

Family Carers Ireland's Submission on the Cost of Disability Study

Family Carers Ireland welcomes the opportunity to submit our views on the issues we believe should be considered in preparation of the cost of disability study to be undertaken by Indecon Economic Consultations on behalf of the Department of Employment Affairs and Social Protection. This submission is based on our experience of supporting and advocating for Ireland's 355,000¹ family carers² who provide some 16 million hours of unpaid care each week while saving the State over €10 billion each year in avoided health and social care costs³. *Family Carers Ireland* have focused our submission on the 3 key questions posed by Indecon (i). Issues to be addressed in the study; (ii). Facilitating the input of family carers and (iii). Relevant national and international literature.

1. Issues to be addressed

(i). Costs of Caring: While the economic implications of providing care are well recognised - higher household costs; being forced to pay-out-of-pocket for services that have been cut back or withdrawn; the opportunity cost of having to give up work, reduce hours of work or forego employment opportunities in order to provide care; and the long term financial implications that can result due an inability to save, make provision for the future and the loss of pension entitlement –there is little research on the direct costs incurred by family carers in contributing to the care of a loved one. *Family Carers Ireland* are deeply disappointed that the study commissioned by the Department of Employment Affairs and Social Protection will consider only the cost of disability, rather than the cost of disability and caring committed to by Minister Regina Doherty during her closing speech at the annual Prebudget Forum in Dublin Castle on July 20th 2018. Notwithstanding differences in the concepts associated with measuring the cost of disability and caregiving, *Family Carers Ireland* believes that an opportunity remains to include questions related to the cost of caring within the scope of the existing study, specifically in relation to the costs incurred directly by carers in the day to day care they provide to a loved one(s).

(ii). Familial subsidisation and the absorption of disability-related costs: While relatively hidden, the role of family in subsidising the living costs of a loved one with a disability is a significant feature of Irish society. For example, many adults reliant on a Disability Allowance of €203 per week can't afford to live independently and so remain living with parents or family. As well as providing for their housing needs, family often meet other costs such as homecare, food, transport, heating, medicines, laundry, waste collection and respite charges. *Family Carers Ireland* believes that as well as identifying the additional costs associating with living with a disability and providing care, the survey should also examine the absorption of these costs i.e. by whom are they paid.

(iii). Definition of Disability: Critical to the scope and interpretation of the study is the definition of disability that will be used. For example the Disability Act, 2005 defines disability as “*a substantial restriction in the capacity of the person to carry on a profession, business or occupation or to participate in social or cultural life by reason of an enduring physical, sensory, mental health or intellectual impairment*”. While the UNCRPD defines people with disabilities as ‘*persons who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others*’. Both of these definitions include people of all ages and disability types, which should be reflected in the study.

¹ CSO Irish Health Survey (2015) shows 10 percent of the population aged over 16 are carers. If extrapolated to the national population, this means Ireland has close to 355,000 carers.

² National Carers Strategy (2012) defines a Family Carer as ‘*someone providing an ongoing significant level of care to a person in need of that care in the home due to illness or disability or frailty*’.

³ Based on Census 2011 and €12 per hour replacement care cost rate.

(iv). Nature and severity of the disability: As highlighted in Indecon’s 2004 Report on the Cost of Disability there is a clear link between the nature and severity of a disability and the scale of extra costs incurred. Consideration should be given to if/how a cost of disability payment could be graded by reference to the degree of need. This also calls into question how the severity of a disability should be assessed as well as the resources required to do so.

(v). Sample Frame: While FCI are not conversant with the entirety of Indecon’s proposed research methodology, we note the intention to survey 33,000 people in receipt of a disability payment. This in itself raises a number of important considerations/questions with regard to the sample frame:

- With some 140,835 recipients of Disability Allowance alone, as well as recipients of other welfare schemes such as Invalidity Pension, Illness Benefit and Blind Pension how is the 33,000 person sample to be selected to ensure representation of all types of disability, age and individual circumstances e.g. living alone or with family, working, urban/rural?
- Consideration should be given to the inclusion of older people with a disability given they are more likely to be in receipt of a pension rather than a disability payment.
- Young people with a disability are entitled to receive Disability Allowance from the age of 16. Consideration will have to be given to how these young people will be treated within the survey.
- Many people with a disability who are in employment will not be eligible for a disability payment due to the income threshold, however their perspective on the additional costs they incur on a daily basis will be critical to the study.
- Clarification is needed on how the researchers intend to secure the input of family carers.

