



Department  
of Health &  
Social Care

*From Maria Caulfield  
Minister for Mental Health and Women's Health*

39 Victoria Street  
London  
SW1H 0EU

Our Ref: Alfie Anthony Kevin Nicholls [REDACTED]

Ms Alison Mutch  
HM Senior Coroner  
Greater Manchester South HM Coroner's Court 1  
Mount Tabor Street  
Stockport  
SK1 3AG

8 May 2024

Dear Ms Alison Mutch,

Thank you for your Regulation 28 report to prevent future deaths dated 14/02/2024 about the death of Alfie Anthony Kevin Nicholls. I am replying as the Minister with responsibility for Mental Health. I understand that you also issued the Regulation 28 report to the Department for Education (DfE). Department officials have therefore also engaged with officials from DfE to prepare a joint response and this letter is being sent on behalf of both departments.

Firstly, I would like to say how saddened I was to read of the circumstances of Alfie's death, and I offer my sincere condolences to his family and loved ones. The circumstances your report describes are concerning and I am grateful to you for bringing these matters to my attention. Please accept my sincere apologies for the delay in responding to this matter and I am thankful for the extension you have granted.

In preparing this response, Departmental officials have made enquiries with NHS England and the Care Quality Commission (CQC) to fully understand and address the concerns you have highlighted.

The report raises a number of concerns around Avoidant Restrictive Food Intake Disorder (ARFID), the normalisation of poor and restricted eating by autistic children, the use of Education, Health and Care Plans (EHCPs) as a holistic tool, the importance of school nurses and dieticians, and wider understanding of guidance on medical emergencies in eating disorders (MEED).

I agree that ARFID is an under-recognised condition which is why NHS England is refreshing guidance on children and young people's eating disorders, to increase the focus on ARFID as well as early identification and intervention. Updated guidance will highlight the importance of improved integration between dedicated community eating disorder services, wider children and young people's mental health and neurodevelopmental services, schools, colleges and

primary care. The aim is to improve awareness, provide expert advice and improve support for children and young people presenting with problems with eating, whilst ensuring swift access to specialist support as soon as an eating disorder is suspected. The guidance will also highlight the importance of tailoring care to meet the needs of children and young people with ARFID, to prepare for varied presentations and to work collaboratively with other teams to address coexisting conditions as needed.

Training plays a crucial role in ensuring there is a wider understanding of ARFID amongst health professionals. That is why the Workforce, Training and Education Team at NHS England have commissioned ARFID training for people working within children's eating disorder services and for the non-specialist workforce. Separately, the CQC Operations Team support operational colleagues across CQC through ongoing awareness building of issues affecting autistic children, young people, and adults, and those with a learning disability. As part of this awareness raising, the team will seek to improve colleague's understanding of the concerns raised by the report, including regarding nutrition.

We are also taking action to improve understanding of autism more generally amongst the health and care workforce. From 1 July 2022, the Health and Care Act 2022 requires CQC registered providers to ensure their staff, including those working in eating disorder services, receive specific training on learning disability and autism appropriate to their role. We are rolling out the Oliver McGowan Mandatory Training on Learning Disability and Autism to support this. This training will help to ensure that staff have the right skills and knowledge to provide safe and compassionate care, including how to provide reasonable adjustments, for autistic people. Over 1.7 million people have completed the first part of Oliver McGowan Mandatory Training on Learning Disability and Autism, an e-learning package.

In addition, in response to the need and demand for better autism training from within the psychiatry profession, NHS England has commissioned the Royal College of Psychiatrists to deliver the National Autism Foundation Training Programme for Psychiatrists. This training is aimed at consultant psychiatrists and higher trainees across all care settings, who are seeking to increase their specialist knowledge and skills in autism, to improve autism appropriate care and support the reduction of diagnostic overshadowing and unnecessary admissions of autistic people to inpatient mental health care settings.

I hope that through the steps we are taking to improve understanding of both ARFID and autism amongst health professionals, as well as the focus within the refreshed eating disorders guidance on collaborative working across teams including with neurodevelopmental services, we can help to avoid future instances of normalisation of poor and restricted eating by autistic children.

In relation to your concerns around school nurses, I agree that the school nursing workforce is fundamental to improving the health and wellbeing of families throughout the school years. The ambition of the NHS Long Term workforce plan is to expand training places for school nurses by 28%, supporting an ambition to nearly double training places to over 650 places by 2031/32. The government has committed £2.4 billion investment to support the delivery of the NHS Long Term Workforce Plan. The issue of school nursing teams in Special Educational Needs Schools will also be shared with CQC's Primary and Community Care specialist team.

