Health Committee

This document contains all written evidence received by the London Assembly Health Committee as part of its investigation into eating disorders in London. All written evidence was received by the Committee between 19 July 2023 and 4 September 2023.

Views expressed in the survey represent the opinions of the respondents rather than those of the London Assembly.

Contents

Autistica

How prevalent are eating disorders, and are there any factors that risk further increasing the number of people developing an eating disorder in London?

Eating disorders are especially prevalent amongst autistic people, with as many as 1 in 5 women in anorexia services meeting diagnostic criteria for autism.[12] In many cases, this group are not identified as autistic until long after eating disorders take hold, often involving an admission to inpatient services. In July 2022, there were almost 8000 people on the waiting list for an autism assessment in London, the vast majority of whom were much longer than the recommended 13 weeks, and the backlog is rising fast.[3] Even with a formal diagnosis, many autistic people and families are sent away with little more than a leaflet,[4567] and do not receive the support they need to maintain good mental health and manage sensory difficulties around food.

Who is most likely to be affected by an eating disorder? How do eating disorders impact London's diverse population differently?

Autistic people are considerably more likely to be affected by eating disorders; while autistic people account for 1-2% of the general population, but up to 20% of women in anorexia services,[89] with similarly heightened prevalence in men.[10] Autistic people also experience reduced levels of recovery from eating disorders and more persistent difficulties with wider mental health compared to their non-autistic peers.[11]

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[1] Mandy W & Tchanturia K (2015). Do women with eating disorders who have social and flexibility difficulties really have autism? A case series. Molecular Autism 6, 6. doi.org/10.1186/2040-2392-6-6

[2] Westwood H, et al. (2017). Clinical evaluation of autistic symptoms in women with anorexia nervosa. Molecular Autism 16(8), 12. doi.org/10.1186/s13229-017-0128-x

[3] NHS Digital (2023). Autism Statistics, April 2022 to March 2023. digital.nhs.uk/data-andinformation/publications/statistical/autism-statis

[4] v Crane L, et al. (2018). Autism Diagnosis in the United Kingdom: Perspectives of Autistic Adults, Parents and Professionals. J Autism Dev Disord 48, 3761-3772. doi.org/10.1007/s10803-018-3639-1

[5] Beresford B, et al. (2020). Evaluating specialist autism teams' provision of care and support for autistic adults without learning disabilities: the SHAPE mixed-methods study. Health Serv Deliv Res 8(48). journalslibrary.nihr.ac.uk/hsdr/hsdr08480

[6] Potter CA (2017). "I received a leaflet and that is all": Father experiences of a diagnosis of autism. Br J Learn Disabil. 45, 95- 105. doi.org/10.1111/bld.12179

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[11] Nielsen S, et al. (2015). Effects of autism spectrum disorders on outcome in teenage-onset anorexia nervosa evaluated by the Morgan-Russell outcome assessment schedule: a controlled community-based study. Molecular Autism 8(6), 14. doi.org/10.1186/s13229-015-0013-4

Contrary to persistent stereotypes around eating disorders as a reflection of body image, emerging evidence suggests that for autistic people this is less likely to be a significant factor. Instead, the root cause is often tied to autistic traits; for example, finding eating difficult due to hypersensitivity to certain tastes and textures, or developing rigid rules and routines around eating and measurements.[12][13][14] Current treatments, designed for non-autistic patients, may therefore require substantial adaptation for autistic patients.[15][16] Combined with wider barriers to accessing healthcare, this also means that it may take longer for autistic people to receive an accurate diagnosis, contributing to a more severe clinical presentation on admission to inpatient care.[17]

How can people in London be supported to recognise their symptoms and seek treatment for eating disorders at an earlier stage of their condition?

Too many autistic people have their needs unrecognised for years or decades, allowing eating disorders and other mental health difficulties to develop and become entrenched. The current waiting times for an autism assessment and lack of support after diagnosis are unacceptable. Research is desperately needed to develop and evaluate more sustainable and holistic models of assessment, interventions for the most pressing support needs of autistic people including eating difficulties, and models for stepped care across the lifespan. Shorter-term measures to tackle the backlog include increasing funded clinical psychology placements, requiring more of those placements to specialise in neurodiversity, and clarifying commissioning arrangements for mental health support for autistic people of all ages. In the meantime, auditing all autistic people amongst current eating disorder service users could help establish whether there were missed opportunities to intervene earlier.

A range of adaptations to standard therapies for eating disorders are already being evaluated in autistic people,[18] but further studies are required to ensure that effective supports can reach clinical practice. Much of the existing evidence base focuses on anorexia nervosa, but anecdotally other eating disorders such as bulimia and Avoidant/Restrictive Food Intake Disorder (ARFID) are also very common in autistic people; further research is needed in this area. Developing more tailored interventions for eating disorders in autistic people will help to tackle difficulties at an earlier stage, before a crisis is reached.

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More generally, autistic people often face poorer health outcomes than their peers.[19][20][21] [22][23] This is in part through difficulties accessing healthcare services due to lack of understanding, inaccessible contact options, and sensory barriers.[24][25][26] Inpatient eating disorder services are often particularly difficult environments for autistic people, impacting the effectiveness of treatment.xxvii Adapting the sensory environment, allowing for a range of communication methods and adjusting expectations for how eating disorder symptoms present and how patients may behave can make a substantial difference.[27][28]

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British Association for Counselling and Psychotherapy (BACP)

What stigma or discrimination, if any, do you think people suffering from eating disorders or disordered eating experience?

May not access services, may experience shame/blame/guilt; for those who cannot pay for therapeutic support (which may in turn help with making a referral to an eating disorder clinic) these people will go under the radar with no early help in place. People from minoritised communities already face barriers to accessing early help services and may not access GP as first port of call.

What initiatives do you think would help better support people in London experiencing eating disorders or disordered eating?

Early help access to counselling provision in school, community, family hub, youth work settings - access to counselling with GP practices. Initiatives to fund counselling provision delivered by registered members of a professional counselling body such as BACP, or UKCP. Funding should be allocated to schools to provide access to counselling provision before any medical interventions are ever needed. Eating disorders are coping mechanisms for trauma and other under-lying psychological conditions or experiences. The recent Children's Commissioners report highlighted waiting times as an issue for both urgent and routine referrals. The report found that the number of children and young people starting treatment for eating disorders has more than doubled since 2016-17. Around 11,800 children and young people began treatment for eating disorders in 2022-23, up from 5,240 in 2016-17. However, in nearly half (45%) of urgent cases, patients were waiting more than 12 weeks to begin treatment, almost three times more than 16% in 2016-17. For routine cases, this drops to 34% in 2022-23 and 20% for 2016-17 respectively. Only 78% of urgent cases and 81% of non-urgent cases are being seen within the target time frame of 1 and 4 weeks respectively in the third quarter of 2022-23. Although this data is England wide it will be reflective in patient experience in London.

BACP stress in all of our campaign work the importance of early access to counselling provision as vital, delivered by a trained and competent children and young people specialist counsellors in schools and community settings. Eating disorders and disorderly eating are the tip of the iceberg, the 'behaviours' presented after unprocessed psychological distress, including childhood trauma, amongst other early adverse childhood experiences. We need to provide more preventative and early help services including Government funded (which could be awarded by devolved health care funding) access to counselling. Areas such as Norfolk and Waveney NHS Trust have developed a referral pathway via their Single Point of Access to mental health support to include commissioned out counselling to trained CYP counsellors (who are members of professional bodies) who have signed up to offer up to ten counselling sessions administered via a host organisation, in this case the Norwich YMCA (bids went out to tender). This model, based on a model set up in Bradford during covid, is easily replicated across other ICS areas. Please contact BACP for further details - jo.holmes@bacp.co.uk

BACP have also called for funding for community hubs, where children and young people up to the age of 25 can access counselling in the community. These hubs follow the YIACS model (youth, information, advice and counselling services) as developed by Youth Access. Longer term funding for third sector counselling providers is also needed to provide further choice and extend the reach of just having a school-based counselling model. Lastly, eating disorder referrals should build in access to counselling as part of the treatment package to compliment the medical model approach to current treatment.

BEAT

Beat is the UK's eating disorder charity, providing information and support 365 days a year through Helplines which people can call, text or email, and through online support including information, message boards and online support groups. Beat campaigns for change in policy and practice, and provides expert training for health, social care, and education professionals. It relies on financial support from the public to run its services.

How prevalent are eating disorders and are there any factors that risk further increasing the number of people developing an eating disorder in London?

We estimate that around 1.25 million people in the UK have an eating disorder. While there have been some significant and well-designed studies conducted in the UK in recent years, overall, there has not been sufficient research to draw firm conclusions about the prevalence of eating disorders in the UK.[29]

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[29] Beat, 2017

Moreover, the number of people seeking treatment has risen considerably in recent years – particularly after the onset of the pandemic. It is not clear how much of this is accounted for by people who had recently developed an eating disorder for the first time or experienced a relapse.

In 2022, the Royal College of Psychiatrists reported that hospital admissions for eating disorders had increased by 84% in the last five years.[30] Children and young people with eating disorders were reported to be the worst affected with a rise of 90%. Eating disorder referrals for children and young people increased by 55% from 2019/20 to 2020/21, with Claire Murdoch, the National Mental health Director, describing a "surge" in urgent eating disorder cases.[31] In adults, eating disorder referrals increased by over a fifth from 2019/20 to 2020/21.[32]

COVID-19 has had a profound, negative impact on people affected by eating disorders. In a 2020 survey of people with an eating disorder, conducted during the first lockdown, 90% of respondents said that that their symptoms had gotten worse as a result of the pandemic.[33]

A study on the impact of COVID-19 on individuals with eating disorders reported a theme among participants of being reluctant to seek help during the pandemic and cited a link to lack of self-worth.[34] This, combined with fears around catching COVID, and public messaging about the pressure on health services, could have contributed to longer delays in seeking help.

A June 2023 study[35] found that between 2020 and 2022, the incidence of eating disorders among girls aged 13 to 16 was 42% higher than expected from antecedent trends, and 32% higher than expected for girls aged 17 to 19. The study found that the higher incidence of eating disorders and self-harm in girls was *"largely attributable to increases within less deprived communities"*. This may suggest that the pandemic had a significant impact in particular on children and young people at risk of developing an eating disorder.