(vi). Capacity Act 2015 and issues of consent: While *Family Carers Ireland* fully support the principles enshrined in the UNCRPD and the right of people with disabilities to live full independent lives, the fact remains that many lack full decision-making capacity and rely on their family to manage their financial affairs. In these cases it will be necessary to speak to their carer/family. While the Assisted Decision-making (Capacity) Act was signed into law in December 2015 it has not yet been fully commenced, and as such anomalies have been created whereby families/carers of people with a disability have no legal right to consent on their behalf or manage their financial affairs, yet the mechanisms provided for by the Capacity Act, including decision-making roles have yet to be established. In the intervening period, at a very basic level, this may have practical implications on a carer or family members’ ability to complete a survey on behalf of their loved one, and more seriously may call into question the routine practice of a family member ‘managing’ the finances of their loved one who has a disability and is unable to manage their own affairs unsupported.

(vii). Recognising the costs incurred by carers and families: An outcome of this study is the possible introduction of a Cost of Disability Payment aimed at equalising living standards between people with disabilities and the rest of society. However, consideration must also be given to how the costs incurred by carers can be offset, including the introduction of more generous tax reliefs and changes to the means-testing of Carers Allowance, for example by increasing income disregards and extending allowable deductions to include the costs of care. (See Appendix for a copy of *Family Carers Ireland’s* Budget 2020 submission which sets out specific proposals for how this can be achieved).

2. Facilitating the input of family carers into the study

Family Carers Ireland welcomes Indecon’s invitation to meet to discuss our perspective on the study and to ensure the voice of carers is adequately reflected. We are a national organisation who for 32 years has worked to improve supports, services and recognition for anyone living with the challenges of caring for a family member or friend who is ill, frail, disabled or has mental health difficulties⁴.

⁴ The Carers Association was established in 1987.

Through our network of 22 resource centres and 66 support groups we engage with approximately 20,000 family carers throughout Ireland every year. *Family Carers Ireland* will be happy to facilitate carers input into the study by distributing surveys, sharing posts on social media and links to the survey, hosting dedicated carer focus groups and providing support to Indecon’s consultants as required.

3. Relevant Irish and International Research:

- [“Paying the Price: The Physical, Mental and Psychological Impact of Caring”](#). Published in May 2019 the report undertaken in collaboration with *Family Carers Ireland*, Irish College of Psychiatrists and UCD shows that almost 2 in 3 carers provide more than 100 hours of care per week; 1 in 4 carers providing 50+ hours of care per week do not get Carers Allowance or Carers Benefit; 72% of carers surveyed worry about not having enough money in the future.
- [Family Carers Ireland Budget 2020 Submission ‘A Decade Lost’](#).
- [Roddy, A. and O’Neill, C., 2019. The economic costs and its predictors for childhood autism spectrum disorders in Ireland: How is the burden distributed?. *Autism*, 23\(5\), pp.1106-1118.](#) The research conducted by NUIG in 2018 found that the average annual cost per child for families who had a child with a clinically diagnosed autism spectrum disorder (ASD) amounted to €28,464.89, related to private ASD services, lost income, and informal care.
- [Cullinan, J. and Roddy, A., 2015. A socioeconomic profile of childhood disability. In *The Economics of Disability*. Manchester University Press.](#) Using data from the *Growing Up in Ireland* survey, this chapter considers the association between a range of socioeconomic measures and the disability status of nine-year-old children in Ireland. The findings suggest that, overall, the primary carer of a child with a disability is considerably less likely to participate in the labour market and considerably more likely to turn down work opportunities, when compared to a primary carer of a child without a disability. These differences are found to be more pronounced, the more limiting is the child’s disability. Similar patterns are also found in relation to parental education and social class. Parents of a child with a disability are less likely to be educated at third level and more likely to be in the lowest social class.
- AARP study, [“Family Caregiving and Out-of-Pocket Costs: 2016 Report,”](#) estimates that family caregivers spend an average of \$6,954 on out-of-pocket costs related to caregiving, nearly 20 percent of their annual income.
- [CARE 2018](#) study undertaken by Northwestern Mutual on lifestyle and financial costs of caring, shows 7 in 10 carers provide financial support and 1 in 3 spend more than 20 percent of their monthly budget on caring.
- [Rogge, N. and Janssen, J., 2019. The Economic Costs of Autism Spectrum Disorder: A Literature Review. *Journal of autism and developmental disorders*, pp.1-28.](#) This literature review points to several US and UK studies showing that parents, family members and caregivers of individuals with ASD sustain several financial consequences and income-related losses due to productivity loss, loss of labour income and loss of leisure time related to the ASD of their child.
- [Scope’s updated 2019 research](#) on the extra costs faced by people with disabilities and families with children with disabilities in the UK showed that these families on average face extra costs of £581 a month, with almost a quarter of facing extra costs of over £1000 a month even after they have received welfare payments designed to help meet those costs.

