Tees, Esk and Wear Valleys
NHS Foundation Trust

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21 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
Regulation 28 Report

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 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 death. I would like to assure you that as an organisation we have taken your concerns very seriously and are committed to work with our partners to improve the care for patients and their families.

For ease of reference, I will address each of these in turn:

Concern 1 – Zoe was diagnosed at age 16 years as being autistic by CAMHS with a designation of Asperger's Syndrome. Her medical records recorded that.

This is also our understanding of when Zoe was diagnosed with autism.

Concern 2 - In or about 2016 she was wrongly attributed by the Mental Health Service, TEWV, clinicians - who knew of her autism - as undergoing Emotionally Unstable Personality Disorder ("EUPD').

Within the Trust we have now 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 recognise that there may be diagnostic overlap and/or a greater likelihood of misdiagnosis, and it is also the case that the criteria for diagnosis of EUPD may no longer be met following the passage of time.

We have commenced examining these unique identifiable records with a view to:

1) understand the rationale and the validity of the diagnosis in these cases, in view of the potential for diagnostic confusion
2) determine if and how the diagnosis has been shared and made clear in the records
3) identify whether the diagnosis has been withdrawn and if so, how this has been communicated both to people and to services.
4) engage with the identified patient and clinical teams proactively and compassionately to arrange a diagnostic review, along with a review of reasonable adjustments to enable people to best access and benefit from services and tailored therapeutic options as appropriate.

Further to the specific data and associated actions detailed above, we have also identified areas in which we clearly need to improve the quality of our data to support improvements in the care we provide. The oversight of the review of these cases will be held by the medical director who will ensure timely completion. This will be reported through the Trust's quality governance routes.

Concern 3 - That attribution was not formally diagnosed, and not discussed with Zoe who found out by chance when looking at her records. She continued to be regarded and treated as if she was experiencing that condition and clinicians would not adapt to her distress caused by that attribution. There was inertia and excessive delay (to May 2020) in removing reference to EUPD which had been discounted in October 2018 all of which added to her distress. These actions and inactions destroyed her relationship with community mental health clinicians, and she did not trust them enough to try to restore any effective care relationship.

There is an expectation that all aspects of diagnosis and treatment will be discussed openly and transparently with people who use services and their carers wherever this is possible and appropriate ('nothing about me without me'). This is a clear principle that the Trust expects clinicians to work towards and is also supported by 'Our Clinical Journey'.

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216980/Liberating-the-NHS-No-decision-about-me-without-me-Government-response.pdf

Our new patient recording information system (CITO) will not only allow a greater clarity around active and discounted diagnoses but will importantly also support patient access to their own records improving mutual understanding and effective

collaboration over both planning and delivery of care. This system will be introduced across all services in 2023. Part of the enabling work for the implementation of the system is the training that we are already providing to clinicians. This will strengthen clinicians' ability to work collaboratively with patients and carers. This collaborative working will be monitored through caseload management and the clinical leadership team, but most critically by feedback from patients and carers about their experience of services and the effectiveness of services.

Concern 4 - She suffered repeated trauma derived from her autistic condition revisiting the causes of her distress which she re-experienced time and again with 'film reel' recollection. That trauma was again not understood.

The delivery of Trauma Informed Care is an integral part of 'Our Clinical Journey', (the Trusts Clinical Strategy) which has been developed with patients, carers clinicians and partners.

The Trust Board have received training in this essential work so that they are better informed, they remain committed to ensuring that it is embedded into clinical journey and subsequent underpinning practice to seek to understand patient needs.
Across the Trust we are delivering autism awareness training to our clinical staff with a focus on how to make reasonable adjustments for autistic people so that they can access and benefit from services. Additionally, we are focussing on avoidance of trauma in this training so the potential to retraumatise autistic people is reduced. We humbly accept that if everybody (including staff) understood autism better, then trauma such as Zoe experienced would be reduced.

The impact of trauma is something that is increasingly understood and included in consideration of risk assessment, formulation, and care planning both locally and nationally however we need to further develop our staff understanding around how autistic people experience trauma. The Trust has developed 'Our Clinical Journey' in partnership with service users and carers. A trauma informed approach underpins this work. The trust is embedding training on trauma informed approaches for staff, to improve practice and the experiences of our service users and families.

Concern 5 - In short, her autism (and thus risk assessment) was misunderstood by the clinicians tasked to keep her safe.

As a Trust we do take very seriously our responsibility to ensure that our patients have the most robust multidisciplinary risk assessment facilitated by trained and competent staff. The safety summary is the Trust's risk assessment tool, and a significant amount of work has been undertaken by the Trust in respect of improving the quality of risk assessments, across both inpatient and community settings to ensure that full and up to date information is included as part of the risk assessment. The harm minimisation training supports an individualised and needs-led approach to risk assessment, and this includes people with Autism and their specific needs. In order to drive this work forward, a Trust-wide quality improvement event was held in August 2021 the Trust Clinical Advisory Group commenced work in reviewing harm minimisation training. This work has been rolled out to all services in the community, including those teams involved in Miss Zaremba's care. As a result of the work

undertaken, the Trust developed the following initiatives to improve risk assessment and management.