Eating disorder services were already severely under-resourced prior to the pandemic[36], and the impacts of COVID-19 mean that they are now even more stretched. As there is typically a delay of three and-a-half years between developing an eating disorder and first seeking help[37], it is likely that the increased demand for specialist treatment will persist.

Who is most likely to be affected by an eating disorder? How do eating disorders impact London's diverse population differently?

Eating disorders affect people of all ages, genders, ethnicities, and backgrounds, and there several different types of eating disorder.

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[30] Royal College of Psychiatrists, 2022
[31] NHS England and NHS Improvement Board, 2021
[32] Written parliamentary question, 2021
[33] Brandley-Bell and Talbot, 2020
[34] Vuillier et. al., 2021
[35] Trafford et. al., 2023
[36] Ignoring the Alarms, Parliamentary and Health Service Ombudsman, 2017
[37] Delaying for years, denied for months, Beat, 2017

Although current data suggests that young women are the most likely to develop an eating disorder, research evidence shows that a much higher proportion of men and boys[38] and older people[39] are affected than is commonly understood. Some evidence suggests that eating disorders may have a similar or even higher prevalence amongst people from ethnic or cultural minority backgrounds when compared to people of 'White British' ethnicity[40]. NICE[41] has highlighted that generally people from these demographics may be more reluctant to come forward and ask for help, and it may be harder for others, including healthcare professionals, to spot an eating disorder if they have misconceptions about who is likely to have one.[42]

These misconceptions can make it harder for individuals from certain groups to access treatment. For example, individuals from ethnic minority communities are less likely to receive a diagnosis, be referred, and ultimately access treatment, for an eating disorder[43]. Around 1 in 4 people with eating disorders are men[44], yet in a recent Beat survey 1 in 5 told us that they have never spoken out about their struggles.[45] High levels of comorbidity have been observed in people with eating disorders[46], but some services will turn away patients with co-morbid conditions.

Steps are being taken to more clearly understand how health inequalities operate in relation to eating disorders. Kent Surrey and Sussex Academic Health Science Network recently launched the FREED Inequalities Toolkit[47], a resource to help healthcare professionals to measure and understand inequalities in eating disorders through the FREED programme.

How can people in London be supported to recognise their symptoms and seek treatment for eating disorders at an earlier stage of their condition?

We know that the sooner someone with an eating disorder receives treatment, the better their chances of making a full and sustained recovery, and the lower the costs to the NHS.[48] Ensuring that both medical professionals and the general public are aware of the early sign and symptoms of an eating disorder and how to get help, is key to enabling as many people as possible to receive support early, preventing their condition from deteriorating further.

Over half of people with eating disorders experience their first symptoms of low weight or binge eating as adults.[49] Despite this, accessing treatment, particularly early in their illness, is difficult

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[38] Sweeting et. al., 2015
[39] Micali et. al., 2017
[40] Solmi et. al., 2015
[41] NICE, 2017
[42] Nazir, 2015
[43] Sinha and Warfa, 2013
[44] Sweeting et. al., 2015
[45] Beat, 2023
[46] Hambleton et. al., 2022
[47] Kent Surrey and Sussex Academic Health Science Network, 2023
[48] Position statement on early intervention for eating disorders, Royal College of Psychiatrists, 2019
[49] EDGI, 2021

for those with eating disorders. Adult eating disorder services are particularly under-resourced, and typically have either long waiting lists or referral criteria (or both). In December 2022 the University of Liverpool published the findings of research into waiting times for adults to access community eating disorder services: 7 in 10 trusts reported waiting times in excess of three months, and overall, the data suggested an average waiting time of five months.[50]

Adults often face a postcode lottery when trying to access treatment for their eating disorder, and little progress has been made to improve this. In 2017 the Parliamentary and Health Service Ombudsman (PHSO) published a damning report into the failings that led to the deaths of three patients with an eating disorder.[51] In February 2023 the Health Service Journal[52] identified at least 19 adults with eating disorders whose deaths sparked concerns from coroners about their care. The coroners described patient safety risks being missed or poorly managed, limited knowledge of eating disorders among doctors and other health professionals, and delays accessing appropriate treatment. These same failings were among the key issues identified by the PHSO 5 years ago.

Beat's position is that 'early intervention' should be defined as "intervention when the earliest, subthreshold signs of an eating disorder begin to emerge".[53] Our Best practice standards call on all providers of community eating disorder services to:

- Run locally specific outreach campaigns to increase community understanding of the early signs of eating disorders and how to access assessment, support and treatment.
- Offer accessible self-referral or suitable alternative referral routes to specialist assessment which do not require people to seek help via their GP.
- Provide assessment and start treatment within no more than 4 weeks of someone seeking help for everyone of any age with any eating disorder presentation.
- Ensure that the service is staffed with sufficient numbers of suitably trained clinical and non-clinical staff in the correct mix of disciplines required to ensure continued and consistent high-quality treatment for all patients regardless of the duration of illness.

These standards also make wider recommendations for Government and the NHS on: long-term workforce planning; medical training; training for non-specialist health and education professionals; inclusion in public mental health campaigns; funding; accountability.

Early intervention has not yet become the norm for eating disorders. Even before the pandemic services were increasingly over-stretched and did not have the staffing to enable them to deliver effective early intervention.

Is access to specialist eating disorder services consistent across different parts of London and how does it compare to other parts of the country?

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[50] Sky News, 2022
[51] Ignoring the Alarms, Parliamentary and Health Service Ombudsman, 2017
[52] Health Service Journal, 2023
[53] Beat, 2022

We welcome the national roll-out of the FREED early intervention model that was developed in South London. We understand that there are currently significant discrepancies between the five services in London that are in the process of adopting the model, with some struggling with their waiting times. As in other parts of the country eating disorder services in London are facing significant challenges in recruiting and retaining the workforce required.

Another area of inconsistency in service provision across London concerns the utilisation of Peer Support Workers (PSWs). When properly trained and supervised PSWs can play a key role, utilising the expertise developed through their lived experience to enrich the care provided by multi-disciplinary teams.[54] Some eating disorder services in London don't employ any Peer Support Workers, whilst others are taking part in pilots to strengthen their workforce with the addition of these new roles.

Is there anything else you wish to share with the Committee that can help inform our investigation into eating disorders in London?

Very little data is published nationally on eating disorder services. That which is published is caveated with warnings about its reliability. The London Mental Health Dashboard[55] is a useful tool, but the data that is included on eating disorders is limited to that which is already mandated and published by NHS England on waiting times for children and young people.

Beat is calling for:

- Adoption of an ambitious understanding of early intervention: "intervention when the earliest, subthreshold signs of an eating disorder begin to emerge" and commitment to achieve this through implementation of best practice standards.[56]
- NHS England, Integrated Care Systems (ICS), and providers to ensure that eating disorder services are accessible without prejudice by diagnosis, severity of illness or the presence of co-morbidities.
- All Community Eating Disorder services in London to make use of properly supervised non-clinical staff to support early intervention, and recruit Peer Support Workers to enrich multidisciplinary teams.
- Long-term workforce-planning and investment at the national and regional levels to ensure London has the supply of clinicians it needs. This must include initiatives to encourage and support more trainees to specialise in eating disorders, and greater support for clinicians' wellbeing.
- A broader range of data on eating disorder services is published in the London Mental Health Dashboard, improving transparency and providing a model for other cities/regions.

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[54] NHSE, 2023
[55] NHS Benchmarking, 2023
[56] Beat, 2022

Carneys Community

How prevalent are eating disorders and are there any factors that risk further increasing the number of people developing an eating disorder in London?

Eating disorders are prevalent, however are often well hidden. Social media, focus on body image and disparity can all lead to eating disorders

Who is most likely to be affected by an eating disorder? How do eating disorders impact London's diverse population differently?

Those from a vulnerable background, with little stability at home and who feel they have a lack of "control" over their lives are likely to be impacted. Also people who have SEN's can be vulnerable to eating disorders.

Eating disorders can impact people differently. We often see people with SEN becoming either obsessed with only eating certain foods or not eating at all, in order to lose weight. This can be enhanced for those who get involved in our boxing, as there is a focus on losing weight. So any "making weight" conversations need to be done carefully and healthy ways to do so must be provided.

How can people in London be supported to recognise their symptoms and seek treatment for eating disorders at an earlier stage of their condition?

More discussions about eating disorders at school and in the media (including social media). There should be more safe spaces where people can speak to trusted adults about things like eating disorders

Do children and young people in London have good access to specialist eating disorder services? Are any improvements needed?

Not something we have ever looked for other than with CAMHS and they are very hard to get to take on a case.

Do adults in London have good access to specialist eating disorder services? Are any improvements needed?

Not sure, but I am not aware of any.

Is access to specialist eating disorder services consistent across different parts of London and how does it compare to other parts of the country?

Not sure, as we mainly cover Wandsworth

Is there anything else you wish to share with the Committee that can help inform our investigation into eating disorders in London?

Body dysmorphia is something that we see a lot, with those involved in weightlifting and body building.

Nick Pollard, co-founder and Director of Family Mental Wealth

Background

Family Mental Wealth is a government-funded social enterprise co-founded by Dr Elizabeth McNaught (an NHS doctor) and her parents Nick & Carol Pollard (lifelong social-entrepreneurs). Our mission is to play a significant role in radically transforming mental health provision for children and young people through digital tools to facilitate family-based self-help, appropriately integrated with educational and clinical support.

We have a particular interest in eating disorders because one of our founders, Dr Elizabeth McNaught, has lived-experience of an eating disorder in her teenage years – see 'Life Hurts: a doctor's personal journey through anorexia' (MD Publishing, 2017).

Dr Elizabeth McNaught and Nick Pollard are also co-authors of the Oxford University Press textbook 'Eating Disorders: An Oxford Specialist Handbook' (OUP 2022).

