Care Alliance Ireland

'Guiding support for family carers'

Submission to the Mental Health Commission on Draft National Standards for CAMHS

August 2026

Introduction:

Care Alliance Ireland is a national charity working to improve the recognition and support of family carers in Ireland. Our network includes over 100 member organisations working directly with family carers across a wide range of care situations, including carers of children and young people with mental health difficulties, such as Mental Health Ireland, ADHD Ireland and Shine, together with a number of intellectual disability organisations

We welcome the opportunity to share our observations on the new draft standards for CAMHS, and offer the perspective of family carers, drawing on our members' direct experience of supporting children and young people with mental health difficulties. Our submission reflects two main concerns:

i. **Family carers should be recognised as partners in care, and as experts in their own right:**

The draft standards make no reference to Ireland's National Carers' Strategy (Department of Health, 2012), which establishes family carers as partners in care. Care Alliance Ireland asks that CAMHS explicitly recognise family carers not only as people to be consulted for the sake of the child's care plan, but as experts in their own right, holding knowledge of the young person that clinical assessment alone cannot capture. This is however conditional: where a family is in a position to provide adequate care, they should be consulted and supported as partners. The child or young person remains the active agent at the centre of their own care throughout. This reflects a broader ask: that CAMHS adopt a social model of care. A social model of care understands children and young people holistically, within their family and community content, rather than an overly paternalistic or medical-model default.

ii. **Young carers are an unaddressed, high-risk population, and CAMHS can be the first Irish service to formally recognise them:**

Who they are: Children and young people under the age of 18 whose lives are in some way impacted by providing care, assistance or support to a family member in the home. Young adult carers (18-24) are considered a separate, equally unrecognised group in Irish carer sector practice.

Why they're a concern: Ireland has no true data on this population as young carers rarely self-identify. The Census also relies on parents to disclose a child's caring role, which limits its accuracy. Census 2022 counted 4,759 carers under 15 years old, or 2% of the carers in the State. Whereas independent research by NUI Galway as part of the Irish Health Behaviour in School-aged Children (HBSC) Study 2018 estimates that 67,000 young people between 10-17 provide care (roughly 13.3% of that age cohort)[1]. Young carers have been identified as a group at risk of social exclusion. They also face additional health problems, including mental health difficulties such as depression, anxiety and self-harm, and curtailed opportunities in progressing through education and the workplace[2] [3].

Why it's CAMHS's responsibility: No Irish service standard has ever placed a duty on a service to formally identify and support young carers. CAMHS is uniquely positioned to be first, its services are already in direct contact with families likely to include a young carer. In some cases, the CAMHS service user is themselves providing undisclosed care for someone at home, or in other cases, the service user has a sibling who provides care for them. Some young carers are very likely already on CAMHS waiting lists and in waiting rooms, unrecognised. Building formal identification into these standards would help to close a known gap in Irish policy and serve the direct interests of the young people CAMHS works with.

Q2. Gaps and Missing Areas

Q2.1 No reference to the National Carers' Strategy or to carers as partners in care explicitly

Relevant to: 'Guiding principles' (p6); Principle 1 (p7); Principle 2 (p7)

The draft standards list a comprehensive evidence base including the Expert Advisory Group, stakeholder consultation, the WHO Quality Standards for child and youth mental health services, and the Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services. However, there is no reference anywhere in the document to Ireland's National Carers' Strategy (Department of Health, 2012), which establishes family carers as partners in care and sets out the State's commitment to recognising and supporting them in that role. This is an essential component of

[1] https://www.universityofgalway.ie/media/healthpromotionresearchcentre/hbscdocs/nationalreports/2018-report---online-version-interactive---updated.pdf cited in https://familycarers.ie/media/bjxnaxeg/young-carers-in-ireland-family-carers-ireland.pdf
[2] https://www.sciencedirect.com/science/article/pii/S2468266725000994?via%3Dihub
[3] https://www.carealliance.ie/Young-Carers

effective care that considers the child and their families in a whole-family approach, shown to have better outcomes[4].

Family care involvement is already present in the guiding principles: Principle 1 states that parents or guardians (relevant consulted carers) are included and involved in decisions about the child or young person's care and treatment, and Principle 2 states that staff work in partnership with children and their families when planning care and support. Both are welcome commitments, however they stop short of the more specific framing used in Ireland's National Carers Strategy (Department of Health, 2012), that family carers are *partners in care* in their own right, with a distinct status that follows from that role, not only from their proximity to the child's care planning. Given that the underlying commitment is already there, our ask is to explicitly name it.