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Appendix 1:

A Decade Lost: Family Carers Ireland Pre-Budget Submission Budget 2020

Ireland's health and social care system depends on family carers. Without the estimated €10 billion in unpaid care Ireland's 355,000 carers provide each year, the health service would collapse. Despite the enormity of their contribution, the scars of the economic crisis remain etched in carer's lives. Research published in May 2019 shows that the situation of family carers has gotten worse in the ten year period since 2009⁵. Carer's health, both physical and mental, has deteriorated as has their access to vital supports and services, including respite. Carer's repeatedly reported in 2009 and in 2019 that they need more respite and homecare hours to support them to be healthy. Despite such calls for support, in the last decade there has been a 70% increase in the number of carers diagnosed with depression; a 24 percent increase in carers reporting poor health; a 30 percent increase in those experiencing anxiety and a 65 percent increase in the number of carers who have no access to respite.

'83 percent of carers do not have access to appropriate respite.'

These findings are a damning indictment of Government's attitude towards carers and are completely at odds with Sláintecare's core objective - to shift the delivery of care from an acute setting towards care in the community and home. Budget 2020 is an opportunity for Government to signal its commitment to carers and to deliver on the promises set out in a Programme for Partnership Government.

Priorities for Budget 2020

1. **Reform the means test for Carer's Allowance.**
2. **Increase the hours a carer can work/study from 15 hours to 18.5 hours.**
3. **End the postcode lottery in homecare and carer supports.**
4. **Replace the Mobility Allowance and Motorised Transport Grant withdrawn in 2013.**
5. **Extend the GP Visit Card to carers in receipt of the Carer's Support Grant.**

1. Reform the Carer's Allowance Means Test

Only one in five of Ireland's 355,000⁶ carers receive Carer's Allowance due to the strict eligibility criteria attached to the payment – circa 81,000 carers. Given that 116,000 carers were eligible for the Carer's Support Grant in 2019, it is reasonable to assume that some 35,000⁷ full-time carers do not qualify for Carer's Allowance due to the means test. These carers, who in many cases provide high level complex care, are not recognised by the State and receive no compensation for the full-time care they provide. Set out below are five proposals that are urgently needed to make Carer's Allowance more accessible to genuine, full-time family carers who are ineligible for Carer's Allowance or who receive a reduced Carer's Allowance despite living on relatively modest incomes.

'A family who have two children, both with a profound disability, have no entitlement to Carer's Allowance due to having a total household income of €65,000.'

Proposal 1: Increase the income disregard from €332.50 to €450 (single) and €665 to €900 (couple).

⁵ Family Carers Ireland, College of Psychiatrists of Ireland & University College Dublin (2019) *Paying the Price: The Physical, Mental and Psychological Impact of Caring*, Ireland: Family Carers Ireland.

⁶ CSO's Irish Health Survey 2015 identified that 10% of the sample population stated they were carers. 355,000 is 10% of the Irish population aged over 15 years.

⁷ 116,000 recipients of the Carer's Support Grant less the 81,000 carers in receipt of Carer's Allowance.

