-disabled person with the same income. This is because of the additional costs incurred due to the disability/condition, as well as the extent that the State wishes to provide full compensation or mitigation of additional costs of living arising from disability. The findings demonstrate that additional resources and/or further measures, in relation to what was available to Irish people with a disability in 2004, may be required.

In their research estimating the extra cost of living for people with disabilities, Cullinan, Gannon, and Lyons⁴⁶ argue that addressing the extra economic costs of disability is a logical step towards alleviating elements of social exclusion for people with disabilities. The authors estimate the economic cost of disability in Ireland in terms of the additional spending needs that arise due to disability. The study defines and estimates models of the private costs incurred by families with individuals who have a disability in Ireland when compared to the wider population, after disability-related payments and supports.

⁴⁵ Indecon (2004) "The Cost of Disability" Available at: <http://nda.ie/File-upload/Indecon-Report-on-the-Cost-of-Disability.pdf> (Accessed September 2021)

⁴⁶ Cullinan, J., Gannon, B. Lyons, S. (2011) "Estimating the extra cost of living for people with disabilities." *Health Economics*, 20 (5), pp. 582-599. Available at: (Accessed September 2021) https://aran.library.nuigalway.ie/bitstream/handle/10379/942/paper_0134.pdf?sequence=1&isAllowed=y (Accessed September 2021)

In applying the standard of living approach for estimating the cost of disability to Ireland, the study starts with the premise that the living standards of households with a member who has a disability will reduce as they have to divert a portion of their income to cover disability-related costs. This diversion of income is then quantified, considering the other factors that impact measured standard of living. This method does not identify the specific items that make up these additional costs, but depending on the available data it can account for variations in the level of costs across disability type and severity.

The findings suggest that the extra economic cost of disability in Ireland is large and varies by severity of disability and household type.

In concluding, the authors argue that government policies aimed to address the additional cost of disabilities for households do not go far enough in addressing the extra costs faced by the disabled community in Ireland. Their findings also have important implications for measurements of poverty in Ireland. If disability reduces the standard of living of households for a given level of income, poverty measures based on income will underestimate the problem, the authors, therefore, support the case for the introduction of disability-adjusted poverty and inequality estimates and equivalence scales.

In 2017, the VPSJ alongside the National Council for the Blind (NCBI), conducted a study into a minimum essential standard of living for a single adult with vision impairment in Ireland.⁴⁷

The aim of this study was to provide facts and data on the additional needs and expenditure which people with vision impairment require in order to have a MESL, and to explore the adequacy of social welfare and related payments in meeting these additional needs and expenditure associated with disability to ensure the adequacy of social transfers and related payments. The Consensual Budget Standards methodology (see Chapter 3 for description of CBS methodology) is used in order to determine the additional needs and costs

associated with vision impairment.

This research built on the existing body of research undertaken by the VPSJ into the goods and services, expenditure and adequate income required by households and individuals in order to have a MESL. Four different groups of people with vision impairment, using the Consensual Budget Standards Methodology, discussed in detail the different MESL budgets, which had been developed for single adults in the general population who lived alone in rented accommodation. They identified, discussed, and reached a negotiated consensus on the additional goods and services needed by people with a visual impairment to maintain a MESL. In keeping with the previous research, the focus was on needs and not wants. Only items which were essential to meet physical, psychological, and social needs are included in the lists of goods and services necessary in order to have an MESL.

The findings of this study showed that the cost of an MESL is higher for a person with vision impairment than for members of the general population who have full sight. The cost of meeting many of the additional needs is relatively low. However, the accumulated costs add substantially to the weekly budget.

While some of the costs cover specialised goods and services which are directly related to vision impairment, other additional costs are associated with the need to ensure social inclusion and participation. The additional taxis and tokens of appreciation for the support of friends who make engagement in social activities possible, all contribute to the cost of an MESL. These and other additional expenses are not taken into consideration by decision makers when deciding entitlement rates.

This study demonstrated that it is possible to establish the estimated cost of an MESL for people with a particular disability in a specific household type. The consensual budget standards methodology proved successful in building a socially negotiated consensus among people with

⁴⁷ MacMahon, B., Moloney N. (2017) "A minimum essential standard of living for a single adult with vision impairment" Available at: https://www.budgeting.ie/download/pdf/full_report_vpsj_ncbi_2017_a_mesl_for_a_single_adult_with_vision_impairment.pdf (Accessed September 2021)

vision impairment living in an urban area.

In 2021, Roddy used the Growing Up in Ireland National survey dataset for nine-year olds to investigate the impact of child chronic illness/disability on earnings, standard of living and the extra cost of disability.⁴⁸

Roddy looks at Irish child disability policies which stem from the Disability Act (2005). She states that this policy allows children with a disability to have their needs assessed, and based on this assessment, to receive special health and publicly funded education services. However, Roddy states that, due to a lack of service provision, children with disabilities do not necessarily receive these services. This can result in their needs not being met or families of the child with a disability paying for private services, which can lead to financial hardship and families entering debt.

Roddy also addresses the Progressing Disability Services for Children and Young People Programme (2020) which focuses on a child's needs rather than a diagnosis focused approach to service access. However, Roddy notes that this programme's approach to accessing services may be favourable towards certain conditions over others.

The study's results show that families with a child with chronic illness/disability experience significant disadvantage and economic hardship. Their household income is reduced due to barriers to entering and sustaining employment, and their standard of living is lower due to their limited income being spent on the extra cost of the disability.

Roddy recommends that a tiered approach to disability support payments be introduced that have broader criteria for inclusion based on varying severity levels which would help to alleviate the financial hardship and lower standard of living that these families face. She states that current State policy in this area is focused on cost cutting, which is only worsening the experience of these families.

Roddy also suggests the need for more innovative policies to provide appropriate and timely access to health and social care services and flexi parental employment, as well as the provision of access to high-quality educational and care facilities.