Revised risk assessment tools have been produced including a new safety summary format, and a new safety plan template which directly link to the risk management plan. The revision to the format has simplified the process to avoid duplication and prompt concise, usable detail is recorded in relation to assessment of risk. This sits alongside the safety plan to capture individualised mitigation strategies linked to the risks identified in the summary document. To sit alongside the new documentation, a training programme was devised and went live in December 2020. It was delivered to all Registered Nurses in the team and the wider members of the MDT as a minimum. Within our risk assessment training we have incorporated and have trained staff that there is a higher risk of suicide of autistic people. Alongside this we have trained staff in facilitating personalised safety planning within both autism awareness training, individual supervision, and the trust suicide prevention strategy.

Additionally, we offer as a trust a full day Understanding Autism Training which has a focus on risk assessment for autistic people, diagnosis and associated risks and needs. This training is further consolidated through the offering of individual Autism supervision and consultation for clinical staff.

Concern 6 - TEWVs provision for care of autistic conditions were underdeveloped, reflecting national want of provision, to include: -

a) **no multidisciplinary clinical assessment and formulation addressed her autism;**

   As a trust we provide a full day Understanding Autism training for clinical and non-clinical staff, which has a focus on risk assessment for autistic people and reflects diagnosis and associated risks and needs. The training is consolidated through the offering of individual Autism supervision and consultation for clinical staff.

   At the time that Zoe was receiving services there was a lack of an autism informed formulation. Support for this for all teams across the Trust is available and utilised from the Trust-wide Autism Project who work with clinical staff to provide this level of autism informed formulation where required.

   To assist staff in practically achieving this goal, additional measures have been introduced into the MDT process to ensure that, where a patient has a diagnosis of autism, their care, treatment, safety summary and safety plan all take that diagnosis into account and provide a comprehensive assessment of need. MDT formulation now includes patients and their advocates, wherever possible, in order to ensure honest and transparent communication when reaching a diagnosis.

   To monitor compliance with this action, patients with an autism diagnosis will have their care plans and safety summaries checked and reviewed by the clinical team, with overall monitoring and responsibility for this lying with the General

Manager and Clinical Director for the locality reporting through to the Medical Director.

b) **no reasonable adjustments were then made in terms of her sensory and environmental needs in any timely fashion, or at all.**

Within the North Yorkshire teams, and across the trust supervision and support is being sought by the generic community teams on a case-by-case basis from clinical experts, who have an appropriate level of expertise to check and challenge the quality of care being provided. This is not only in relation to the specific care and treatment pathway for the individuals concerned, but also looks at the ability and understand of the team to provide reasonable adjustments when working with patients who have an autism diagnosis or who present with such traits. This sits alongside the training that is being delivered to local teams to increase knowledge and understanding of these issues. The level of uptake of this support is being closely monitored by the Autism Project Team and I can confirm that the teams are regularly making use of the knowledge and expertise of their specialist autism colleagues when working with this patient group. Additionally, as part of the Trusts Clinical Journey there is a commitment to increase personalised care planning which would include reasonable adjustments to meet individual needs.

c) **no person centred (thus autism centred) holistic plan was developed to work in partnership with Zoe that took account of her autism, and her gender. As the evidence revealed one "cannot uncouple autism and other psychological/psychiatric experiences". Instead, she withdrew from engagement with TEWV community health clinicians;**

As a trust we offer a full day Understanding Autism training for both clinical and non-clinical staff, which has a focus on developing holistic plans of care for autistic people and reflects diagnosis and associated risks and needs. This is consolidated through the offering of individual autism supervision and consultation for clinical staff. The utilisation of supervision and consultation has increased over the last twelve months ensuring that care plans consider the needs of the autistic patient. Work is actively taking place to ensure that Autistic people's needs can be reflected within the new care planning process.

However, this is a significant shift in practice and the trust is committed to ongoing embedding of evaluation and sustainability work to implement this change in practice.

d) **there was no local provision within TEWV for specialist autism assessment and adapted psychological therapy. Commissioned providers of these essential cares were out with TEWV, requiring specific Funding Request (which was granted) for a course of assessment and therapy. Those providers did not offer statutory acute mental health services support, including out of hours/crisis support. TEWV did not provide what the commissioned providers were supplying. There was a want of effective communications between these 'teams' not least as patient data was not**

accessible by one to the others electronic records (patient consent permitting) and the fact of disengagement. There was a sense of 'silo' working, militating against partnership working, that encouraged unfavourably the undesirable "uncoupling' of experience;

We acknowledge that commissioning arrangements which are currently led by The Clinical Commissioning Group, are complex and are provided by multiple organisations. The current position is that Adult Autism diagnostic services are commissioned through The York Retreat for York and North Yorkshire and are commissioned through TEWV for Durham and Tees Valley.