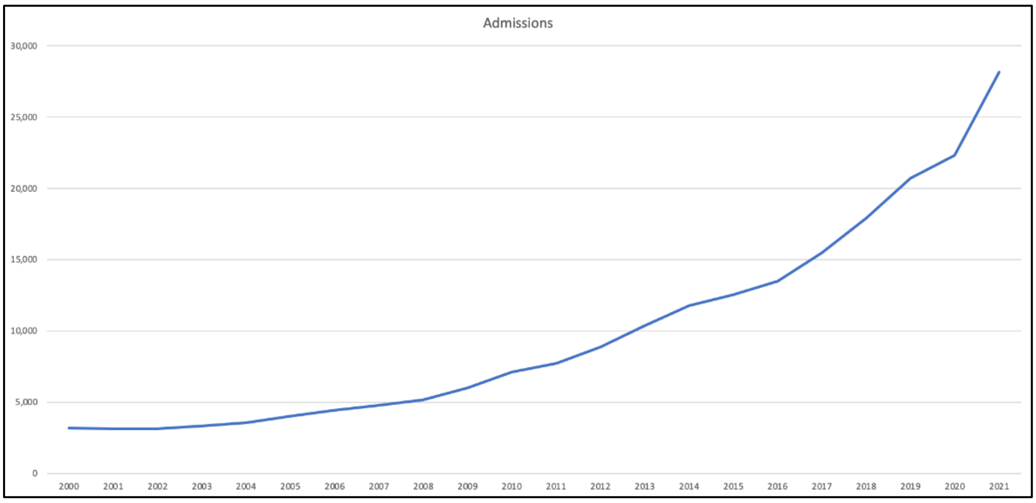
Family Mental Wealth (in collaboration with the South London & Maudsley NHS Foundation Trust and Oxford University Press) has also published an eLearning course, for all Healthcare Professionals and Allied Health Professionals, based upon this Oxford University Press textbook – see http://www.familymentalwealth.com/HealthProfessionals

How prevalent are eating disorders and are there any factors that risk further increasing the number of people developing an eating disorder in London?

Although the estimated figure of 1.25 million people in the UK is often quoted (as it is in your call for evidence), it is important to note that:

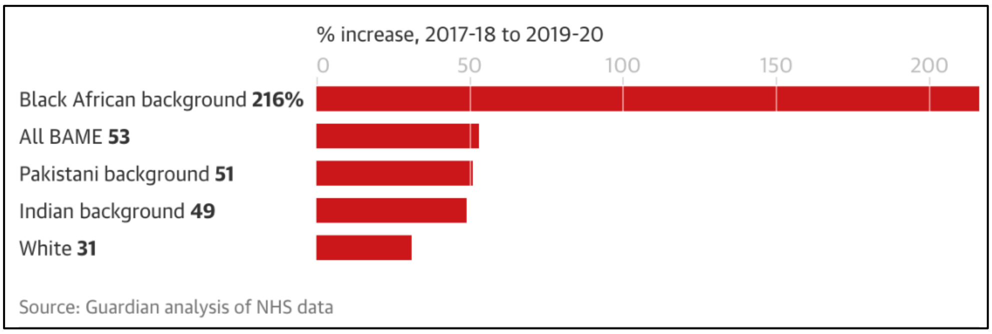
- Eating disorders are secretive illnesses and therefore the actual prevalence figures are likely to be higher than any figures that are discovered or estimated through any particular piece of research.
- Although most people are aware of Anorexia Nervosa and Bulimia Nervosa, and increasingly people are becoming aware of Binge Eating Disorder, there are many more forms of eating disorders that are less well known but do have a significant impact upon the person's health, education, and employment, and in many cases can pose a real threat to life. The Oxford University Press textbook *'Eating Disorders: An Oxford Specialist Handbook'* (OUP 2022) details seven different types of eating disorders: Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder, Avoidant/Restrictive Food Intake Disorders, Pica, Rumination Disorder, and Other Specified Feeding or Eating Disorder. In addition to these, the textbook also covers other eating disorder diagnoses that are increasingly being identified through research, and recognised in clinical practice, including: Orthorexia Nervosa and Type 1 Diabetes with Disordered Eating. Therefore, any estimation of the prevalence of eating disorders should take account of all different forms of eating disorders.

What is very clear from the research is that the prevalence of eating disorders is increasing. Although, as explained above, it is difficult to be certain of the actual prevalence figures in the population, what is known with quantifiable certainty, is the number of hospital admissions with a primary or secondary diagnosis of an eating disorder. NHS England published figures in March 2023 (see https://digital.nhs.uk/supplementary-information/2023/self-harm-and-eating-disorders-admissions-by-age-and-sex) and we have constructed the totals into a graph:



Who is most likely to be affected by an eating disorder? How do eating disorders impact London's diverse population differently?

Eating disorders can affect anyone, regardless of age, gender, socio-economic status, and ethic or cultural background. However, analysis of NHS England data by the Guardian newspaper (see https://www.theguardian.com/society/2020/oct/18/nhs-hospital-admissions-eating-disorders-rise-among-ethnic-minorities) has highlighted that hospital admissions are rising at a faster rate amongst the ethnic minoritised population. The following is a graphic from the Guardian website:



Source: Guardian analysis of NHS data

How can people in London be supported to recognise their symptoms and seek treatment for eating disorders at an earlier stage of their condition?

The current eating disorders guidelines from the National Institute for Health and Care Excellence (NICE) provide a detailed list of symptoms of eating disorders. However, these are not in a format that is ideally accessible for the general population – or indeed most non-specialist clinicians.

Therefore, at Family Mental Wealth, and in the Oxford University Press textbook 'Eating Disorders: An Oxford Specialist Handbook' (OUP 2022) we provide a simple mnemonic which our research shows is accessible and useful for the general public and clinicians alike:

Absence
Are they absenting themselves from food-related activities?

Body
Are they obsessively worrying about the shape of their body?

Control
Are they compulsively in control, or out of control, of food?

Diet
Are they radically changing their diet?

Exercise
Are they exercising excessively or obsessionally?

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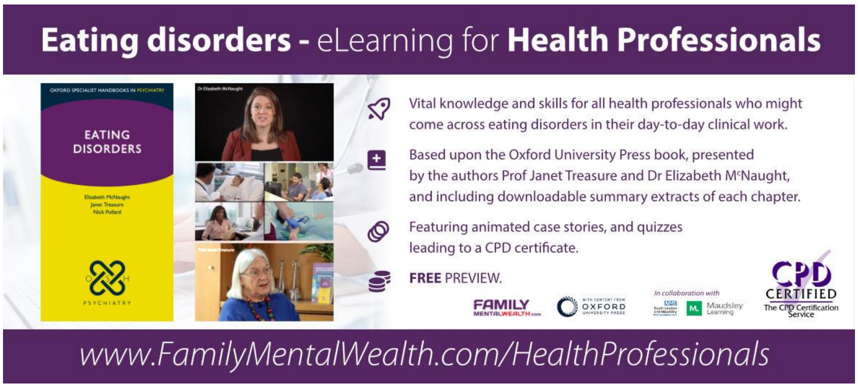
This mnemonic is taught in the eLearning for health professionals that accompanies the textbook (http://www.familymentalwealth.com/HealthProfessionals)



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And this mnemonic is also taught in the eLearning for teachers and school classroom resources provided free for all schools by Family Mental Wealth (http://www.familymentalwealth.com/SpotTheSigns).

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Do children and young people in London have good access to specialist eating disorder services? Are any improvements needed?

Do adults in London have good access to specialist eating disorder services? Are any improvements needed?

Answering questions 4 & 5 together…

The problems are widely recognised:

- There is a problem of accessing specialist treatment for eating disorders (for children, young people, and adults), as part of the wider problem of accessing specialist treatment for any mental health condition. For example, 60% of children and young people who have a diagnosable mental health disorder do not receive specialist treatment (The Health Foundation, 2022).
- The reasons for this include increasing demand (NHS Confederation 2022) and staffing shortages (Royal College of Psychiatrists, 2021) – neither of which show any signs of abating.
- It has long been recognised that 75% of adult mental ill-health began in childhood (Kim-Cohen, 2003), so failure to address these issues leads to long-term (sometimes life-long) implications for the health of the population and costs to the NHS.

However, two clear and achievable means of addressing this problem are not yet widely recognised:

1. It is not just specialist clinicians who can, and should, contribute to the prevention and management of eating disorders. ALL healthcare professionals and allied health professionals will come across people with eating disorders in their day-to-day clinical work, and have the opportunity to contribute to the NHS aspiration to 'make every contact count'. For example, the early symptoms of an eating disorder may first be

identified by a dentist, pharmacist, or physiotherapist – if they have the vital knowledge to spot the signs. And then, throughout the management and treatment of these illnesses, every healthcare professional and allied health professional can play their part in supporting the recovery journey. As Prof Janet Treasure (a world-renowned expert on the subject from King's College, London, with a lifetime's experience in specialist care) puts it: "Recognising and managing eating disorders requires a team with all types of clinicians who play their part, bringing different types of expertise at different times to help the person." That is why, together with Prof Treasure, we have created the eLearning that accompanies the Oxford University Press textbook 'Eating Disorders: An Oxford Specialist Handbook' (OUP 2022) – geared for ALL healthcare professionals and allied health professionals, so they can play their part in recognising, managing, and supporting specialist treatment for these devastating illnesses (http://www.familymentalwealth.com/HealthProfessionals).

2. The current NICE Guidelines recommend involvement of parents/carers, who can play a key role in prevention and treatment of eating disorders in their children and young people, especially when appropriately integrated with clinical interventions. But this requires them to have appropriate knowledge and skills. The 'New Maudsley Method for Skills-based Caring', developed by King's College London, and the South London & Maudsley NHS Foundation Trust, is effective at equipping families with such vital knowledge and skills (Hibbs 2015, Treasure 2020). That is why, together with the South London & Maudsley NHS Foundation Trust, we have created an online parent/carer toolkit based upon the New Maudsley Method (see http://www.headway.family/).


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Is access to specialist eating disorder services consistent across different parts of London and how does it compare to other parts of the country?

Sorry, we don't have access to research data to answer this question.

Is there anything else you wish to share with the Committee that can help inform our investigation into eating disorders in London?

Eating disorders do not just impact the health, education, and employment of those who develop them. These devastating illnesses also impact the wider economy, see eg:

- Research by Ernst and Young (EY, 2021) estimates the wider cost of eating disorders to UK society could be as much as £11.2bn annually (see https://www.yumpu.com/en/document/read/65877873/the-cost-of-eating-disorders-in-the-uk-2019-and-2020-with-annex.)
- Research by the City Mental Health Alliance, PwC, and Morgan Stanley (CMHA, 2023) reported that 48% of working parents said their children's mental ill-health has impacted their performance at work, including regular disruptions and an inability to concentrate on the job (see https://citymha.org.uk/Resources/Parents-Toolkit/Impact-of-childrens-mental-health-on-working-parents)

Therefore, there is a clear business case for the London Assembly investing in tools and resources, such as those described above, in order to prevent the impact of eating disorders on the population of London.