In 2021, Indecon Research Economists, appointed by the Department of Social Protection, published their second research report on the 'Cost of Disability in Ireland', (Indecon, 2021). The report states that the Department of Social Protection's 2020 annual report showed that illness, disability and carers programmes accounted for an estimated 15.4% of the department's total expenditure, with 414,405 recipients of these payments. Indecon state that given the high number of individuals impacted by disability in Ireland, it is important to examine the costs incurred by these individuals to provide an evidence base for policy makers. As such, quantitative estimates of the cost of disability are needed to inform decisions on how to best support people with disabilities.⁴⁹

The aims of the report are to examine the conceptual underpinnings of the cost of disability, measure the cost of disability, and examine the implications for public policy and service delivery.

Indecon conducted the study using a multi-phase methodological approach. These were as follows:

Phase 1:

Project inception, data collection, review of existing documentation, stakeholder engagement.

Phase 2:

Review of International research, defining disability and outlining main cost components.

Phase 3:

Econometric modelling of costs of disability.

Phase 4:

Direct measurement approach to estimated costs of disability.

Phase 5:

⁴⁸ Roddy, A., (2021) "Income and conversion handicaps: estimating the impact of child chronic illness/disability on family income and the extra cost of child chronic illness/child disability in Ireland using a standard of living approach" The European Journal of Health Economics (2021) available at: <https://doi.org/10.1007/s10198-021-01371-4> (Accessed September 2021)

⁴⁹ Indecon (2021) "The Cost of Disability in Ireland" Available at: <https://www.gov.ie/en/publication/1d84e-the-cost-of-disability-in-ireland-research-report/> (Accessed December 2021)

Formulate policy conclusions, produce final report.

The researchers undertook new econometric modelling of the costs of disability using data from the Survey on Income and Living Conditions, and also used a bottom up approach through analysing expenditure diaries and surveys. These detailed surveys of individuals living with disabilities in Ireland informed the research, allowing those with a disability to contribute directly to the report. 4,734 individuals living with a disability responded to Indecon's survey.

The research defines the cost of a disability as the extra spending needs stemming from the disability and note that these costs would vary greatly depending on age, household type, severity of disability, and nature of disability. The authors also emphasise that there is no single cost of disability, but rather a spectrum from low additional costs to extremely high additional costs, dependant on the individual circumstances.

The study highlights the importance of the "Standard of Living" or equivalence approach, which estimates the economic cost of a disability by measuring household living standards, and then observing what levels of income different household types achieve an equivalent standard of living using econometric techniques. Using this method, the study found that on average, households with a disability have nearly €8,000 less equivalised income a year than households without a disability.

Submissions received by Indecon from disability representative bodies highlighted the greatest areas of additional costs, including: housing adaptation, hearing aids, travel costs, utility bills, therapeutic supports and specialised care services, assistive technology, cost of accessing services, food and clothing, social costs and home help costs.

The report's survey of individuals living with a disability in Ireland identified additional costs of disability in the areas of equipment, aids and appliances, mobility, transport and communications, medicines, care and assistance

services, and additional living expenses.

Indecon's 2021 survey showed that households with a disability spend on average an additional €9,027 annually on items specifically related to the disability. The report states that some of these additional costs may already be addressed by public supports, but that these are the costs which individuals living with a disability indicated as facing due to their disability.

Indecon's 2021 report also considers the additional costs which those living with a disability may incur but cannot afford to pay. The survey asked respondents for the value of extra living costs experienced due to their disability that they could not afford to meet. The average annual cost across the whole survey sample (which includes people that indicated that there were no extra costs that they could not afford) was just over €540.

The estimate for the overall cost of disability for all survey respondents (including costs that they actually paid and estimates of costs that they indicated they could not afford) was an additional €11,734 annually. The analysis also indicated that across all disability types, those who reported being "strongly limited" by their disability have a higher total additional cost

Indecon's econometric modelling found that the weekly cost of disability in the most severe cases is between €277 and €279 weekly, based on the annual median disposable income of €35,430 for years 2015-2018, and between €227 and €228 weekly if estimated based on the annual median income of €29005 for households with a member who has a severe disability for years 2015-2018.

Based on the study's detailed empirical research, Indecon estimates the overall average cost of disability in Ireland to range from €9,482 to €11,734 annually.

The authors state that it is important to note that these estimates are averaged across populations of people with potentially different levels of need, different circumstances and different costs. Therefore, there are likely to be individuals facing considerably higher costs too. They state that

this suggests the need for the State to provide supports through a range of facets, including income supports, need assessed grants and service provision. 58% of survey respondents viewed income supports as the most helpful form of support, 16% stated extra grants as the most helpful form of support, whilst 31% indicated that better services would be most helpful. The report finds that a multi-faceted approach of all three types of support represents the most cost-effective means of achieving policy objectives in relation to reducing poverty, improving income equality and the quality of life for those living with disabilities in Ireland.

The key conclusions of Indecon's 2021 report are as follows:

1. There are considerable additional costs faced by individuals with disability which are currently not being met by existing programs and payments.
2. There are additional unmet costs that individuals cannot afford.
3. Individuals with disability face huge challenges in living independently and are at high risk of experiencing poverty and social exclusion.
4. Measures to address the additional cost of disability should be based on a multifaceted approach, involving payments, access to services, and targeted grant programs.
5. There are significant challenges in accessing employment for individuals with disability.
6. The introduction of any additional support should be targeted on those most in need and who face the greatest additional costs of disability.
7. The levels of disability payments and allowances should be altered to reflect very different cost of disability based on severities and types of disability.
8. There is a need to recognise the impact on families of individuals with disability and in particular the loss of earnings and sacrifices

made by families in caring for those most in need.

9. In designing supports for individuals with disabilities the focus should be on the needs of the individual and their family.
10. Ongoing monitoring and evaluation of supports should take place to allow for the best use of scarce resources.

Although Indecon's report does not explicitly discuss the "cost of caring" as is being explored in this study, it does acknowledge the importance of recognising the role of the family in caring for those most in need and recognises the impact that this has on families, specifically in relation to foregone income and sacrifices made by the family. Indecon also state that in future designing of supports for individuals with a disability, the needs of the individual and their family should be the focus.