Proposed wording for **'Guiding Principles' section, alongside existing evidence base:** *"...and reflect the guiding principles agreed in conjunction with the Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services, and Ireland's National Carers' Strategy (Department of Health, 2012), which recognises family carers as partners in care."*

Proposed **addition to Principle 2:** *"… Staff work in partnership with children and their families when planning care and support, recognising family carers as partners in care in their own right."*

We want to be clear about the limits of this ask. Recognising family carers as partners in care does not mean treating every family as an adequate source of care and support. CAMHS services sometimes see children and young people whose family are not in a position to provide that. Nor does it dilute the child or young person's own standing as an active agent in decisions about their life, which the draft standards are right to centre throughout. Our ask is more specific: where a child or young person's family is in a position to provide adequate care and support, they should be consulted, involved and supported as partners in that role. This is additive to a child-centred approach, and is the principle underlying each of the points raised below.

Q2.2 Family carers positioned as recipients of information, not as holders of expertise

Relevant to: 1.4, 4.4, 4.5

[4] https://www.maynoothuniversity.ie/news-events/mu-research-recommends-family-approach-within-mental-health-services

Standards 1.4, 4.4 and 4.5 are framed around carers being informed, supported and involved, which are all necessary, but stop short of recognising family carers' own knowledge and lived experience as a resource that services should actively draw on in assessment and care planning. This matters because it reflects an overtly medical/deficit-model (services hold the expertise, carers merely receive information about decisions) rather than a social-model and a collaborative approach, which is otherwise a stated ambition of the standards through their person-centred, trauma-informed and neuro-affirmative language. As 2.1 outlines, this applies where a family carer is in a position to contribute that knowledge, alongside (not instead of) the child or young person's own voice.

Proposed addition under 1.4:

"1.4.6 The knowledge, insight and lived experience of relevant consulted carers are recognised as a valued contribution to assessment, care planning and review, alongside clinical and professional expertise."

Q2.3 Definition of 'relevant consulted carer' is narrower than family carers' lived reality

Relevant to: Glossary (p51); 4.6.1

The glossary defines a relevant consulted carer as "the parents, guardians or agencies to be consulted during the care planning and treatment of a child or young person." This is narrower than how family carers are understood in Irish carer policy more broadly, and could exclude grandparents, kinship carers, or other family members providing significant day-to-day care who are not the legal guardian. Standard 4.6.1's commitment to an inclusive definition of "family" is welcome, but the glossary definition of the carer term itself should be consistent with it.

Proposed definition: *"Relevant consulted carer: a parent, guardian, kinship carer or other family member with a significant, ongoing caring role in the life of the child or young person, or an agency acting in that capacity, to be consulted during care planning and treatment."*

Q2.4 Carer wellbeing is a single, short clause

Relevant to 4.5.1

4.5.1 states only that "supports are available to promote the emotional wellbeing of relevant consulted carers." This is the only place in the standards where carer wellbeing appears, and it does so lightly, given the well-documented impact of caring for a child in

mental health crisis (burnout, isolation, secondary trauma). We raise this as part of a holistic, whole-family approach to the child's care: a carer better able to sustain their role serves the child directly, and we ask that CAMHS commit to actively signposting family carers to relevant supports where appropriate for the benefit of the child themselves and their wider support system.

Proposed addition: "4.5.1 Supports are available to promote the emotional wellbeing of relevant consulted carers, including signposting to peer support, respite and carer-specific services. 4.5.1a Carer wellbeing is supported as part of a holistic approach to the child or young person's care, in recognition that a carer's capacity to care is affected by their own wellbeing."

Q2.5 Carer experience of transitions not explicitly named

Relevant to 4.10

4.10 addresses transitions thoroughly for the child or young person, including those turning 16 and over, and 4.10.5 records that the views of parents or carers are considered. However, the standard does not name the carer's own experience of transition, for example, carers of a young person moving into adult mental health services can lose information access and support structures overnight, even as their caring role continues.

Proposed addition: *"4.10.6 Relevant consulted carers are supported through service transitions in their own right, including clarity on their continued role, information access and support options once the child or young person moves to another service."*

Q2.6 Young carers and sibling carers: no formal recognition or identification pathway

Relevant to: 2.13, 5.1.5, 4.7.6, 6.2.7, 8.1.6

This is one of the more significant gaps in the draft. Young carers are children and young people whose lives are in some way impacted by providing care, assistance or support to a family member. Young carers face a higher risk of mental health difficulties than their peers and are also less likely than non-caring peers to access support for themselves. This happens often because neither the young person nor the services around them recognise

that they are a carer. This is a well-established finding in carer research, and a recognised gap in Irish policy generally[5] [6].

an CAMHS teams are already in contact with families who are likely to include a young carer. Sometimes the CAMHS client is themselves an undisclosed young carer. Sometimes the CAMHS client has a sibling who is a young carer. Either way, CAMHS is well placed to identify them.

