

Sir Bernard Jenkin MP,
Committee Chair,
Public Administration and Constitutional Affairs Committee,
Houses of Commons,
London,
SW1A 0AA

Wednesday 1st May 2019

Dear Sir Bernard Jenkin,

- 1.0) I am writing on behalf of YoungMinds to provide a written submission to your Committee's inquiry into the progress that has been made to improve eating disorder services since the publication of the Parliamentary and Health Services Ombudsman report. We are pleased that your Committee has chosen to re-examine this important issue.
- 1.1) YoungMinds is the leading children and young people's mental health charity in the UK, and we put the experiences of children, young people and families at the heart of everything we do.
- 1.2) This submission will draw on the insights and lived experiences of the children, young people, parents, carers and professionals that we work with and insights we have gained through calls made by parents and carers to our Parents Helpline Service.
- 2.0) Whilst eating disorders such as anorexia, bulimia, binge eating disorder or compulsive eating disorders affect people of all ages, it has been found that they often emerge in adolescence, with the risk being highest for young people between 13 and 17 years of age¹. For this reason, it is essential that young people are able to access high quality treatment to avoid unnecessary deterioration in their mental health.
- 2.1) The recently published survey of the mental health of children and young people found that 0.4% of 5 to 19 year olds in England has an eating disorder². The prevalence of the disorder differs by age and sex, with rates of eating disorders being highest in girls aged 17 to 19 (1.6%) than in other demographic groups.

¹ National Institute for Health Care and Excellence (2017) 'Eating disorders: recognition and treatment' Available at: <https://www.nice.org.uk/guidance/ng69/chapter/Recommendations>

² NHS Digital (2018) 'Mental Health of Children and Young People in England, 2017' Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-of-children-and-young-people-in-england/2017/2017>

- 3.0) Over the past few years, there has been a significant increase in the resources provided to children and young people’s eating disorder services. Notably, in 2014 the government announced an additional £30 million in recurrent funding over five years to improve support, care and treatment options for children and young people through community eating disorder teams³. This funding has been allocated at the local level through Clinical Commissioning Groups. Further to this, we welcome the commitment in the NHS Long-Term Plan to continue the investment in community provision for children and young people’s eating disorder services⁴.
- 3.1) Coinciding with increased investment, new waiting times standards for children and young people with an eating disorder came into force in April 2017. The target is that ‘by 2020/21 95% of young people in need of an eating disorders service will be seen within four weeks for routine cases, and within one week for urgent cases’⁵.
- 3.2) There have been significant improvements to young people’s access to eating disorder services since the targets were established. Across England, 81.3% of children and young people are now seen within one week for an urgent referral and 80.2% within 4 weeks for a routine referral⁶.
- 3.3) However, as the table below shows, there is considerable variation across England in meeting the access targets, and some CCGs have reported that less than 50% of the children and young with an urgent referral for eating disorders are being seen within one week.

Target	South East England	South West England	North of England	Midlands and East of England	London
% of CYP with eating disorders seen within 1 week (urgent)	76.9%	77.8%	81.6%	83.1%	86.1%
% of CYP with eating disorders seen within 4 weeks (routine)	69.5%	69.8%	83.4%	86.7%	89.6%

³ <https://www.gov.uk/government/news/deputy-pm-announces-150m-investment-to-transform-treatment-for-eating-disorders>

⁴ NHS England (2019) The NHS Long Term Plan available at: <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf>

⁵ NHS England (2016) Implementing the Five Year Forward View for Mental Health. Available : <https://www.england.nhs.uk/wp-content/uploads/2016/07/fyfv-mh.pdf>

⁶ Data from NHS Five Year Forward View Dashboard Q2 2018/2019 available at: <https://www.england.nhs.uk/publication/mental-health-five-year-forward-view-dashboard/>