This demonstrates Indecon's understanding that the substantial additional costs of living with a disability is not just experienced by the individual, but in many cases their family carers and wider household too. In the case of this study into the additional costs associated with an adolescent child with a profound intellectual disability, these costs fall onto the parents who are the child's full-time carers.

Despite differences in methodology and approach to the research, all of the Irish literature reviewed found that there are additional costs associated with having a disability, and that these can vary in size depending on severity and type of disability or condition. The different research demonstrates that the standard of living for a person with a disability tends to be lower, on average, than someone without a disability with the same income. These studies all conclude that the State supports and provisions in place at the time of these studies were not enough to cover the additional costs incurred by people living with a disability and that more needed to be done in order to cover these costs.

With regards to the current report, on the impact

for their child. The additional costs associated with the child's disability fall onto their family, the lower standard of living is experienced by the entire household and the state supports offered to the child and their carer are not doing enough to support the household to cover these additional expenses coming from the disability.

The Irish research also highlights the issues being experienced by families caring for a child with a disability in relation to a lack of service provision from the state, meaning that, where finances allow, parents are having to pay for private services and in doing so are experiencing financial hardship or going into debt.

The research also demonstrates the barriers of entry to employment that carers experience, leading to reduced income and standards of living.

In relation to measurements of poverty, the research also suggests that typical approaches to measuring poverty would underestimate the experience of those living with disabilities as their standard of living tends to be lower than that of someone without a disability with the same income. Because of this, disability adjusted poverty measures are suggested.

In relation to the Budget Standards approach, Indecon's report did not use it as their primary methodology, but rather as an indicative methodology to compare to their other findings. They did however state the usefulness of the approach in providing examples of specific costs experienced by people with disabilities. The VPSJ study with the NCBI highlights the success of this methodology in establishing a socially negotiated consensus among the participants. The outcome of this study also supports the value of using this methodology to estimate the cost of a MESL for people with different disabilities.

(ii.) UK Literature:

In 1991, Berthoud conducted a study called "Meeting the Costs of Disability." This study acknowledged that there are a series of ways in which the financial "costs" of disability can be

discussed. The first approach is a focus on the loss of earnings which many disabled people experience, or which their relatives face if they have to give up work to provide care; the second focuses on the cost to public or voluntary organisations of treatment, care, training or other specialised services provided free to disabled people whilst the third looks at the extra cost of living faced by disabled people.⁵⁰

This study explored the following question: given current public services (that in the UK in 1991), what is the effect of disability on the way in which people spend their current income?

Berthoud identified that the most important problem in identifying extra spending on the needs created by disability lies in the fact that expenditure is constrained by income – you can't spend what you do not have. The study stated that if you were to focus on how people's expenditure would respond to changes in their income, it would seem unlikely that the cost of a disability would be a fixed amount, but rather as income rises some of the extra will be spent on goods and services which were required only because the individual was disabled, but which did not take precedence over basic needs while income was short. This suggests that the demand for disability-related items is subject to budgeting constraints just like any other form of consumption.

Berthoud also discusses three possible ways of measuring the additional costs of disability:

- The first involves asking disabled people how much extra they spend on the relevant items. The comparison is with how they would spend their money if they had no disability. People can also be asked whether there are any specific items on which they spend less as a direct result of their disability.
- The second method involves taking detailed measurements of all expenditures of a sample of disabled people and comparing the results with similar data from a sample of non-disabled people. Here the comparison is with other people.

⁵⁰ Berthoud, R. (1991). Meeting the costs of disability. In G. Dalley (Ed.), *Disability and social policy*. London: Policy Studies Institute. Available at: <https://www.guerillapolicy.org/publications/archivepdfs/Disability%20and%20social/BERTHOUD.pdf> (Accessed September 2021)

- The third method looks for evidence of a reduction in the standard of living which disabled people can support from a given income. It therefore turns away from specific additional costs to focus on the secondary effects on living standards.

Berthoud study also discusses the costs associated with having a child with a disability, citing a study carried out in 1978 by Baldwin of the Social Policy Research Unit at York University. This study was based on interviews with 480 families who had children with a severe disability who were engaged with community services and were in receipt of disability benefits of some form; these families were then matched with a sub-sample of otherwise similar families but without a child with a disability. This comparative study found that extra costs experienced by the families with a child with a disability appear to have been mainly related to transport and food, followed by durables and clothing.

Berthoud found that research which used direct surveys and income comparison of people or households with a disability all yield results which are broadly consistent with the conclusion that disability costs increase with severity, the costs are not fixed, but rise with income, i.e., as the income rises, the proportion of the income spent on disability costs also rise. However, he found that these measurements can tend to underestimate the true effect disability has on people's spending. The study also concluded that Standard of Living approaches were more speculative, but could not be dismissed, and that this method suggests that the true cost of disability may be substantially higher than the conservative estimates based on other approaches.

In 1998 research was conducted by Dobson and Middleton from the Joseph Rowntree Foundation into "The Cost of Childhood Disability."⁵¹ The aim of this study was to collaborate with parents of severely disabled children to establish minimum essential needs and then to use these as the basis for developing estimates of additional costs. The budget standards estimated that it costs at least three times more than the amount required to

bring up a child without a disability established in a study using a similar methodology. The study estimated that benefits for severely disabled children would need to be increased by between 20 and 50 per cent, depending on the child's age and type of impairment, to meet the costs of the minimum essential budgets (based on UK benefits at that time.)

By using case studies of severely disabled children, it was possible to calculate the maximum benefits that children with three different conditions might be entitled to. The conditions were mobility disability, sensory impairment and traumatic or intermittent conditions. Comparing maximum benefit income with the consensual budgets for the three types of disability shows that benefits fall far short of what parents believe to be the minimum costs necessary for severely disabled children.