Despite increasing steadily during the period 2000 to 2008, the income disregard for Carer's Allowance has remained stagnant for the last 11 years, meaning Government has failed to achieve the commitment set out in *Towards 2016* to expand the income disregard for Carer's Allowance so that those on average industrial incomes can qualify (p.55). Average industrial earnings in Quarter 3 2018 were €762⁸ while the income disregard for Carer's Allowance remains at €332.50 (single)/€665 (couple).

Carer's Allowance Income Disregard 2000 - 2018

Budget	2000	2001	2002	2003	2004	2005	2006	2007	2008	2008/2019
Single	€95	€158	€191	€210	€250	€270	€290	€320	€332.50	No change
Couple	€190	€317	€382	€420	€500	€540	€580	€640	€665	
Increase	+ 350%									0%

The failure to ensure that the income disregard kept pace with average earnings is compounded by the fact that the current rate of Carer's Allowance of €219 is €1.50 less than it was in 2009, despite a 7.5 percent increase in the Consumer Price Index (CPI) during this period. This means that the equalised value of Carer's Allowance at the rate paid in 2009 of €220.50 is €237 in 2019.

Proposal 2: Extend the allowable deductions and assess income on its net rather than gross value

Because the assessment of means is applied to gross rather than net income and does not take into account mortgage repayments, dependent children, college fees, Fair Deal contributions, medical costs etc., the assessment does not reflect the reality faced by many caring families, who may appear financially comfortable based on their gross income, but are struggling to make ends meet when living expenses and the cost of care are deducted. The deductions currently allowed are limited to a €332.50/€665 weekly income disregard, PRSI, union dues, superannuation and travel expenses⁹, but do not reflect the actual income going into the household. *Family Carers Ireland* argue that the means test should be applied to net rather than gross income similar to the assessment applied to Carer's Benefit¹⁰. By comparison the financial assessment for an Under 70s Medical Card allows for a host of deductions including mortgage repayments, childcare costs, home insurance, nursing home costs, education expenses, travel and parking costs. The scheme also gives an allowance ranging from €38 to €78 for each dependent child living in the household and older children attending third level education.

Comparison of Disregards for Carer's Allowance and the U70 Medical Card

Carer's Allowance Means Test		Medical Card
Disregarded	Not Disregarded	Disregards
€332.50 (single)/ €665 (couple). Social protection payments. PRSI. Union Dues. Superannuation/Pension Contributions. €15 allowance for travel to work.	Universal Social Charge. Income Tax. Medical costs. Mortgage/loan repayments. Education costs. Savings/Investments/2nd property (excess €20k). Fair Deal contributions.	Disregard of €38-€78pw per child. Childcare costs. Rent/mortgage payments. Mortgage-related insurance. Fire and contents insurance. Mortgage protection insurance. Life assurance. Maintenance payments. Nursing home costs.

⁸ CSO data May 2019.

⁹ Applied at a standard rate of €15 but can be increased depending on distance from work.

¹⁰ With Carer's Benefit the €332.50 a carer is allowed to earn is based on net income after income tax, USC, PRSI, superannuation, pension levy, union dues, subscriptions to Friendly Societies and health insurance premiums are deducted.

		Travel costs - public transport or mileage at 18c per km. Where a couple need two cars a double allowance applies. Cost of parking. Specified HSE, DEASP payments and Education Grants.
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Proposal 3: Increase the €20,000 disregard to €50,000 in the Capital Formula.

The formula for assessing means from capital (savings, shares and property) for Carer's Allowance should be increased in line with the Disability Allowance, where the first €50,000 of capital is disregarded rather than €20,000, reflecting the desire of carers to provide for their loved ones after their death. Despite significant changes in Ireland's economy, the capital formula used for Carer's Allowance has not changed since 2005.

Capital Formula

Carer's Allowance		Disability Allowance	
Capital	Weekly means	Capital	Weekly means
First €20,000	Nil	First €50,000	Nil
Next €10,000	€1 per €1,000	Next €10,000	€1 per €1,000
Next €10,000	€2 per €1,000	Next €10,000	€2 per €1,000
Balance (over €40K)	€4 per €1,000	Balance (over €70K)	€4 per €1,000

Proposal 4: Make Carer's Allowance exempt from tax.

