Submission from

Our Children Deserve Better - Families for Reform of CAMHS

to:

- **Minister for Mental Health Mary Butler**
- **Minister for Health Stephen Donnelly**
- **Minister for Children, Equality, Disability, Integration and Youth Roderic O'Gorman**

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Contents

1. Introduction 3

2. Background 3

3. Recent Reports 4

4. Childrens Mental health in Ireland: Key Statistics 5

5. Reforms Sought 4

Reform 1: Ring-fenced funding for CAMHS 5

Reform 2: Address the clinical and administrative staffing shortage in CAMHS 6

Reform 3: Remedy issues preventing access to CAMH Services (including lengthy waiting lists and lack of consistency around acceptance of referrals to the service) 7

Reform 4: Integrate the children's mental health services with other children's services 9

Reform 5: End the practice of discrimination against autistic children in the provision of mental health services 10

Reform 6: Increase availability of supports and the types of supports offered to promote a child-centred approach to recovery 11

Reform 7: Increase the number of CAMHS-ID teams and ensure a clear referral path to access them 12

Reform 8: Appoint a key worker and provide a clear Care Plan to every under the remit of CAMHS 12

Reform 9: Substantially improve the communication and provision of information between CAMHS and families under their remit 13

Reform 10: Ensure the introduction of a transparent, accessible and safe review and complaints process. 14

1. Introduction

"Our Children Deserve Better - Families for Reform of CAMHS" is a group of over 100 families across Ireland calling for urgent and real reform of the Child and Adolescent Mental Health Service (CAMHS).

Our children are found in communities, groups and families across Ireland. Nobody knows if or when mental health challenges will occur, but we all hope that support will be available if we or our loved ones need it.

At present, the children of this country are being consistently failed and their families left alone without adequate support at a time when they most need it. Despite the importance of early intervention, lengthy waiting lists often result in a child's mental health significantly deteriorating or becoming life-threatening before an initial appointment is even offered.

Serious concerns about CAMHS have been reported repeatedly. The HSE has acknowledged that *"there are service deficits, both in terms of access, capacity, and consistency in the quality of services"*[1] and an apology has issued. Yet we have seen no real reform.

While the Government is currently considering the reduction of the number of CAMHS teams across the country[2], we demand more. More for our children and more for the 22,000 children being referred to the service every year[3].

This document sets out the key reforms that *Families for Reform of CAMHS* is calling on the Ministers and the Irish Government to implement as a matter of priority.

2. Background

In Ireland, mental health services for children are provided by Primary Care for mild to moderate mental illness and by CAMHS for children who have moderate to severe mental illness.

At present there are 11,000 children awaiting appointments for primary care psychology, with over 4,000 of these children waiting over a year. [4] There are 4,500 children waiting for first-time CAMHS appointments and this accounts only for the children who have not been turned away from the service. In addition, the number of children with medical referrals to CAMHS being refused by the Service has jumped by 12% since 2020.

For those children who secure an appointment with CAMHS, they are often met with a service that lacks capacity to provide appropriate therapeutic interventions and with absent or poor care planning.[5]

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[1] Oireachtas sub-committee on mental health, 14 February 2023 HSE chief operations officer Damien McCallion
[2] Parliamentary Question response:26974/23: as a means of tackling the lack of staff by centralising services
[3] Oireachtas sub-committee on mental health, 14 February 2023 HSE chief operations officer Damien McCallion
[4] Oireachtas Debate: 24/05/2023
[5] See Mental Health Commission's Interim Report, January 2023.

3. Recent Reports

In January, an Interim report was published by the Mental Health Commission ahead of a final report - due later this year - as a result of "*the serious concerns and consequent risks for some patients*" of CAMHS which requires urgent and targeted action. The Report highlighted an overwhelmed and poorly governed system with inadequate staffing and resources contributing to inefficient and unsafe CAMHS services.