The shortfalls in benefits that the study discusses are based on figures that assume families are receiving the maximum benefits available. However, the researchers stated that parents participating in the study stressed the difficulties of finding out about and claiming benefits.

The study also found that most of these families are unable to increase their income through paid employment because of the demands of caring as well as the lack of suitable childcare. Parents report constant battles with the range of service providers who are there to support them. Services varied from area to area and this lack of consistency increased the frustration and difficulties of parents.

Participants also stated that sometimes having an income from work can create more problems than it solves, as the upper income threshold for the granting of additional financial help is set too low and excludes many families who are just above these limits. The dilemma is that if they work, they may miss out on formal statutory help. But the alternative of not working means that they are destined always to be poor.

The central difficulty for parents of severely disabled children is that these minimum essential budgets represent what parents consider to be

⁵¹ Dobson, B. and Middleton, S. (1998) Paying to care: The cost of childhood disability York: Joseph Rowntree Foundation (748). Available at: <https://www.jrf.org.uk/report/paying-care-cost-childhood-disability> (Accessed September 2021)

necessary and not what their children actually receive. Parents attempt to minimise the gap between their income and the levels of spending that they believe are needed by going into debt, spending less on themselves and on other family members, and completely altering their lifestyles and aspirations.

One of the biggest problems faced by parents in trying to juggle their budgets is that the need for extra spending often comes suddenly and unpredictably. Parents identified cycles in their budgets linked to their child's health. When their child is comparatively well and settled, they manage better. However, when the child is ill, they spend considerably more money and it is at this point that many go into debt, as they often have no savings or flexibility within their budgets.

In 2004, the Joseph Rowntree Foundation in Loughborough University in the UK released a study called "Disabled people's costs of Living – More than you would think".⁵² The purpose of this study was to investigate the additional needs and associated financial costs of disability from the perspective of disabled people themselves and to provide clear evidence on the extent of these additional costs.

The budget standards in this study are determined by disabled people themselves, as it is believed that they understand the needs and priorities that are associated with disability better than anyone else. Disabled people, in groups, drew up, debated, negotiated and agreed the lists of items and resources needed to maintain a minimum standard of living.

Through debate and negotiation, the groups reached consensus on the minimum essential resources necessary to meet disabled people's needs so that they would achieve, as far as possible, a 'level playing field' with people without disabilities.

The research found the disabled person budget standards vary according to the nature of the

additional needs arising from disability.

The study concluded that the additional costs of disability are substantial and measurements of poverty among disabled people that do not take these additional costs into account will underestimate the true extent of poverty experienced by disabled people.

In 2015, Loughborough University's Centre for Research in Social Policy conducted Consensual Budget Standards research into the additional costs of living for people who are sight impaired and people who are hearing impaired.⁵³

This research identified a minimum income standard for people with certain sensory impairments and demonstrates the scope for doing similar research with people who have different types of impairment or disability.

This research clearly shows how living with a disability can bring additional costs in reaching a minimum acceptable standard of living, with additional costs arising from a wide variety of sources, ranging from specialist equipment to adaptations in the specifications of everyday items like televisions and mobile phones to extra costs associated with maintaining social relationships.

Loughborough University continued the Consensual Budget Standards research into those with sight loss in 2016 and 2017.

This series of studies have shown that additional costs increase with more severe sight loss and with older age, and the final study shows the financial impact when these factors combine.

The researchers state that such studies of the additional cost of disability will never capture every case, and this is not their intention. Rather, they have set out to create greater understanding of where costs tend to be the greatest, and how this can vary as people's circumstances change.

Scope, a disability equality charity based in England and Wales have published their "Disability

⁵² Smith, Noel; Middleton, Sue; Ashton-Brooks, Kate; Cox, Lynne; Dobson, Barbara M.; Reith, Lorna (2004) "Disabled people's costs of living: more than you would think." Loughborough University. Available at: https://repository.lboro.ac.uk/articles/online_resource/Disabled_people_s_costs_of_living_more_than_you_would_think/9598310 (Accessed September 2021)

⁵³ Hill, K., Davis, A., Hirsch, D., Padley, M., Smith, N. (2015) "Disability and Minimum Living Standards: The additional costs of living for people who are sight impaired and people who are Deaf" Loughborough: Centre for Research in Social Policy, Loughborough University

"Price Tag" report in 2018 and 2019. They use the Standard of Living Approach in order to measure the extra costs of a disability.⁵⁴

They state their reports have found startling inequality, driven by the excessive payments that disabled people end up making for essential goods and services. Extra costs can also take the form of unmet needs. They found that not every disabled person and their family would be able to meet their extra costs but could face choices and trade-offs at the expense of their quality of life. The pressure of trying to meet these extra costs hinders disabled people's ability to move into work making it harder to build savings and plan for the future. In short, it makes it harder for disabled people to participate fully in society. (Scope, 2019)

In 2019 they applied their extra costs research to another key theme of their strategy: ensuring the best start in life for disabled children and their families. Their 2019 report focuses on calculating and understanding the extra costs families face when parenting children with disabilities, as well as recalculating the extra costs for adults with disabilities. (Scope, 2019)

With regards to the extra costs experienced by families parenting a child with a disability, they found that parents of a disabled child experienced significant extra costs, and that on average, parents with disabled children face extra costs equivalent to almost half of their income (47 per cent). Their findings also show that disability benefits don't compensate for the majority of the extra costs faced by families with disabled children.

Scope's study also included a qualitative interview aspect which determined some of the drivers of these extra costs. The key areas where extra costs were incurred by the families of disabled children were; Transport costs associated with car travel and parking, hospital visits and special equipment. Toy costs associated with more expensive specialist toys and play equipment. Clothing costs associated with suitable clothes being more expensive and having to be replaced more frequently due to wear

and tear. Energy costs associated with heating the home and more frequent washing of bedding and clothing. Therapies costs associated with the child (physiotherapy, hydrotherapy, speech and language therapy), as well as for their parents (counselling and emotional support) and finally, Home adaptation costs associated with changes to living spaces to make them safer and more accessible for disabled children.