Carer's Allowance is taxable and carers with another source of income or whose spouse/partner is working are likely to have to pay tax on the payment. The taxation of Carer's Allowance gives rise to a number of practical issues, not least of which is the failure of many carers to understand their responsibility to inform Revenue of their receipt of Carer's Allowance and the subsequent tax liability that may ensue. It also makes little practical sense that some social welfare payments are exempt from tax, for example Jobseeker's Allowance or Disability Allowance, while Carer's Allowance, for which carers must provide full-time care, is subject to tax. *Family Carers Ireland* understand that the Department of Employment Affairs and Social Protection along with Revenue are currently reviewing the taxation of social welfare payments and urge that consideration be given to making Carer's Allowance exempt from tax in line with other welfare payments and in recognition of the significant contribution made by carers.

Taxable and Tax Exempt Social Welfare Payments

NOT Taxable	Taxable
Jobseeker's Allowance /Benefit/ Transition. Pre-Retirement Allowance. Supplementary Welfare Allowance. Back to Work Family Dividend. Child Benefit. Back to School Clothing and Footwear Allow. Carer's Support Grant. Constant Attendance Allowance. Disability Allowance. Disablement Gratuity. Domiciliary Care Allowance. Farm Assist. Working Family Payment.	Carer's Allowance / Carer's Benefit Adoptive Benefit. Blind Pension. Death Benefit Pension. Deserted Wife's Benefit / Allowance. Disablement Pension. Health and Safety Benefit. Illness Benefit. Invalidity Pension. Incapacity Supplement. Injury Benefit. Jobseeker's Benefit (first €13 excluded). Maternity Benefit.

Fuel Allowance. Guardian's Payment (Contributory). Guardian's Payment (Non-Contributory). Household Benefits Package. Telephone Support Allowance. Widowed or Surviving Civil Partner Grant.	One-Parent Family Payment. Partial Capacity Benefit. Paternity Benefit. State Pension (Contributory/ Non Contributory) Widow(ers) Pension.
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Proposal 5: Exclude carer payments in the financial assessment of the Working Family Payment.

Since January 2012 Carer's Allowance and Carer's Benefit have been included in the assessment of means for the Working Family Payment (formerly Family Income Supplement)¹¹. Prior to this all carer payments were excluded. This change has had a considerable impact on caring families where a significant amount of the Working Family Payment is lost due to the receipt of Carer's Allowance or Carer's Benefit. For example in a family with four children where a parent earns €400 per week, the Working Family Payment was halved from €260 per week to €129 when their spouse was awarded Carer's Allowance.

2. Increase the hours a carer can work/study from 15 hours to 18.5 hours per week.

Continuing to work while caring for a loved is a necessity for many carers who depend on income from employment to supplement their social welfare payment and to meet the additional costs associated with caring. It is also critical for carers to retain a foothold in the labour market while contributing to their social insurance record and protecting their future pension entitlement. Under current rules, carers cannot work (even on a voluntary capacity) or study for more than 15 hours per week to be eligible for Carer's Allowance, Carer's Benefit or the Carer's Support Grant. This condition has not changed since Budget 2006 when the hours were increased from 10 to 15 hours per week.

There is growing anger amongst carers regarding the 15 hour restriction, particularly for carers who are free to work or study while the cared for person attends school or day care or carers who want to prepare for life after care by undertaking further education or training. It should also be noted that with regard to education the Department includes not only 'classroom contact hours' within the 15 hours, but also considers travel time to and from college, time spent on coursework etc., which means that few, if any, courses are short enough to satisfy the 15 hour limit.

The qualifying condition for both Carer's Allowance and Carer's Benefit that the carer provide full-time care, which is specified as a minimum 35 hours per week, could easily be satisfied while allowing a carer to work for 18.5 hours. The imposition of the 15 hour ceiling is regarded by many as regressive, overly restrictive and counter to the Department's own mission to promote active participation in employment and inclusion in society.

'Carers will be empowered to participate as fully as possible in economic and social life.' (National Carers Strategy, Goal 4)

3. End the Postcode Lottery in Homecare and Carer Supports.

Proposal 1: Urgently address the homecare crisis.

