



**Opening Statement of *Families for Reform of CAMHS*
to the Oireachtas Health Committee,
Wednesday 17th January, 2024**

I would like to start by thanking the Committee for inviting us in to speak today.

As families we often have a shared feeling of our children being forgotten and our families ignored so we can't tell you how important this opportunity is for our group.

And just how crucial action and the urgent reform of CAMHS is.

Our group, *Families for Reform of CAMHS*, is a new group set up at the beginning of last summer.

Myself, Grainne and Emer, here with you today are just 3 of the parents involved and behind us we have the support of a further 820 members.

Our children are found in communities, neighbourhoods and groups right across Ireland.

For most of our members, it wasn't until we went looking for help, that we realised that mental health supports and a functioning mental health service is largely non-existent in Ireland.

That children nationwide are being failed and our families left alone without adequate support at a time when we need it most.

Reports

In the past 12 months, reports from the Mental Health Commission and the United Nations Committee on the Rights of the Child have highlighted serious concerns about the insufficient and inadequate mental health services for children. Portraying an overwhelmed and poorly governed system with inadequate staffing and resources.

But none of these concerns are new. And were raised in the UN Committee's 2016 report and in the Mental Health Commission's 2017 report.

Not only are our families being let down but also dedicated staff within CAMHS who are trying their best to help our children despite the system and not with the support of it.

The Government and the HSE have acknowledged service deficits and yet we have seen no real reform nor no real commitment to bring about change.

And children continue to suffer as a result.

Waiting list

In Ireland there are approximately 4,400 children currently awaiting first-time CAMHS appointments.

The collective number is stark. But the reality for each of the 4,400 families on the waiting list, who can't access support now, when they desperately need it, is heartbreaking.

And it is hard to sum up the feelings you experience as your child's mental health is deteriorating and you are unsure whether support will come too late.

Accessing support within the service

Once you are in the door, however, serious challenges remain.

Therapeutic supports are extremely hard to access and children are often only offered medication.

We have families who were told that their child would be discharged if they did not accept medication.

We have families who have been discharged and not told about it.

We have families who were left without support when weaning their child off serious medications.

Only 12% of our members have a care plan and key worker for their child.

35% of our members would like to make a complaint but have chosen not to because they are worried about how it would impact their child's care.

And this so strongly speaks to the vulnerable position families find themselves in, it is so difficult to get into CAMHS in the first place, that families feel they have to accept whatever is offered.

We are reliant on CAMHS.

Our children are reliant on a service that the mental health inspector cannot assure us is safe.

Reliant on a service that is not regulated.

And reliant on a service which you have to battle to gain access to and battle again to get any support beyond medication.

Key Messages

There are two key messages that we would like to convey today. We are calling on the Government to urgently:

1. Commit to and implement the Mental Health Commission's 49 recommendations to reform CAMHS, including the regulation of CAMHS; and
2. Secondly, to end the discrimination against autistic children and against children with intellectual disabilities, in the provision of mental health services.

(1) Mental Health Commission's 49 Recommendations

The official reply as to whether the Government will commit to the Mental Health Commission's recommendations is that *"Many of these reforms are being progressed, [...] under [...] national mental health policies [...] and HSE Annual Service Plans"*.

While we have no issue with the policies and service plans in place, many of which for years have already set out commitments to the reforms that we are calling for, the reality is that they are not being delivered on.

If the Government is truly committed to the reform of CAMHS, as it says it is, we urge them to publicly commit to the Mental Health Commission's recommendations. These recommendations overlap substantially with the reforms that our group is calling for. And importantly call for the regulation of CAMHS.

In this regard, we welcome the proposed legislation by Deputies David Cullinane and Mark Ward which would regulate CAMHS under the Mental Health Act and ensure that recommendations from the Mental Health Commission were taken on board and progress monitored annually.

(2) Discrimination against autistic children and children with intellectual disabilities

The second issue we would like to focus on is the discrimination experienced by autistic children and children with intellectual disabilities in mental health services.

Autistic children

85% of our members with an autistic child said that having a diagnosis of autism has negatively impacted the service and support received by their child in CAMHS.

Members mentioned that anxiety or depression was just dismissed as being part of autism rather than acknowledging and offering support for the actual mental health issues being experienced.

This is deeply concerning to us. Anxiety, depression and other mental health disorders are separate, treatable conditions. Denying a mental health diagnosis and denying mental health supports on the basis of a child being autistic cannot be justified in our opinion and is completely discriminatory.

And this is not some unheard of secret, our members are being advised by their GPs, by teachers, social workers, OTs and speech and language therapists to *not* disclose a diagnosis of autism as it is widely recognised as a barrier to gaining help from CAMHS.

One of the most concerning trends identified in our survey was that of autistic children with suicidal ideation being turned away by CAMHS. This is dangerous. And the stories being shared are heartbreaking. Parents promising their children that they will get them help and keep them safe and then being unable to do so.

Children with intellectual disabilities

81% of our members who have children with intellectual disabilities have no access to any mental health service at all.

Since September 2022, children with intellectual disabilities are no longer accepted by CAMHS but are to be seen by the specialist service known as CAMHS-ID.

However this service largely doesn't exist. There are only 4-5 partial teams in the country when there should be 16.

So essentially children with intellectual disabilities were discharged from CAMHS to nothing and to no appropriate support.

If you are in an area with no team, you cannot be referred across to an area with a team. Families have no where to turn and no timelines have been given as to when a functioning service or even a stop-gap telehealth service can be put in place.

Thank you.