



Services and supports provided by the State for autistic people and their families:

Opening Statement to the Joint Committee on Autism

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Mr. Chairman, Deputies and Senators thank you for the opportunity to speak with you this afternoon. I'm joined by my colleague Clare Duffy Policy and Public Affairs Manager with *Family Carers Ireland*. Unfortunately, Mary Courtney who cares for her son Darragh is unable to join us as planned due to an illness in the family.

Family Carers Ireland (FCI) is the national charity dedicated to supporting Ireland's 500,000 family carers. Many of these carers provide support to an autistic person(s).

From the outset, we wish to acknowledge and welcome the work of this Committee. We fully support any effort by the State to improve support for autistic people and their families and that allows them to enjoy equal and full participation in education, employment and society. As other experts who have appeared before the Committee have endorsed, we believe the way best way to achieve this is through a rights-based approach, that recognises the significant strengths of autistic people and that places their voices and those of their families at the heart of planning and decision making. We also call for the full implementation of the UCPRD, including the ratification of the Optional Protocol.

Unfortunately, there is no equivalent treaty to articulate or protect the rights of family carers, and as such it is our responsibility in FCI to ensure that carers are supported and that the immense contribution they make is recognised and valued and included in any future Autism Strategy. Our contribution will therefore focus mainly on the needs of those caring for a person(s) with autism whilst also addressing the needs of the autistic person. These family members and friends who provide this care are most often the autistic person's greatest advocate and supporter.

In the interest of time, I will focus on the two areas we believe require the most urgent attention.

Realising the Constitutional Rights of Children with Autism

Children have a Constitutional right to be educated in a place and manner that is appropriate to their needs. They also have a Constitutional right to an Assessment of Need (AON). Across numerous cases, the High Court has been resolute in its findings— a lack of resources is no justification for the State to breach its obligations or to allow statutory timelines to be ignored.

Too often, children who are referred for early intervention face endless delays, may not get any or all of the services recommended, or will simply age out of services. We all know that a failure to provide children with early intervention misses a critical window of opportunity and increases the risk of significant developmental delays and ultimately costs the State exponentially in the long term.

Denying children with autism their right to an AON, education and support is not only an attack on that child, but it is also detrimental to their family, who are forced to pick up the pieces and fill the many deficits in our broken health and education system, often at a significant personal cost. Research by FCI and the College of Psychiatrists published in 2019 shows the enormous physical, mental and psychological impact that caring can have when carers are left unsupported. This survey of over 1,100 carers found that almost half had been diagnosed with mental ill-health, 67 percent suffered from physical ill-health and 75 per cent are worried about their health and well-being.¹

The failure of the State to meet its constitutional obligations also has significant financial implications, forcing many families to pay privately for assessments and interventions that they can ill afford. A study undertaken by the Vincentian Partnership for Social Justice, before the cost of living crisis and published last year shows that a household caring for an adolescent child with a profound disability faces additional costs of €244 per week when compared to a non-caring household. A significant proportion of this cost relates to having to pay privately for services that should be publicly available.

¹ 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.

As a result, the prevalence of debt, fuel and food poverty is higher amongst caring households than the general population.

It is imperative that all children with a disability get the supports they need early and often in the years when it makes the greatest difference. We are calling on Government to urgently address the gross inadequacy of children's disability services by implementing the PfG commitment to extend the NTPF to secure timely assessment for both child and adult psychological services, and to consider a similar extension of the NTPF to include occupational therapy, speech and language therapy and physiotherapy. Surely supporting children with autism to reach their full potential is as important as replacing hips and removing cataracts – both routine procedures offered through the NTPF.

In relation to inclusive education, FCI welcomes the review of the EPSEN Act, the reform of the Summer Programme and the activation of emergency legislation which compels schools to open special classes. These initiatives are long overdue, and any benefits deriving from them will ultimately be judged on whether they deliver much-needed change for autistic children and their families. We also stress that opening new school places does not alone create inclusive education, but rather must be accompanied by future planning, funding, staff resources, staff training and cultural change to embed educational inclusivity into the new norm.

Adopting a Whole of Family Approach

Living independently is a goal that we all share, however, some autistic people, particularly those with co-occurring conditions require the full-time care and support of their family. When a child or adult has autism, it affects the whole family and, in some cases, can put a severe strain on family life. In these situations, it is critical that a whole of family approach is taken and supports are in place to enable and sustain family members in their caring role.

An essential element of carer support for these families is access to regular and appropriate respite both within and outside the home. Respite provides relief from the daily demands of caring and allows parents to spend time with their other children, which is critically important. It also allows the person receiving care to have a break from their family carer and home environment whilst providing opportunity for socialisation and specialised care. Access to regular respite has also been shown to reduce the need for full-time residential care. It is deeply concerning therefore that family carers have no entitlement to respite, which means that many carers care 24/7 365 days a year without a break. While we acknowledge the efforts of Government to improve respite provision, access to regular respite remains a pipe dream for the majority of caring families.

At present, we do not have data on the number of respite places available for children or adults. This is a significant problem. We are calling for a national audit of respite provision to be undertaken by the HSE. We believe that a national respite register should be established to allow family carers to register their need for respite along with the age and details of the person for whom they care. This would provide a geographical inventory of respite need by age group and condition type. We are also calling for all full-time family carers to be given the right to a minimum 20 days respite each year, in line with the statutory annual leave afforded to paid employees. You are I are entitled to twenty-some days of annual leave per year – a family year is not entitled to a single day off.

Finally, even before Covid-19, it was agreed that a broader discussion was needed on the role of care work, including the rights and needs of family carers, the financial support available, and whether the value of care work to our society requires recognition in the Constitution. The report of the Citizen's Assembly on Care was resolute in this regard expressing a high level of ambition for change in the how family carers are recognised, valued, and supported. It recommends the reform of Carer's Allowance including changes to the means-test; increasing the hours carers can work or study; reimbursing the costs associated with care; increasing respite provision and providing a dedicated pension for family carers. We welcome the recent announcement of improvements in the State Pensions system for

long-term carers effective from January 2024, however, FCI urges Government to be ambitious and reform the Carers Allowance scheme towards a payment based on needs not means, along the lines of a Participation Income for Carers, that appropriately recognises and compensates fulltime family carers.

Of particular significance is the Assembly's recommendation to replace Article 41.2 of the Constitution, and Taoiseach Leo Varadkar's recent announcement that a referendum on care and equality will take place in November. The replacement of Article 41.2 with wording that recognises the societal value of care and obliges the State to take reasonable measures to support carers, is a milestone moment and will create an important constitutional affirmation of the public and essential good that care work provides to society and the State.

Thank you again for your invitation to meet you today. My colleagues and I are happy to take any questions you may have.