



OPENING STATEMENT TO THE DAIL SUB COMMITTEE ON MENTAL HEALTH.

TUESDAY 13TH JUNE 2023

Good morning! Thank you Chair and thank you to the Committee for inviting ADHD Ireland to appear before you today. We welcome the attention being given by the Committee to the important issue of mental health and ADHD.

Who are ADHD Ireland?

ADHD Ireland is the national representative organisation for those with this condition. Our mission is simply 'To make life better for all those affected by ADHD'. This year we will deliver over 400 activities to support our community, we will receive over 6,000 contacts from members of the public, our website will have over 250,000 visits, all delivered by 10 exceptionally motivated passionate staff (6 WTE), along with our Board and volunteers. We receive 80%+ of our funding through the HSE as a Section 39 organisation.

What is ADHD?

ADHD stands for Attention Deficit Hyperactivity Disorder. It is listed in the Diagnostic and Statistical Manual for Mental Disorders as a neurodevelopmental condition, which means that the brain has developed differently. There are three different types of ADHD: ADHD predominantly inattentive type, ADHD predominantly hyperactive/impulsive type, and ADHD combined type (meaning both inattention and hyperactivity/impulsivity are present at clinical levels). Those meeting criteria for inattentive type ADHD will present as easily distracted, resulting in difficulty organising or finishing tasks, following instructions of conversations, and to paying attention to details. Those meeting criteria for hyperactive/impulsive type presents with a need to move or have an internal feeling of restlessness. They may fidget or talk a lot and find it difficult to sit for long periods of time. Impulsivity means that the individual might interrupt others or speak out of turn or at inopportune moments, and/or act without thinking through the consequences of actions.

Currently, more boys are diagnosed than girls. Diagnosis is based on detailed history taking, observable behaviour, and standardised rating scales to inform clinical judgement. There are no national protocols for the assessment of ADHD, and practice varies across public service teams. Prevalence estimates vary from country to country because of a multitude of factors including ability to access public services for diagnosis. A meta-analysis of available studies estimate that prevalence is between 2 and 7%, with it decreasing with increasing age. Large population studies in America suggest a 5% prevalence rate. ADHD is therefore a common neurodevelopmental diagnosis, particularly in childhood.

For young children under 5 parenting programmes to support positive behaviour are considered a first line intervention. These programmes are also recommended for older children alone or in conjunction with other interventions such as medication, environmental modifications and Cognitive Behavioural Therapy.

Child Services

ADHD diagnosis falls under the remit of Child and Adolescent Mental Health Services (CAMHS) in Ireland. CAMHS is a service for both ADHD and those with moderate/severe mental health concerns. CAMHS teams are multidisciplinary typically made up of psychology, occupational therapy, speech and language therapy, nursing, social work, social care, and under the clinical lead of psychiatry. Theoretically, with this team all needs of the ADHD child can be met.

The first hurdle for a family is accessing CAMHS. Using data from Lucena CAMHS, I can tell you that on average across teams in South Dublin and Wicklow from 2006 to 2021 there was a 54% increase of referrals without an increase in staffing. This includes a large number of query ADHD. Although no formal research is available, from experience this increase is due in part to parents noticing ADHD features when trying to engage their children with homeschooling during the COVID restrictions. In addition, there has also been increased awareness and acceptance of ADHD in Ireland over the last few years. What we see now is open communication on social media between young people on the topic of ADHD. From this, we have had an increased number of referrals to CAMHS for ADHD assessment initiated by the young person themselves (self-identification or diagnosis). As there is no screening for ADHD completed by referrers, oftentimes many of the latter do not go on to reach diagnostic threshold but require assessment nonetheless. These children all get added to a growing waitlist.

A limitation of having ADHD under the remit of CAMHS is that when faced with waitlist prioritisation, urgent referrals for children considered at risk with severe mental health concerns will always be seen before an ADHD referral. CAMHS waitlists are therefore largely populated by children awaiting ADHD assessment.

