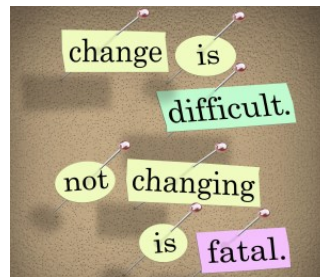
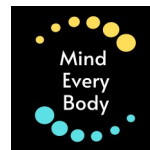


Eating Disorder Services: The Reality of Care and the Urgent Need for Reform



Leinster House
AV Room Briefing
26/6/2024



Model of Care vs. Reality

Staffing and Funding

Model of Care (2018): Development of **20 adult inpatient ED beds**, in addition to the 3 existing adult inpatient beds.
2024: Still **only 3** adult inpatient ED beds (catchment based in Dublin)

HSE: “While a small number of people benefit from more intensive treatment through day programmes or inpatient care, **the most effective treatment setting is in the community.**”

Model of Care (2018): “A reduction in demand for inpatient beds expected **once outpatient and day services are developed.**”

2024: Only 12 out of 16 eating disorder hubs are completed. It takes 12-18 months to complete each team.

Model of Care (2018): “A quality national ED service **cannot be provided** without additional resources for EDs being funded.”

2018: 2018, €1.5 million was allocated with €137,000 spent

2019: €1.6 million was allocated and **nothing was spent**

2020: No funding

2023: No additional funding for eating disorder services

2024: HSE recruitment embargo

Model of Care vs. Reality

A Connected Service

Model of Care (2018): “It is recommended that each team initially focuses on developing specialised outpatient and day-patient capacity in order to **bridge the gap** between inpatient and outpatient services within mental health services nationally.”

Anecdotally: Day-patient programmes are often not offered, or do not have the staff to accept patients. There are currently **little or no transitional supports** between hospital to home, and the risk of relapse is very high.

Model of Care (2018): “Appropriate, personalised evidence-based advice, treatment and support is **accessible** to patients at each level of care.”

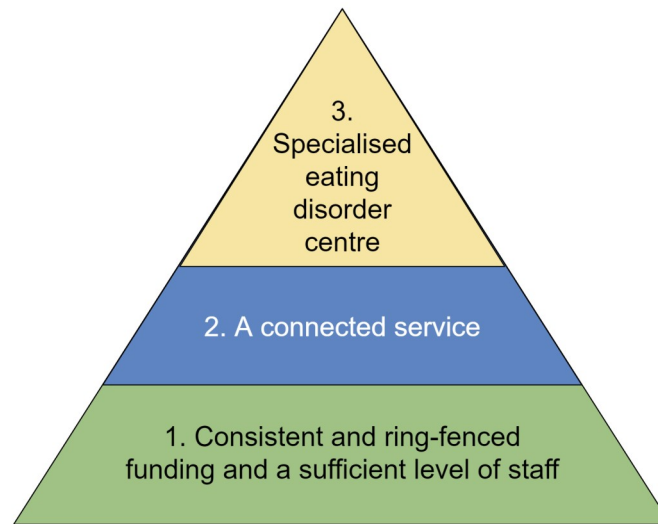
Anecdotally: Lack of staff both outpatient, day-patient, and inpatient restricts access to care, as do **catchment area limitations**. Inpatient mental health admission policies and practices often focus on weight, and whether or not an individual is eating orally, as a criteria for admission.

Outpatient services use **weight as a criteria** to restrict access to therapeutic supports.

Model of Care (2018): “Patients move up and down the levels of care according to their level of need, and **remain at higher levels (e.g. day service) for the period that is clinically necessary.**”

2024: Many private day-patient and inpatient services are **limited** to 12-weeks, regardless of whether an individual is healthy enough to be discharged.

Top Three Asks



Funding:

- **Update** the expired 2018 Eating Disorder Services Model of Care.
- **Hire and train** more staff.
- Address recruitment and retention issues.
- Provide a **sufficient** level of outpatient services.
- **Expand** specialist eating disorder teams.

