

### Attention: Mrs Penelope Schofield

Worthing Coroner's Office Centenary House, Durrington lane,

Worthing, BN13 2QB National Medical Director NHS England & NHS Improvement Skipton House 80 London Road London SE1 6LH

3<sup>rd</sup> September 2021

Dear Mrs Penelope Schofield,

# Re: Regulation 28 Report to Prevent Future Deaths – Charlotte Lucy Swift - 09/04/2021

Thank you for your Regulation 28 Report dated 11<sup>th</sup> May 2021 concerning the sad death of Charlotte Lucy Swift on 9<sup>th</sup> April 2020. Firstly, I would like to express our sincerest condolences to Charlotte's family.

The regulation 28 report concludes Charlotte's death was a result of natural causes associated with anorexia nervosa and following the inquest, you raised concerns in the report to NHS England regarding the wait for a specialist eating disorder inpatient bed. You also advised evidence given at the inquest indicated there was a national shortage of inpatient beds/placements and this was putting individuals at risk.

NHS England and Improvement (NHSEI) understand that eating disorders are serious and life-threatening conditions and are committed to improving eating disorder services. We have developed a national programme of work backed by significant committed investment to ensure that systemwide changes to improve eating disorder services are delivered. NHS England (NHSE) has provided the response below considering the concerns you have raised, giving explanation to the changes that are taking place now, and in the near future.

#### **Optimal Service Model for Eating Disorders**

By way of an overview as to current guidance and model of service, clinical consensus and guidance on eating disorders from the National Institute for Health & Care Excellence (NICE) indicates that the optimal model of service delivery for people with an eating disorder is a dedicated, multidisciplinary Community Eating Disorder (CED) service. Care should be delivered in the community, supported by intensive day patient or inpatient treatment only when required for people with a high level of physical or psychiatric risk that cannot be managed safely in the community. Adult eating disorder services should provide a seamless pathway for young adults supporting a positive experience of transitioning from children and young people (CYP) CED services where needed and avoiding unhelpful 'cliff edges in care'.

# NHS England and NHS Improvement

The focus of the eating disorder pathway is early community intervention and access should be based on clinical need, not Body Mass Index (BMI). The NICE guidelines state that 'single measures such as BMI or duration of illness' should not be used to determine whether to offer treatment for an eating disorder. This is reiterated in the CYP Eating Disorder guidance which also includes the role of paediatricians within the eating disorder community teams. This guidance was extended in 2019 to support implementation of NICE recommendations on improved integration with inpatient settings and to share helpful resources on best practice.

## National Policy – NHS Long Term Plan (LTP)

Following significant expansion by NHS England (NHSE) of services for children and young people with eating disorders since 2015, there is now increasing commitment and a requirement under the NHS Long Term Plan (LTP) across a range of stakeholders to improve both timely access to, and the quality of evidence-based treatment in eating disorder services for adults and older adults. National policy establishes a clear rationale for localities to focus on improving care for individuals with eating disorders.

As part of the LTP, local areas will be supported to redesign and reorganise community mental health services to move towards a new place-based, multidisciplinary service across health and social care aligned with primary care networks. Improving access to services for adults with eating disorders is a priority for the NHS as part of the LTP for mental health.

#### Progress to date against LTP

#### Service Expansion & Re-modelling

New and expanding community-based mental health care will provide treatment and support for 370,000 adults - including those with eating disorders - closer to home, and the NHS committed to increasing investment in mental health services faster than the NHS budget creating a new ringfenced local investment fund worth at least  $\pounds 2.3$  billion a year by 2023/24, which will be used to provide patients with greater choice and control over their care and support them to live well in their communities.

LTP funding for 2021/22 is accompanied by a Delivery Plan for Mental Health, which asks all services undertaking Adult Eating Disorder (AED) transformation to:

- Increase clinical and non-clinical capacity in AED services to meet spend and access trajectories set out in community transformation plans
- Increase number of patients and reduce waiting times for support and intervention in AED pathways
- Ensure AED pathways remove any barriers to access (e.g., weight or BMI), can accept self-referrals and VCS referrals, and are implementing early intervention models e.g., FREED
- Ensure AED pathways have medical monitoring protocols in place with primary care

Alongside this work, NHS led Provider Collaboratives create the opportunity to redesign the pathway for adults and CYP with eating disorders bringing care closer to home by giving them the responsibility for managing the budget associated with the specialist care for this group. Therefore, through a rebalancing of provision, and moving away from a focus on inpatient services to a model of expansion of

community-based services, adults with eating disorders will be able to access treatment earlier, and closer to home, leading to better outcomes for them and their families.