To cope with rising waitlists for services, the HSE have recently been funding 'waitlist initiatives'. These are advertised as temporary contracts making suitable recruitment difficult, and retention of any gains difficult (with waitlists rising again once the initiative ends).

There is no guidance for clinicians working in CAMHS on what a good ADHD assessment looks like, and what good intervention for ADHD looks like.

Although children on the waitlist have benefited from speedier assessment as part of waitlist initiatives, the use of the waitlist as a key metric by the HSE for how CAMHS teams are functioning is an ongoing issue. Once these children have been assessed they now require supports, and demand for intervention within CAMHS far exceeds capacity. All disciplines are understaffed on CAMHS teams compared to recommendations in the Vision for Change documents. As an example, social work is staffed in Lucena CAMHS on average across teams at 37%. Recently, I ran an analysis on all the referrals to Tusla on my own CAMHS team over the space of a year. ADHD children were 5.5 times more likely to have a Tusla referral compared to other CAMHS attendees. This group of children are in most of need of social work but have limited access through CAMHS. Similarly with psychology, overall staffing in

Lucena is at 40.5% (ranging from 23% to 53%) compared to Vision for Change recommendations. This means there is no CBT for ADHD. Across disciplines, access to intervention is limited for ADHD children because of staffing shortages.

Again, a major barrier to access is the location of ADHD services in the CAMHS system, where children with moderate/severe mental health concerns like depression, anxiety, OCD, psychosis and eating disorders will be prioritised for intervention over the ADHD cohort. It is common that only medication is available to these children.

Of note is the ADMiRE team in Linn Dara CAMHS which is a separately staffed ADHD specific team. Consideration should be given to extending this model across services.

It is worth noting that CAMHS provides intervention for moderate/severe ADHD only. There is a lack of clarity on where those with mild presentations should be supported, with many of these children falling between services. This needs to be addressed with urgency.

A further issue with current service provision is the segregation of child services in Ireland, with each having different remits. ADHD is a neurodivergence. Other common neurodivergences include autism, dyslexia and dyspraxia. The co-occurrence rate is high amongst neurodivergences (e.g., 30% of ADHD children are also autistic). This means that children need to access multiple services to access diagnosis and intervention. There is also overlap of features of neurodivergences, and very often, clarity on the presence of other diagnoses is needed before ADHD can be considered. CAMHS rely on other services like the CDNT and NEPS to provide assessment which falls outside their remit. Children are often on multiple waitlists for assessment, and CAMHS is often the service provider which is most accessible. This means children are being referred with multiple needs, and even if a diagnosis of ADHD can be confirmed CAMHS cannot meet all the needs of these children. Neurodivergent children are not receiving holistic care in Ireland.

In the UK, noting similar issues, pilot neurodivergence teams have been established by the NHS providing assessment and intervention for neurodivergence more generally. For example, in Hull and East Riding this team provides autism, ADHD, specific learning difficulty, sensory needs and sleep supports. Strong consideration should be given to the establishment of similar teams in Ireland.

Of final note for children's service is the high prevalence of private assessment as a direct consequence of families being unable to access CAMHS in a timely way. Private assessment is unregulated in Ireland. It is common for children to be referred to CAMHS for intervention with a private assessment already completed. CAMHS will do their own assessment to stand over the management of ADHD. Of concern is that a substantial minority of private assessments are not upheld following this reassessment. Children regularly do not meet the diagnostic threshold for ADHD, and often differential diagnoses are not considered (most commonly autism and dyslexia which can account for some ADHD features). There should be a minimum standard of assessment for ADHD. The PSI are currently developing 'best practice' guidelines for assessment, but when published will only apply to psychology and the organisation has no power to enforce compliance. There should also be complaint channels established for the public to raise concerns about assessment practice in both the

public and private sector, with a panel of peers to determine if practice is below a set standard.

