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Bealtaine 2024

Joint Committee on Children, Equality, Disability, Integration and Youth

Report on CAMHS and Dual Diagnosis

May 2024

33/CDEI/22

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Leas-Cathaoirleach

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Senator Erin McGreehan, Fianna Fáil

Senator Ned O'Sullivan, Fianna Fáil

Senator Lynn Ruane, Independent

Senator Mary Seery Kearney, Fine Gael

Foreword

The time for reports, reconfigurations, and pilots for addressing the crisis in youth mental health has long passed. Yet, because of the slow pace of action in this area, several overdue reforms, especially those aimed at improving supports for those with a dual diagnosis, are only now in their infancy. The Committee is therefore trying to be optimistic about recent and ongoing changes in approach and personnel, while being mindful that it has been down this road with the HSE before, when it undertook a module on the assessments of need process for children. Following that engagement, the Committee published a report containing several recommendations aimed at improving the situation, but it would appear the situation regressed.[1]

Of particular concern for the purposes of this report, is dual diagnosis and the extra challenges that young people with a mental health need, who are either autistic or experiencing addiction/substance abuse, have accessing support. This is particularly pressing when you consider that autistic people are seven times more vulnerable to suicide and that addiction/substance abuse also carries an increased suicide risk.[2] Lives are literally on the line and a failure to introduce immediate and meaningful measures now is a failure to do all we can to prevent young lives being lost.

This Committee rarely makes unreasonable demands of Ministers or Departments and is generally quite understanding that where the recommendations it makes cannot be implemented there is a valid reason. As we are coming towards the end of this Dáil, the Committee requests that the recommendations made in this report are considered by relevant Minister(s) and implemented during the lifetime of this Dáil. We owe it to our young people, whose mental wellbeing plummeted in recent years, yet who did so much during the Covid-19 pandemic to keep loved ones safe.[3]

The following are some key asks:

- An immediate top-up of funding, separate to the existing budgetary allocation, of €25M should be provided for further implementing Sharing the Vision.

[1] High Court: HSE ordered to provide assessment of need for disabled child after third set of judicial review proceedings | Irish Legal News
[2] The Dáil discussed this on 7 March 2024 during a debate on the final report of the Joint Committee on Autism: Report of the Joint Committee on Autism: Motion – Dáil Éireann (33rd Dáil) – Thursday, 7 Mar 2024 – Houses of the Oireachtas
[3] Mental health - Consilium (europa.eu) and Mental health | Health at a Glance 2023 : OECD Indicators | OECD iLibrary (oecd-ilibrary.org)

- Separate funding of no less than €25M should be provided immediately for resourcing organisations in the community and voluntary sector that provide mental health supports and general youth support services, as these are key to prevention and early intervention.
- More meaningful, ambitious and measurable targets should be set in relation to mental health. The improved targets should revolve around waiting lists, but just as importantly, around satisfaction among parents and young people, good standards of care and positive outcomes for users of CAMHS.
- Changes in hours, pay and tax should be implemented as tools to recruit and retain workers in the health services, disability services and social services sectors.
- Pathways to quickly developing graduates and upskilling experts in relevant fields must be activated and capitalised on as a matter of urgency to address the staffing crisis in health, disability and social services.
- CAMHS should be exempt from any ongoing and future recruitment freezes.

Kathleen Funchion TD
Cathaoirleach to the Committee
May 2024

Introduction, witnesses, transcripts and acronyms

At the outset it is important to flag:

- If any young person needs immediate support Text About It by spunout is free, anonymous and available 24/7. Text HELLO to 50808 to start a conversation or *0861800280 for An Post or 48 network customers.*
- Following the Interim Finnerty report, a review was set up to investigate cases where a young person has not been seen by the service in six months. Parents or guardians with a concern or query about their child currently attending CAMHS can call the HSE at 1800 700 700 to arrange for someone from the child's CAMHS team to contact them if necessary.

Despite the heroic efforts of many working in the sector, disability and mental health supports are not currently being adequately provided by the State, nor have they been for some time. This represents a serious infringement of people's rights and persists, despite increased investment and what appears to be an endless stream of new protocols, pilots, policies, reconfigurations, action plans and road maps. This failure is evidenced by extremely long waitlists, people going to court to have their rights to interventions upheld, others emigrating, reports of parents deferring to Tusla because they cannot cope due to inadequate support, as well as commentary by legal and health experts, campaigners and the media. The HSE has also recently issued apologies to this affect.

Child and Adolescent Mental Health Services (CAMHS), in particular, has received much scrutiny and criticism of late. This has led to a number of Oireachtas Committees considering issues related to CAMHS. For example, on 8 November and 15 November 2023, the Joint Committee on Disability Matters discussed CAMHS at length in the context of *Rights-Based Care for People with Disabilities* and on 11 October 2023 and 17 January 2024 the Joint Committee on Health discussed CAMHS. This Committee decided to focus primarily on access to CAMHS for individuals who have received a dual diagnosis.

Dual diagnosis was defined by stakeholders who came before the Committee as follows:

> "Our mental health policy defines "dual diagnosis" as the term used when a person experiences both a substance misuse issue and a mental health difficulty such as depression, anxiety or psychosis. Treatment options must address both. Dual

> diagnosis may also refer to someone who has a mental health difficulty alongside an intellectual disability, autism or both." - Mental Health Reform
>
> "Dual diagnosis means that one person can have a moderate-to-severe mental illness at the same time as a substance use disorder or a behaviour or process addiction. Young people with dual diagnosis may become anxious, depressed, psychotic. Like any other group of people, they can have suicidal ideation, harm themselves, or attempt suicide. They may have significant autism spectrum disorder behaviours and traits, and significant attention deficit hyperactivity disorder behaviours, and they can have problems with eating behaviour just like anyone else." – SASSY

The HSE publication on its model of care for dual diagnosis states that research suggests that up to half of those attending Community Mental Health Teams have co-morbid substance use disorder. It also states:

> "The definition of Dual Diagnosis for this Model of Care is: 'the co-morbid disorders due to substance use and/or addictive behaviours along with the presence of mental disorder(s)'. The disorders of substance use include disorders of alcohol use."

Much good work has already been done in terms of analysing the general problems associated with CAMHS. Detailed reviews and reports, such as the Maskey report, Youth Mental Health Taskforce report, Sharing the Vision, various reports by the Ombudsman for Children, and the Finnerty report have identified the main issues preventing the service from running effectively for most children and young people and provide a pathway on how to resolve them.

