

Green Paper on Disability Reform

Introduction

The Vincentian MESL Research Centre at SVP welcomes the opportunity to contribute to the Department of Social Protection's consultation on the Green Paper on Disability Reform. The need for reform and improvement in the area of disability payments has long been called for by people with disabilities and the groups and organisations that represent and advocate for them. The Research Centre would like to strongly acknowledge the need for the voice of people with disabilities to be at the centre of the process of reforming these areas which bear such significance on their lives.

Outline of Submission

This submission will summarise what the MESL research is, and the previous disability and caring related research projects that the Vincentian MESL Research Centre has undertaken. It will then discuss the findings of these reports, alongside the findings of Indecon's Cost of Disability report and look at income adequacy based on the proposed rates of payment of the Personal Support Payment outlined in the Green Paper. The submission will then look at the importance of service provision, as found in the Research Centre's previous research and Indecon's report, before discussing disability payments and employment within the Green Paper. The submission will then conclude and provide the Research Centre's recommendations.

The MESL Research

The Minimum Essential Standard of Living (MESL) research is decided on by members of the public, working together in deliberative focus groups to reach consensus on what is the minimum people need to live and partake in Irish society. It is a standard of living which people agree no one should be expected to live below. It represents the minimum required to meet physical, social, and psychological needs, and enable a life with dignity.

The research works with multiple phases of deliberative focus groups, to reach a social consensus on the goods and services people need to have for a minimum, but socially acceptable, standard of living. The MESL provides the weekly cost of this set of essential goods and services that are required to meet minimum needs and enable people to live with dignity.

In this way the MESL is a tangible measure, grounded in lived experience and derived from social consensus, of what is required for participation, dignity and avoiding poverty. It operationalises a direct measure of poverty and a life with dignity, providing an evidence-based benchmark for assessing income adequacy.

Disability and Caring - MESL Research

In 2017, the Research Centre published its report, “A minimum essential standard of living for a single adult with vision impairment”, commissioned by NCBI (now known as Vision Ireland). The project established the additional needs and expenditure required by people with vision impairment, in order to achieve a Minimum Essential Standard of Living, comparable to that of people in the general population who have full vision. The research centre engaged in deliberative focus groups of individuals with vision impairment so as to ground the research in their lived experience.

The report found that, as of 2016, the core cost of a MESL for a single adult with vision impairment was 18% higher per week than that for a single adult with full sight. The report highlighted that the additional costs associated with vision impairment arose from the need for items and services that enable an individual to realise their right to independent living in the community. Taxis were the highest additional weekly cost outlined by the focus group participants, as they play an important role in daily life of people with vision impairment, for social inclusion purposes, and to safely get to and from medical appointments.

Following on from that, in 2022, the research centre published its report “Care at Home: Costs of Care arising from Disability”, commissioned by Family Carers Ireland. This report presents the cost of a Minimum Essential Stand of Living for a two-parent family caring for an adolescent child with a profound intellectual disability. Like the previous report, the research centre engaged in deliberative focus groups with family carers in order to ground the research in their lived experience.

The research found that, based on 2021 data, the core cost of a MESL for a two-parent household caring for an adolescent child who has a profound intellectual disability is significantly higher, approximately 48%, than that for the household without additional caring responsibilities and disability. The additional cost of caring arose from the need for goods and services specific to the disability. It found that the household budget areas with the largest additional disability related costs were; Transport, Caring Costs, Household Goods, Personal Care, Health, Clothing and Household Adaptations.

Findings from MESL and other research

A key point highlighted in both MESL reports discussed is how specific the additional expenses experienced by individuals with a disability are, based on the nature and severity of their disability. The findings of the above reports are based on specific case studies of households living with, or caring for, a clearly outlined disability. Care at Home: Costs of Care arising from Disability quotes Hill et al (2017), who states that “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.” Placing a number on the cost of disability is a complicated task that is personal to the individual with a disability in question. The Research Centre’s previous work does, however, show how considerable these costs can be.

