

Children with Disabilities and their Families during the Covid-19 Pandemic

Dr. Susan Flynn, Asst. Professor, School of Social Work and Social Policy

Despite the exceptionality of present times, for some, the sense of déjà vu is as unsettling as it is undeniable. Well over a decade ago, as Ireland plummeted into the gravest period of economic recession in almost a century, the expression 'we are all in this together' began to echo across media and public space as a sentiment of consolidation.

For disability advocates, activists and allies, this was negligent on more than one count. Owing to inadequate social welfare assistance and a substantial existing disposition to poverty among other concerns, many children and adults with disabilities were facing a heightened level of poverty and material and social deprivation. Worth accenting here, was the magnitude of disadvantage that was often far from on par with abled peers. Now, some 11 years later, the phrase "we are all in this together" has resurfaced, and this time it is during a global Covid-19 coronavirus pandemic that the vexed question is prompted: are we really all in this together?

Preliminary indications have been that many of the most marginalised groups in society are experiencing pronounced difficulty. Within this, families who have a child or children with disability in Ireland are a high-risk group in the pandemic for several reasons. Evidence shows that disability is linked to higher multiple morbidity leading to decreased capacity to fight infection, as many children with disabilities experience multiple health conditions. Cocooning is therefore required for some of these children. In Ireland, children with disabilities often rely on wider social support infrastructures due to having complex needs that may include contact with many health and social care professionals.

Assistance with personal hygiene care, dressing and attending to medical treatments such as with feeding tubes, are among support tasks that make social distancing impossible for some children. Moreover, whilst disability policy in Ireland has moved away from provision of care in large-scale institutional settings, many children still receive varying degrees of care in congregated settings such as through respite and residential care homes where contact with alternating staff and peers increases social exposure. Similarly, some children with disabilities have complex medical needs that require intermittent periods of in-patient care and home care exposing them to hospital environments where they are at pronounced risk of infection.

For children who remain predominately at home with their families, there are other factors to be considered. Governmental social distancing measures and service changes has left some parents and family members with huge caring responsibilities whilst critical supports like home respite care and home help are jeopardised. Children with disabilities may also experience behavioural difficulties linked to particular conditions such as sensory problems that could be exasperated by disruptions to their routines and supports. Even everyday necessities such as walks in the community now entail risks that abled populations often don't encounter such as the need to touch public surfaces such as guiderails for children with mobility issues or surfaces to read braille.

Additional psychological and emotional distress may be encountered if the child faces barriers to comprehending what is happening in their life, for example, in the case of intellectual disability. Here, related concerns such as undermined capacity to apply social distancing measures and poor health literacy also surface. More broadly, due to the genetic basis of some disabilities, households may also have multiple children with disabilities augmenting the risk related to factors already identified. Overall, it is perhaps evident that families who have a child or children with disability may be enduring

exceptionally difficult circumstances that include both common disruptions caused by the pandemic and those additional stresses unique to disability.

From the outset, I alluded to a sense of déjà vu. It is now arguably conclusive, for me, that troubling themes which were generated within qualitative research on the lived experience of economic recession a decade ago, for my PhD research on children with disability and their families in Ireland, are of striking familiarity to problems emerging for families today. This includes extreme levels of stress for children and families driven to their last tether. Whilst of course, Covid-19 also brings new and exceptional challenges to these families that cannot be underestimated, it also remains critical that past mistakes such as lack of prioritisation, funding and resources for disability services are not repeated. Particularly, this will be the case as vital measures to address Covid-19 are underway and forecasted to produce economic recession, once again in Ireland.

Comments: sflynn7@tcd.ie

The views expressed here are those of the author and do not represent an institutional/official position of the School of Social Work and Social Policy, or Trinity College Dublin.