The Committee's rationale for focusing on CAMHS and dual diagnosis specifically is that Members have concerns that those with a dual diagnosis may be excluded from essential supports. The Committee wished to highlight this, to hear what positive steps are being taken to address it, and to advocate for a faster expansion of services that can appropriately support such children and young people, in line with their rights. This report is not exhaustive but discusses some of the ways children with a dual diagnosis are being impacted and some of the steps the HSE is taking to remedy that. It explores these matters through the following key issues:

1. Funding and Personnel
2. Access
3. Suitability
4. Prevention
5. Strategy and Operations
6. Governance and Legislation

List of witnesses and transcript

Meeting date	Witnesses
6 December 2023 Transcript	**Session 1** The Substance Abuse Service Specific to Youth (SASSY): • Dr Gerry McCarney, Child and Adolescent Psychiatrist • Ms Maeve Geraghty, Counsellor Mental Health Reform: • Ms Ber Grogan, Policy and Research Manager • Ms Neil Moore Ryan, Grassroots Forum Member **Session 2** HSE: • Mr Bernard Gloster, Chief Executive • Dr Amanda Burke, Child and Adolescent Consultant Psychiatrist and National Clinical Lead for Child and Youth Mental Health • Ms Mellany Mcloone, Chief Officer, Dublin North City and County

Acronyms

CAMHS = Child and Adolescent Mental Health Services

HSE = Health Service Executive

SASSY = Substance Abuse Service Specific to Youth

YODA = Youth Drug and Alcohol Service

UN = United Nations

UNCRC = United Nations Convention on the Rights of the Child

PMB = Private Member's Bill

ISPCC = Irish Society for the Prevention of Cruelty to Children

PBO = Parliamentary Budget Office

NDP = National Development Plan

AON = Assessment of Needs

A&E = Accident and Emergency Department

GP = General Practitioner

CHO = Community Healthcare Organisations

All recommendations

The Committee recommends that:

1. An immediate top-up of funding, separate to the existing budgetary allocation, of €25M should be provided for further implementing Sharing the Vision.
2. Separate funding of no less than €25M should be provided immediately for resourcing organisations in the community and voluntary sector that provide mental health supports and general youth support services, as these are key to prevention and early intervention.
3. The mental health budget should be increased substantially year-on-year, for the next decade. This spending should be seen as an investment that will lead to less people experiencing severe or complex mental health issues and will ultimately save the State money in the long term.
4. More meaningful, ambitious and measurable targets should be set in relation to mental health. The improved targets should revolve around waiting lists, but just as importantly, around satisfaction among parents and young people, good standards of care and positive outcomes for users of CAMHS.
5. Changes in hours, pay and tax should be implemented as tools to recruit and retain workers in the health services, disability services and social services sectors.
6. Pathways to quickly developing graduates and upskilling experts in relevant fields must be activated and capitalised on as a matter of urgency to address the staffing crisis in health, disability and social services.
7. CAMHS should be exempt from any ongoing and future recruitment freezes.
8. Health, disability and social services must be recognised as essential services and protected and staffed accordingly.
9. A young person being autistic should not be used as an exclusion criterion for assessment or treatment of young people by CAMHS.
10. Access to CAMHS must be available for those with a dual diagnosis, i.e., young people with severe mental health issues, who are also autistic or experiencing addiction/substance abuse.

11. Where possible, CAMHS should coordinate with those who either know the child or make the referral.
12. The existing protocols, frameworks and guidance for joint working across the services that support vulnerable children need to be implemented and followed.
13. Strong legal provisions should be made to ensure that the State meets children's needs and that the relevant bodies cooperate to deliver that.
14. The nuts-and-bolts issues within HSE teams on the ground need to be addressed.
15. The obstacles to high level policies, procedures and guidance actually being implemented on a day-to-day and case-to-case level need to be overcome, as a priority.
16. The autism protocol and the single point of access should be implemented as a priority and in a way that takes accounts of young people's rights and delivers a good standard of care.
17. Improvements are needed in the translation of policy changes at management level into workable procedures on the ground that improve young people's access to and experiences of CAMHS.
18. Consistency is needed across CAMHS teams, with care being timely, child centred and rights-based across the board.
19. Reports of overmedication must continue to be investigated and addressed and medication should not be used as a substitute for contact time with therapists, which must be available to young people experiencing severe mental health issues, in real time.
20. Young people's cases cannot, ever again, 'fall through the cracks' or 'go off the radar', as has been the case in the past.
21. The youth mental health pathfinder project should be implemented.
22. Care plans and key workers should be provided for each young person engaging with CAMHS.

23. YODA and SASSY should be resourced to a much greater degree, and other similar teams established around the country.

24. Services should be improved by:

    - Increasing CAMHS ability to deal with addiction/substance abuse.
    - Increasing adolescent addiction services ability to deal with mental health symptoms.
    - Building a culture of communication and collaboration between the two services.

25. Staff numbers need to increase but so too does the multidisciplinary nature of teams; psychiatrists, clinical nurse specialists, clinical psychologists, occupational therapists, counsellors, and importantly family therapists, and more being required.

26. The World Health Organization's QualityRights e-training, which is on human rights and mental health and is free, should be undertaken by all those working in the area of mental health services, including trainee grades.

27. Aside from CAMHS, the other organisations in a position to support those experiencing less severe mental health issues need to be resourced to 'catch up' with the crisis in youth mental health and expand the range of services needed to work cohesively together.

28. Given reports of young people being deemed too high-profile for Jigsaw but not severe enough for CAMHS, the existing organisations need to be resourced to widen their criteria, or alternatively a middle ground service set up.

29. The school curriculum should include modern media literacy to help equip young people with the tools to deal with content they encounter online that could negatively impact their mental health.

30. As recommended by the UN Committee on the Rights of the Child, the root causes of suicide and self-harming need to be addressed, through psychological, educational and social measures and therapies for children and their families.

31. Much improved strategic co-ordination of child and young person-centred care is needed both at policy level and at implementation level.

32. The exclusion of autistic young people from CAMHS hubs and the reference to that in the CAMHS Hubs Model of Care document should be remedied.
33. Breaches of the right of children to enjoy the highest attainable standard of physical and mental health must stop.
34. Legislation to adequately regulate CAMHS should be enacted as a matter of urgency.
35. Provisions should be made for 16- and 17-year-olds to make decisions about their healthcare treatment, including mental health treatment, which align with those in development as part of the reform of the Mental Health Act.

Funding and Personnel

Funding

Mental Health Reform highlighted that there was no new development funding allocated to Sharing the Vision, Ireland's national mental health policy, in 2024, nor any increase in funding for organisations in the community and voluntary sector that provide mental health supports, even though demand for their services has increased exponentially. Mental Health Reform have called for an additional €25M in the budget for voluntary and community providers, such as organisations like Jigsaw, Pieta, the ISPCC and A Lust for Life, to meet the growing demand for support. Funding voluntary and community providers, and services generally aimed at supporting young people before they experience severe mental health issues, as well as making Sharing the Vision a reality, will be key to slowing the cascade of cases into CAMHS, which is designed to cater for severe cases only. This is discussed further in the Section on *Prevention*.