At Family Mental Wealth, we would be delighted to explore with the London Assembly how we might collaborate to provide the people of London with all of the tools and resources described above, so that clinicians, schools, and parents/carers can reduce the devastating impact of eating disorders on the population of London.

Goldsmiths, University of London

The following submission represents the collated views of Sue Dixon, Department of Educational Studies at Goldsmiths, University of London and Group members of the Central London Self Help Support Group for adults with an Eating Disorder

Due to specialisation and lived experiences in eating disorders, the author and collaborators were well placed to respond to this inquiry to provide insight into the experiences of people with an eating disorder living in London.

About the author

Sue Dixon is joint Head of Teacher Education at Goldsmiths, University of London. Outside of Goldsmiths, Sue is a volunteer group contact and co facilitator of the Central London Self Help Support Group for adults with an eating disorder. She was shortlisted in May 2014 for a BEAT national lifetime achievement award in recognition of her longstanding voluntary commitment to BEAT and the Self Help Group that she co-facilitates in Central London which spans over 25 years. She is a part time Psychology PhD candidate who is researching eating disorders and recovery within the context of support groups. Additionally, she is a private part time counsellor/ psychotherapist, practising in London.

About the Central London Self Help Support Group

This peer support group is facilitated by four facilitators who have a variety of lived experiences of EDs. The group has been established in London for many decades. It meets twice a month on the 2nd and 4th Wednesday of each month face to face in a rented facilities (2nd Wednesday) and via Zoom (4th Wednesday). It is an open group so anyone with an ED (diagnosed or not) can self refer themselves to the group. It has no recourse to public funds.

The group advertises itself via the national charity BEAT's database (formerly the Eating Disorders Association when the group was first started). Attendees have also found out about the group via their therapists and also through some outpatient services in London.

In addition to the author, twelve members of the Central London Group have contributed their thoughts and lived experiences to this response. Their direct words have been used in places and are italicised and represented in a different font.

Executive summary

1. There are a number of risk factors leading to people developing an eating disorder in London. These include socialising pressures around eating out; financial pressures including food poverty; impact on pressure of body image around media; insecure housing and unstable employment.

2. Diverse groups have EDs but often they are underrepresented in NHS clinical settings. There is disparity in the data for minority groups.

3. There is a need for a recognition of the inequality in the NHS system and the barriers that individuals with an ED may face to access the right support. Approaches to supporting people to recognise that they may have an ED include targeting specific groups, changing the narrative around EDs, ensuring that media represents all types of EDs and training GPs.

4. The lived experiences of people with an ED in London reveals that where they are located is often contingent as to whether they receive the support they need. In some cases, there are lengthy waiting lists with wait times of over a year for adult services. This can be compounded if someone moves to a new borough. This has meant that some people have lost their place on the waiting list as they need to be referred to a service within their new borough. This could mean a further delay in receiving treatment.

5. Funding / bursaries for nurses to have specialist training in EDs is an approach to providing additional support within the NHS system.

6. The Committee need to review the criteria that services use to decide on who is offered treatment to ensure that all those who need support are offered it in a timely fashion.

7. There are opportunities for the NHS to link with charities and voluntary groups to draw on the knowledge and experiences of people with lived experience. Support groups can offer a holding space for people waiting for treatment.

How prevalent are eating disorders and are there any factors that risk further increasing the number of people developing an eating disorder in London?

It is our opinion that there are a number of factors which potentially exacerbate the prevalence of eating disorders (EDs). We have identified six such factors and where relevant drawn on the experiences of individual group members.

The realities of living in London

London can be a complex city to navigate due to its vastness and the diversity of the population. There is a significant risk of feeling socially isolated as meeting and interacting with new people can be problematic, as often the opportunities to socialise revolve around food related activities. From experience, some members of the group who have moved to London have identified the struggles they have had establishing or re-establishing emotional and social networks they may have had in their hometown or country. We have people attend the group from many parts of the world “and a recurring theme is loneliness when moving to a big city, and this can be correlated to a flare up in their eating disorder" and continues to be borne out in the group. Moreover, an ED can be used as a way to assuage those difficult feelings of loneliness and isolation.

The Impact of the Covid-19 Pandemic

During the pandemic when the country was placed in lockdown and when gatherings were restricted, the Central London Group had to meet online instead of in-person. For many young people and adults, living in shared spaces (sometimes crowded) with little privacy throughout the pandemic, and being cut off from their social support networks at university or work has had a negative long-term impact on their mental health. This was evidenced for example within the context of the group as some members were unable to access the group because they felt that they had no private space to participate online. The group had been an important part of supporting their recovery. The fear of flatmates or families finding out about their ED was a real fear and a barrier to continuing to reach out to the group in an online space. This put back the recovery for some in terms of relapse as they did not have the space to touch base with others in the same situation as themselves and access support.

Finance

Living in London financially for some means that money has been very tight. This has been heightened more recently with the cost-of-living crisis. For some it can present an opportunity to cite finance as a reason not to nourish themselves properly: "so, an excuse to spend less on food" and a way to manage the feelings associated with this: "austerity and the financial problems and the lack of security that come with them (EDs are sometimes, though not always, an attempt to impose control in an otherwise uncontrollable situation)."

Furthermore, poverty, especially food poverty, can put some people at risk of developing "disordered eating habits like restriction, binge-eating patterns and feelings of guilt or anxiety around food." The binge purge cycle of some EDs can put some individuals with an ED at risk of being in debt to pay for the food used in binges which can amount to a significant sum of money.

Another group member noted that "poor living conditions or lack of a stable home" is a risk factor. Several group members have experienced moving accommodation a number of times due to a variety of reasons such as: the landlord selling the property; not getting on with flatmates; or the cost of the rent increasing out of their financial reach. Group members have noted how challenging it is to live with others when trying to conceal their ED or engage in a recovery programme or having to move back in with parents due to financial constraints. Some who have experienced recovery have relapsed and needed further support as a result. Employment is another risk factor as it has been documented that many of the service industries were impacted pre, during and post covid. This made individuals with an ED vulnerable in terms of losing their employment. Sometimes individuals with an ED may lack the confidence or not have the good health to apply for new jobs, especially if they have not recovered or are in recovery. Situations have arisen for some who have managed to have reasonable adjustments implemented in their workplace due to having supportive managers and HR departments, which they have then had to renegotiate if they move to a new place of employment. This can be a real source of anxiety. Not all places of employment are understanding for the need for an employee to attend regular visits to the hospital or an allied health professional on an ongoing basis.

Internal and external pressures related to messages about weight and diet

The "public / political conversation around weight" which is often linked to obesity and the cost to the public purse can send a confusing message regarding what constitutes healthy eating to young people who may be going through puberty and the resultant changes to their bodies. Schools are required to teach children about physical health and wellbeing as per the DfE statutory guidance: 'Relationships Education, Relationships and Sex Education (RSE) and Health Education'.[57] One aspect of this is teaching children about calories within the context of healthy eating. Additionally, obesity is referenced several times within this guidance as regards what primary aged pupils are expected to know by the end of primary school, e.g., 'pupils should know the characteristics of a poor diet and risks associated with unhealthy eating (including, for example, obesity and tooth decay) and other behaviours (e.g., the impact of alcohol on diet or health).' If not taught sensitively and knowledgably the wrong message can be taken away by pupils and this can lead to disordered eating.

Moreover, the introduction of "calories on menus in restaurants" has hampered the recovery journey for several in the group. There is a desire to want to recover and engage in social eating and move away from calorie counting. However, being faced with calories on menus can trigger the ED voice into restricting intake or engaging in compensatory behaviour. Furthermore, this may lead to an over heightened awareness of what they are eating and rigid control of how many calories they consume; this may be a trigger for the start of an ED. Linked with this is the fact that women's bodies are a source of external scrutiny by society in general and many members in the group, who are already self-critical of their bodies, find themselves "internalising [a] socially defined ideal body" and a "susceptibility to the diet culture, and unrealistic beauty standards", which is often promoted in mainstream media and social media.

Accessing health services/professional support

The NHS is overstretched and at capacity. The demand for ED specialist input outweighs the current provision in London; there is a real shortage and lengthy waiting lists (this point is discussed further in question four). Many in the group believe that there are "no preventive measures or help in London and it is difficult to get any support."

Transitions

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[57] Relationships Education, Relationships and Sex Education (RSE) and Health Education, DFE 2019 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1090195/Relationships_Education_RSE_and_Health_Education.pdf

Young people and adults experience a number of transitions in their life. One such transition is the transition from Child and Adolescent Mental Health Service (CAMHS) to adult services which can mean someone who has had treatment as a child may fall through the net when they have to be referred to adult service. They may be placed on a waiting list and not have the continuity of care that they require.

Similarly, when a young person starts university in another location away from the family home there are often not appropriate processes to refer them to the relevant service near to their university. These two transitions put people at risk of their ED getting worse. Likewise, a young person away from home for the first time may develop an ED as a way to manage how they feel.

Who is most likely to be affected by an eating disorder? How do eating disorders impact London's diverse population differently?

Eating disorders can affect anybody regardless of their age, ethnicity, gender, race, socio-economic status, gender identity or sexual orientation.

Some groups are more vulnerable than others though, especially teenage girls aged 15 to 19 (2 per 1,000 newly diagnosed).[58] Women and girls are most likely to be affected by eating disorders. This is borne out in the gender demographic of the Central London Group who are overwhelmingly female, and this is representative of research into EDs. However, we have had men and attendees who identify as non-binary attend the group infrequently. The number of men with an ED are on the rise and ranges between 10% and 25% of the estimated ED population[59], though men may experience difficulties reaching out for support. There is a perception that EDs are a female affliction which may further increase stigma for men with eating disorders.

Another group that are affected by EDs but who sometimes go under the clinical radar are people from a Black and Asian Global Minority background, leading to a possible perception that they are likely to get an ED. One member reflected on their work in schools and noted that they were "seeing more and more young black women (and sometimes young black men) presenting with eating disorders, and having concerns about their friends and family members. It's hard for me to say what is behind this: perhaps the increased conversation around racism and diversity and inclusion has bought this issue to the forefront, or a higher awareness of mental health within Black communities has led to more people coming forwards."