The draft already refers briefly to sibling support under 2.11 (family-centred care). We ask that this reference be strengthened in two ways: first, as a commitment to supporting siblings; and second, as a route to identifying young carers, whether they are the sibling or client themselves. At present, the draft mentions siblings only as part of general fami. The draft does not yet name siblings as a group CAMHS should actively look out for.

Proposed addition to 2.11: "General support is available to siblings of children and young people using CAMHS, both in its own right and as a route through which a sibling providing a caring role may be identified."

Our own review of the National Carers' Strategy[7] found real concern among respondents about children carrying caring responsibilities. That review identified two specific asks: a greater role for education providers, and more proactive outreach and engagement from service providers to identify and support young carers. CAMHS is the leading service provider for children and adolescents with mental health difficulties. That makes CAMHS one of the services this call for proactive outreach was aimed at.

We are therefore asking the MHC to build formal identification into the standards, not as a single feature statement, but across five points in the framework, set out below:

a. **Identification at assessment and review: Theme 5 (Developmentally Appropriate, Evidence-Based Care)**

[5] Leu, A., & Becker, S. (2017). A cross-national and comparative classification of in-country awareness and policy responses to 'young carers'. *Journal of Youth Studies, 20*(6), 750–762. https://doi.org/10.1080/13676261.2016.1260698

[6] Leu, A., Berger, F. M. P., Heino, M., Nap, H. H., Untas, A., Boccaletti, L., … Becker, S. (2023). The 2021 cross-national and comparative classification of in-country awareness and policy responses to 'young carers.' *Journal of Youth Studies*, *26*(5), 619–636. https://doi.org/10.1080/13676261.2022.2027899

[7] Care Alliance Ireland (2021), Review of the National Carers' Strategy (2012): https://www.carealliance.ie/userfiles/files/CarerEngageNCSReport2021.pdf

5.1 sets out care pathways and records but does not currently ask services to establish whether the child, young person, or a sibling has a caring role within the family.

Proposed addition: *"5.1.5 Initial assessment, and subsequent care plan reviews, routinely and sensitively explore whether the child or young person, or a sibling, undertakes a caring role for a parent or family member, using a consistent identification approach across the service."*

b. **A standalone recognition standard: Theme 2 (Safety and Wellbeing), replacing the current single line at 2.11.3**

Given the scale of the risk, this issue should move from a feature statement to a standard statement in its own right. We propose this sits alongside 2.11 as a new standard, numbered 2.13.

Proposed addition: "2.13 Services formally identify young carers and sibling carers within families using CAMHS and support their access to age-appropriate information and support in their own right. 2.13.1 A consistent approach is used to identify young carers and sibling carers, applied at first contact and at subsequent reviews. 2.13.2 Once identified, young carers and sibling carers are offered accessible, age-appropriate information about their own wellbeing and about available young carer supports. 2.13.3 Identification and referral are recorded, with the young carer or sibling carer's consent, to support continuity if the family's circumstances or CAMHS involvement changes."

c. **Referral pathway: Theme 4 (Child, Family and Community Engagement)**

4.7 commits to strong links with schools, youth services and community organisations, but does not name young carer services specifically. Family Carers Ireland runs Ireland's only national young carer support programme. This includes a dedicated Young Carer Support Manager, regional young carer groups, and free membership for young carers aged 10-24. CAMHS teams should link into this programme directly.

Proposed addition: "4.7.6 Clear referral pathways are in place to young carer support services for children and young people identified as young carers or sibling carers."

d. **Workforce training: Theme 6 (Competent and Appropriate Workforce)**

6.2.7 lists training areas for staff: trauma-informed practice, neurodiversity, safeguarding, cultural competence, communication and family-centred care as training areas. Young

carer recognition is not on this list, despite it being a distinct, learnable skill in its own right. See the example of Carer's Trust UK-based training resources (link here)[8].

Proposed addition: *"6.2.7 ...including in trauma-informed practice, neurodiversity, safeguarding, cultural competence, communication, family-centred care, and the identification and support of young carers and sibling carers."*

e. **Data: Theme 8 (Quality Improvement and Information Governance)**

8.1.6 already commits to gathering feedback from families and carers. We would ask that services also capture how many young carers and sibling carers are identified and referred each year. This data should be anonymised and aggregated. This is a known data gap in Ireland, and CAMHS could become a valuable source of national data on the scale of young caring.

"8.1.6a Aggregated, anonymised data on the number of young carers and sibling carers identified and referred is collected and reported as part of the service's quality improvement data."