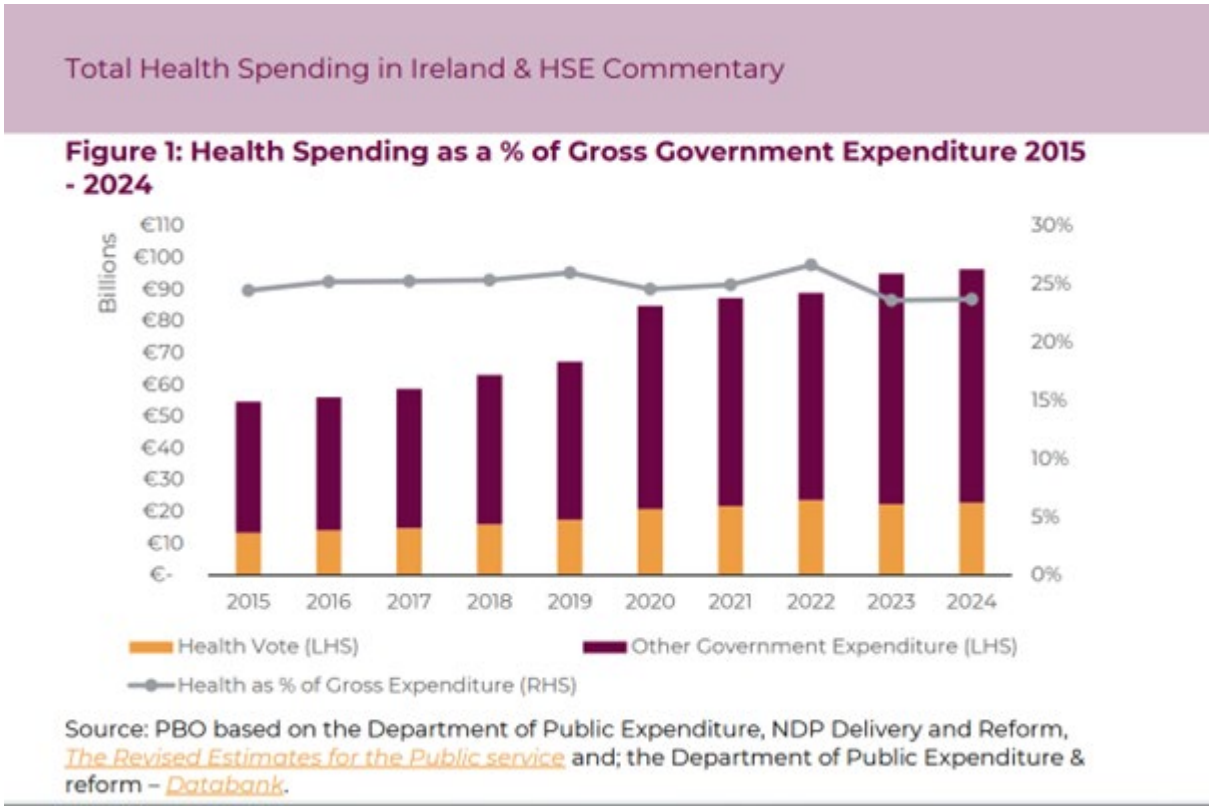
During discussions with the HSE there often seems to be a reluctance to discuss funding gaps, and speakers are quick to stress when elements of funding are at so-called 'record highs', however, this warrants careful consideration. The real question should be whether the investment is relative to demand. If a genuine demand for a service is at an all-time high, as with CAMHS, then it follows that the resources available to that service should also be at an all-time high and the argument that further spending is not required, because we're

spending more than ever, does not hold up. Record spending should not be used to mollify calls for further resourcing of a service. The level of investment should follow, and even anticipate, the level of need.

At the outset it is worth looking at some statistics around health spending to situate calls for increased funding for youth mental health. The following figures are approximate, but are helpful none-the-less:

- The Interim Finnerty report noted that while children aged up to 18 made up 25 per cent of the population, CAMHS got just 10.8% of the overall mental health budget.
- The Final Finnerty report noted that while children aged up to 18 make up 26 per cent of the population, CAMHS got just 12% of the overall mental health budget.
- Under Sláintecare recommendations, the Government has set a target for total mental health funding to be at 10% of overall health expenditure by 2025. The Final Finnerty report noted it as standing at just over 6%.
- 15–24-year-olds are the age group most likely to use drugs (accounting for 19% of use).[4]
- The National Drugs strategy received less funding in budget 2024 (€9.75m) than in budget 2023 (€10.5m).[5]
- As per graph A below, it appears that health spending as a percentage of gross Government expenditure has remained relatively stable for the period from 2015 – 2024.

[4] Slide 1 (citizensassembly.ie)
[5] Factsheet: budget 2023 measures for National Drugs Strategy & inclusion health. - Drugs and Alcohol Budget 2024 - d7b2c043-f672-4098-b55b-18f5fc0f6f0d.pdf (www.gov.ie) New services for children with mental health and drug disorders (irishexaminer.com)



Graph 1: Health spending as a percentage of gross Government expenditure has remained relatively stable for the period from 2015 to 2024. Source: Parliamentary Budget Office

These figures are helpful in indicating the general direction funding needs to go, namely upwards. However, the true value of targets and goals is dependent on their real-life impact. Of most importance is not what has been allocated as a proportion of what, but rather whether people who need to access CAMHS are being supported in line with good standards of care, and whether young people and their families are satisfied with the support they are getting.

If the Government meets it target 10% of overall health expenditure being allocated to mental health funding by 2025, but CAMHS is still not operating effectively, and children continue to be harmed as a result (as clearly documented in the Finnerty reports), then that target will not have any meaningful value. More meaningful and ambitious targets should be set and the HSE should be held accountable for their delivery. The improved targets should revolve around waiting lists, but just as importantly, around satisfaction among parents and young people, good standards of care and positive outcomes for users of CAMHS.

The Committee recommends that an immediate top-up of funding, separate to the existing budgetary allocation, of €25M is provided for further implementing Sharing the Vision. It also recommends that €25M in provided for resourcing organisations in the community and voluntary sector that provide mental health supports in the same vein. Furthermore, the mental health budget should be increased substantially in coming years. This spending should be seen as an investment that will lead to less people experiencing severe or complex mental health issues and will ultimately save the State money in the long term.