At present research is being undertaken at Loughborough University into the experiences of autistic children and their families in the UK, and the impact that these experiences have on their living costs. The research will be conducted through exploration of literature and concepts related to autism and its costs, gathering of perspectives of organisations working with children with autism, interviews with such children and their parents and deliberative focus groups to agree on what additional expenditures are required in a given case.⁵⁵

The UK literature discussed further echoes the findings of the Irish literature. There are considerable additional costs experienced by those living with a disability, and these costs vary depending on severity of disability and level of need. Also, State supports available to those living with a disability do not adequately cover these additional expenses, and standard poverty measures do not fully grasp the experience of those living with a disability.

The UK literature highlights how additional expenses for people living with a disability can arise from a wide variety of sources. Those mentioned include transport, food, clothing, personal assistance, home adaptations, essential equipment, hospital visits, energy costs, therapies costs and social inclusion costs.

Additionally, the UK literature goes further in discussing the experience of parents/guardians caring for a child with a disability and the additional expenses, and difficulties arising from these expenses. It highlights struggles relating to

⁵⁴ Scope (2019) "The Disability Price tag 2019" available at: <https://www.scope.org.uk/campaigns/extra-costs/disability-price-tag/> (Accessed September 2021)

⁵⁵ Loughborough University (2021) "Our Students – Chloe Blackwell" available at: <https://www.lboro.ac.uk/subjects/social-policy-studies/students/chloe-blackwell/> (Accessed September 2021)

receiving inadequate State assistance and service provision. Issues relating to seeking employment, due to the demands of caring for a disabled child when adequate childcare is not easily accessible, therefore impacting the potential income of the household. It also discusses how parents bridge the gap between income and spending in various ways, such as going into debt, spending less on themselves and other family members and altering their lifestyles and aspirations.

In relation to the Consensual Budget Standards methodology, the considerable use of this approach in measuring the additional costs associated with disability in the UK literature further demonstrates the appropriateness of this method for research of this type, as well as highlighting the importance of including individuals with disabilities, or their family's/carer's, in the research.

(iii.) Other International Literature:

A systematized review of the global literature on the direct costs associated with living with a disability at the individual or household level found that, despite differences in the research type, a consistent pattern emerged in the distribution of costs across the studies included in the review—individuals with disability have considerable extra costs, and that these costs vary, depending on severity of disability, lifecycle, and household type.⁵⁶ Overall, the review found that findings concerning disability costs stress the importance that variation in needs are considered in the construction of poverty thresholds and State benefits for the disabled population. They state that quantifying the extra costs of disability and adjusted poverty rates can assist policy makers in allocating sufficient resources to provide disability support services in accordance with their obligations under national and international disability law. It can also provide a basis for constructing eligibility and benefit levels for disability support programs and in examining the adequacy of supports.

They also highlight the need for more participatory research and that collaboration with disabled

people's organizations, persons with disabilities and disability researchers are needed to identify issues related to extra costs and how they relate to other issues such as barriers to goods and services.

Again, this research echoes the findings from the Irish and UK research discussed, with regard to the considerable extra costs experienced by people with disabilities, and the varying nature of these costs depending on severity of disability and other variables. With regards to the current study, these considerable extra costs are experienced by the parents who are caring for their disabled child, rather than the child themselves.

The study also includes discussion of poverty measures, and the importance of adequate State supports to assist in covering the additional costs a disability. This review also emphasises the need for participatory research, such as the Consensual Budgets Standards approach, for appropriate and accurate research into the cost of a disability.

(iv.) Profound Intellectual Disability

National and international definitions of intellectual disability generally share three key criteria. These are:

1. A significant impairment of adaptive behaviour (social functioning);
2. A significant impairment of intellectual functioning, with
3. Both impairments arising before adulthood.

Intellectual disability (ID) is the presence of a significantly reduced ability to understand new or complex information and to learn new skills, with a reduced ability to cope independently, which starts before childhood and adolescence and has a lasting effect on development. However, the presence of low intelligence (IQ below 70) is not, of itself, a sufficient reason for deciding whether an individual requires health and social care support. An assessment of social and adaptive functioning and communication skills should also be considered when determining need.⁵⁷

Enable Ireland in their information material for

⁵⁶ Mitra, S., Palmer, M., Kim, H., Mont, D. and Groce, N. (2017) "Extra costs of living with a disability: A review and agenda for research." *Disability and Health Journal* 10 (4) pp. 475-484 available at: https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2967775 (Accessed September 2021)

⁵⁷ HSE (2021) "MHID - National Model of Service" Available: <https://www.hse.ie/eng/services/publications/mentalhealth/hse-national-mhid-model-of-service-january-2021.pdf> (accessed February 2022)

parents' state that three criteria are required to be met before an intellectual disability can be identified;⁵⁸

1. Intellectual impairment

IQ is one way of classifying intellectual disability however there are problems with using IQ alone. Measurements can vary during a person's growth and development, particularly in childhood. Also, many people have individual strengths and abilities which are not captured in IQ tests. It is important to also consider the degree of social functioning and adaption.

2. Social or adaptive dysfunction

Measuring the degree of impairment or social functioning can be difficult. Social and adaptive dysfunction considers day to day activities such as relating to others, communicating, eating, drinking, toileting and gross and fine motor skills (e.g. pencil grip, walking and balance.)

3. Early onset

The third criteria is that these impairments can be identified in the developmental period of life. They are present from childhood and not acquired later as a result of an accident, adult disease or illness, or dementia.

Classifications of Disability

The terms mild, moderate, severe and profound are used to describe the severity of an intellectual disability. As the focus of the current study is on individuals with a profound intellectual disability, the following consideration is limited to that aspect of disability.

Persons with profound intellectual disability often have congenital syndromes. These individuals need significant support in their daily life, and they require close supervision and help with self-care activities. Significant support is required to

enhance their ability to communicate and physical limitations is common amongst individuals with profound intellectual disability.