- 3.4) As the Nice Guidelines outline, someone with an eating disorder should start an evidence-based NICE approved treatment as soon as possible to improve outcomes⁷ and to prevent a deterioration in the young person's mental health. This is especially important with eating disorders when considering the high mortality rate that has been found with conditions such as anorexia nervosa⁸.
- 3.5) In a [YoungMinds' participation report](#) as part of the Amplified project with NHS England⁹, one young person told us their experience that 'people with eating disorders whose weight wasn't as critically low as mine didn't get offered the same help or as fast' (Female, North East, 16-17). It is essential that all young people that need treatment for their eating disorder do so and that this is consistent across the country.
- 4.0) The PSHO report highlighted a key concern that young people who are accessing eating disorder services face when they need to transition to other services due to change in their geographical location or because of changes in their care needs.
- 4.1) Research has estimated that the average duration of the eating disorders anorexia and bulimia nervosa are eight and five years respectively¹⁰. At YoungMinds, we have heard from parents whose children have received care for an eating disorder in inpatient units. They have expressed serious concerns about the lack of information, guidance and support that they and their child receive following discharge from services, with cases of relapse and resuming behaviours of their eating disorder following discharge.
- 4.2) Due to the enduring nature of eating disorders, it is therefore essential that continuity of care is provided to young people that are accessing services, and that adequate support is provided during any necessary transitions between services, in order to prevent the disruption in their care. As the PSHO report recognised following the failures in Averil's case, this needs to be underpinned by effective communication and joint agency working.
- 4.3) Additionally, we hear from young people that they want to be involved in the decisions that are made about their care and changes to their treatment. In a

⁷ National Institute for Health Care and Excellence (2017) 'Eating disorders: recognition and treatment'

Available at: <https://www.nice.org.uk/guidance/ng69/chapter/Recommendations>

⁸ Arcelus J, Mitchell AJ, Wales J. et al, "Mortality Rates in Patients with Anorexia Nervosa and Other Eating Disorders: A Meta Analysis of 36 Studies." Arch Gen Psychiatry 2011, 68: 724-31.

⁹ YoungMinds (2018) 'Your Voices Amplified: Amplified Insights Survey'. The report was based on the lived experience of young people and parents and the perspectives of professionals across all children and young people's mental health services and therefore was not focused specifically on eating disorders. Available at: <https://youngminds.org.uk/media/2152/amplified-insights-survey-2018.pdf>

¹⁰ Vos T, et al. The burden of mental disorders in Victoria. Social Psychiatry Psychiatric Epidemiology. 2001;36:53-62

YoungMinds survey¹¹, 92% of young people stated that they want their views on treatment to be respected throughout the treatment process. However, half of the respondents that were accessing mental health services¹² said that they don't feel involved in decision making about their individual treatment. Eating disorder services must ensure that children are involved in the decisions about their treatment, changes to the staff that they work with and the services that they access.

- 5.0) Many people with an eating disorder receive treatment in Child and Adolescent Mental Health Services (CAMHS) Tier 4 inpatient hospitals or adult mental health hospitals. According to the CQC, eating disorders are one of the most common reasons for admission to a Tier 4 CAMHS unit¹³.
- 5.1) As part of our participation work, parents have told us that they would like to see more support when their child is discharged from inpatient units. This includes how families will be supported with behavioural risks and management options and emergency support following discharge.
- 5.2) Many of the calls that we have received from parents about their child's experience of receiving care in an inpatient ward highlighted their confusion and lack of knowledge of their rights. This concern is not limited to young people receiving treatment for eating disorders and we have been told this consistently by children and young people and their families when they access mental health hospitals.
- 5.3) Consequently, YoungMinds and the National Autistic Society have co-created the '[Always Charter](#)' with children and young people who have lived experience of inpatient care, and their families. The '[Always Charter](#)' identifies the principles of care that young people and families think should always exist in mental health hospitals¹⁴. These include young people receiving care in their local community unless there is a clinical need, being assessed by professionals that have the skills to understand their mental health need, being involved in decisions about their care and being treated with dignity and respect, including the use of restraint.
- 5.4) We, therefore, recommend the introduction of a duty on providers to promote and actively communicate to children, young people and their parents / carers their rights when they are referred or admitted, and for these to be codified (based on the 'ALWAYS Charter'), and enforced through regulatory and NHS contract compliance mechanisms.

¹¹ YoungMinds (2018) 'Your Voices Amplified: Amplified Insights Survey', *ibid*

¹² Statistic based on 53% of respondents that reported that they were currently receiving treatment at the time of the survey.

¹³ Care Quality Commission (2018) 'Are we listening? Review of children and young people's mental health services. Available at: https://www.cqc.org.uk/sites/default/files/20180308b_arewelisting_report.pdf

¹⁴ YoungMinds, [Always Campaign](#)

5.5) We also recommend that as part of the inquiry, the Committee considers how the rights of children and young people in eating disorder units are upheld and communicated to them and their families.

If you would like to discuss any of the points raised in this submission or for a representative of YoungMinds to provide further evidence to the Committee, please do not hesitate to get in contact.

Yours sincerely,

Emily Dobson,
Policy and Parliamentary Officer,
YoungMinds