The Department of Health's commitment to establish a Statutory Home Support Scheme by 2021 is welcome, however families cannot wait until then to see homecare services improve. Pending the introduction of the statutory scheme, interim measures are urgently needed to address the consistent underfunding of homecare which is leaving thousands of people stuck in hospitals or forced into nursing homes when they could return home or stay at home if appropriate care was provided. It also places enormous pressure on carers to care for their loved one(s) alone and unsupported. Recent reports of growing pressure on the homecare budget means that the 6,300 people currently on the homecare

¹¹ The inclusion of carer payments was phased with 25% assessed in year 1, 50% year 2, 75% in year 3 and 100% in year 4.

waiting list have little chance of securing home support and further attests the urgent need for additional funding. *Family Carers Ireland* are calling for an increase of €110 million in the home supports budget in Budget 2020 in an effort to begin to meet actual demand for the scheme.

Proposal 2: Fund *Family Carers Ireland* to deliver our ‘Carers Guarantee’ proposal.

Despite being in line with Government policy and the clear advantages of caring for people in their own homes, funding for carers has not reflected this priority nor are essential supports offered consistently across the country. Health funding continues to be channelled disproportionately towards hospitals whilst access to community and homecare remain underfunded, inequitable and inconsistent due to their discretionary basis. Inconsistent funding, based on historical funding arrangements, means access to essential supports such as respite, home care and training is subject to a postcode lottery, whereby where a person lives, rather than what they need will determine if they can access a service or not. *Family Carers Ireland’s* ‘Carers Guarantee’ proposal sets out how, for an additional €3.2m in annual funding, we will guarantee the delivery of a core basket of services to carers across the country regardless of where they live. These services will include: access to emergency respite; intensive one-to-one support for carers in crisis; a suite of training programmes ranging from basic care skills workshops to QQI accredited ‘Caring with Confidence’ training; targeted support groups and networks for carers and access to information and advocacy clinics in local community centres, primary care centres and hospitals. If Government fail to ensure the uniform delivery of supports across the country, even more carers will reach crisis point, bringing the sustainability of their caring role into question.

‘The services you receive are dependent on where you live rather than what you need.’

Carers Guarantee of supports
 📍 **Eliminate** postcode lottery of supports for carers

For additional €3.2m pa Family Carers can access core supports locally including:

- Emergency Respite**
Major family events; medical treatment for carer
- Individual support**
One to one support for families in distress or crisis
- Training**
Basic care skills, more specialised training – end of life, life limiting conditions, challenging behaviour
- Networking**
Peer support meetings & clinics, shared experiences
- Information & Advocacy**
Advice, information on rights and entitlements, support with appeals

Family Carers Ireland

4. Replace the Mobility Allowance and Motorised Transport Grant withdrawn in 2013

The failure to replace the Mobility Allowance and Motorised Transport Schemes, withdrawn in 2013 on the grounds of age discrimination, has led to the illogical situation whereby those who received a Mobility Allowance prior to 2013 have been allowed to keep it while others now equally in need are locked out. It also means that the only transport support available to families is the Disabled Drivers and Passengers Scheme, which is targeted only at those with severe physical disabilities, with absolutely no support available to those with an intellectual disability or cognitive impairment. This prioritises the transport needs of people with physical disabilities over those with an intellectual/cognitive disability. *Family Carers Ireland* believe this is subject to legal challenge.

5. Extend the GP Visit Card to carers in receipt of the Carer's Support Grant.

The introduction of GP Visit Cards for carers in receipt of Carer's Allowance and Carer's Benefit in 2018 was a welcome first step in recognising the health and wellbeing needs of carers. However, its method of delivery means it only reaches a proportion of carers. It also imposes a means test on carers' access to the GP Visit Card by virtue of the means test applied to Carer's Allowance. This is entirely at odds with Government's plan for the universal roll-out of free GP care and counter to the universal access afforded to the over 70's and children under 5 years who are rightly not means tested. In order to reach a greater number of full-time carers and in keeping with Government's own policy of universal access, the GP Visit Card should be made available to the all carers in receipt of the non-means tested Carer's Support Grant, estimated to reach an additional 22,000 carers.