The last few budgets should have been hugely mental health focused in recognition of the impacts of the covid-19 pandemic, the crisis in youth mental health and the parity of esteem we now know mental health should have vis-à-vis physical health. Situating calls for increased mental health spending within a slightly wider analysis of budgets, targets and demand like this raises serious questions about the wisdom of imposing a recruitment freeze on CAMHS, which is aimed at children and young people experiencing severe mental health issues such a suicidal intent. As the next section will discuss, even before the latest recruitment freeze, CAMHS struggled terribly with attracting and keeping personnel.

Personnel

Staffing problems, including understaffing and recruitment and retention difficulties, have consistently been the biggest challenge in health services, disability services and social services over the lifetime of this Committee and for many years before that. Such services have been in crisis as a result for some time now.

This Committee, in its report on Assessments of Need for Children, published in February 2023, highlighted the clear impetus to increase salaries for therapists. It stated:

> "If a recruiter cannot attract the talent required on the salary they are offering, then they generally put the wages up. The state, through the HSE must do the same, for essential front-line workers, including therapists... Changes in hours, pay and tax should be implemented to recruit and retain workers in the sector."

The Committee reiterates this recommendation. Given the level of impact personnel issues continue to have, the Committee has not seen drastic or meaningful enough actions taken in response. All levers available must now be pulled, with gusto, to address shortages of personnel. Wages and work conditions for the essential personnel we need to run such

services must be significantly improved and pathways to quickly developing graduates and experts in relevant fields must be activated and capitalised on as a matter of urgency.

A narrative has emerged that funding is not lacking in the health, disability and social services sectors, but that qualified professionals are. Mental Health Reform and others have produced evidenced based resources, critiquing that narrative and highlighting that a sustained increase in both funding and personnel is needed.[6] The Committee sees the two as inherently linked, because funding can be used to attract personnel, and it is much easier to attract people to work in services that are well funded. Thankfully, during the Committee's deliberations, Bernard Gloster of the HSE showed an appreciation that being fully funded for a certain number of positions and even filling all of those positions does not mean services are properly resourced. He stated:

> "There comes a time when we are at full complement for what we are funded to do. I have made the distinction many times. That is what we are funded to do, it is not what we are saying we need."

Health, disability, and social services have been consistently undervalued and staff and users of such services penalised as a result. One illustration of this that the Committee previously discussed was the diversion of therapists to work in Covid-19 swabbing test centres during the pandemic. A recent example is the imposition of a recruitment freeze in response to the HSE overspend, which does apply to CAMHS.

Discussions in the Dáil highlighted that the effects of the embargo on hiring will extend for much longer than the measure itself by encouraging health professionals to continue to emigrate.[7] The Committee is not proud that this needs to be stated, but, CAMHS, the service that deals with children on the brink of suicide, and is experiencing unprecedented demand for its services, should be exempt from any ongoing and future recruitment freezes. The continued devaluation of health, disability and social services must stop. Children's rights to life and wellbeing demand nothing less.

Young people with a dual diagnosis are likely to be more affected by a lack of funding and personnel, given that the challenges they face may require the help of professionals with experience in multiple areas, such as addiction or disability along with mental health.

[6] See for example Mental Health Reform's pre-budget submission 2024.
[7] Health Service Recruitment Freeze: Motion [Private Members] – Dáil Éireann (33rd Dáil) – Tuesday, 21 Nov 2023 – Houses of the Oireachtas

SASSY echoed this, stating that while they and CAMHS do work well together, the scarcity of professionals is the real issue. There is only a "a tiny team and it is not available outside Dublin", they said. These specific staff shortages are discussed more in the section on *Suitability*.

Recommendations
1. An immediate top-up of funding, separate to the existing budgetary allocation, of €25M should be provided for further implementing Sharing the Vision.
2. Separate funding of no less than €25M should be provided immediately for resourcing organisations in the community and voluntary sector that provide mental health supports and general youth support services, as these are key to prevention and early intervention.
3. The mental health budget should be increased substantially year-on-year, for the next decade. This spending should be seen as an investment that will lead to less people experiencing severe or complex mental health issues and will ultimately save the State money in the long term.
4. More meaningful, ambitious and measurable targets should be set in relation to mental health. The improved targets should revolve around waiting lists, but just as importantly, around satisfaction among parents and young people, good standards of care and positive outcomes for users of CAMHS.
5. Changes in hours, pay and tax should be implemented as tools to recruit and retain workers in the health services, disability services and social services sectors.
6. Pathways to quickly developing graduates and upskilling experts in relevant fields must be activated and capitalised on as a matter of urgency to address the staffing crisis in health, disability and social services.
7. CAMHS should be exempt from any ongoing and future recruitment freezes.
8. Health, disability and social services must be recognised as essential services and protected and staffed accordingly.

Access

The Committee heard that CAMHS waiting lists have almost doubled since 2019. It also heard that, at times, the length the waiting list means young people can 'age off' a waiting list, or CAMHS might not accept a referral when the difference between the time involved in reaching the top of the waiting list and reaching the age of 18 is too small. This leaves young people at what is already a challenging age vulnerable to slipping through the cracks and cannot continue.

The difficulties involved in accessing support from CAMHS are amplified for those with a dual diagnosis. The Committee heard some reports of total gatekeeping, whereby, at the mention of either autism or addiction/substance abuse, in addition to mental health issues, young people are excluded from accessing CAMHS. This is despite both of these cohorts being more likely to require mental health support.[8]

The fact that CAMHS does not accept some young people on the basis of addiction or substance abuse but does not have enough bespoke services to cater for that cohort across the country is not acceptable. The Committee agrees with Mental Health Reform that supports should be tailored to, and revolve around, the needs of children and young people, rather than expecting them to conform to existing structures. Dr Gerry McCarney, who works with a SASSY team, told the Committee that this is of most concern in cases where suicidal threats or ideation and/or self-harm are present and stated:

> "It is a fact of modern life that a high percentage of young people will experiment with and use drugs and-or alcohol to a degree that is not healthy, and they should have access to mental health services as required."

Substance abuse or addiction should not be used as an exclusion criterion for assessment or treatment of young people by CAMHS.

Also unacceptable is the exclusion of autistic children and young people. The submission from Families for Reform of CAMHS details hundreds of such cases. In addition, it documents multiple cases where referrals from GPs or consultants are not accepted, and A&E is the only route to CAMHS. This occurred even in cases of serious suicidal ideation, including cases where young people had self-harmed and/or set dates and times for

[8] Mental health - Consilium (europa.eu) and see also submission from Families for reform of CAMHS.

suicide. Members of the Committee also shared similar experiences they have had when trying to help with referring people into CAMHS, which was described as being like a silo with no windows and no door. The Committee also heard that in some cases CAMHS does not coordinate with those who either know the child or make the referral, despite the potential benefits of such communication. A young person being autistic should not be used as an exclusion criterion for assessment or treatment of young people by CAMHS.