ADHD Into Adulthood

Using internationally accepted figures, there are 'at least' 110K ADHD adults in Ireland today. There are no figures on how many of these are getting formal support for their ADHD, however we expect it is less than 10%. ADHD is now known to persist into adulthood, with approximately 65% of children continuing to have features into adulthood and 15% meeting the full diagnostic criteria.

It is also now known that ADHD adults will have higher rates of marital breakdown, higher rates of unemployment, higher rates of substance misuse, higher rates of anxiety and depression along with lower life expectancy (with some estimates of up to 5 years).

Ground-breaking research which was funded by NOSP (National Office of Suicide Prevention) and conducted in partnership with UCD, the HSE and ADHD Ireland published last year showed that in terms of suicide risk:

20% of all ADHD adults have attempted suicide in their lifetime
50% of all ADHD adults have self-harmed in the past
10% consider suicide an option for the future

The results are in line with international studies which have shown that ADHD adults have elevated levels of suicidal behaviours.

Apart from the impact on family and lives, there is an ongoing cost to Irish society in general. Research would show that the socio-economic cost to Ireland each year is €1,800,000,000. Reasonable estimates show that 15% of adults getting treated by the Mental Health service with the HSE will have undiagnosed ADHD. We, as a society are overpaying for ignoring this condition and we will continue to pay €1.8Bn each year till we do pay attention to it!

ADHD Ireland works as hard as it can to support adults with ADHD. We work closely with both UCD and the HSE to develop what can be seen as world leading initiatives for ADHD adults. For instance, in November 2022, Minister Mary Butler launched our new 'Adults with ADHD' app, which already has 10,000 downloads. This is one of the few 'evidence-based' apps for ADHD adults worldwide and was delivered as a true working partnership between UCD, the HSE and ADHD Ireland.

The Understanding and Managing Adult ADHD Programme (UMAAP) is a 6-week workshop series, combining psychoeducation on adult ADHD with Acceptance and Commitment Therapy (ACT). UMAAP has been developed to address the lack of services available for ADHD adults in Ireland and as an early intervention within a stepped-care model. And again, is a collaboration between ADHD Ireland, UCD and the HSE National Clinical Programme for ADHD in Adults.

We run what we call the 'largest online support group for adults with ADHD in the world' every 2nd Tuesday and will continue to do so until proved otherwise. We also run webinars, social activities and much more as well for adults.

While purely anecdotal we are hearing from a wide range of personnel in the HSE that community mental health services are being overwhelmed by adults looking for ADHD assessment and treatment. We are hearing that some clinics are reporting that up to 1/3rd of new referrals are now for ADHD. Getting a diagnosis privately even if you can afford it, is also no less onerous, particularly if medication is indicated.

Key take outs:

1. ADHD is a serious condition which without assessment and treatment can have serious lifelong consequences. However, when it is picked up and treated early, outcomes are generally good.
2. The prevalence rate for ADHD is 5% or 1 in 20, which equates to one child in every classroom.
3. The social-economic cost of adult ADHD is €1.8 billion per annum.
4. There are very limited assessment and treatment routes for adults in Ireland.
5. The CAMHS system need to be overhauled for all our children with mental health conditions, with consideration given to the removal of ADHD from CAMHS and the establishment of specialist teams for ADHD in Ireland, and/or neurodivergent teams.
6. There are no national protocols for the assessment of ADHD and guidelines for ADHD intervention in Ireland.
7. Care for children meeting criteria for mild ADHD need to be developed.
8. Teams assessing and providing intervention for ADHD need to be adequately staffed to provide this care with full time permanent contracts.
9. Those working in ADHD services need to be provided training in differential diagnosis with updated knowledge of autism identification and assessment specifically.
10. GPs need support with navigating services to promote appropriate referring.
11. Private assessment needs to be regulated.

ADHD Ireland looks forward to working with this Committee, relevant Ministers, and all members of the Dáil to ensure that services are adequately resourced; that they are rebuilt as required and that each person with ADHD in Irish society can live meaningful, happy, productive lives.

Go raibh maith agaibh.