Q2.7 Waiting times and interim support: carer-facing gap

Relevant to: 3.2.6, 3.2.7

3.2.6 commits to interim supports for children and young people awaiting appointments or reviews; 3.2.7 commits to regular updates for carers on waiting times. This is a welcome commitment considering the well-reported burden of long-waiting times, many children and young people can wait up to a year or more for their first appointment[9]. We urge the MHC to ensure this is a commitment in practice and not only in writing, as vulnerable children and young people cannot get access while on waiting lists. Additionally, what is missing is any interim support offered directly to the carer during what can be a long and distressing wait, this is consistent with what we hear from our members and from carer support literature more broadly.

Proposed addition to 3.2.6: *"3.2.6 Interim supports are available to children and young people, and to relevant consulted carers, awaiting appointments, reviews or care planning meetings."*

Q2.8 Mediation: resourcing and independence

[8] https://carers.org/resources/all-resources/90-training-resources-to-help-with-improving-the-identification-and-support-of-young-carers

[9] https://www2.hse.ie/mental-health/services-support/camhs/referrals/

Relevant to: 4.5.7

4.5.7 makes mediation available "where disagreements arise" between carers, staff or young people. We welcome this, but the standard does not address how mediation is resourced or how its independence from the service is assured, both of which affect whether carers will trust and use it.

Proposed addition: *"4.5.7 Mediation is available to children and young people, relevant consulted carers or staff where disagreements arise, provided by a party independent of the immediate care team and adequately resourced to respond in a timely way."*

Q3. Clarity and Accessibility

Q3.1 Carer-facing information formats

Relevant to: 1.4.5, 1.5.4–1.5.5, *3.4.2*

1.5.4–1.5.5 and 3.4.2 set out clear commitments to accessible information for children and young people (interpreters, Easy Read, plain language, translated materials). 1.4.5 makes a parallel but much briefer commitment for carers ("clear, accessible and culturally appropriate formats"). We would ask that the same explicit list of formats committed to children and young people under 3.4.2 apply equally, and be stated equally explicitly, to relevant consulted carers

Q3.2 Maintaining confidentiality while communicating why a carer is excluded from information

Relevant to: 1.4.3, 4.3.1

1.4.3 and 4.3.1 correctly balance carer involvement against the child or young person's rights and preferences, including confidentiality. From the perspective of family carers, the source of distress is rarely the balance itself but the lack of clear communication about why a carer is being excluded from particular information at a particular time. We suggest that 1.4, 4.3 and 4.5 each distinguish four elements of family involvement: (i) receiving information about the child's care, (ii) disclosure of confidential information about the child, (iii) provision of general family support, and (iv) involvement in care planning or safety support. Naming which of these is in play at a given point tells a family member or carer why they are or aren't being given something, rather than leaving it to be inferred.

Proposed addition to 4.3.1: "Confidentiality and its limits are explained accurately to relevant consulted carers at the outset, distinguishing receiving information, disclosure of

information, general family support and involvement in care planning. Information is not routinely disclosed to a carer solely because the child or young person is under 18; any disclosure requires a lawful basis, necessity and proportionality, and should normally be discussed with the child or young person in advance. Where a relevant consulted carer holds responsibility for the child's safety and care at home, they are given sufficient lawful information and guidance to carry out that responsibility."

Q4. Putting the Standards into Practice

The standards already contain strong commitments (4.5.4 on continuity of support, and the mediation provision at 4.5.7) that risk staying words on a page without adequate resourcing behind them. Implementation, rather than wording, is what will determine whether family carers experience these standards as real in practice.

4.5.5's commitment to staff training in trauma-informed communication with carers could explicitly extend to family carer expertise and a social-model understanding of disability, not solely communication skills. Existing interagency commitments (2.1.6 Tusla; 4.7.2 schools) could be extended to name family carer support organisations explicitly, including Family Carers Ireland and, through Care Alliance Ireland, the wider carer support network.

A young carer identification standard (2.13) is only as useful as the referral pathway behind it. We would encourage CAMHS to engage directly and collaboratively with organisations already working with young carers (principally Family Carers Ireland) rather than build identification in isolation.

Identifying a sibling as a young carer also raises its own sensitivities: the sibling is not necessarily the CAMHS primary service user, so services will need clarity on consent, on what (if anything) goes into the young person's own record, and on how this is handled if a sibling does not want to be identified as a carer.

Conclusion (Q5. Additional Comments):

We were not involved in the original stakeholder consultation that informed this draft, but we are glad of the opportunity to contribute now and would welcome ongoing engagement with the MHC as the standards are finalised and implementation guidance is developed.

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