In contrast to the submissions and testimony the Committee received, and the experiences Members of the Committee shared, the HSE said: "there is absolutely no exclusion for people with autism from CAMHS. The CAMHS operational guidance is very clear that if a person has a moderate to severe mental illness or autistic spectrum disorder, they come under the responsibility of CAMHS, so they can attend both services." The contrast between that statement and what appears to have been happening in reality is jarring. An autism protocol and a single point of access were some of the initiatives the HSE told the Committee it has underway to resolve these issues.

On the single point of access, the HSE told the Committee that it will develop better relationships and inter-service collaboration and "are working on" "will pilot it" and "it will start next year". Members are of the view that there has been an awareness of these issues for some time and there are existing protocols and avenues for inter-service collaboration in place. The child and adolescent mental health services operational guideline was published in June 2019.

The time to remedy this was long ago, not at an ill-defined point in the future. Young people who have already missed out on access to vital supports should receive the support they need in a timely manner, in line with their rights and the State's responsibilities. Under this single point of access, a referral will be triaged by a team of clinicians which will not just include CAMHS, disability and primary care but also partner agencies like Jigsaw, Pieta House and, hopefully Tusla, the HSE said. Many of these are already listed on various HSE webpages and documents as already being able to refer children to CAMHS and work with CAMHS.[9]

This all begs the question - is basic coordination and collaboration across the services dealing with vulnerable young people, that should be already happening, being dressed up

[9] camhs-operational-guideline-2019.pdf (hse.ie) and Kerry Child and Adolescent Mental Health Service - HSE.ie

as some groundbreaking initiative? In its Report on pre-legislative scrutiny of the General Scheme of a Child Care (Amendment) Bill 2023, the Committee made several recommendations around strong legal provisions to ensure that the State meets children's needs and that the relevant bodies cooperate to deliver that. The Committee stands by those recommendations but is disheartened to have to resort to creating legal obligations for the State to uphold children's rights, particularly in light of the failure to deliver assessments of need to children under the Disability Act, which illustrates that not even minimum legal obligations are being met in many cases. However, where the State's obligations are set out in legislation at least parents can go to the courts to have children's rights upheld as a last resort.

On the autism protocol, the Committee was informed by the HSE that it is "well developed" and "it has not been fully designed" and it "has been piloted in two areas and that is now being rolled out to four. We hope it will become mainstream early next year". Yet the protocol "is going to be ratified and rolled out". The chief executive of the HSE, Bernard Gloster said:

> "On the autism protocol, I am satisfied that is now at a point where it is mandated. When it is mandated that means it is not an optional piece to do or not do; it is mandated and therefore must be done. That is what the protocol will be."

It is not clear from these discussions what is mandated, ratified, in testing or otherwise, why the operational guidance that states autistic children can attend both CAMHS and disability services is not translating to that happening in reality, nor when meaningful improvements for children and young people will come from such measures. Teething problems in relation to the Fórsa side of things were also mentioned, but the nature of those problems was not discussed.

It is confusing for the Committee that what the HSE is saying it will do, should already be being done, according to statements made during meetings such as this one, or on its own webpages and in existing operational guidance documents.[10]

On the other hand, Bernard Gloster was clear in his determination to improve things and in his respect for parents and their frustrations in dealing with CAMHS. He said:

[10] Kerry Child and Adolescent Mental Health Service - HSE.ie

> "I want a message to go out from the committee in response to parents that I will not lead a health service which treats people as if they are a problem because they advocate for their children."

The nature of these discussions with the HSE on these issues is eerily familiar to the meetings the Committee has had previously in relation to assessments of need. The Committee at that time was heartened by promises from Minister of State, Anne Rabbitte, T.D. that things would improve. Yet, the Committee could not help but sense disharmony from its discussions with HSE managers and the Minister of State at that time, whereby progressive initiatives weren't effectively bedding in and filtering down to the point where the experiences of young people on the ground actually improved. Not a single deadline the HSE discussed with the Committee in relation to measures being taken to improve assessments of need at that time was met and, ultimately, things worsened instead of improving, when the HSE's new assessment of need was found to breach the Disability Act.

The Committee does not raise these issues to nit-pick or create work for an already overstretched health service. It does so simply to sound an alarm that all still does not seem well, that improvements must be tangible for those in need of support and to highlight that further delays in addressing these issues and a failure to implement improvements from top to bottom in the HSE will be unacceptable.

Clearly, accessing support is difficult for those with a dual diagnosis and accessing *suitable* support even more so. The suitability of services available for such young people is explored in the next section.

Recommendations

9. A young person being autistic should not be used as an exclusion criterion for assessment or treatment of young people by CAMHS.
10. Access to CAMHS must be available for those with a dual diagnosis, i.e., young people with severe mental health issues, who are also autistic or experiencing addiction/substance abuse.
11. Where possible, CAMHS should coordinate with those who either know the child or make the referral.

12. The existing protocols, frameworks and guidance for joint working across the services that support vulnerable children need to be implemented and followed.

13. Strong legal provisions should be made to ensure that the State meets children's needs and that the relevant bodies cooperate to deliver that.

14. The nuts-and-bolts issues within HSE teams on the ground need to be addressed.

15. The obstacles to high level policies, procedures and guidance actually being implemented on a day-to-day and case-to-case level need to be overcome, as a priority.

16. The autism protocol and the single point of access should be implemented as a priority and in a way that takes accounts of young people's rights and delivers a good standard of care.

17. Improvements are needed in the translation of policy changes at management level into workable procedures on the ground that improve young people's access to and experiences of CAMHS.

Suitability

As discussed, accessing a CAMHS appointment is a huge challenge, and getting in the door is much harder for those with a dual diagnosis. Once a young person gets in the door, it appears many issues then arise in terms of the nature and suitability of supports available. These range from inconsistencies in the treatment and the culture across teams, to overmedication and a lack of rights based, child centred approach to care, particularly for autistic people.

Mistreatment of autistic children and young people

Many young people appear to have been given inadequate or inappropriate supports from CAMHS simply on the basis of being autistic. The following are some examples provided in the submission from Families for Reform of CAMHS:

> "Was told that my child's suicidal thoughts and plans were not really mental health issues and just their autism."
>
> "The GP said we might want to keep quiet about ASD being a possibility if we are accepted."
>
> "Appointments were about how everything was down to the fact that she is autistic. She denied that our daughter has an anxiety disorder - she now has complete agoraphobia."
>
> "Once CAMHS found out that my son had autism all his issues were put down to autism."