Autistic people who are accessing care within TEWV should receive reasonably adjusted mental health care, assessment and intervention including reasonably adjusted psychological intervention. However, specialist autism assessment and adapted autism specific psychological interventions require a specific Individual funding request for adults within York and North Yorkshire and this is usually delivered by the Retreat in York.

However, the landscape of commissioning is changing, and responsibilities are moving from Clinical Commissioning Groups to Integrated Care Systems. This brings significant opportunities to ensure that care delivery is more connected, and that partnership working is consistent across health providers as well as across social care and the voluntary sector.

We have learned from Zoe's sad death and shared with our clinical teams the importance of communication with our partners, to ensure that patients' needs are addressed in a more cohesive and person-centred manner.

We are committed to working alongside our partners now to ensure that communication is as timely and constructive to the meet the needs of our patients.

e) **statistical evidence indicated that autistic individuals are more at risk of suicide than those with no neurodevelopmental condition, and females at greater risk that their male counterparts;**

This evidence is built into the Trust's 'Understanding Autism' training that is offered to all clinical and non-clinical staff. We have incorporated this statistical evidence within the Trust's Suicide Prevention Strategy and our newly developed Clinical journey. The Trust wide Autism Project is represented on the Trust wide Suicide Prevention group ensuring that this increased risk, and an autism perspective has been incorporated into training and clinical guidance available to clinicians.

f) **there was a clinical (but not measured) experience that more patients were presenting to the statutory service with autistic conditions and, it follows, more patients would be at risk of suicide;**

We are using the information that we shared in our response to your letter that you sent to myself dated 21st of April 2022 to further understand our patient demographics and clinical information to inform our strategic planning, training plan and clinical supervision emphasis to further support clinicians to deliver safe and effective care.

g) **from 2016 to her death, Zoe was detained under s 2/3 MHA 1983 17 times and presented to A and E around 37 times with evident self-harm and apparent attempts on her life. She repeated high risk behaviours, she had no Care Co-ordinator nor effective Care Plan (which ought to have been in place) because she had not engaged with TEWV community services;**

There has been a previous external review of Zoe's care that considers this point and a subsequent action plan which was developed with Mrs Zaremba. These identified as an action that community mental health team leaders need to make flexible decisions based on an individual needs which may need to cross services and traditional ways of working. This may mean that it's necessary to move away from usual ways of working in relation to allocation of a care coordinator or where care is delivered to ensure that all efforts are made to collaboratively meet patient needs.

This action plan is being monitored through trust governance processes.

h) **Zoe lurched from crisis to crisis remaining at high risk to her own safety; she died because she could no longer cope with the sense of injustice caused by others that overwhelmed her thinking. She felt she was not being listened to by community mental health services. Her therapy from outside providers - which was proving helpful to her - was disrupted by COVID-19 limitations on face-to-face consultations; Both locally, including regional, but also nationally the evidence revealed a few serious issues that require urgent and immediate action to support autistic people well, not just from a sensory and environmental basis (which TEWV have started to improve albeit from a low baseline according to the evidence received). Urgent solutions are required to prevent future deaths of autistic patients especially with mental health needs;**

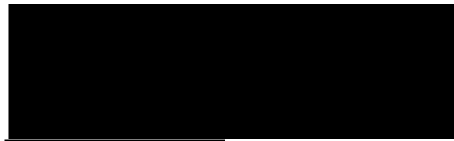
We have undertaken a wide consultation with patients, carers, staff, and external partners to co-create a more inclusive and collaborative service. This consultation took several forms including 'Our Big Conversation', which used online crowd-sourcing methodology, as well as programme boards to follow through the key service changes. We have a commitment to be working in equal partnership with people with lived experience and have now brought this directly to the heart of the organisation by appointing 2 Lived Experience Directors to the executive team. We are also expanding our peer support worker numbers.

We are adopting the nationally recommended changes to care planning to ensure that this is more collaborative and focussed on holistic needs with individualised recovery plans based on the DIALOG model. Increasingly, across the system, we

are working with partners to integrate care, and this is supported in our area by the newly created Integrated Care System for Humber & North Yorkshire.
We expect the above developments to significantly impact on the level of trust engendered by services including young people like Zoe.

I trust this provides you with assurance that the appropriate actions are and have been taken to address the concerns raised. However, should you require any further information please do not hesitate to contact me.

Yours sincerely



,
Chief Executive Officer