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[58] Micali N, Hagberg KW, Petersen I, et al
The incidence of eating disorders in the UK in 2000–2009: findings from the General Practice Research Database
BMJ Open 2013;3:e002646. doi: 10.1136/bmjopen-2013-002646

[59] Sweeting, H., Walker, L., MacLean, A., Patterson, C., Räisänen, U., & Hunt, K. (2015). Prevalence of eating disorders in males: A review of rates reported in academic research and UK mass media. International Journal of Men's Health, 14(2), 10.3149/jmh.1402.86

Data, however, suggest that Black communities are not highly visible in London ED outpatient and in patient settings, when they should be, based on demographic ethnicity data pertaining to London (46.2% of the London population identify as being from a Black, Asian, or mixed 'other' ethic group).[60] One group member reflected on this lack of presence: "I can't speak for people of colour, but in my experience of accessing treatment it has always seemed that most patients are white. This surely cannot be a reflection of an ethnicity bias in incidence, but more likely an issue of barriers to seeking treatment." More research therefore is needed into why there are low numbers of black people accessing support or possibly not being put forward for support.

There has been growing research into ED and people who are neurodivergent which are helping clinicians to better understand their experiences.[61] They are a population who "are at risk because of things like behavioural inflexibility, anxiety, food/texture sensitivities etc." They are at risk of developing an ED, not being put forward for specialist support when they do have an ED due to a lack of understanding and experience of some clinicians, or not finding the treatment as helpful as people who are not neurodivergent.

The needs of the LGBTQI+ community with respect to EDs is an area that is garnering more attention. The number of people identifying as Lesbian, Gay or Bisexual in London according to the Office for National Statistics[62] is 2.9% as Gay or Lesbian, 1.7% as Bisexual and 0.8% as Other.

The national charity Stonewall[63] commissioned You Gov to carry out research in mental health of the LGBTQ community. Of the 5,000 people who participated, 'One in eight LGBT people (12 per cent) have said they experienced an eating disorder in the year prior to the study. One in four non-binary people (24 per cent) have experienced this in the last year compared to 13 per cent of LGBT women and nine per cent GBT men' (p. 9). These statistics which were reported in 2018 demonstrate that the LGBTQ community are group that require specialist ED support.

One group member who is involved in mental health work noted that they were aware "that higher numbers of the LGBTQI+ community are seeking support for eating disorders, and teachers across London are reporting higher overall numbers of eating disorders in the classroom than they were prior to the pandemic."

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[60] Regional Ethnicity diversity data published December 2022. https://www.ethnicity-facts-figures.service.gov.uk/uk-population-by-ethnicity/national-and-regional-populations/regional-ethnic-diversity/latest#:~:text=2021%20Census%20data%20for%20England,17.0%25%20with%20white%20ethnic%20minorities

[61] Babb, C., Brede, J., Jones, C. R. G., Serpell, L., Mandy, W., & Fox, J. (2022). A comparison of the eating disorder service experiences of autistic and non-autistic women in the UK. European Eating Disorders Review, 30(5), 616–627

[62] ONS Sexual Orientation, UK 2020

[63] LGBT in Britain Health Report, You Gov. Commissioned by the charity Stonewall published 2018.

To surmise, “due to barriers in recognising EDs (due to stereotypes about who gets them) and barriers to seeking healthcare among various social groups (BAME, LGBT+ neurodivergent), the population with EDs is likely to be more diverse than official statistics indicate.” Official statistics for the numbers of people with an ED are based on estimates as not everyone with an ED will present themselves. Estimates have ranged between 1.25 and 1.6 million.[64]

How can people in London be supported to recognise their symptoms and seek treatment for eating disorders at an earlier stage of their condition?

We believe that the underlying consideration that needs to be borne in mind is a recognition that there is an inequality in the NHS system which needs to be addressed (this is also discussed further in question 4). Resources (lack of) is a significant problem, but sadly not one that is easily resolved. We have identified some potential approaches that may help to ameliorate the situation and encourage people to recognise they have a problem and thus seek professional support.

Awareness raising

Educating the public about EDs is key through e.g., "a public awareness campaign about where to get help as some people struggling may not be aware they have an eating disorder, or may tell themselves it’s not too bad and they don’t need help.”

Such campaigns can target particular groups (young and old) starting with helping people to understand the signs and symptoms of an ED so they can recognise whether their behaviours and thinking around eating, food and weight are disordered. Often people “have quite disordered views about weight and food but it's seen as normal, or framed as 'health conscious' and they may not realise what it is and the initial experience of how to seek help if you do have an ED should be both explained what to do, but also be made easier.”

One group member liked the Dove campaign: “I really like the recent Dove advert where it showed a real girl growing up and starting to experience social media etc and eventually developed an eating disorder.” Another group member reflected on the fact that “there have been a few good documentaries about how EDs can affect men”, but that they have “rarely seen it spoken about” and that “documentaries about EDs in general, rarely reflect the diverse spectrum of patients, nor the range of experiences they will have had that led to their ED”. The lack of diversity of different types of EDs helps to sustain the notion that EDs are about people who restrict, becoming very thin as a result.

There is a shift in how bodies are depicted in the media “in terms of body shapes and ethnicities etc. in advertising which could be helpful, because in London you are exposed to a lot of advertising all the time (e.g., even at tube stations, on buses). There is still a long way to

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[64] The charity BEAT suggests 1.25 million. https://www.beateatingdisorders.org.uk/get-information-and-support/about-eating-disorders/how-many-people-eating-disorder-uk/

go if more people from underrepresented groups are going to put themselves forward for professional support.”

Training of healthcare professionals

Healthcare professionals need to be targeted too. Research has found that doctors receive less than two hours of input on EDs in their training.[65] GPs are a natural starting point as they are gatekeepers to accessing the right specialist support. Charities like BEAT are trying to address this through offering post qualification training for doctors. If GPs were more cognisant as to the signs and symptoms of an ED, they might be more able to signpost patients to treatment sooner and create confidence in patients to disclose that they have a problem. People in the group have had varying levels of success with their GP. Some have been turned away from help because their GP does not agree that they have an ED, often referencing their decision to weight and/or BMI. Some have GPs who are not personable, so they do not feel able to talk about something (the ED and the behaviours) that for them has much shame attached to it.

Making links with voluntary services

There are opportunities for NHS trusts to make links with voluntary organisations like the Central London Self Help Support Group. Some members have found out about the group via the treatment service they have had outpatient input with. The group as a whole feel strongly about this and see the value in peer support. The group has acted as a holding place for people who are waiting for treatment or who have been rejected from services as they do not meet the BMI criteria, for example. Peer support can help to prevent relapse and promote recovery, as well as encouraging people to seek professional support. Through hearing about the experiences of others who have navigated the NHS system or approached their GP, many members of the group over the years have felt able to seek professional support.

We suggest that the government / NHS trusts or anyone who holds the purse strings to affect change:

“work with local and cultural communities to reach people with information they can understand and relate to; promote mental health and ED-specific voluntary sector organisations already helping affected people; use social media appropriate to different groups; ensure public health campaigns on a range of issues are informed by an awareness of EDs and do not unintentionally promote messages that reinforce ED attitudes or behaviours (especially important around exercise, weight and what it means to have a healthy life).”

Intervention

Research has found that early intervention has better treatment outcomes. Awareness campaigns, if successful, can help not just healthcare professionals but also help educators, friends and family of a person who has an ED. Some people with an ED may need the support

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[9] Ayton A, Ibrahim A. Does UK medical education provide doctors with sufficient skills and knowledge to manage patients with eating disorders safely? Postgrad Med J. 2018 Jul;94(1113):374-380

of those close to them to pluck up the courage to approach their GP. Friends and family need ongoing support to best understand how to support their loved ones with their treatment and recovery.

There exists a service model called First Episode Rapid Early Intervention for Eating Disorders (FREED)[66][67] which is aimed at 16- to 25-year-olds with an ED history of less than three years. This model addresses some of the risk factors identified in question one such as transition and offers a wealth of online resources.

Do adults in London have good access to specialist eating disorder services? Are any improvements needed?

Access to specialist services is often contingent on a postcode lottery or one's ability to pay for private treatment (often via one's parents/ relatives). This has been the experience of some members of the group. Below is one person's lived experience:

"I think it varies by trust/area. I was very lucky in 2012 to be seen by a very good team in NE London, and be, by chance, placed in a private hospital (there were no NHS beds). This placement saved my life. The outpatient CBT I received afterwards was also very good. However, once I had reached my allocated number of sessions, I was of course discharged. When I reached out for support again in mid-2019, it was a year before I was offered any therapy, by which time the lockdown necessitated that it be via Zoom. This was awful, and I did not feel the therapist was suitably experienced to help me, and she clearly did not think so either, as she suggested that *I* might like to stop the sessions for now (it had to come from me, apparently). It was reported that I was not responding to therapy, and they had no further options as I had seemingly exhausted those that they had to offer, and obviously had a long waiting list of new referrals needing treatment. So, I would say in the first instance, yes, but there is no provision for people with long-term conditions (which, let's face it, is the majority of sufferers)."

Another challenge is waiting lists. Some members experienced long waits for treatment as was the case for five members:

"When I was in treatment, it took 11 months on the waiting list, and my therapist said some very triggering things at times. Improvements are certainly needed."

"Most adults do not have good access to eating disorder services. It can be very hard to get a referral due to a lack of understanding around EDs among GPs, and even if a referral does get made, waiting lists are often extremely long and people are not offered any help in the interim. I waited 13 months for an appointment at the Maudsley ED service and had very little support or contact from the service while I was waiting."

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[66] https://www.england.nhs.uk/mental-health/case-studies/other-mental-health-case-studies/first-episode-rapid-early-intervention-for-eating-disorders-freed/

[67] https://freedfromed.co.uk/what-is-freed-for-patients-carers

Another member described their experience of the long wait for professional support as being "traumatic due to the continuous focus on weight rather than underlying causes."

Evidence points to there being a correlation between a longer waiting time and relapse, insomuch as the longer a person had to wait for treatment the higher the risk of a relapse.[68]

Another member experienced several long waits for treatment, but when they received treatment, they found it helpful:

"Wait lists have always been long in my experience here (3 separate occasions), but the most recent one took 1y to assessment and then another almost 2y after that for treatment (appreciate covid has added to this). Every referral I have had, I have had to do a lot of chasing of the referral before I was offered an assessment, and communication from the services was bad. Again, I thankfully have not had this experience, but I know many people have not been accepted for treatment as they're not 'bad enough', which just makes people want to get sicker. But once I have been in services and accessed treatment, the communication has been good, and support has been amazing. So, I think it's more access, communication, wait lists, etc that need improvement."