Individuals with mild to moderate disability are less likely to have associated medical conditions than those with severe or profound intellectual disability.⁵⁹

The Irish National Council for Special Education presents profound intellectual disability as follows;⁶⁰

Children with severe to profound intellectual disabilities are likely to be severely impaired in their functioning in respect of a basic awareness and understanding of themselves, of the people around them and of the world they live in. Many of these children will have additional needs, responsive and/or self-injurious behaviour, emotional disturbance, epilepsy, hearing impairment, physical impairment, severe impairment in communication skills and visual impairment.

In relation to IQ, it may be used as an indicator of general learning disability, a child with a severe intellectual disability is described as having an IQ in the range 20 to 35 on standardised IQ tests, and a child with a profound general learning disability is described as having an IQ under 20.

Children with severe to profound intellectual disabilities exhibit a wide and diverse range of characteristics, including a dependence on others to satisfy basic needs such as feeding and toileting, difficulties in mobility, problems with generalising skills from one situation to another, significant delays in reaching developmental milestones and significant speech and/or communication difficulties. Some children may have associated behavioural problems. Children may have limited communication skills but many people with a profound level of intellectual disability use speech, body language and facial expressions to communicate. The person's difficulties in expressing themselves does not diminish their communicative intent.

⁵⁸ Enable Ireland () "Learning Disability – Information for Parents" available at: <https://www.enableireland.ie/sites/default/files/publication/Learning%20Disability-R4%20final%20NE.pdf> (Accessed September 2021)

⁵⁹ Boat, TF, Wu JT. (2015) "Committee to Evaluate the Supplemental Security Income Disability Program for Children with Mental Disorders." Institute of Medicine; Division of Behavioural and Social Sciences and Education; The National Academies of Sciences, Engineering, and Medicine. Washington (DC): National Academies Press (US) Available at: <https://www.ncbi.nlm.nih.gov/books/NBK332877/> (Accessed September 2021)

⁶⁰ National Council for Special Education (2021) "Severe/Profound General Learning Disability" available at: <https://www.sess.ie/categories/general-learning-disabilities/severeprofound-general-learning-disability> (Accessed September 2021)

APPENDIX 2 NET COST OF HOUSING ADAPTATION

The Housing Adaptation Grant is subject to a means test and provides for up to 95% of cost of adaptations to a maximum of €30,000. There are multiple eligibility criteria and with regards to income the grant is limited to households with assessable gross salary of €60,000 or below. Relevant social welfare supports (e.g. Carer's Allowance/Benefit, Working Family Payment, Child Benefit, etc.) are not assessed as part of the household income, a portion of gross salary (€5,000) is disregarded for each dependent child in the household and a further disregard (€5,000) when the person to whom the grant relates is being cared for by a relative full-time. There are five tiers of grant support available, ranging 95% of costs (to a maximum of €30,000) to 30% of costs (to a maximum of €9,000). The VAT payable on the adaptation works is also refundable.

While these supports can provide a substantial portion of the cost of adaptation works, the household will need to meet a proportion of the cost.

The net cost of the adaptations, to the household, is the gross cost of the works, less the VAT refund and adaptation grant (if any), plus the cost of a home improvement loan to meet the proportion outstanding. The cost of the home improvement loan is calculated on the basis of a 10-year term, and the most competitive APR available at the time of pricing is included.

The table below demonstrates the range of potential adaptation cost faced by the household at different income levels. The net cost to the household, including loan interest, is presented for each of the five grant bands and when no grant support is available.

standards of households with a member who has a disability will reduce as they have to divert a portion of their income to cover disability-related costs. This diversion of income is then quantified, considering the other factors that impact measured standard of living. This method does not identify the specific items that make up these additional costs, but depending on the available data it can account for variations in the level of costs across disability type and severity.

Table 4: Housing Adaptation, range of net costs by assessable annual gross household income band.

| | Up to €30,000 | €30,001 - €35,000 | €35,001 - €40,000 | €40,001 - €50,000 | €50,001 - €60,000 | Over €60,000 |
|------------------------------|-------------------|----------------------|----------------------|----------------------|----------------------|-----------------|
| Grant % Max Grant | 95% €30,000.00 | 85% €25,000.00 | 75% €22,500.00 | 50% €15,000.00 | 30% €9,000.00 | 0% €0.00 |
| Works, Gross | €43,000.00 | €43,000.00 | €43,000.00 | €43,000.00 | €43,000.00 | €43,000.00 |
| VAT Refund | €5,805.00 | €5,805.00 | €5,805.00 | €5,805.00 | €5,805.00 | €5,805.00 |
| Works, Net | €37,195.00 | €37,195.00 | €37,195.00 | €37,195.00 | €37,195.00 | €37,195.00 |
| Grant Amount | €30,000.00 | €25,000.00 | €22,500.00 | €15,000.00 | €9,000.00 | €0.00 |
| Outstanding | €7,195.00 | €12,195.00 | €14,695.00 | €22,195.00 | €28,195.00 | €37,195.00 |
| Loan Term | 120 Months | 120 Months | 120 Months | 120 Months | 120 Months | 120 Months |
| Loan APR | 8.2% | 8.2% | 8.2% | 8.2% | 8.2% | 8.2% |
| Total Interest | €3,371.89 | €5,715.11 | €6,886.72 | €10,401.55 | €13,213.41 | €17,431.20 |
| Final Cost | €10,566.89 | €17,910.11 | €21,581.72 | €32,596.55 | €41,408.41 | €54,626.20 |

All items within the MESL baskets have an expected lifespan. The full price of each item is spread equally over the lifespan, to produce an average weekly cost. This approach is applied to items bought frequently (for example food items with a lifespan of one or two weeks) and also to items bought less often such as furniture where the lifespan is counted in years. In the case of the housing adaptations, the average weekly cost is calculated on the basis of a 15-year lifespan.