Staff:

- **Reduce** CAMHS waitlists.
- **Complete** outpatient teams and specialist eating disorder teams.
- **Reopen** beds in CAMHS facilities and **open** additional specialised hospital beds.

Connected Service:

- Provide **early interventions** and **supports** for sufferers and parents.
- Standardised **information and supports** while waiting for assessment and treatment.
- **Meal support** available in the community if required.
- A **keyworker** who is actively involved in every step of the process, and can make sure a **care plan** is being implemented.
- **Same level of service** across all CAMHS inpatient facilities.
- **Day hospitals needed** as both **step-up and step-down** from full inpatient admission.
- **Therapy and mental health supports** need to be provided immediately and every step of the way, **regardless of weight or acute hospitalisation**.
- **Recourse or advocacy services** for families who encounter difficulties in care.
- **Clear and transparent communication** to families regarding treatment processes and care plans.
- Include **pathways for neurodiversity**.

Specialised Eating Disorder Centre:

- **Knowledgeable** staff with **specialised** training.
- Physical and mental health treatment can **co-occur**.
- **No catchment restrictions**.
- **Better use of funding** than a disjointed, disconnected service.
- **Better chance of recovery** with **consistent care**, not constantly changing teams or hospital environments.

Amanda's story

*'My journey as an adult with Anorexia'
By Amanda Lynch*

I've been diagnosed with anorexia 14 years. Throughout my illness up until February 2023 no services in the HSE existed to help me. **I in the past, had to fight the HSE for funding for private treatment.** My illness got more and more entrenched as the years went on, as when I was discharged from the private programme, I was sent back to general adult mental health services where they didn't specialise in my illness.

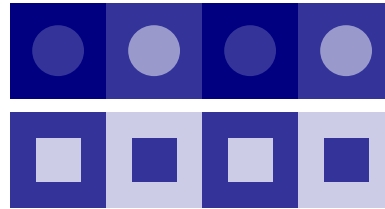
"I have never relapsed from my illness, because I've never ever reached a point of recovery, as there were never adequate supports in the community to help me."

This has resulted in me becoming extremely unwell, and in March 2022, I was deemed so unwell that I lacked capacity, and was made a ward of court in 2022.

This wardship lasted until this year in February 2024. I was discharged from wardship, not because I am better, but because I am more able to engage in accepting acute medical treatment when I become medically unstable due to the severity of my illness.

Amanda's story

In the last two years I have been admitted to acute medical hospital more times than I can count, I have been in ICU 4 times for medical stabilisation and feeding under sedation, I stopped breathing on my last ICU admission and my oxygen dropped to 50% causing me to be resuscitated.



In addition to ICU admissions, the high court granted the hospital permission to force feed me and sedate me under physical restraint, I've been pinned to the bed, while doctors forced NG tubes into my nose down to my stomach in order to feed me, not to mention the mental trauma in order to save my life.

I hold no negativity towards the wonderful staff at the hospital, whom I now have a great rapport with, although it was extremely challenging in the early days, and I also hold no negativity towards the High Court, despite it being a very challenging situation my Judge and legal team were exceptional at all times. If I am being honest I think everyone involved we are all a bit traumatised by the events of the past two years.

Amanda's story

I need to reiterate, that the extremes of my case, are not standard, **however I feel like none of this would have happened had I been given support early on in my illness.**

"It's recommended early intervention is key, and it's extremely important to get support in the first 3 year of the illness presenting. I however went over 12 years until the HSE developed their eating disorder outpatient clinic in north Dublin in February 2023."

