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Your Ref: 00931-2020

17 June 2022

Mr J Broadbridge
HM Assistant Coroner for
North Yorkshire and York
NYCC The Old Court House
3 Racecourse Lane
Northallerton
North Yorkshire
DL7 8QZ

Dear Mr Broadbridge

Re: Zoe Zaremba (deceased)

Further to your letter of concern of 21st April 2022 and the subsequent **regulation 28 report to prevent future deaths**, I write to detail the data requested, the actions the Trust has taken and those that we continue to implement to address the concerns you identified during the inquest into Zoe Zaremba's (Zoe's) death. I would like to reassure you that as an organisation we have taken your concerns very seriously and for ease of reference I will address each of these in turn:

Firstly, with reference to your letter of concern:

1. No of Patients with ASD treated by the Trust when they had received their formal diagnosis

Within the trust Electronic Care Record we have several Autism Markers which include, an ICD-10 Diagnosis of Autism, a referral reason of suspected/confirmed as Autistic and or referral action of 'suspected as autistic'. Some patients may have both an autism diagnosis and an autism referral reason/referral action however the numbers are for unique patients in the trust.

The numbers are highlighted below: -

- 2676 patients who are currently open to Trust services have an Autism ICD-10 diagnosis.
- 7291 patients who are currently open to Trust services have a referral reason of suspected/confirmed autism.

- 979 patients who are currently open to Trust services have a referral action of suspected autism.
- The total number of patients open to Trust services with an Autism marker is thus 10116. Whilst this does not equate to the number with a validated diagnosis of autism, it represents approximately 17% of the total number of people open to the Trust.
- In North Yorkshire the commissioned service for assessment and support is external to the Trust and so the numbers are correspondingly less in terms of those waiting for an assessment.



people with an Autism Marker.xlsx

For people who have received their diagnosis outside of our services, we will not have dates of their diagnosis.

Whether Sensory assessment and or therapy has occurred

Sensory assessment is not a standalone assessment. For individuals with autism there may be sensory components to their presentation. Assessment of this is part of a multidisciplinary assessment, and not undertaken by a specific profession or professional but by a range of potential professionals who are working with the individual to understand their specific needs. There will not be a 'sensory assessment' but for example there may be a sensory component to the way an individual enjoys their meals, there may be sensory components which influence an individual's ability to interact with others. It is important to have a clear understanding of the individual's presentation and it is important that reasonable adjustments are made around all their specific needs, some of which may have a sensory component. Any sensory integration assessment or therapy that an individual receives will be commissioned from services outside of TEWV.

2. No of patients who are female and their ages and age range



Gender and Age range of people wi

The attachment details the age range and gender of people within TEWV services with an Autism marker. As you will see, there is a reasonably even distribution of males and females, with a small majority being male. This contrasts with historic data where the discrepancy was greater (and weighted towards males) and suggests a greater sensitivity within the trust to the presentation of autism in females.

3. No of patients who have been diagnosed with EUPD/ BPD and whether this has been validated / Reviewed

Within the Trust we have identified 134 patients that have both an Autism marker and a documented diagnosis of Emotionally Unstable Personality disorder (EUPD) which includes Borderline Personality Disorder (BPD).

We have begun to examine these unique identifiable records with a view to:

- 1) understanding the rationale and the validity of the diagnosis in these cases, in view of the potential for diagnostic confusion.
- 2) determining if and how the diagnosis has been shared and made clear in the records.
- 3) whether the diagnosis has been withdrawn and if so, how this has been communicated both to people and to services.
- 4) engaging with clinical teams proactively and acknowledge that this could possibly be a very significant and positively distressing process to arrange a diagnostic review for patients and therefore we need to take time to do this properly along with a review of reasonable adjustments and tailored therapeutic options as appropriate.
- 5) Learning from Zoe's death and the subsequent inquiries has already been communicated by the patient safety team, and most recently the need to be validating or reviewing any diagnosis of EUPD has been highlighted by the medical director to a meeting of all senior medical staff (1st June 2022).

Further to the specific data and associated actions detailed above, we have identified areas in which we can improve the quality of our data in order to support improvements in the care we provide. We have already improved how we record reasonable adjustments, and we have an opportunity to consider further enhancing our data recording around autism when we introduce a new data framework (CITO) later in the year.

Yours sincerely



Brent Kilmurray,
Chief Executive Officer