

'Guiding support for family carers'

Dear Ms. Fallon,

We are contacting you in relation to your welcome invitation for submissions to your committee in relation to Impact of Covid-19 on people with disabilities (PWD) and the disability sector.

In parallel with the impact on PWD, we wish to highlight the impact Covid-19 is having on the 391,260 family carers¹ in Ireland.

For this reason, we would like our submission below to be considered by the committee, and also that we be considered one of the named stakeholders for this topic.

Submission

In early March, due to the public safety measures announced by the Government, families were thrown into a situation whereby respite, day care, special educational support and other services virtually disappeared overnight. These services remain (as of June 2020) largely cancelled.

Not only that, but families which experienced elevated levels of fear of themselves contracting and indeed spreading Covid-19 to their family members with disabilities, then struggled to access PPE and some had restrictions placed on access to home care.

Recently published research² point to the heightened level of depression, ill health, anxiety and isolation experienced by family carers during Covid-19. For example, 60% of family carer respondents to a survey by Family Carers Ireland worry about a decline in their own mental health as a result of Covid-19³. The type of, and intensity of care being provided by family carers is changing and increasing⁴. Caregivers during Covid-19 had a 21% greater risk of being depressed than non-caregivers⁵ – highlighting some of the difficulties being faced by this population at the current time.

Many in the general population, who were thrown into a level of lockdown in recent months, have for the first time experienced what life is like for many family carers and people with certain conditions and disabilities who live with this restricted movement and

¹ A family carer is a person who provides support and care at home to a person living with a disability, long-term health concern, mental health difficulty or other conditions which necessitates significant care.

² Carers UK, 'Caring behind Closed Doors: Forgotten Families in the Coronavirus Outbreak' (Carers UK, 2020); Family Carers Ireland, 'Caring Through COVID: Life in Lockdown' (Family Carers Ireland, 2020); Stephen Gallagher and Mark Wetherell, 'Risk of Depression in Family Caregivers: Unintended Consequence of COVID-19', preprint (Psychiatry and Clinical Psychology, 17 June 2020), <https://doi.org/10.1101/2020.06.15.20131532>; The Alzheimer Society of Ireland, 'Covid-19: Impact & Need for People With Dementia and Family Carers' (The Alzheimer Society of Ireland, 2020).

³ Family Carers Ireland, 'Caring Through COVID: Life in Lockdown'.

⁴ Carers UK, 'Caring behind Closed Doors: Forgotten Families in the Coronavirus Outbreak'.

⁵ Gallagher and Wetherell, 'Risk of Depression in Family Caregivers'.

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vulnerability all the time. Others, who for the first time needed to provide a level of support to ageing relative – or someone who is medically vulnerable - due to cocooning, got a glimpse of what family caring entailed.

Thankfully, few individuals being cared for at home have contracted Covid-19. This contrasts with the higher rates of infection, and tragically death, in residential settings, in particular those in nursing homes. This highlights even more the crucial and safe care that families provide people with disabilities, day in day out; the need for more accessible and flexible home care supports and an easing of the long-standing means-testing for carers allowance eligibility. We are also aware that access to respite is increasingly vital as families find themselves spending far more time with each other in close quarters than ever before – this can have a toll on the strongest of relationships at the best of times. With day services, schools, and respite services having been cancelled or significantly curtailed, we look forward to the safe opening of these services over time.

A significant issue which the disability sector must be aware of is the need for increased communication between the HSE, service providers and families. We appreciate that there have been many swift and necessary decisions made, and that the situation has been very fluid. However, the inadequate and sometimes complete lack of communication with families has been an issue consistently raised by family carers across disability, long-term health, mental health and ageing services.

Our own organisations response to Covid-19 was swift. In March 16th we pivoted our work, and in collaboration with a number of our member organisations, former family carers and HSE volunteers, set up a professionally moderated online support group, that now supports in excess of 1,500 family carers and provide a range of online interventions including 1-2-1 support.

We wish you well in your deliberations.

Zoe Hughes

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Care Alliance Ireland