This report was followed in February, by the Observations of the United Nations Committee on the Rights of the Child. The Committee raised serious concerns about the *"insufficient and inadequate mental health services for children"* in Ireland and urged the Government to *"ensure the availability of therapeutic mental health services and programmes for children",* including by *"significantly increasing the resources allocated for the implementation and monitoring of the mental health policy".*

The concerns and recommendations pointed to in recent reports are not new. The Mental Health Commission previously highlighted serious concerns in its 2017 Report relating to inadequate staffing, variation in funding, waiting lists, referrals and emergency cover. In the 2016 Observations, the United Nations Committee on the Rights of the Child recommended that the Government *"undertake measures to improve the capacity and quality of its mental health services for children and adolescents"*. [6]

4. Reforms Sought

Families for Reform of CAMHS believe that all children have a right to facilities, appropriate support, treatment and intervention to ensure the highest attainable standard of mental health and rehabilitation in line with Article 24 of the United Nations Convention on the Rights of the Child[7].

The group has identified 10 key reforms that it calls on the Ministers and the Irish Government to implement as a matter of urgency:

1) **Ring-fenced funding for CAMHS;**
2) **Address the staffing shortage in CAMHS (both clinical and administrative staff);**
3) **Remedy issues preventing access to CAMH Services (including lengthy waiting lists and lack of consistency around acceptance of referrals to the service);**
4) **Integrate the children's mental health services with other children's services;**
5) **End the practice of discrimination against autistic children in the provision of mental health services;**
6) **Increase availability of supports and the types of supports offered to promote a child-centred approach to recovery;**

[6] https://www.childrensrights.ie/resources/un-committee-rights-child-concluding

[7] Article 24 of the United Nations Convention on the Rights of the Child

7) **Increase the number of CAMHS-ID teams and ensure a clear referral path to access them;**
8) **Appoint a key worker and provide a clear Care Plan to every child under the remit of CAMHS;**
9) **Substantially improve the communication and provision of information between CAMHS and families under their remit; and**
10) **Ensure the introduction of a transparent, accessible and safe review and complaints process.**

Numerous Government and HSE policies are consistent with the reforms being called for and a number of the reforms have already been committed to but never delivered on. We urge the Ministers and the Government to now move into a place of real implementation so that the prioritisation of children's mental health services is not limited to ideals and rhetoric.

5. Childrens Mental health in Ireland: Key Statistics

As the statistics below illustrate, mental health challenges amongst children in Ireland is common. They are not solely confined to a minority of the population and many families will be impacted at some point in time.

Suicide

- In 2017, Ireland was ranked fourth highest in the EU/OECD region for teen suicide. For girls, Ireland ranked the highest for girls dying by suicide in Europe.[8]

Self-harm (including attempted suicide)

- The number of children aged 10-14 years who are self-harming has increased indicating that the age of onset of self-harm is decreasing[9].
- In 2020, One in every 128 girls between the ages of 15-19 presented to hospital due to self-harm[10].

Mental health

- In 2021, Ireland ranked in the bottom one-third of 41 countries in the EU/OECD for child mental health[11]

[8] https://www.unicef.ca/sites/default/files/2017-06/UNICEF%20Innocenti%20Report%20Card%2014%20EN.pdf
[9] Ibid.
[10] https://www.nsrf.ie/wp-content/uploads/2022/11/NSRF-National-Self-Harm-Registry-Ireland-annual-report-2020-Final-for-website.pdf one in every 233 boys between the ages of 15-19. Self harm includes intentional drug overdose, self-cutting, attempted hanging, attempted drowning, self-poisoning.
[11] Ireland was placed 26th out of 41 countries for child mental health: https://www.unicef-irc.org/publications/pdf/Report-Card-16-Worlds-of-Influence-child-wellbeing.pdf

Reform 1: Ring-fenced funding for CAMHS

At present, there is no specific annual budget allocated to mental health services for children in Ireland but rather funding is provided for under an overall centralised mental health budget. The Mental Health Commission highlighted the issue that this approach is causing in terms of competition between mental health services for resources, "*the CHOs* [Community Healthcare Organisations] *could not plan for the services they needed for Camhs, based on a Camhs budget, and there was unavoidable competition between projects for adult and children's mental health services when looking for funding.*" [12]

Given the urgency of the reforms required within CAMHS and the requirement for prioritisation and appropriate planning of these services, *Families for Reform of CAMHS* is calling for ring-fenced funding for CAMHS. Ring-fenced funding for CAMHS would be in line with the UNCRC Committee recommendation that the Government incorporate a child rights-based approach into the State budgeting process and define specific budget lines for all children[13].