Inconsistency in practice and culture

To its credit, the HSE has acknowledged that there is a massive geographical variation in wait times and the support offered across the country, and efforts are underway to alleviate this so-called 'postcode lottery'. The attitude towards parents and carers seems to vary too. Acknowledging this, Bernard Gloster said:

> "I would be misleading the committee if I said anything other than that there is a very varied culture across our health and social care services. It is rooted in a historical, paternalistic culture of professionals knowing what is best for people. Thankfully, we also have some very progressive members of our workforce who do

> not subscribe to this view, so I think there is a sea change happening in respect of the issue... I am paid to be frustrated whereas parents are not."

Overmedication

Overmedication by CAMHS has been widely reported across various channels and cannot continue. Reports from young people who have engaged with CAMHS feeling almost coerced into taking meds are particularly concerning. It was acknowledged that overmedication is likely a symptom of the other issues effecting CAMHS, whereby a shortage of therapists exposes young people to receiving less therapeutic interventions than they need, like talk therapies, and results in issues being addressed much later than they should be. Similar insights were shared by Members reflecting on their impression of CAMHS. As one Deputy said:

> "If all you have is a hammer, every problem looks like a nail, as the old saying goes. By the time young people are whittled through these exclusions and gatekeeping and end up being seen by CAMHS, quite frequently, medication is all that is offered. We heard in the earlier session that service users felt they were overmedicated, resisted medication, and were basically told that if they did not take the medication, they would not get a service."[11]

The HSE acknowledged that some CAMHS teams do not have access to the psychological or talking therapies they need and said medication should be prescribed in conjunction with talking therapies but that there are waiting lists for those. It told the Committee that it had received some new development funding to tackle that this year which will be allocated to talking therapies and that the new youth mental health office is looking at innovative ways to tackle waiting lists. CAMHS also informed the Committee that a prescribing audit was carried out and the results were very positive. Apart from unacceptable results in Kerry, it found no evidence of overprescribing.

Child centred, rights-based care

Given the testimony the Committee heard, questions arise as to whether progress towards child centred and rights-based care is being achieved at an acceptable pace. Support

[11] Deputy Patrick Costello, 6 December 2023.

services need to respond to the children's needs rather than expecting them to conform to existing structures. On this, Mental Health Reform stated:

> "Too often, young people end up slipping through the cracks, encountering service gaps that do not cater to their needs or find themselves stuck on lengthy waiting lists, only to discover they have been waiting in the wrong queue or knocking on the wrong door all along."

Mental Health Reform also advocated strongly for the implementation of the youth mental health pathfinder project, to develop child and young person-centred care pathways, and to develop a central referral system drawing from the learning from the current pilot in CHO 9. The Committee supports these recommendations. The pathfinder project is discussed further in the section on *Strategy and Operations*.

One witness, Ms Neil Moore Ryan, very generously spoke of her lived experience of dealing with CAMHS as a young autistic woman, as well as what she heard from other people engaging with CAMHS anecdotally. She detailed flippant attitudes towards her struggles with self-harm and suicidal ideation, feeling strong-armed into taking medication in order to access care and overmedication, which appeared to be a common experience among her peers. The following are some extracts from Ms Moore Ryan's contribution:

> "It can become easy for politicians or service providers to forget that each of the 4,400 children and young people waiting are members of our families, friend groups, communities, schools, sports teams, and neighbourhoods. If we are at the point of accessing or trying to access CAMHS, we have already gone through a number of other steps to even get to the point of being on a waiting list. Imagine the hurt it causes to then be turned away because you also have autism, or an intellectual disability, or a substance misuse issue."

> "I asked not to be put on it, but I was very much made to feel I would not be engaged with if I was not put on it. I actively said that I did not want to be on medication, and they put me on it anyway. They were happy once I was on it. They just upped my dose from then on."

> "CAMHS... should be a safe haven for vulnerable young people and children."

Care plans and key workers were discussed as tools for ensuring care is child centred and involves listening to the young person and taking their views onboard. Mental Health Reform stressed that doing so is best practice, is provided for in HSE guidelines and operating procedures in line with the young person's legal human rights, and leads to better outcomes. SASSY echoed this, telling the Committee that trying to get a key worker or a care plan is very difficult. This is reflected in statistics from Families for Reform of CAMHS about their members, as follows:

- 12% have a key worker and care plan for their child despite the HSE CAMHS Operational Guidelines setting out that these should be provided to each child.
- 59% have an autistic child and of that group 85% believe that having a diagnosis of autism has negatively impacted the service and support received by their child.[12]

From these figures and discussions, it seems like getting in the door of a service like CAMHS to then seek support, never mind it being the right door or support actually being provided, is a huge challenge. A care plan or a key worker are almost a luxury in the context of a system that cannot even give an initial appointment to thousands of young people experiencing severe mental health challenges. This has to change.

The Committee heard that in relation to those with a mental health need who are experiencing addiction/substance abuse, the SASSY and YODA teams, which are the dual diagnosis adolescent teams in Dublin, work very well. However, substance abuse is more likely where support services aren't available, so, services not seeing young people because they are abusing substances, because they are trying to self-medicate, because they can't get the support they require represents a damaging viscous circle. It is worth summarising some key aspects of YODA and SASSYs work, to highlight how services more broadly could make meaningful child centred and rights-based care a reality. Some characteristics of those teams are as follows:

- Young people can be assessed and treated accordingly, whether they have mild, moderate or severe mental illness.

[12] https://www.families-for-reform-of-camhs.com/about

- They are psychiatric led but also have child and adolescent psychotherapists who are trained to listen to what young people are saying, rather than jumping to conclusions and diagnosing or dismissing.
- They see young people within two weeks of referral to make an assessment and to prioritise.
- Having multidisciplinary teams including counsellors available gives them opportunity to listen because many young people feel that they are not actually listened to.
- The teams are tier 3 – this means they have experience in young people's mental health and adolescent development but also in substance misuse.

Such services do provide examples of what can be achieved, but are only available in a small catchment area, to a small number of people and are staffed with a 'tiny' team. Similar services need to be rolled out nationally, the Committee heard.

Dr Bobby Smyth, a consultant child and adolescent psychiatrist working in adolescent addiction treatment services, provided the Committee with a submission made in a personal capacity. He said that there has been a surge in referrals, and this has coincided with major difficulties in staff recruitment and retention in CAMHS. However, he also outlined some reasons to be hopeful, stating that it does appear that progress in now being made in the area of dual diagnosis, with the new HSE model of care for dual diagnosis having helped. Furthermore, Dr Smyth says communication between CAMHS, and adolescent addiction services has improved. Some of Dr Smyth's recommendations for further improvement of such services include:

- Increasing CAMHS ability to deal with addiction/substance abuse.
- Increasing adolescent addiction services ability to deal with mental health symptoms.
- Building a culture of communication and collaboration between the two services.