For another the journey sounded like a marathon:

"I think when you reach the help, it can be really good, and I have had really good experiences. But I think firstly, a lot of people fall at the first hurdle (i.e., actually getting the GP to refer you). Thankfully my GPs here have all been very helpful, but I know lots of others haven't."

Suggested improvements

We recommend that there is increased training for GPs. One member who works in mental health has noted that "there are so so many people who want to work in psychology, and there are so many vacant gaps in ED services (and other mental health services) which these people could fill." More funding places and bursaries for nurses or therapists to specialise in EDs should be created to grow the workforce and to help make being an ED specialist an attractive specialism to work in. Furthermore, "improving working conditions in the NHS", is critical "as a lot of people who do work in these services end up leaving to work privately."

Another source of concern which would benefit from further consideration is how specialist services manage referrals. One member provided an example of how they were not able to access their local service: "All the eating disorder services within North London are held by one provider, BEH St Ann's Eating Disorders Services. They only accept referrals for severe Eating Disorders (based on a BMI criteria) which means there is no early intervention or access." One surmises that this may be due to funding restrictions and supporting those who are at most risk

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[68] PricewaterhouseCoopers LLP (2015) *The Costs of Eating Disorders. Social, Health and Economic Impacts.* https://www.basw.co.uk/system/files/resources/basw_104500-2_0.pdf

to health. “It is essential that the Committee examine how many referrals are being rejected by BEH” [and other specialist services] “without an alternative source of support being provided." Too many people are being turned away from services due to low BMI, despite recommendations saying that BMI should not be a determiner of specialist input.

Concurrent to this, is what happens if people move out of their area (whilst they are on a waiting list) and the impact on where and how they are referred. This was a real concern for one group member:

“A lot of people in London are renting and are therefore moving between homes every year or two, and this sometimes means you move to a different borough, often not by choice. As you have to live or have a GP in a certain borough to be referred to that area’s eating disorder service, this can make things difficult when you might be on that wait list for 2+ years and you worry that if you move house you might be taken off the list.”

Better funding and collaboration are potential areas for improvement:

“There is a place for charities and individuals who are making an extreme contribution to improving the situation, but they need much more funding and collaboration with public bodies, flyers, and awareness campaigns, and most importantly collaboration with professional NHS staff. The disease is often not taken seriously by professional staff, or the waiting times are so long that the condition of those affected only worsens. One is pretty much left alone.”

Experts by Experience[69] is something that appears to be used by a variety of NHS trusts and services. NHS specialist services need to support and encourage more peer, lived experience informal support organisations such as the Central London Self Help Support Group and collaborate with them, and thus become more conversant with what they offer. Informal networks provide invaluable support that the NHS cannot offer due to limitations on budgets. We are very willing to collaborate with the committee in the future and offer more insight into the London picture and the informal support that we offer and have offered for many decades.

Recommendation:

We recommend that the waiting lists for treatment and support at the specialist ED services within London are reviewed so waiting times are reduced.

We recommend too that more resources are made available for the training of more specialist practitioners to enable earlier intervention for more individuals with an ED.

Further correspondence

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[69] Experts by experience information about role: https://www.england.nhs.uk/long-read/care-education-and-treatment-review-experts-by-experience-and-clinical-experts-role-descriptors/

We would be pleased to speak further about our response. Please contact Sue Dixon, Head of Teacher Education / Group Contact and co facilitator of the Central London Self Help Support Group for adults with an eating disorder, s.j.dixon@gold.ac.uk.

Jessika Morgan-McNeil, Occupational Therapist, Eating Disorders Day Unit at South West London & St.

George’s Mental Health NHS Trust

How prevalent are eating disorders and are there any factors that risk further increasing the number of people developing an eating disorder in London?

Eating disorders are extremely prevalent, with binge eating disorder being the most common. I think a lot of people only see eating disorders as anorexia or bulimia but really they are so much more than that. They are also about so much more than just food, eating disorders affect all aspects of life. Current risk factors are really to do with lots of things feeling out of control at the moment in terms of climate change, cost of living crisis and the covid 19 pandemic. This could cause someone to try and take back some control by controlling their weight, shape or food.

Who is most likely to be affected by an eating disorder? How do eating disorders impact London’s diverse population differently?

Currently people from BAME backgrounds are more under represented in eating disorders treatments. This can be due to lots of different factors and more work needs to be done to educate staff and the public about how eating disorders symptoms may show up differently. I think there is also a lot of work to do be in the LGBTQIA+ community, especially around trans healthcare and eating disorders. Patients who have come through our service who have identified as non-binary find it challenging to accept how their body will change with weight gain, especially if born in a female body. This can act as a further barrier to weight restoration and recovery.

How can people in London be supported to recognise their symptoms and seek treatment for eating disorders at an earlier stage of their condition?

More educational adverts or TV programmes which may show eating disorders in a more diverse range.

Do adults in London have good access to specialist eating disorder services? Are any improvements needed?

Generally services are good, however capacity to accept patients can be limited due to there not being enough staff for the referral rate. There is also not enough occupational therapists in eating disorder services and considering as eating disorders affect every part of a persons life, this feels like quite a vital service for people to have access to. As an OT myself working on a day unit I often cannot do half the things I would like to do, simply because I am the only OT and have to split my time between other generic tasks.

Local Dental Committees (LDC) Confederation

The LDC Confederation is a membership body for Local Dental Committees. We are responding on behalf of our members in London; North West London LDC, South West London LDC, South East London LDC, and Camden and Islington LDC. Together these LDCs cover 22 London boroughs and around 3,500 dentists providing NHS primary care dental services.

The LDC Confederation welcomes the Committee's investigation into eating disorders in London. As noted in the scope of the investigation eating disorders are increasing, and with that increase comes associated risk to overall health. With the move to Integrated Care Systems, the LDC Confederation considers that there is greater scope for services to work more closely together to support patients through a range of conditions including eating disorders and we hope that this investigation will highlight innovative ways of working.

The investigation poses seven questions. As a representative body for primary care dental services we are not in a position to provide answers to some of the specific questions but will provide evidence on the impact of eating disorders on oral health and the importance of integrated care providing a holistic pathway for patients with eating disorders.

Summary of Key Points and Recommendations

The LDC Confederation has been raising awareness about oral health and eating disorders since 2018:

- Eating disorders can have a serious impact on oral health.
- Dentists are well placed to identify the impact of eating disorders.

The London Assembly Health Committee to take a lead on recommending the following reforms:

- NICE guidelines on eating disorders (NG69) makes only a passing reference to dental care, and needs to be revised to focus on structured pathways to make every contact count.
- Clear pathways for those with eating disorders need to be put in place to ensure referral into dental practices.
- Training needs to be provided to dentists and their team to ensure every contact counts with referral pathways from dentists to eating disorder support put in place through local training hubs.
- Dieticians to have increased access to training on eating disorders and the impact on oral health delivered through local training hubs.[70]
- Local Healthwatch to be involved in delivering greater public awareness about the impact of eating disorders on oral health.
- In order for this investigation to have maximum effect we recommend a review of the implementation of recommendations in the new Mayoralty and London Assembly.

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[70] The role of dieticians was discussed by the London Eating Disorders Conference 2023 on day 1 of their March conference.

Submission

Eating disorders and oral health are intimately connected.[71] Firstly by the effect of different diets on oral health and secondly because of the effect of eating disorders themselves on the body, including dental health. Related, though outside the scope of this investigation is the effect of poor oral health, including dentition on people's ability to have a healthy and varied diet. The LDC Confederation raised eating disorders and oral health as a matter of concern at the national LDC Conference in 2018 where a motion was proposed on improved training and national pathways. We also pressed for increased integration of dental services and awareness about the impact of diet on oral health in our response to the Mayor's 2018 food strategy consultation A Healthy and Sustainable Food Strategy for London. We were disappointed that our recommendations were not mentioned in the final report. Dental health is an important part of overall health and we recommend that it is considered in all strategies in the future where health, diet or lifestyle is discussed.

The Oral Health Foundation lists the impact of eating disorders on oral health:
"Potential negative effects of vitamin and nutrient deficiencies can cause the body to shut down and not function properly and that will also be reflected in the mouth. Revealing oral signs of eating disorders include:

- Enamel erosion
- Dry mouth
- Enlarged salivary glands
- Cracked/dry lips
- Mouth sores
- Tooth decay
- Sensitive teeth
- Bruising and/or injury to the mouth

Those who purge through vomiting can also erode tooth enamel through excessive contact with stomach acid.[72]"

The result of the issues listed above can be dental complications leading to time off work or away from school, as well as contributing to issues of body dysmorphia as people become more concerned about their appearance. This may be exacerbated as people continue to spend more time on social media or remote working and relying on video calls.[73]

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[71] Association between poor oral health and eating disorders: Systematic review and meta-analysis" S Kisely, H Baghaie, R Lalloo, and N. W. Johnson The British Journal of Psychiatry 02 January 2018 https://www.cambridge.org/core/journals/the-british-journal-of-psychiatry/article/association-between-poor-oral-health-and-eating-disorders-systematic-review-and-metaanalysis/4DCA614AB4A471A480AFD934D89162DB

[72] https://www.dentalhealth.org/blog/how-eating-disorders-can-affect-your-mouth last accessed 09.08.2023

[73] https://theconversation.com/staring-at-an-image-of-yourself-on-zoom-has-serious-consequences-for-mental-health-especially-for-women-180384 last accessed 09.08.2023

Current guidance on eating disorders from the National Institute of Health and Care Excellence (NG69) makes only passing reference to the dental team.[74] A review of this guidance is required to make the link between oral health and eating disorders more explicit and to support training and pathways involving dental services.

Dentists and their teams represent a strong opportunity for engagement with those who have an eating disorder. As noted above the effect of eating disorders on oral health is clear and dentists and their team will be ideally placed to recognise the signs of eating disorders when providing dental care. The Oral Health Foundation has recommended that dentists are ideally placed to be involved in interventions and signposting to appropriate care and this is supported by BEAT, the national eating disorder charity.[75]

Training hubs are ideally placed to bring together multidisciplinary teams to discuss and learn about the effect of eating disorders on different aspects of health. As well as learning about the different effects eating disorders can have, the training hubs could provide information about the pathways between services to help improve patient care. With the advent of Integrated Care Systems the opportunity for greater integration and therefore streamlined pathways is now available. These must be put in place with a greater level of ambition than has historically been the case.