Families for Reform of CAMHS **calls for:**

(1) annual ring-fenced funding for CAMHS which takes into account the commitments made by Government and the HSE over the last decade and the funding required to ensure a safe, effective and child-centred service going forward.

Reform 2: Address the clinical and administrative staffing shortage in CAMHS

The Mental Health Commission's Interim Report found that CAMHS teams are seriously understaffed, with not one CAMHS team being fully staffed and with some teams operating at below 50% of what they should be. The Report also highlighted that:

- Despite serious difficulties in retention and recruitment, many posts that should be funded to provide a basic service are not approved nor funded[14].
- There is great variations in staffing levels and availability of different disciplines across CAMHS, leading inequalities where some services are not able to provide basic treatments which other CHOs do.
- There are no Practice Managers and only four clinical (Team) Coordinators in the CHOs reviewed, where there should be one Practice Manager and one Team Coordinator in each CAMHS team.

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[12] Mental Health Commission's Interim Report, January 2023.

[13] Observations of the United Nations Committee on the Rights of the Child, February 2023.

[14] Approval for staff is done by the HSE centrally and not locally which *"leaves skill gaps in teams and clinicians in posts that have not been prioritised and leads to the CHOs having a lack of control as to the services they provided."* Mental Health Commission's Interim Report, January 2023.

- In general, teams are operating at about 50% of their recommended administrative staff. This impacts the amount of clinical time as clinicians try to cover administrative and clerical duties.
- There are team co-ordinators in only four teams out of the 45 teams reviewed to date, despite this being a recommendation of *A Vision for Change in 2006* (with no proposals on this in *Sharing the Vision*).

While we acknowledge the current difficulties in retention and recruitment issues, there are steps which should be taken as a matter of urgency to begin tackling the staffing issue and the consequent challenges it causes.

***Families for Reform of CAMHS* calls for:**

2(i) Adequate funding and greater transparency and streamlining/decentralisation of the approval system to fill vacant clinical posts;

2(ii) Consideration and identification of other models to deliver a mental health service for children based on international best practice and implementation of same;

2(iii) Increase the availability and quality of Primary Care and Social Care services to decrease the strain on CAMHS service and better facilitate early intervention before CAMHS intervention is required;

2(iv) Set benchmarks for CAMHS staffing nationally and develop clear action plans on how these targets will be met and maintained;

2(v) Ensure a practice manager and team coordinator for each CAMHS team; and

2(vi) Ensure CAMHS teams are fully staffed from an administrative perspective so that clinical staff can focus fully on their clinical duties.

Reform 3: Remedy issues preventing access to CAMH Services (including lengthy waiting lists and lack of consistency around acceptance of referrals to the service)

Waiting Lists:

Many of our children were on waiting lists for considerable periods of time before any support was available. There was no support available for our families while the mental health challenges being experienced by our children were less serious in nature. Instead, we had to watch our child's mental health deteriorate and wait until the symptoms became extremely serious and potentially life-threatening before an appointment from CAMHS could be secured.

Oftentimes members of this group were so worried about the wellbeing of their child, that they were compelled to take the step of going to the Emergency Department of their local hospital in order to receive an appointment with CAMHS.

This is the complete opposite of early intervention.

A Vision for Change, the State's previous mental health policy, recommended the establishment of 129 CAMHS teams[15]. It was due for implementation in 2016. The recommendation has not been implemented and its successor policy *Sharing the Vision* set out no objective in this regard.

At present there are 75 CAMHS teams in place and Government is considering reducing the number of teams to 50 or 55. The reduced number of teams would be '*fully staffed and funded and able to offer the supports families want*[16]', however we feel that this approach is highly questionable.

Reducing and centralising CAMHS teams does not appear to be a solution to staffing issues but rather a reshuffling of existing resources to give the appearance of change. If this change is carried out in a manner similar to the recent reshuffling of CDNT teams, the change will inevitably lead to further delays given the administrative and logistical challenges and time requirements to carry out such a move.