He underlines the importance of such measures in ensuring young people do not fall between the stools and signposts some innovative ways to make better use of smaller staff compliments. One of these is the idea of a split post, whereby someone he knows who works in adolescent addiction services also work part-time in the local CAMHS team.

However, his submission consistently outlines the importance of increasing staff numbers and disciplines and attributes the measured improvements he has seen to increases in the number and range of professionals on teams, which must be a priority. In particular, Dr Smyth says that additional staffing to facilitate the model of care for dual diagnosis must be extended south and westward, so that services are more widely available outside Dublin and the East. Psychiatrists, clinical nurse specialists, clinical psychologists, occupational therapists, counsellors, and importantly family therapists, are needed, as family therapy is a very valuable component of adolescent addiction treatment.

One free resource that was highlighted in relation to mental health training was the World Health Organization's QualityRights e-training, which is on human rights and mental health and is free. The Mental Health Commission praised the quality of this training and recommended it. The Committee supports this recommendation.

Recommendations
18. Consistency is needed across CAMHS teams, with care being timely, child centred and rights-based across the board.
19. Reports of overmedication must continue to be investigated and addressed and medication should not be used as a substitute for contact time with therapists, which must be available to young people experiencing severe mental health issues, in real time.
20. Young people's cases cannot, ever again, 'fall through the cracks' or 'go off the radar', as has been the case in the past.
21. The youth mental health pathfinder project should be implemented.
22. Care plans and key workers should be provided for each young person engaging with CAMHS.
23. YODA and SASSY should be resourced to a much greater degree, and other similar teams established around the country.
24. Services should be improved by: • Increasing CAMHS ability to deal with addiction/substance abuse. • Increasing adolescent addiction services ability to deal with mental health symptoms.

- Building a culture of communication and collaboration between the two services.

25. Staff numbers need to increase but so too does the multidisciplinary nature of teams; psychiatrists, clinical nurse specialists, clinical psychologists, occupational therapists, counsellors, and importantly family therapists, and more being required.

26. The World Health Organization's QualityRights e-training, which is on human rights and mental health and is free, should be undertaken by all those working in the area of mental health services, including trainee grades.

Prevention

The failure to adequately fund mental health is counter intuitive given what we know about the benefits to an individual as well as the cost savings to be made by the State by making such services available early and widely. Almost all stakeholders who engaged with the Committee referred to the importance of prevention and early intervention in terms of mental health.

CAMHS is supposed to be for the two percent of young people who experience severe mental health difficulties. The general consensus among stakeholders is that we need to look at *and* beyond CAMHS at the other organisations who can deal with less severe mental health issues and how they are fitting into the picture and ensure that the range of services work cohesively together. Jigsaw was referenced as another key service, but a young person can be deemed too high-profile for its service and not severe enough for CAMHS. The Committee heard that there is a huge gap between Jigsaw and CAMHS for young people who just do not seem to fit the criteria for either. The existing organisations need to be resourced to widen their criteria, or alternatively a middle ground service set up.

As discussed in the section on *Funding*, prevention and early intervention services as well as community and youth-based services have been underfunded and need additional resources to 'catch up' with the crisis in youth mental health. Mental Health Reform called for more funding for voluntary and community mental health services, such as Jigsaw, Pieta, the ISPCC and A Lust for Life, asking "why are we trying to fix the later pieces when we should be looking at what is happening earlier?" Such organisations are vital to early intervention and prevention. The Committee strongly supports this recommendation.

Early intervention and prevention can of course happen outside of clinical or therapeutic settings, with homes, schools, friendship groups and hobbies being key sites for young people to air issues and build the skills they need to cope and live well. However, due to the Covid-19 pandemic and the pace of technological and environmental change, the current generation of young people have encountered serious challenges. This underlines the importance of getting the right supports to children now, across a range of settings, including for those with a dual diagnosis.

Youth work and a school curriculum that reflects the challenges of modern life are two tools the Committee has touched on before. The Committee reiterates the recommendations

made in its report on Youth Work as well as calls it has made before for modern media literacy to be taught in schools. The Committee is very concerned at early reports that the proposed new school curriculum does not include modern media literacy and recommends that this is rectified.

The UN Committee on the Rights of the Child previously called on Ireland to address the root causes of suicide and self-harming through psychological, educational and social measures and therapies for children and their families.[13] The Committee emphatically supports that call.

Recommendations
27. Aside from CAMHS, the other organisations in a position to support those experiencing less severe mental health issues need to be resourced to 'catch up' with the crisis in youth mental health and expand the range of services needed to work cohesively together.
28. Given reports of young people being deemed too high-profile for Jigsaw but not severe enough for CAMHS, the existing organisations need to be resourced to widen their criteria, or alternatively a middle ground service set up.
29. The school curriculum should include modern media literacy to help equip young people with the tools to deal with content they encounter online that could negatively impact their mental health.
30. As recommended by the UN Committee on the Rights of the Child, the root causes of suicide and self-harming need to be addressed, through psychological, educational and social measures and therapies for children and their families.

[13] FINALMHRCMHCSubmissionUNCRC.pdf (mentalhealthreform.ie)

Strategy and Operations

Two of the main operational challenges facing CAMHS are consistency nationwide in how young people are supported and effective coordination and collaboration across the services young people in need of support engage with. These longstanding problems have been well-documented elsewhere and were acknowledged by the HSE in discussions with Members. While there is standard HSE operating guidance, this does not always translate to a consistent culture or approach across teams on the ground. The National Youth Mental Health Task Force Report 2017 identified many of the operational challenges still under discussion and paved the way for their resolution. It stated:

> "It is envisaged that this process will continue alongside another inter-departmental initiative, the Youth Mental Health Pathfinder. This pathfinder project is an internal process designed to effectively collaborate across departments on an issue that spans more than one department, i.e., youth mental health."

The pathfinder project is also part of the Programme for Government, and its implementation is one of Mental Health Reforms key recommendations. Despite this, it has not been delivered and responses from relevant Ministers have partially attributed the delay – now going on seven years – to the covid-19 pandemic.[14]

Some of the new strategies the HSE is pursuing to try to address these operational issues include; efforts to enable two existing substance misuse teams to do more on dual diagnosis, development of a further two teams and a hub and spoke model to support young people across wider geographical areas, the first time appointment of a National Lead for Child and Youth Mental Health and efforts to recruit a clinical director for CAMHS in Cork-Kerry.