Local Healthwatch are important local partners for providing information to the public about services. As well as receiving feedback from service users, which would be helpful in identifying local gaps in pathways, they also represent an opportunity for providing information. Greater awareness about the impact of eating disorders on oral health should be provided to the public and may encourage them to seek help from dental professionals and also to reevaluate their diet in light of the unforeseen consequences on oral health.

Royal College of Psychiatrists (RCPsych)

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[74] https://www.nice.org.uk/guidance/ng69/resources/eating-disorders-recognition-and-treatment-pdf-1837582159813 last accessed 09.08.2023

[75] https://www.hippocraticpost.com/mental-health/dental-teams-can-identify-eating-disorders/ last accessed 09.08.2023

Is there good access to ED Services in London?

1.1 London has some of world leading academic centers (Kings College London, SLAM, UCL, Imperial College)

1.2. The following NHS Trusts offer eating disorder services in London:
1.2.1. Central and North West London NHS Foundation Trust
1.2.2. Royal Free London NHS Foundation Trust
1.2.3. Barnet, Enfield and Haringey Mental Health NHS Trust (St Annes Hospital)
1.2.4.East London NHS Foundation Trust
1.2.5. North East London NHS Foundation Trust
1.2.6.West London NHS Trust
1.2.7.South London and Maudsley NHS Foundation Trust
1.2.8.South West London and St George's Mental Health NHS Trust

1.3. Access to CAMHS ED services monitored by CAMHS Access and Waiting times (but unable to reach NHSE standards of 1 week for urgent cases, and 4 weeks for routine cases. Please see the attached document for more details).
1.4. Access to adult services is problematic: several trusts exclude mild-tomoderate cases and have long waiting times. Historical differences and post-code lotteries: This is similar to elsewhere in the country, due to insufficient funding to match CAMHS funding.
1.4.1. FREED[76] (eligibility <25 years old, <3 years history): Partially implemented across London (most well-established in SLAM).
1.5. ARFID services are limited across age ranges. There is limited evidence for the most effective treatment, but the majority of cases have complex physical and neurodevelopmental comorbidities and require a multiagency approach, including paediatric, medical, and psychological evaluation and treatment.
1.6. Limited NHS inpatient beds, long waiting times, out-of-area placements, poor quality control. The outcomes of inpatient treatment are not collected or published, which prevents learning from the outcomes and needs to be addressed urgently.
1.6.1. Young people are often treated in paediatric wards for prolonged periods. 1.6.2.Private providers are part of the Provider Collaboratives.
1.6.2.1. Priory Group
1.6.2.2. Cygnet
1.6.2.3. Ellern Mede (<25 years olds)
1.6.2.4. Schoen Clinic(<25 years olds)

1.7. Intensive community treatment in CAMHS Eating Disorder Services:

1.7.1. CYP-ED services in London are setting up intensive community treatment programs as alternatives to hospital treatment. SLAM and the Royal Free CAMHS ED service have

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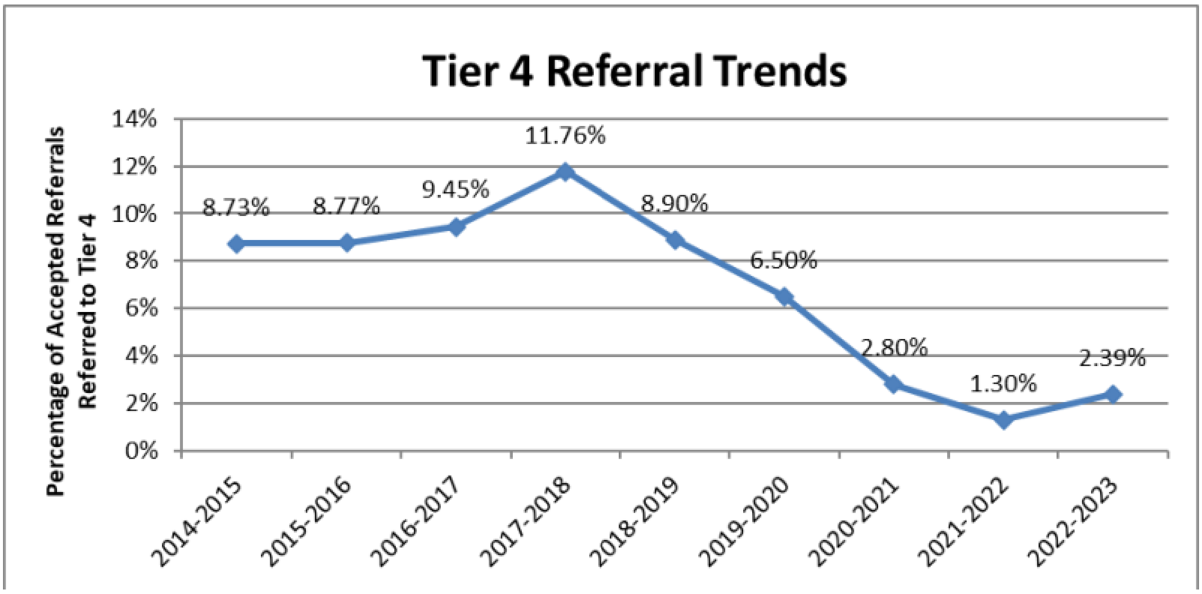
[76]

established intensive treatment programs which support clinically unwell young people with eating disorders at home with their families and caregivers. These services provide good clinical outcomes and have shown a reduction in admissions to the CAMHS Tier-4 Specialist Eating Disorder Units, thereby avoiding long-term separation from families.

Number of referrals to CAMHS Tier 4 SEDUs from Royal Free Hospital CAMHS ED service



Are GPs making the right referrals, and do they have sufficient training to refer patients with ED?

2.1. The limited training of GPs remains an ongoing concern[77] (except for e-learning). Some local arrangements in which the GP leads are identified work well.

What are waiting times like once a referral has happened?

3.1. What impact have waiting time standards had on the referrals for CYP ED?

3.1.1. Positive impact but has not kept up with rising demand. The surge of referrals during Covid,3 but still 35-65% higher than before the pandemic.
3.1.2. None of the ICBs meet access and waiting time standards, significant variations (please see attached document)

3.2. Could waiting time standards have a similar impact for adult services?

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[77] A. Ayton and A. Ibrahim, "Does UK medical education provide doctors with sufficient skills and knowledge to manage patients with eating disorders safely?," Postgrad Med J 94, no. 1113 (Jul 2018), https://doi.org/10.1136/postgradmedj-2018-135658, https://www.ncbi.nlm.nih.gov/pubmed/29866707 https://pmj.bmj.com/content/94/1113/374.long

3.2.1.Yes, it would be very helpful and would be in line with the 2017 PHSO recommendations.[78] However, a substantial investment is required to achieve this goal. We do not have data on adult services across London, but one service reported receiving >900 referrals/year (in London ~7000-8000 referrals to adult eating disorder services), and the waiting time for evidence-based treatment is approximately one year for routine cases (patients with a BMI of 16-19). Better access to FREED and urgent cases. Significant postcode lottery.
3.2.2. A recent large-scale survey in 2019 showed that adult community eating disorder services received only 15% of the funding required to match the staffing levels outlined by the NHSE CAMHS workforce calculator guidance. The estimated cost of investment in staffing levels to match CAMHS standards was £7 million/1 million population in 2019 prices (~8 million in 2023 prices).[79]
3.2.3. It is unclear how much of the NHSE community transformation fund investment has reached the frontline.

How is London responding to increasing demand on ED services?

4.1. What is the impact on workforce?

4.1.1. As stated in the NHS Stepping forward to 2020/21: The mental health workforce plan for England[80] and the NHS Mental Health Implementation Plan 2019/20 – 2023/24[81], the NHSE set a target to have an additional 910 consultant psychiatrists in post by March 2023; in the past seven years, only 221.9 FTE consultants were added to the workforce.[82]

4.1.2.According to the RCPsych workforce census[83], there were 78 eating disorder consultant psychiatrists in post England in 2021, of whom 20.5 % (16) were in London. Several specialists

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[78] House of Commons Public Administration and Constitutional Affairs Committee, Ignoring the Alarms followup: Too many avoidable deaths from eating disorders, Parliamentary Copyright House of Commons (London, 2019), https://publications.parliament.uk/pa/cm201719/cmselect/cmpubadm/855/855.pdf; Parliamentary and Health Service Ombudsman, Ignoring the alarms: How NHS eating disorder services are failing patients (London, 2017), https://www.ombudsman.org.uk/sites/default/files/page/ACCESSIBILE%20PDF%20-%20Anorexia%20Report.pdf

[79] D. Viljoen et al., "The alarms should no longer be ignored: survey of the demand, capacity and provision of adult community eating disorder services in England and Scotland before COVID-19," BJPsych Bull (Aug 1 2023), https://doi.org/10.1192/bjb.2023.57, https://www.ncbi.nlm.nih.gov/pubmed/37525957 https://www.cambridge.org/core/services/aop-cambridgecore/content/view/03BFEA3BEDDA43057DD96DB048B8C700/S2056469423000578a.pdf/div-class-title-thealarms-should-no-longer-be-ignored-survey-of-the-demand-capacity-and-provision-of-adult-community-eatingdisorder-services-in-england-and-scotland-before-covid-19-div.pdf.

[80] Health Education England. Stepping forward to 2020/21: The mental health workforce plan for England. July 2017. https://www.hee.nhs.uk/sites/default/files/documents/Stepping%20forward%20to%20202021%20-%20The%20mental%20health%20workforce%20plan%20for%20england.pdf

[81] NHS England. Mental Health Implementation Plan 2019/20 – 2023/24. July 2019. https://www.longtermplan.nhs.uk/wp-content/uploads/2019/07/nhs-mental-health-implementation-plan2019-20-2023-24.pdf

[82] RCPsych analysis of NHS Digital. NHS workforce statistics. 2016-2023. https://digital.nhs.uk/data-andinformation/publications/statistical/nhs-workforce-statis

[83] 9 Royal College of Psychiatrists. Census 2021. December 2021. https://www.rcpsych.ac.uk/improvingcare/workforce/our-workforce-census

work entirely in an independent sector, which does not contribute to training or research. In comparison with previous years, there was no growth in the number of ED consultants across London in 2021, as there were also 16 consultants in London in 2019.