The more likely outcome is that families will continue to sit on lengthy waiting lists before being seen and will now be travelling an extra 30 minutes for appointments for services where the CAMHS team are servicing a much wider number of families and continue to not have the number of staff required for the number of children requiring support.

Families for Reform of CAMHS is calling for the issue of waiting lists to be tackled by increasing staff numbers and resources in line with the reforms set out above under 2(i) and 2(vi) and to consult with families before progressing with any further plans to reduce CAMHS teams.

Lack of consistency around acceptance of referrals to the service

The Interim Report of the Mental Health Commission highlighted that the rates for acceptance of referrals varied hugely between 38% and 81%. Many of our children receive repeated refusals to be accepted by CAMHS despite GP letters setting out the necessity for that support. When CAMHS refuse to see our children, we are forced to reapply and reapply again or to take the step to attend the Emergency Department before being accepted to the Service.

In addition, many of our members have had difficulty referring their autistic child to the service despite there being clear mental health challenges being experienced (See Reform 5 below).

This is not good enough. It creates a lack of trust in the system, increases the stress and distress of families already in crisis and, without any supports available, it puts our children at risk. We are calling for greater transparency around the CAMHS criteria for acceptance for an assessment and a fair assessment that is applied nationally.

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[15] *A Vision for Change* recommended 2 CAMHS teams should be established for each sector of 100,000 and that each team should comprise one consultant psychiatrist, one doctor in training, two psychiatric nurses, two clinical psychologists, two social workers, one occupational therapist, one speech and language therapist, one child care worker and two administrative staff.

[16] PQ 26974/23 Minister for Mental Health Mary Butler

Families for Reform of CAMHS calls for:

3(i) **The increase of staffing and resources, in line with those recommended in [*A Vision for Change*] to tackle lengthy waitlists and provide timely support to children experiencing mental health issues;**

3(ii) **Early consultation with families on the impact that centralising CAMHS supports would result in for them; and**

3(iii) **Greater transparency around the CAMHS criteria for acceptance of referrals to the service and consistent application nationally.**

Reform 4: Integrate the children's mental health services with other children's services

At present CAMHS is under the governance of the HSE Mental Health Services which is separate from all other children's services such as Primary Care psychology, speech and language therapy and occupational therapy, Tusla and the Community Disability Network Teams (CDNTs), which provide other mental health and disability services for children.

Although separately governed, the intention is that these services would be coordinated, and relevant supports would be available to the child depending on their changing needs.

This is far from the reality.

Members of our group are mostly faced with a myriad of endless and uncoordinated waiting lists and are left in a position where each service points to a different service as being the one responsible. In addition, once a child is on a CAMHS waiting list, they place on another waiting list is stalled/paused even if the service is to provide a different type of support such as under the CDNT and even if they were on that other waiting list for a number of years already.

Joint working appears rare and suggested meetings between CDNT and CAMHS never seem to come to fruition. This 'pass the buck' approach can leave us stuck and in a position where our children are not getting any relevant/effective support.

Families for reform of CAMHS is calling for the integration of CAMHS with other Children's services:

Families for Reform of CAMHS calls for:

4(i) **Proper links and joined up working between services with a clear move away from the current 'pass the buck' approach.**

4(ii) **Allocation of a key worker who acts as a single point of contact for each child and family to help them navigate the system and coordinate across services. [See also Reform 8]**

Reform 5: End the practice of discrimination against autistic children in the provision of mental health services

CAMHS Operational Guidelines set out that admission can be refused to autistic children "where there is an absence of a moderate to severe mental disorder" but that where there is such a disorder, "*it is the role of CAMHS to provide appropriate multi-disciplinary mental health assessment and treatment for the mental disorder. This may involve joint working or shared care with other agencies including HSE Primary Care, Children's Disability Network Teams, and other agencies supporting children and adolescents.*"

At the time when a child is being referred to CAMHS, it is unlikely that they have already received a diagnosis of a "moderate to severe mental disorder" but are experiencing symptoms which require support and assessment to see what might be causing the issues.

We are dependent on CAMHS to make that assessment and diagnosis.