For example, in a scenario with one adult in full-time employment earning the median full-time salary⁶¹ the household would be eligible for the second band of the Housing Adaptation Grant, providing for 85% of the cost of the works up to a maximum of €25,000. The household then requires a loan to meet the outstanding cost of €12,195. The total interest payable over the ten-year term of the loan brings the net cost for the household to €17,910.11. When this net cost is spread across the expected 15 year lifespan of the adaptation works, the average weekly cost is €22.96.

⁶¹ Median full-time earnings in 2018 were €40,074 (Eurostat, 2021)

Eurostat (2021) Structure of earnings survey: annual earnings. Online database (accessed 14/12/2021): https://ec.europa.eu/eurostat/databrowser/view/EARN_SES_ANNUAL/default/table?lang=en

APPENDIX 3

MESL EXPENDITURE & NET HOUSEHOLD INCOME TABLES

Table 5: Two Parents & Adolescent Child with a Profound Intellectual Disability
Net MESL Expenditure Need & Net Household Income, per week, by Gross Annual Salary Band.

| NMW | | Mesl Expenditure Need | | | | | | |
|---------------------------------------|------------|-----------------------|-------------|-------------|-------------|-----------|-----------|-----------|
| Annual Salary | €20,475 | €25,000 | €30,000 | €35,000 | €40,000 | €45,000 | €50,000 | €55,000 |
| Salary | | | | | | | | |
| MESL Core* | €706.35 | €706.35 | €706.35 | €706.35 | €737.80 | €737.80 | €737.80 | €738.94 |
| Adaptation | €13.55 | €13.55 | €13.55 | €13.55 | €13.55 | €22.96 | €27.67 | €41.79 |
| Housing | €220.38 | €220.38 | €220.38 | €220.38 | €220.38 | €220.38 | €220.38 | €220.38 |
| Total MESL Expenditure | €940.28 | €940.28 | €940.28 | €940.28 | €971.74 | €981.15 | €987.00 | €1,001.12 |
| Social Welfare | | | | | | | | |
| Gross Salary | €393.75 | €480.77 | €576.92 | €673.08 | €769.23 | €865.38 | €961.54 | €1,057.69 |
| Income Tax (joint assessment) | ... | ... | ... | ... | €38.43 | €68.89 | €88.35 | €108.82 |
| USC 1 | €4.41 | €6.15 | €8.07 | €16.59 | €20.91 | €25.24 | €29.57 | €33.89 |
| PRSI 1 | €10.71 | €19.23 | €23.08 | €26.92 | €30.77 | €34.62 | €38.46 | €42.31 |
| Net Salary | €378.63 | €455.39 | €545.77 | €629.57 | €679.12 | €736.64 | €805.16 | €872.68 |
| Carer's Allowance | €248.00 | €248.00 | €248.00 | €248.00 | €248.00 | €228.00 | €180.50 | €135.50 |
| Domiciliary Care Allowance | €71.42 | €71.42 | €71.42 | €71.42 | €71.42 | €71.42 | €71.42 | €71.42 |
| Carer's Support Grant | €35.58 | €35.58 | €35.58 | €35.58 | €35.58 | €35.58 | €35.58 | €35.58 |
| Child Benefit | €32.31 | €32.31 | €32.31 | €32.31 | €32.31 | €32.31 | €32.31 | €32.31 |
| Christmas Bonus | €6.14 | €6.14 | €6.14 | €6.14 | €6.14 | €5.76 | €4.84 | €3.98 |
| Medical Card | Full | Full | Doctor Only | Doctor Only | Doctor Only | None | None | None |
| Household Income | €772.08 | €848.84 | €939.22 | €1,023.02 | €1,072.57 | €1,109.70 | €1,129.81 | €1,151.46 |
| Income Adequacy | Inadequate | Inadequate | Inadequate | Adequate | Adequate | Adequate | Adequate | Adequate |
| (Household Income - MESL Expenditure) | - €168.19 | - €91.44 | - €1.05 | €51.28 | €100.83 | €128.55 | €142.81 | €150.34 |

**Table 5 Two Parents & Adolescent Child with a Profound Intellectual Disability
Net MESL Expenditure Need & Net Household Income, per week, by Gross Annual Salary Band**

| | | MIS | | |
|--|-----------|------------------------------|-----------|-----------|
| Annual Salary | €60,000 | €65,000 | €70,000 | €75,000 |
| | | Mesl Expenditure Need | | |
| MESL Core* | €738.94 | €738.94 | €750.10 | €750.10 |
| Adaptation | €41.79 | €53.09 | €70.03 | €737.80 |
| Housing | €220.38 | €220.38 | €220.38 | €13.55 |
| Total MESL Expenditure | €1,001.12 | €1,012.42 | €1,023.57 | €220.38 |
| | | Salary | | |
| Gross Salary | €1,153.85 | €1,250.00 | €1,346.15 | €1,442.31 |
| Income Tax (joint assessment) | €128.28 | €148.74 | €170.00 | €208.46 |
| USC 1 | €38.22 | €42.55 | €46.87 | ... |
| PRSI 1 | €46.15 | €50.00 | €53.85 | €54.54 |
| Net Salary | €941.20 | €1,008.71 | €1,075.43 | €1,414.14 |
| | | Social Welfare | | |
| Carer's Allowance | €88.00 | €43.00 | ... | €618.75 |
| Domiciliary Care Allowance | €71.42 | €71.42 | ... | ... |
| Carer's Support Grant | €35.58 | €35.58 | €71.42 | €248.00 |
| Child Benefit | €32.31 | €32.31 | €71.42 | €71.42 |
| Christmas Bonus | €3.07 | €2.20 | €32.31 | €35.58 |
| Medical Card | None | None | €32.31 | €35.58 |
| Household Income | €1,171.57 | €1,193.22 | €1,216.11 | €32.31 |
| Income Adequacy | Adequate | Adequate | Adequate | €32.31 |
| (Household Income - MESL Expenditure) | €170.45 | €180.81 | €192.55 | €1,262.30 |
| | | | | €973.31 |
| | | | | Marginal |
| | | | | €1.57 |