4.1.3.In London, the ED consultant vacancy rate in 2021 was 15.8%, with three vacant substantive consultant posts.[84]

10 4.1.4. In 2021, there were 3 ED SAS doctors in London and 18 in England. The ED SAS doctor vacancy rate for London was 25.0%, with one vacant SAS post, which is lower than the national vacancy rate of 28.0% (seven vacant SAS posts)[85].

4.1.5.This means that patients are going without the vital healthcare they need. It also affects staff well-being, workload, and retention. Government reforms such as the Mental Health Act and Clinically led Review of Standards depend on a larger workforce. We welcome recent publication of the NHS Long Term Workforce Plan, including commitments to double medical school places to 15,000 by 2031. This must be fully delivered.

4.1.6.There is a need to increase training placements and expand the consultant psychiatric workforce in eating disorder services.

4.1.7.The workforce is experiencing burnout, high turnover, and leaving for the private sector as take-home pay is higher and the risk and workload are at a lower risk. This has a negative impact on training and research, as well as on the stability of NHS services.

What impact has the 2017 Parliamentary and Health Service Ombudsman report had on services?

5 .1. Limited progress, as repeated by the PHSO in 2023:[86] Patients report poor practices, including the promotion of palliative care for young adults.

5.2. Training:

5.2.1.no improvement in undergraduate or postgraduate training,
5.2.2. E-learning materials for foundation doctors and GPs
5.2.3. Whole team training for specialist teams
5.2.4. Credentialing at the consultant level, supported by HEE & RCPsych (300 applications in two years, could only accommodate 60 candidates–much more needed. No recognition of subspecialty status by the GMC. This contributes to the unacceptable variations in practice.

5.3. No additional targeted funding for adult services

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[84] ibid
[85] ibid
[86] Parliamentary and Health Service Ombudsman, "Urgent action needed to prevent eating disorder deaths.," (27/02/2023 2023). https://www.ombudsman.org.uk/news-and-blog/news/urgent-action-needed-preventeating-disorder-deaths

5.4. The same errors are being repeated.

5.5. The coordination of care is challenging.

Is there parity between children and adult services?

6.1. NO. Adults often have to wait for months or up to 1–2 years for evidence-based treatment.

6.2. Does this have an impact on transition between child/adult services? The proportion of transfers is low, but young people often have complex and severe eating disorders.

Is there any learning London could take from the Oxford I-CBTE approach? And is there the possibility on a similar approach being introduced in London?

7.1. A total of 21,000 adults and 8,000 children were admitted to hospitals with life-threatening eating disorders. However, there is an urgent need to improve the quality and effectiveness of inpatient treatment as the outcomes are poor.

7.2. Integrated CBTE is built on 30 years of research, initially developed in Oxford by Prof Fairburn (who received a prestigious APA award in 2022),[87] and further developed for patients with severe anorexia nervosa who require inpatient treatment in Italy.[88] Oxford introduced the model in 2017 and published our results in 2022.[89] This is the only study in the UK that compared different inpatient treatment models in real-life settings and included outcome data 1 year after discharge. We showed that I-CBTE can achieve a 70% recovery rate and 70% reduction in readmissions.

7.3. Predictors of outcomes included BMI normalisation, ongoing CBTE, and collaborative treatment.

7.4. It is a whole system and team approach that integrates psychological treatment and nutritional rehabilitation across the entire care pathway.

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[87] 13 C. G. Fairburn et al., "Transdiagnostic cognitive-behavioral therapy for patients with eating disorders: a twosite trial with 60-week follow-up," Am J Psychiatry 166, no. 3 (Mar 2009), https://doi.org/10.1176/appi.ajp.2008.08040608, https://www.ncbi.nlm.nih.gov/pubmed/19074978 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3035831/pdf/ukmss-4631.pdf.

[88] 14 R. Dalle Grave et al., "Inpatient cognitive behaviour therapy for anorexia nervosa: a randomized controlled trial," Psychother Psychosom 82, no. 6 (2013), https://doi.org/10.1159/000350058, https://www.ncbi.nlm.nih.gov/pubmed/24060628 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3884188/pdf/pps-0082-0390.pdf .

[89] 15 A. Ibrahim et al., "Integrated enhanced cognitive behavioural (I-CBTE) therapy significantly improves effectiveness of inpatient treatment of anorexia nervosa in real life settings," J Eat Disord 10, no. 1 (Jul 8 2022), https://doi.org/10.1186/s40337-022-00620-y, https://www.ncbi.nlm.nih.gov/pubmed/35804403

7.5. Significantly better recovery rates and reduced readmissions were observed regardless of the age or length of illness.

Summary Table of the differences between I-CBTE and Treatment as Usual (TAU)

		I-CBTE	TAU
Preparation for admission	Admission planning	yes	variable
	Individual Formulation	yes	variable
	Jointly agreed goals	yes	variable
	Agreed timescale	13 weeks	undetermined
Inpatient treatment	Whole team CBTE treatment	CBTE groups, formulation & individual therapy	Eclectic groups & individual psychology
	Treatment of comorbidities	Yes	Variable
	Speed of weight gain	1-1.5 kg/week	0.5-1kg/week
	Agreed weight restoration	Min BMI:20	Variable, ~BMI:17
Day treatment	Day treatment	7 weeks	variable
Aftercare	Outpatient psychological treatment	20 weeks (40 sessions in total)	variable
Outcomes	Length of stay (days)	125	132
	Admission BMI	14.6	14.6
	Discharge BMI	19.7	17.0
	Full remission 1 year after discharge	**70%**	**<5%**
	Readmission rate	**14%**	**44%**

7 .6. It is perfectly possible to introduce it in London. This requires the training of inpatient staff and additional psychological input across the care pathway. Online training (https://www.cbte.co/) and manuals[90] are available, and we would be happy to support individual teams.

Is there inequality in access to treatment and experience of services for eating disorders? (specifically focused on experience of men and different ethnic groups)

8.1. Men and ethnic minorities are underrepresented, while anorexia is overrepresented in secondary services. According to the 2019 Health Survey[91], 5% of women and 3% of men over the age of 16 reported severe impairment due to their eating disorder. In contrast, more than 90% of the patients in specialist services are female.

8.2. What is the experience of people in larger bodies accessing services, and what role does BMI play in referrals?

8.2.1.Many services have ration referrals due to underfunding, and exclude mild to moderate cases (based on BMI)

8.2.2. This is a significant, unmet need.

What are community services like for eating disorders in London?

9.1. Recent publications from SLAM

9.2. Intensive community treatment teams in CAMHS

How is the NHS is supporting families of people effected by ED?

10.1. Most evidence-based treatments involve families and caregivers.
These include:

10.1.1. FBT
10.1.2. TRIANGLE
10.1.3. CBTE
10.1.4. Charities: BEAT. FEAST

What can the mayor do to improve services (given he has limited influence in the space)? E.g. how could he influence different public sector bodies

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[90] 6 R. Dalle Grave, M. Sartirana, and S. Calugi, Complex Cases and Comorbidity in Eating Disorders (Springer, 2021). https://link.springer.com/book/10.1007/978-3-030-69341-1; R. Dalle Grave, Multistep Cognitive Behavioral Therapy for Eating Disorders (Plymouth, UK: Jason Aronson, 2013)

[91] "Health Survey for England 2019," NHS Digital, part of the UK Government Statistical Service, 2020, accessed 15/12, 2020, https://digital.nhs.uk/data-and-information/publications/statistical/health-survey-for-england/2019/health-survey-for-england-2019-data-tables

11.1. The Mayor **can help improve awareness and reduce stigma** related to eating disorders:
11.1.1. Eating Disorders affect both the physical and mental health of the individual, and without appropriate treatment can become debilitating or life-threatening. Eating disorders are treatable, and long-term complications are preventable.

11.1.2.The mean age of onset of eating disorders is approximately 18 years, and they affect people of all sizes and ethnicities.

11.1.3.London has many universities and a large proportion of the student population reports high rates of eating problems.[92] Improving services for students and training on eating disorders for healthcare professionals and educational staff would greatly improve early recognition and treatment, and prevent a chronic course and related disabilities.

11.2. The prevention of eating disorders would benefit from the integration with obesity prevention strategies. This should include working with the weight loss and social media industries and schools. The availability of freshly cooked food, particularly in children, is important for normal appetite regulation. Free school meals focusing on nutrition instead of calorie counting and exercise for fun rather than weight loss can be very helpful.

11.3. The Mayor can help improve workforce in London.

11.3.1.In addition to improving training, affordable housing for frontline workers (including psychiatrists) would help the recruitment and retention of staff for services.

11.4.Improving access to treatment:

11.4.1. While we recognise that funding for NHS eating disorder services is dependent on government policies, the mayor can lobby for investment and should monitor if funding is reaching the frontline and used to improve patient safety and outcomes.

11.4.2. There is a lack of public information on the effectiveness of services, and mandatory and meaningful outcome monitoring would greatly improve the effective use of available funding.

11.4.3. Financial support for patients and families attending appointments would help disadvantaged groups access services.

11.5.Research:

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[92] NHS Digital, "Mental Health of Children and Young People in England 2022 - wave 3 follow up to the 2017 survey: Data Tables," (2022). https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-of-children-and-young-people-in-england/2022-follow-up-to-the-2017-survey/data-sets

11.5.1. London is a leading international centre for research on eating disorders. However, funding for research on eating disorders falls significantly behind other comparable physical diseases, such as diabetes or obesity, even though there is a significant overlap between these illnesses. Promoting interdisciplinary research and collaborating with relevant industries could lead to novel and more effective treatments in the future.

London Head of School Of Paediatrics, Health Education England

My experience of eating disorders is based around my work as a paediatrician and managing children's services.

Firstly, the massive increase in this as an issue is inescapable, but really hits home when each and every childrens ward in London will have 2-4 young people, predominantly but not exclusively girls who are unwell enough with their eating disorder that hospitalisation for a re-feeding programme the only option. This is entirely new. 20 years ago there might have been one such patient each year.

The second thing to note is that they are in an acute children's ward. Not a CAMHS facility. Often those working in children's ward will not be trained in eating disorders specifically but will have picked things up on the job as their workload has expanded as inpatient CAMHS facilities overwhelmed. This points to a massive gap in pro-active commissioning for this patient group.

Lastly, there will be children who are medically sick and have eating disorders, one often the consequence of the other. Here commissioning is counter-productive, where (medical) doctors can't work in CAMHS institutions and vice versa. The very opposite of joined up care.

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