Yet our experience has been that CAMHS is routinely turning away our autistic children and refusing medical referrals without even meeting and assessing the child to see whether a mental health disorder is present. Many of our members have to make repeated referrals for their autistic children, some turn to the Emergency Departments of hospitals to receive an initial diagnosis which can then be used to access CAMHS, and some never receive help. A burden of proof is placed on families of autistic kids over and above that placed on families of neurotypical children.

Where the initial referral is accepted, families are oftentimes then met with an uphill struggle where all symptoms are linked back to the autism diagnosis and the family is told that the CDNT should be providing the support. Again the burden is placed on families to *repeatedly* explain and set out how the issues being experienced are not typical of the child, inconsistent with their usual personality and traits and are causing severe distress.

The fact that autistic children disproportionately experience mental health challenges[17] and often experience a dual diagnosis of autism and a mental health challenge appears, in our

***Families for Reform of CAMHS* calls for:**

5(i)	**An end to the systemic discrimination against autistic children in the provision of mental health services and greater recognition of the prevalence of mental health issues amongst autistic children.**
5(ii)	**An end to the refusal of assessments for mental health issues for autistic children without ever meeting them.**
5(ii)	**Greater training for CAMHS staff on supporting autistic children**

[17] Autistic children 28 times more likely to consider suicide than non-Autistic children: https://asiam.ie/camhs-report-must-address-structural-discrimination-experienced-by-autistic-children-and-young-people/

experience, to be ignored during the referral and initial assessment stages. *Families for Reform of CAMHS* calls on the Ministers and Government to end the systemic discrimination of autistic children.

Reform 6: Increase availability of supports and the types of supports offered to promote a child-centred approach to recovery

Supports

At present, the supports most frequently offered to our children include medication and training courses for parents. While medication and training courses can be very valuable, obtaining therapeutic supports can be very difficult and, in some cases, impossible.

The Mental Health Commission's Interim Report found a wide variability of services being provided with some teams not having "*the necessary capacity and training to provide standardised therapy in many cases"* and which leads to *"inequalities of care for children dependent on their address".*

We call for more consistent availability of therapeutic supports and proactive intervention for our children. We also call for eating disorder services and gender and sexuality services to be provided by all CAMHS teams.

Out of Hour Services

Currently, the majority of children can only access out-of-hours mental health treatment through hospital emergency departments as most CAMHS operate a 9 – 5, Monday to Friday model. Attending a hospital emergency department can be a distressing and overwhelming experience for a child. We call on Ministers and the Government to fulfil the commitment provided in the 2019 Health Service Executive Service Plan to develop a seven day per week CAMHS service.

***Families for Reform of CAMHS* calls for:**

6(i) **Therapeutic supports and proactive intervention for our children based on their individual needs available consistently across the country;**

6(ii) **An end of the practice of discharging (or threatening to discharge) children whose families decide not to use medication or take part in a parenting course;**

6(iii) **Proper provision of eating disorder services and gender & sexuality services**

6(iv) **Delivery of the commitment to provide out-of-hours mental health treatment for children.**

Reform 7: Increase the number of CAMHS-ID teams and ensure a clear referral path to access them

The CAMHS-ID model was launched in September 2022. The Mental Health Commission's Interim Report highlighted that there should be 16 teams across the country, but nationally there are only 4 teams. Staff capacity is at 23% of recommended levels and adult teams are better resourced.

We call for the urgent allocation of CAMHS ID teams for all areas and a clear pathway of referral for families to access these services.

***Families for Reform of CAMHS* calls for:**

7(i) The provision of the full 16 CAMHS-ID teams across the country to implement the CAMHS-ID model; and

7(ii) A clear referral pathway for CAMHS-ID.

Reform 8: Appoint a key worker and provide a clear Care Plan to every child under the remit of CAMHS

The HSE CAMHS Operational Guidelines 2019 sets out that each child should be allocated a key work and that they and their parent(s) should be informed who their key worker is. The key worker is to take responsibility for remaining actively in contact with the family and coordinate care provided by all team members. In addition, the Guidelines set out that each child should have an Individual Care Plan which describes the levels of care and treatment needed to meet the assessed needs, is outcomes focused and is developed in collaboration with the child and their parent(s).

Our experience is that many of our children have not been assigned a key worker and if they have there has been little contact nor a meaningful fulfilment of this role.