Table 6 : Two Parents & Adolescent Child without additional Caring and Disability Needs
Net MESL Expenditure Need & Net Household Income, per week, by Gross Annual Salary Band

| NMW | | Mesl Expenditure Need | | | | | | |
|---------------------------------------|-------------|-----------------------|----------|----------|-----------|-----------|-----------|-----------|
| Annual Salary | €20,475 | €25,000 | €30,000 | €35,000 | €40,000 | €45,000 | €50,000 | €55,000 |
| Mesl Core* | | | | | | | | |
| MESL Core* | €505.70 | €505.70 | €512.54 | €512.54 | €512.54 | €512.54 | €512.54 | €512.54 |
| Adaptation | ... | ... | ... | ... | ... | ... | ... | ... |
| Housing | €220.38 | €220.38 | €220.38 | €220.38 | €220.38 | €220.38 | €220.38 | €220.38 |
| Total MESL Expenditure | €726.09 | €726.09 | €732.93 | €732.93 | €732.93 | €732.93 | €732.93 | €732.93 |
| Salary | | | | | | | | |
| Gross Salary | €393.75 | €480.77 | €576.92 | €673.08 | €769.23 | €865.38 | €961.54 | €1,057.69 |
| Income Tax (joint assessment) | €13.46 | €42.31 | €71.15 | €100.00 | €128.85 | €163.08 | €220.77 | |
| USC 1 | €4.41 | €7.93 | €12.26 | €16.59 | €20.91 | €25.24 | €29.57 | €33.89 |
| PRSI 1 | €10.71 | €19.23 | €23.08 | €26.92 | €30.77 | €34.62 | €38.46 | €42.31 |
| Gross Salary 2 | €196.88 | €240.38 | €288.46 | €336.54 | €384.62 | €432.69 | €480.77 | €528.85 |
| USC 2 | ... | ... | €2.30 | €3.27 | €4.23 | €5.77 | €7.93 | €10.10 |
| PRSI 2 | ... | ... | ... | ... | €8.82 | €17.31 | €19.23 | €21.15 |
| Net Salary | €575.51 | €680.53 | €785.44 | €891.69 | €989.12 | €1,086.30 | €1,184.04 | €1,258.32 |
| Social Welfare | | | | | | | | |
| Child Benefit | €32.31 | €32.31 | €32.31 | €32.31 | €32.31 | €32.31 | €32.31 | €32.31 |
| Working Family Payment | ... | ... | ... | ... | ... | ... | ... | ... |
| BSCFA | ... | ... | ... | ... | ... | ... | ... | ... |
| Medical Card | Doctor Only | None | None | None | None | None | None | None |
| Household Income | €607.81 | €712.84 | €817.74 | €923.99 | €1,021.42 | €1,118.61 | €1,216.35 | €1,290.63 |
| Income Adequacy | Inadequate | Adequate | Adequate | Adequate | Adequate | Adequate | Adequate | Adequate |
| (Household Income - MESL Expenditure) | - €118.27 | - €13.25 | €84.82 | €191.07 | €288.49 | €385.68 | €483.42 | €557.70 |

Table 6: Two Parents & Adolescent Child without additional Caring and Disability Needs
Net MESL Expenditure Need & Net Household Income, per week, by Gross Annual Salary Band

| MIS | | | | | |
|---------------------------------------|-----------|-----------|-----------|-----------|----------|
| | | | | | |
| Mesl Expenditure Need | | | | | |
| MESL Core* | €512.54 | €512.54 | €512.54 | €512.54 | €505.70 |
| Adaptation | ... | ... | ... | ... | ... |
| Housing | €220.38 | €220.38 | €220.38 | €220.38 | €220.38 |
| Total MESL Expenditure | €732.93 | €732.93 | €732.93 | €732.93 | €726.09 |
| Salary | | | | | |
| Gross Salary | €1,153.85 | €1,250.00 | €1,346.15 | €1,442.31 | €495.00 |
| Income Tax (joint assessment) | €278.46 | €336.15 | €393.85 | €451.54 | €17.73 |
| USC 1 | €38.22 | €42.55 | €46.87 | €54.54 | €8.57 |
| PRSI 1 | €46.15 | €50.00 | €53.85 | €57.69 | €19.80 |
| Gross Salary 2 | €576.92 | €625.00 | €673.08 | €721.15 | €247.50 |
| USC 2 | €12.26 | €14.42 | €16.59 | €18.75 | ... |
| PRSI 2 | €23.08 | €25.00 | €26.92 | €28.85 | ... |
| Net Salary | €1,332.60 | €1,406.88 | €1,481.16 | €1,552.10 | €696.40 |
| Social Welfare | | | | | |
| Child Benefit | €32.31 | €32.31 | €32.31 | €32.31 | €32.31 |
| Working Family Payment | ... | ... | ... | ... | ... |
| BSCFA | ... | ... | ... | ... | ... |
| Medical Card | None | None | None | None | GP Visit |
| Household Income | €1,364.91 | €1,439.18 | €1,513.46 | €1,584.41 | €728.70 |
| Income Adequacy | Adequate | Adequate | Adequate | Adequate | Marginal |
| (Household Income - MESL Expenditure) | €631.98 | €706.26 | €780.53 | €851.48 | €2.62 |

www.familycarers.ie

www.budgeting.ie

www.misc.ie

Family Carers Ireland

National Office
Market Square
Tullamore,
Co. Offaly

Vincentian Partnership for Social Justice

Ozanam House
53 Mountjoy Square
Gardiner Street
Dublin 1

FIND OUT MORE

If you have any queries in relation to this research report, please contact:

Dr Nikki Dunne, Research Officer, Family Carers Ireland

E: ndunne@familycarers.ie

National Freephone Careline 1800 24 07 24

Charity No. 10962

www.familycarers.ie



MINIMUM
ESSENTIAL
BUDGET
STANDARDS
RESEARCH CENTRE



Family
Carers
Ireland
No one should have to care alone