On efforts to enable two existing substance misuse teams able to do more on dual diagnosis, and the development of further hubs and spokes, Dr Gerry McCarney (SASSY) told the Committee that:

> "The plan is to have two more hub teams, one in Galway and one in Cork. Those teams would have this hub-and-spoke model, where the four hubs will cover their

[14] Nithe i dtosach suíonna - Commencement Matters – Seanad Éireann (26th Seanad) – Thursday, 15 Jun 2023 – Houses of the Oireachtas and Mental Health Services – Wednesday, 22 Feb 2023 – Parliamentary Questions (33rd Dáil) – Houses of the Oireachtas

> own catchment area but will also be in a position to offer more support virtually and some face to face. It will certainly be virtually to areas outside the catchment area so the expertise can travel more easily and be available. To do that, however, we need to have these spokes. That means we need to have a skeletal team at least. The skeletal teams that were envisaged consisted of a clinical nurse specialist and a counsellor in each CHO area. There were nine CHO areas and now, with regionalisation coming down the track, that will be six. We have to see how that will reconfigure, but the plan was, regardless of where people lived, that there would be a person to refer a child, if he or she were using substances."

Dr McCarney also said there are hopes to develop capacity to handle process addictions, such as gaming and gambling addictions and that recruitment and under resourcing have been the main challenges. He none-the-less hopes that SASSY will manage to take some of the pressure off CAMHS.

On waiting lists for disability services, the HSE commended the huge amount being done through its voluntary provider colleagues, said it has exhausted the private sector, and that it is looking at potential avenues for group therapy. It said it will fund any credible providers of alternative therapies, such as equine, music or play therapy, so that families are at least getting some support while they wait for the full service.

Under the clinical directorate model, which Dr Amanda Burke of the HSE said she advocates strongly for, all teams work under one clinical directorate. This could therefore aid the lack of standardised service across teams. As of the Committee's meeting in December 2023, the HSE had been unsuccessful in filling the director post in Cork-Kerry but told the Committee "we will certainly roll that out." There is a HSE Clinical Lead for Youth Mental Health and a National Lead for Child and Youth Mental Health currently in post.[15] None-the-less, Mental Health Reform recommend the reinstatement of a national director for mental health.

Under Sharing the Vision, CAMHS hubs have been developed to offer short-term intensive support to children going through an acute mental health crisis. Families for Reform of CAMHS highlighted that the CAMHS Hubs Model of Care document, sets out in its section on *Exclusions* that the CAMHS hubs do not accept:

[15] First National Lead appointed to head New Office for Child and Youth Mental Health - HSE.ie

> "Children and young people who have a primary diagnosis of Autism: Their needs are best met in services such as HSE Primary Care and/or Children's Disability Network Teams. Where the child or adolescent presents with a moderate to severe mental disorder and autism, the role of CAMHS may include in-reach consultation where the child or adolescent remains with the referrer or the child/adolescent is accepted for multidisciplinary case management for mental health condition; with autism supports if required remaining the remit of Primary Care or Disability services."

The exclusion of autistic young people from these hubs is concerning. There is no explanation in the report as to the exclusion and supports for autistic people are not discussed elsewhere in its pages.

Recommendations
31. Much improved strategic co-ordination of child and young person-centred care is needed both at policy level and at implementation level.
32. The exclusion of autistic young people from CAMHS hubs and the reference to that in the CAMHS Hubs Model of Care document should be remedied.

Governance and Legislation

Ireland and the UNCRC

In February 2023, the UN Committee on the Rights of the Child, which monitors implementation of the United Nations Convention on the Rights of the Child (UNCRC), expressed serious concerns about the inadequate and insufficient mental health services

for young people in Ireland.[16] Under Article 24 of the UNCRC, all children have a right to enjoy the highest attainable standard of physical and mental health. Appearing before the Disability Committee in November 2023, Dr Finnerty acknowledged that this right may have been breached for many children with mental health issues.[17]

Legislating for the regulation of CAMHS

Oversight, governance and regulation have been lacking for services such as CAMHS due to the inadequate mental health legislation. Addressing this has been a topic of discussion for some time and has been a Government commitment for the last nine years.[18] The sub-Committee on Mental Health's Report on Pre-Legislative Scrutiny of the Draft Heads of Bill to Amend the Mental Health Act 2001 (oireachtas.ie) was published in 2022.

The number one recommendation in the Finnerty report is as follows:

> "The immediate and independent regulation of CAMHS by the Mental Health Commission must be put in place to ensure the State and the HSE act swiftly to implement the governance and clinical reforms to help guarantee that all children have access to evidence-based and safe services, regardless of geographical location or ability to pay."

In February 2024, a Private Members Bill to this effect was introduced in the Dáil. It was welcomed by Families for Reform of CAMHS.[19] Deputies from all parties and none spoke in support of the Bill's aims. A Government amendment was moved and passed, by 72 votes to 60, to the effect that the Bill will be deemed to be read a second time, and therefore have an opportunity to progress, in nine months' time. The amendment stated that during the Summer legislative session (April-July) the Government Bill will:

> "Introduce the registration, inspection and regulation of all community mental health services, including Child and Adolescent Mental Health Services on a statutory basis in a much more comprehensive manner than provided for in the Sinn Féin Bill."

[16] Ireland's child mental health services 'insufficient and inadequate' - UN rights body – The Irish Times
[17] Joint Committee on Disability Matters debate - Wednesday, 8 Nov 2023 (oireachtas.ie)
[18] Government inaction causes continued delays to Mental Health Amendment Bill - Mental Health Reform
[19] Joint Committee on Health debate - Wednesday, 17 Jan 2024 (oireachtas.ie)

During the discussions on the PMB, several deputies from various parties expressed concern that the Government Bill may not have time to pass all stages in the Dáil, and bring CAMHS under proper regulation, before the next election, leaving CAMHS in limbo for another extended period. The Government Mental Health Bill is listed for drafting, not publication in the recently published Government Legislation Programme Spring 2024.

Assisted Decision-Making support for young people

Under the Assisted Decision-Making (Capacity) Act, for people over 18 there are decision support arrangements and laws in place, but 16-year-olds and 17-year-olds are still excluded from that, despite this Committee having recommended the following in its Report on Pre-legislative Scrutiny of the General Scheme of the Assisted Decision-Making (Capacity) (Amendment) Bill 2021 :

> "The Bill should include provisions for 16- and 17-year-olds to make decisions about their healthcare treatment, including mental health treatment, which align with those in development as part of the reform of the Mental Health Act."

Such provisions are important in terms of harmonising legislation, recognising parity of esteem for mental health vis-à-vis physical health and empowering young people.

Recommendations
33. Breaches of the right of children to enjoy the highest attainable standard of physical and mental health must stop.
34. Legislation to adequately regulate CAMHS should be enacted as a matter of urgency.
35. Provisions should be made for 16- and 17-year-olds to make decisions about their healthcare treatment, including mental health treatment, which align with those in development as part of the reform of the Mental Health Act.

Appendix 1: Submissions

List of written submissions

Stakeholder

Dr Bobby Smyth, Adolescent Addiction Services

Families for Reform of CAMHS