The Mental Health Commission's Interim Report found that in 40% of clinical files there was no documented key worker and that where there was a key worker, care planning was either absent or of such poor quality to be meaningless in many teams.

We are calling for the appointment of a key worker for each child who fulfils the functions set out in the CAMHS Operational Guidelines and the development of an Individual Care Plan which is developed with and communicated to parents so that they are aware of next steps and how their child is being supported. Ideally the role of a key worker would be expanded to help a family coordinate their child's care, not only within the mental health service but across systems.

An additional idea would be to create a contact point for families who looks at the overall needs of the child and works to identify and coordinate services on their behalf. The advantage of this approach would be to save time for services by preventing instances where children are being referred to the wrong services and to avoid scenarios where families are being passed from service to service.

Families for Reform of CAMHS **calls for:**	
8(i)	**The appointment of a key worker for each child who fulfils the functions set out in the CAMHS Operational Guidelines and who coordinates with other Childrens Services;**
8(ii)	**The development of an Individual Care Plan for each child which is developed with the family and communicated to parents so that they are aware of next steps and how their child is being supported; and**
8(iii)	**Consideration of creating a new point of contact for families whose role it would be to assess the overall needs of the child and work to identify the relevant supports and coordinate services on their behalf.**

Reform 9: Substantially improve the communication and provision of information between CAMHS and families under their remit

The common experience of most our members involves the necessity to make frequent and repeated phone calls to CAMHS to try and find out any information in respect of our child's care or when their next appointment date might be. As emails are not accepted, members often resort to writing letters if they reach a dead-end with phoning.

With a high turnover of staff, families often do not know who is on their child's team and who is looking after their care. They are generally not informed of the services that their local CAMHS can provide nor how CAMHS operates.

Information is not provided around relevant supports, for example the Long-term Illness Scheme or Domiciliary Care Allowance nor other local groups or organisations which might be of assistance.

The Joint Working Protocol Primary Care, Disability and Child and Adolescent Mental Health Services sets out that CAMHS "*will aim to provide comprehensive information to families and other referrers and by communicating with all relevant parties effectively and efficiently".* This has not been the experience of our families.

Families for Reform of CAMHS **calls for:**

9(i)	**Proactive and responsive communication between CAMHS and families about the care of their child;**
9(ii)	**The provision to families of a list of services offered by their local CAMHS team and a "Whose Who" of the team looking after their child;**
9(iii)	**The provision of a short booklet or a copy of the CAMHS Operational Guidelines to each family to ensure that they are aware of the structures of CAMHS and the services that they should expect; and**
9(iii)	**The provision of information to families in relation to relevant supports that might be of help to that family.**

Reform 10: Ensure the introduction of a transparent, accessible and safe review and complaints process.

The HSE CAMHS Operational Guidelines 2019 sets out that:

- Every child and adolescent attending CAMHS, and their parent(s), should be invited to contribute to feedback about their experience of CAMHS. This can be in the form of positive comments, suggestions or complaints.
- The details of the complaints procedure and the nominated person for dealing with complaints should be on display in a prominent position within each CAMHS premises.

However, opportunity for feedback or information about how to make a complaint is something that has not, in general, been provided to our members.

Objective 3 of the National Strategy on Children and Young People's Participation in Decision-Making *is that "Children and young people will have a voice in decisions that affect their health and well-being, including on the health and social services delivered to them."* However, in the 2023 survey held by the Ombudsman for Children, only 11% of children believed that the CAMHS staff listened to them and 27% believed the staff were dismissive.

Families for Reform of CAMHS calls for greater opportunity for children and their families to be listened to and heard and to have early opportunities to provide feedback.

Members of our group have expressed concern about whether submitting a complaint would have a negative impact on the care their child received. And those members who had made a complaint in the past did not have a positive experience.

Families for Reform of CAMHS **calls for:**

10(i)	**Children and their families being listened to and having a voice in decisions involving their care;**
10(ii)	**Opportunity for early and regular feedback;**
10(iii)	**The provision of information to all families about how to submit feedback or a complaint and the process involved; and**
10(iv)	**The development of a transparent, accessible and safe complaints process.**