I still require quite frequent acute hospital admissions for medical stabilisation and NG tube feeding, and have not managed to stay out of hospital longer than 5 months since 2022. **My eating disorder team try their best to support me, however their services are unfortunately limited,** they don't have a full team due to the gross lack of funding by the government, they don't have access to dedicated eating disorder beds, or a day programme, so **when I become unwell, I have to go to a medical hospital,** where my consultant psychiatrist doesn't work, resulting in a lack of continuity of care. **This at the beginning of my hospital journey was hugely distressing.**

Amanda's story

At this point in my illness, I am unsure if I will recover, and I've been told my health and situation is very "precarious", I have been told I am going to die on many occasions, however this is something I struggle to comprehend, my eating disorder makes me believe I am not 'that unwell'.

I feel like eating disorders are quite often focused on as a "young person's illness" and adults in the situation are often forgotten. I am not trying to plot one against the other, we all deserve care and treatment, that said, in my opinion it's the adults with eating disorders who have been most let down, as we have gone our entire illness with no treatment that existed for us in the HSE. As a result of this, statistically it's us adults who die of eating disorders, and it's us adults who are labelled "Severe and enduring eating disorder" or a (SEED Patient)

I am currently what doctors would deem medically unstable, and **I should unfortunately be in hospital again right now** for medical stabilisation and refeeding, as I am having critically low blood glucose levels lower than they have ever been through out my illness, as well as other complications, **however here I am at Dáil Éireann trying to fight for actual eating disorder beds/services**, specifically dedicated to treating people like me so that I can have access to a multidisciplinary team, so that there is a continuity of care both inpatient, as well as outpatient. I am still alive, however there are many who aren't, this government failed them, and continues to fail people with eating disorders, and things need to change.

Quotes From Carers

"There is NO proper transition from child to adult services."

"Attending the High Court whilst watching your daughter literally dying in front of your eyes is a feeling we will never forget."

"Had this been identified earlier, our daughter and our entire family may not have had to go through the horrific ordeal that we have had to endure for many years now."

"There is a revolving door service from Adult Mental Health units to Medical units and vice versa to rapid relapse again once home."

"There were no psychiatrists available to take on her care although we tried everywhere. The GP was fed up of writing referrals."

Quotes From Sufferers

"They rang politicians pushed for specialist care and we fought for HSE funding it was a very long process and the first time I was denied it took me to have a cardiac arrest for the HSE to take me seriously and offer me funding."

"I literally could not do anything without thinking of the ED and I mean when I was driving, watching TV, in work and even when my kids were born."

"It's frightening what it can do and how devious it can be, if I had not got the help when I did I would no longer be here."

From mindeverybody.com

Facts & Statistics

The World Health Organisation (WHO) and the American Psychiatric Association (APA) recognise eating disorders as mental health disorders. The WHO first classified eating disorders in 1977, the APA in 1980.

Early assessment and evidence based treatment improves the likelihood of recovery. NICE (2017) Eating disorders: recognition and treatment.

International research indicates that just 5% to 15% of people with eating disorders seek help; 85% report that it is hard to access treatment. Butterfly Foundation (2015).

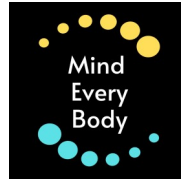
Based on epidemiological projections, an estimated 188,895 people in Ireland will experience an eating disorder at some point in their lives.

It is estimated that approximately 1,757 new cases occur in Ireland each year in the 10-49 age group.

Information from bodywhys.ie

Mind EveryBody

Mind EveryBody was founded in November 2023 by Amy Hanley as a campaign to seek reform in Eating Disorder services across Ireland. We are currently an advocacy group consisting of professionals, carers, and sufferers of eating disorders.



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mindeverybody.com

Supported Families

Supported Families are Zuzanna Gajowiec and Deirdre Reddan. Together, they bring professional knowledge, personal experience and a huge passion for educating and empowering parents, partners and professionals on Eating Disorder recovery.



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Bodywhys

Founded in 1995, Bodywhys is the national voluntary organisation supporting people affected by eating disorders. Their mission is to ensure support, awareness and understanding of eating disorders amongst the wider community as well as advocating for the rights and healthcare needs of people affected by eating disorders.



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