Indecon’s Cost of Disability report, published in 2021, also acknowledges the significant costs faced by individuals with a disability. The research reports that, as of 2021, the actual costs faced by individuals with severe disabilities on average range from €9,600 to €12,300 per annum, and for those with limited disabilities from €8,700 to €10,000 per annum. This, again, showcases how varied and specific the additional costs of disability are, depending on the individual in question, and the nature and severity of their disability. The report states that the levels of disability payments and allowances should be changed to reflect the very different costs of disability by severity and type of disability, and that in designing supports for individuals with disabilities, the focus should always be on the needs of the individuals and their families.

The Green Paper on Disability Reform’s proposal to introduce a new tiered Personal Support Payment scheme does address Indecon’s finding that concentration of any additional supports should be targeted on those most in need and who face the greatest additional costs of disability. It does so in the sense that those categorised into Level 1, “High Support – very low capacity to work”, will receive the highest rate of payment, while those categorised into Level 3, “Low Support – moderate to high capacity to work”, will receive the lowest rate of payment.

However, Indecon’s other findings and suggestions, discussed above, have unfortunately not been addressed by the proposed new support scheme.

Income Adequacy

The proposed rates of the Personal Support Payment are based on pre-existing payment rates, which are not personal to the individual with a disability in any way. It is proposed that the rate of payment for Level 1 will be aligned with the Contributory State Pension rate of payment, Level 3 will be aligned with the current standard payment rate for Disability Allowance, while the Level 2 payment rate will fall in between.

The MESL 2023 Annual Update found that an Older Single Adult living alone and in receipt of the Contributory State Pension would experience income inadequacy in both urban and rural settings, with their income meeting 93.4% of urban MESL needs, and only 79.4% of rural MESL needs.

This means that, in 2023, an older person relying on the Contributory State Pension would not have a sufficient income to allow them to live and partake in Irish society at a standard of living which people agree no one should be expected to live below. Their income would not be enough to provide them with the goods and services that people regard as essential for households to meet their physical, social, and psychological needs, and are required for participation, dignity and avoiding poverty.

The Green Paper describes an individual categorised into Level 1 as having “a significant level of disability with a very low capacity to work. In most cases, they are unlikely to be able to perform any work or to sustain themselves either fully or partly through paid employment for as long as their incapacity persists.” The MESL needs of an individual with a disability who is categorised at this level, based on the Research Centre’s previous work, as well as Indecon’s findings on the costs of a severe disability, are likely to cost far more than the MESL needs of an Older Single Adult living alone, who is assumed to be in good health.

Therefore, it can be inferred that the income inadequacy that would be experienced by an individual with a disability categorised in Level 1, in receipt of a rate of payment that aligns with the rate of the Contributory State Pension, would be greater again than that experienced by the Older Single Adult living alone.

Service Provision

Another point which is highlighted within the Research Centre’s previous work is the important role that services and indirect supports can have in reducing the MESL costs experienced by individuals with a disability.

“Care at Home: Costs of Care arising from Disability” (2022) found that the inequality and inadequacy of service and support provision available to households caring for a member with a disability impacted the expenditure patterns of these households. Focus Group participants frequently used the term “postcode lottery” to describe the adequacy and accessibility of disability services across the country. They recognised that these supports are essential to ensure the rights, development, quality of life and wellbeing of their children. It was found that many parents felt they had no alternative but to meet the relevant costs

themselves, to avoid the regression and harm caused by delay in accessing these services. The research found that there is a long standing and urgent need to address at a national level the situation of inequality in access to adequate services and equipment for individuals with a disability in Ireland.

The report also found that indirect supports can play a significant role in reducing the potential MESL expenditure needs of the household type examined within the research. In 2022, for a two-parent household caring from an adolescent child with a profound intellectual disability, the receipt of three supports, a means tested Medical Card, the Household Benefits Package and the Housing Adaptation Grant (at the maximum tier) reduced potential MESL expenditure need by up to €100 per week.

Although much of the onus of these supports and services would not fall on the Department of Social Protection, it is important to acknowledge that these areas are not mutually exclusive. Rates of payment will impact eligibility to access services and supports, while access to adequate and affordable services and supports will reduce the additional costs experienced by individuals with a disability (while also importantly reducing the harm that comes from going without).