In respect of education staff, DfE's Universal Services contract brings together Special Educational Needs and Disability (SEND) specific continuous professional development (CPD) and support for the school and further education workforce, which includes autism training and resources to staff. Since the programme commenced in May 2022, over 160,000 professionals have undertaken autism training provided by the Autism Education Trust (AET)

through their 'train the trainer' model. Training covers a range of topics, including the sensory challenges that autistic children and young people might experience. We will share these concerns with AET and the Department will consider what training content on autism is most beneficial for the education workforce.

To expand access to early mental health support to children and young people, Mental Health Support Teams (MHSTs) are continuing to be rolled out to schools and colleges. By the end of March 2025, MHSTs will cover an estimated 50% of pupils in schools and further education in England. Additionally, all state schools and colleges have been offered a grant to train a senior mental health lead by 2025, enabling them to introduce effective whole school approaches to mental health and wellbeing. Over 15,100 settings have claimed a grant so far.

You highlight the importance of considering a child more holistically within the EHCP process, to ensure those plans are being used to understand the inter-relationship between health and education. I agree that it is essential that health and education partners work closely together to ensure that children and young people receive the right support, at the right time.

The purpose of an EHCP, which is to make special educational provision to meet the special educational needs of the child or young person; to secure the best possible outcomes for them across education, health and social care; and, as they get older, prepare them for adulthood. The EHCP needs assessment must identify the child or young person's special educational needs, together with any relevant health or social care needs. If the local authority decides it is necessary to issue an EHCP, the plan must specify the outcomes sought for the child or young person and the provision which will deliver those outcomes.

Where an assessment of an individual child or young person's needs indicates that support from services outside of education such as health or social care is required, it is important that they receive it as quickly as possible. Relevant local clinicians, such as community paediatricians, will participate in the development of the child's or young person's EHCP, advising on the child's needs and the provision appropriate to meet them. All partners involved (including education settings, the local authority, health services and other providers) should work closely together to agree arrangements for funding responsibilities and accessing or commissioning specialist services as appropriate. The SEND Code of Practice is clear that where health care provision is specified in the EHCP, the integrated care board (ICB) (or where relevant, NHS England) must ensure that it is made available to the child or young person.

DfE is currently leading work to pilot improvements to the EHCP system, including testing a new EHCP template, and the findings of your report have been shared with the team leading this work. The new EHCP template seeks to deliver better quality plans which are more clearly specified and quantified across education, health and care. If the evidence generated through the change programme supports it, the DfE will look at the best way to roll the new template out more widely.

NHS England has also published statutory guidance setting out that every ICB is expected to have a board-level executive lead for children and young people with SEND who will support the chief executive and the board to ensure that the ICB performs its functions effectively in the interests of children and young people with SEND (0-25). The ICB executive lead is responsible for working in partnership with a wide range of other services including across health and education, to drive quality improvement and outcomes for children and young people with SEND and their families; and ensuring there are effective joint working and funding arrangements in place across both education and health and care.

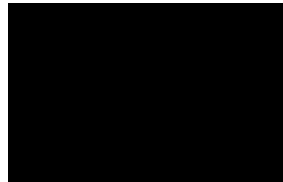
CQC will continue to contribute to multi-agency inspections to better understand how health, education and care services work together. With their inspectorate partners, CQC will continue to report on areas of concern for children and young people with Special Educational Needs and Disabilities. They will use the learning from your report to inform their inspection activity.

CQC Operations colleagues are requesting any investigation report, action plans and learning from the trust so they can gain assurance that there are measures in place to reduce the risk of a similar death, or incident, happening. The trust has carried out lessons learned and are striving to offer better support for other children in the area who may suffer from ARFID, with more MDT working and access to more specialists.

You highlighted the importance of raising awareness of the medical emergencies in eating disorders (MEED) guidance and I can assure you that NHS England continues to work with systems and healthcare professionals to support the wider adoption of the MEED guidance. This commitment was recently reiterated in the *Suicide prevention in England: 5-year cross-sector strategy* which was published last year.

I hope this response is helpful. Thank you for bringing these concerns to my attention.

Yours sincerely,



**MARIA CAULFIELD**