Additionally local plans submitted to NHSE indicate that at least 22 Integrated Care Systems (ICSs) are starting work to transform their community AED pathways in line with published guidance in 2021/22, with over £6m of initial dedicated investment, with remaining ICS localities due to commence in 2022/23 while in 2019/20 and 2020/21, 12 STPs/ICSs "Early Implementers" were funded to test new models of integrated care, including improvements to Community Eating Disorder services. Learnings from these sites will be shared wider with systems and help inform future development and to further support local strategic planning and development of transformed AED pathways in line with published guidance, regional adult eating disorder clinical leads have now been appointed across England.

#### Early Intervention

Early intervention is critical for those with eating disorders. In 2019/20 NHS England funded 18 eating disorder services to implement the early intervention model - First Episode Rapid Early Intervention for Eating Disorders (FREED), to support the early identification of eating disorders to support young people in the early stages of eating disorders and ensure they can access services sooner. FREED is an evidence-based early-intervention model, for people aged 16-25, presenting with a first episode of eating disorders that has lasted for less than three years. Evidence shows that this model reduces the waiting times for assessment and treatment and that patients experience better outcomes.

The implementation of FREED is part of a broader ambition to create a more comprehensive and integrated mental health offer for 0-25 year olds, which sees children and young people's and adult eating disorder services working together to improve the pathway of care for young adults.

#### Training

NHSE are also working in partnership with Health Education England (HEE) to deliver a comprehensive training programme to improve the support received by those with eating disorder, including training in cognitive behavioural therapy for eating disorder, and other evidence-based interventions. Around 240 staff (from around 90 teams) have received training in how to better support those with an eating disorder diagnosis and training numbers are set to increase this year.

#### Specialised Commissioning for inpatient eating disorder beds

The high level of demand for access to Specialised Commissioning AED inpatient beds is being addressed through the development of the Provider Collaboratives and new models of care considering the whole patient pathway from Primary Care to Tier 4 national services. The implementation of NHS-Led Provider Collaboratives began in October 2020, with 19 NHS-Led Provider Collaboratives now live and the remaining Phase One Provider Collaboratives being implemented by 1 October 2021.

NHS-Led Provider Collaboratives seek to transform care pathways for people who need specialised services, covering both the CYP and AED inpatient pathways.

Local clinical leaders are working with Patient & Public Voice (PPV) and Expert by Experience (EbyE) representatives, regional colleagues, new provider collaboratives clinical, operational and commissioning leads, alongside NHSE Provider Collaboratives and MH Policy teams to support the development of new care models, to address the significant pressures, capacity and access issues across the system and reduce the reliance on inpatient beds in line with the evidence base for Eating Disorders.

The national mental health specialised commissioning team is supporting regional teams and wider eating disorder service transformation through specialist expert advice provided by NHSE Clinical Reference Groups and National Programme of Care for Specialised Mental Health. Additionally, a national inpatient Demand & Capacity exercise has recently been undertaken and findings from this will be used to support the reconfiguration of existing eating disorder beds and the development of whole patient pathways through Provider Collaboratives and ICS as required by the NHS Long Term Plan.

#### Impact of COVID-19 Pandemic

Eating disorder services have been working hard to minimise disruptions in care due to the COVID-19 pandemic by using digital solutions where appropriate, or COVID-safe face-to-face appointments when needed. An additional £58m also has been allocated to support community mental health services responding to COVID, including a focus on accelerating transformation across eating disorder pathways, with a focus on early intervention models and close working with voluntary and community sector partners.

Inpatient access remains somewhat impacted by Covid-19 due to the number of acute presentations seen across regions as the country came out of the first lockdown. Lessons learned from the first lockdown have been embedded in restoration and recovery plans for adult eating disorders inpatient services to ensure future proofing of service delivery as the pandemic continues and services are transformed in line with national guidance.

Patients who require admission to inpatient services are to be supported with intensive community care and treatment programmes while awaiting admission. There is also a broader range of AED community services which are locally commissioned by CCGs. These local arrangements vary across England and are primarily aimed at addressing the needs of patients with disordered eating which does not require admission to an inpatient setting or need the highly intensive treatments offered by the NHSE commissioned specialist services.

While locally commissioned arrangements vary, in all cases patients with severe eating disorders or considered to be at high risk, will be referred directly to the specialist services commissioned by NHSE for assessment and or admission/treatment.

Once again, I'd like to express my deepest sympathies to Charlotte's family and I hope the above response from NHS England has gone some way to allaying the concerns raised in your Regulation 28 report.

Thank you for bringing this/these important patient safety issues to my attention and please do not hesitate to contact me should you need any further information.

Yours sincerely,

Wykan Clah

Medical Director for Professional Leadership and Clinical Effectiveness

Lead Medical Director for Covid-19 Medical Workforce Cell

NHS England & NHS Improvement