

Opening Statement to the Joint Committee on Social Protection

Mr. Chairman, Deputies and Senators thank you for the opportunity to speak with you this afternoon. I am the Research Manager with Family Carers Ireland, the national charity dedicated to supporting Ireland's 500,000 family carers. I'm joined by my colleague Catherine Cox, Head of Communications and Policy at Family Carers Ireland and Emily Thyne, who cares for her son Malachy.

From the outset, we wish to acknowledge and welcome the work of this Committee, particularly in its efforts to better recognise and improve supports for family carers. *Family Carers Ireland* has repeatedly called for an overhaul of the Carer's Allowance scheme, which was first introduced 33 years ago, and we believe is now outdated, undervalues care work and is completely inadequate particularly with the current cost of living crisis. We therefore warmly welcome the recommendations of this Committee to increase the Carer's Allowance income disregards and work towards the full abolition of the means test and the possible introduction of a Participation Income for family carers by 2027.

In early 2024, Ireland will hold a referendum on equality and care, as recommended by the Citizens' Assembly and the Joint Oireachtas Committee on Gender Equality. If successful, the new Article 41.2 will enshrine the value of care work in the Constitution and oblige the State to take reasonable measures to support carers. Additionally, both the Citizens' Assembly and Oireachtas Committee on Gender Equality made unequivocal recommendations in relation to the reform of Carer's Allowance, with the latter specifically recommending that consideration be given to the potential introduction of a participation income that acknowledges the contribution carers give to society.

With the unequivocal recommendations of both the Citizens' Assembly and the Oireachtas Committee and a referendum on care just months away, we believe now is the time for fundamental change in how we recognise and compensate family carers. We believe it is time to begin to transition from the outdated means-tested Carer's Allowance scheme and work towards a more equitable and gender-balanced scheme for carers. One that reflects the reality of contemporary caring relationships and families today, and that values and fairly compensates the immense contribution made by carers as well as the State's reliance on them. This ambitious change requires the Department to approach its categorisation and assessment of carers in a new and progressive way. We believe that the ambition, motivation and political will exists to achieve this.

We are delighted to have been partners on this research project with Professor Mary Murphy, Dr Pauline Cullen and Mr Shane Gough from Maynooth University. We are grateful to the Irish Human Rights and Equality Commission for funding the research, which demonstrates how the introduction of a Participation Income for family carers is a feasible alternative to the outdated means-tested Carer's Allowance. Professor Murphy will present the findings and recommendations from the research. But first, Emily will speak about her experience of accessing Carer's Allowance. Thank you again for your invitation to meet you today. My colleagues and I are happy to take any questions you may have.

Thanks to you all for inviting me along today and for letting me talk to you about my circumstances. My name is Emily Thyne and I am a full time carer for my son Malachy. I would like to be clear that I am speaking not only for myself but for the many others who are in a similar caring role. I've been receiving Carer's Allowance since around February 2022 although I had started the application process in October '21, when the country was just making its first tentative steps coming out of lockdown. My industry was one of the worst affected. I was a freelance violinist. My last concert was

in the Bord Gais and was the first concert the National Symphony Orchestra played in front of a live audience since lockdown had started a year and a half before.

I had been receiving the PUP since its rollout, but had stopped and started a number of times due to the nature of my work. Between that, and being freelance, I did not fit neatly into any boxes regarding income and tax. I was registered, as all freelancers are, as self-employed, but that in itself implies I was running a business and generating my own work. I had to explain countless times that I was hired by other people through plain old word of mouth, and for being good I might add!

At first, I spent a lot of time on the phone to Citizens Information, trying to get my head around how to apply, and a lot of time printing forms. Then there was the endless amount of information needed to prove everything: doctors' certs stating Malachy's condition and how disabled he was, what he could do, what he couldn't do; 2 years of bank statements (my bank charged me €2.50 per page for that) and 6 months of statements for savings accounts, credit union, my partner's current account, even his Revolut account that he only uses for the sharing of buying coffees with colleagues at work.

After our finances were scrutinised, the hours I spend caring for Malachy were then picked apart. I explained that yes, he goes to school, yes my partner comes home by 6 and yes he's mostly around at the weekends and yes we have friends that take him now and again for respite. It felt like all the focus was on the time I "had to myself" rather than the time I spent caring for my son.

When I finally received my first Carer's Allowance payment I was relieved, and it felt like I'd won a prize. Reality has now kicked in, however. I looked up minimum wage the other day just out of curiosity. 11.30 per hour for 2023. Then I calculated that if I worked an 8 hour day 7 days a week - 8 hours is about right for school days but weekends are more like 12 hour days with no breaks - I'm getting paid a little over 4 euro an hour for the care that Malachy depends on.

At least I get paid something though. I have a friend who cares full time for her profoundly disabled son and receives no Carer's Allowance simply because her husband earns too much money. I can relate to this in some way as when I was being assessed it was noted that we had some savings. I had to point out that because of my husband's fairly average salary we would perhaps not be eligible for the full housing adaptation grant and so would have to use every last penny to adapt our 3 bedroom mid-terrace house to accommodate a downstairs bedroom and bathroom.

So here we are, me with my 4 euro an hour and my husband with his average salary. He cycles 30 minutes each way in to work and home again, with leftovers from last night's dinner in his bag for lunch. We have one car. I do the household shopping. I put fuel in the car. I supply the kids with clothes and shoes, stationery, occasional treats, all the stuff that kids need. Nearly every week I have to ask him for financial top ups. While he is trying to keep his bank balance healthy so that when we go to ask for more mortgage for the build, they won't laugh in our faces.

Malachy is 7. He is non-verbal, PEG-fed and is only now beginning to walk. And he has a full range of behavioural difficulties. They call it Severe Developmental Delay - I call it extreme parenting. To be fair, when he is in good form he's great craic. But when he has a meltdown he can get into such a heightened state that when I try to sooth him he lashes out at me with fists or fingernails. Our other kids' lives are also hugely impacted. They have less of our time. There is less money. There is very little down time for any of us. Malachy won't ever be independent. We will never buy him a housewarming present. We might always need to feed him and change his nappy. No retirement then. And as carers, we live with that every day. For 4 euro an hour. And many don't even get that, due to the means test.

Thank you.