Indecon's Cost of Disability report finds that measures to address the additional costs of disability should be based on a multifaceted approach involving increased payments, enhanced access to service provision and specific targeted grant programmes. The Department of Social Protection should be commended in taking steps towards making change in the area of Disability payments to improve outcomes for people with disabilities, however, disability reform requires change to happen across all Government Departments, with collaboration and transparency throughout.

Cost of Disability and Employment

This submission has focused on research regarding the cost of a disability, drawing on the knowledge and expertise of the Research Centre on this topic. The issues around employment for people with a disability have not been examined by the Research Centre. However, the evidence outlined above demonstrates that it is unsuitable to conflate the areas of disability payments and employment of people with disabilities within the same proposed scheme.

These are two significant areas that are deserving of their own space for change and reform, but by trying to address disability payments and employment for people with disabilities within the one proposal, neither issue is being adequately addressed.

Regardless of whether a person with a disability is in employment or not, the additional costs associated with their disability will still exist. Being in employment will likely increase the income of the individual, however, as previous MESL research and the Indecon report clearly shows, their living costs will be higher than that of an individual who does not have a disability. Therefore, the income that they receive for their employment will not go as far to cover their living costs as it would for an individual who does not have a disability.

The introduction of an evidence-based, universal Cost of Disability payment, separate from employment-related social protection payments, would provide people with a disability financial support that is specifically related to the cost of their disability, regardless of their capacity to work or employment status.

Conclusion

Previous MESL disability-related research, alongside Indecon's Cost of Disability report, have shown that, depending on the nature and severity of the disability, the additional costs associated with having a disability can be very significant. These reports have also demonstrated that the cost of a disability can vary depending on the nature and severity of the disability, and can be very specific to the individual in question.

The Green Paper's proposal to introduce a tiered Personal Support Payment does not address many of the recommendations that were outlined in Indecon's report – including that the levels of disability payments and allowances should be changed to reflect the very different costs of disability by severity and type of disability, and that in designing supports for individuals with disabilities, the focus should always be on the needs of the individuals and their families.

The proposed Personal Support Payment rates are instead aligned with pre-existing payment rates that are not based on any evidence related to the cost of disability. MESL research shows that the proposed highest rate of the Personal Support Payment, aligned with the rate of the Contributory State pension, would provide an inadequate income to a single older person living alone, who is assumed to be in good health. Therefore, it is inferred that a person with a disability receiving this rate of payment would experience income inadequacy to a greater extent.

Both the previous MESL research and Indecon's report outline the need for improved disability service provision to reduce the additional costs experienced by people with disabilities. This requires cross departmental cooperation and collaboration. The Department of Social Protection cannot work in isolation to achieve disability reform.

The proposed scheme combines the issues of support with the cost of disability and employment of people with a disability. These are two significant areas that are deserving of their own space for change and reform, but by trying to address disability payments and employment for people with disabilities within the one proposal, neither issue is being adequately addressed.

Recommendations

Again, the Vincentian MESL Research Centre welcomes the opportunity to contribute to the Department of Social Protection's consultation on the Green paper on Disability Reform, and makes the following recommendations;

- Ensure that people with a disability's voice are at the centre of all processes relating to the changing of disability payments and employment supports.
- Work cross-departmentally to reform all disability related areas, with a specific focus on disability service provision improvement.
- Introduce an evidence-based, universal Cost of Disability payment, separate to employment related-supports, to address the additional costs experienced by people with a disability.

Sources Referenced

A MESL for a Single Adult with Vision Impairment (2017) available online:
<https://www.budgeting.ie/publications/a-mesl-for-a-single-adult-with-vision-impairment/>

Care at Home, Costs of Care arising from Disability (2022) available online:
<https://www.budgeting.ie/publications/care-at-home/>

Indecon – The Cost of Disability in Ireland (2021) available online: <https://www.gov.ie/en/publication/1d84e-the-cost-of-disability-in-ireland-research-report/>

MESL 2023 – Annual Update (2023) available online: <https://www.budgeting.ie/publications/mesl-2023/>