

[REDACTED]
Date: 4 April 2024

Private & Confidential

Ms Alison Mutch
H M Senior Coroner
1 Mount Tabor Street
Stockport
SK1 3XE

Dear Ms Mutch

Inquest into the death of Alfie Anthony Kevin Nicholls – Date of Death 17th December 2021

I refer to the Regulation 28 Prevention of Future Deaths Report issued following the inquest into the death of the above named. I am sorry to learn of the circumstances of Alfie's death and offer my sincere condolences to his family.

To support the response to the following matters of concern I will refer to the multi-agency learning event that was completed by Stockport Safeguarding Childrens Partnership [SSCP] in July 2023 following Alfie's death. The action plan from the Learning Event is having oversight via the Partnerships Learning from Practice Hub model.

The inquest heard evidence that Avoidant Restrictive Food Intake Disorder (ARFID) was not widely understood by those involved with children and adults who may be impacted by it. That included a lack of awareness of what it was and how to approach it amongst Health, Education and Social Work professionals. The inquest was told that until awareness of it improved then similar situations to that of Alfie could go unrecognised with similar consequences.

A variety of training sessions have been delivered in Stockport during 2023 which includes:

- (1) Pennine Care NHS Foundation Trust Community Eating Disorders Service [CEDS] ARFID is Everybody's Business Network Event November 2023 with a plan to repeat in Spring 2024.
- (2) Stockport NHS Foundation Trust Children and Young People's Mental Health Education Practitioner includes ARFID in the training delivered to staff and it has been included as part of the Level 3 Safeguarding Children training offer.
- (3) Stockport Dietetic Service have completed the Maudsley ARFID training in 2023.
- (4) Spring North ARFID Training Sessions have been shared across the locality and several Stockport practitioners across health and social care have completed the training and there is currently a waiting list.
- (5) The SSCP Learning Event Action Plan includes the development of a 7-minute briefing that will be easily available across the Partnership to all agencies.

Evidence before the Inquest was that in addition to there being increased awareness amongst professionals there needed to be strategies within and across Health, Education and Social care to ensure effective strategies were put in place and those with ARFID or at risk of developing ARFID were identified and managed effectively.

Following the SSCP Learning Event there will be a process mapping of current provision planned for May 2024 as there have been several developments since Alfie sadly died to support professionals across Health, Education and Social care to ensure effective strategies are in place to ensure those with ARFID or at risk of developing ARFID were identified and managed effectively.

Recent developments include:

- A new dietetic referral pathway for restricted eating which includes a tool to support parents who are concerned. Training of School Nurses and Health Visitors has commenced and will be a rolling program throughout the year to screen when parents raise concerns with 3-day food diaries as part of that pathway.
- Revised medical guidance for paediatricians has been put in place regarding nutritional screening & medical management.

A feature of the evidence before the Inquest was a normalisation of poor and restricted eating by children with autism. This meant that the impact on their overall health and wellbeing was not considered. Children with autism were measured against each other in relation to their eating with phrases such as “we have children with poorer diets ...” being used.

Following Alfie’s death, Stockport NHS Foundation Trust has undertaken a review of all children known to paediatricians to ensure all had a referral to dietetics, appropriate blood tests and access to food supplements.

Recent evidence that there has been a ‘mind shift’ in the normalisation and medical management of children with autism with restricted eating has been demonstrated by 3 children having percutaneous endoscopic gastrostomy [PEG] to enhance their nutritional intake.

Paediatricians and the CEDS continue to link through the monthly multi-disciplinary meetings where they can discuss children, they are worried about, and refer to the CEDS ARFID pathway if appropriate. Although the CEDS ARFID pathway is for children over the age of 8 at the MDT there is the opportunity to discuss children under the age of 8 and CEDS advise on the management.

There are also plans in place to introduce a nutritional element to assessments and plans within Stockport neurodiversity pathways.

Whilst there was an Education, Health and Care Plan (EHCP) in place for Alfie there was little evidence that EHCPs were being used as a holistic tool to understand the inter relationship between health and education. There was evidence that those writing EHCPs needed to consider a child more holistically for the EHCP to cover all the aspects that it was meant to cover and not just to focus on education.

Stockport Designated Clinical Officer [DCO] SEND has been leading on assurance work to improve the quality of EHCP particularly looking at the health information which is included within them.

There are now 2 health links with the Local Authority EHCP team who are supporting the development of a EHCP multi-agency audit process. The DCO also meets with the health links monthly.

The DCO is also leading work to ensure the use of the EHCP ‘flag’ within EMIS, the record keeping system for health visitors and school nursing.

The SSCP Learning Event Action Plan requests assurance from the EHCP Team that a review is undertaken of children with restrictive eating or ARFID and that health information is included.

Schools are responsible for leading the EHCP annual review, so will lead on seeking updating advice and ensuring this element of the plan is reviewed in the meeting. If as an outcome of the EHCP annual review the plan needs to be amended, they the school will provide all the information gathered to the EHCP caseworker to update the plan document.

At the SSCP Learning from Practice Hub it was noted that staff at Alfie's school are now adding information in relation to restricted eating into the health section of the EHCP plan.

Work has also commenced to update the Stockport 'Medical Needs in School Policy' for children who may have restricted eating but do not have an EHCP in place.

The Inquest heard that the school nurse service could play a vital role in identifying health issues and supporting other professionals. This key role was significantly impacted by the high demand on the service and the very high caseloads school nurses working with complex children were being asked to carry nationally.

In Stockport the 0-19 yr service is commissioned by Public Health. Stockport reflects the national picture of very high caseloads for school nurses working with complex children. In 2022 a school nursing transformation was undertaken which included an increase to provision resulting in an identified school nurse covering Alfie's school plus 3 other schools.

Stockport School nurses are having an away day this week solely dedicated to ARFID which will support their skills in nutritional assessment and introduce them to the new dietetic pathway.

There is a GM workstream regarding special schools and nursing requirements exploring a GM response.

The role of a dietician in supporting children with eating disorders could be fundamental in maximising the nutritional value of what they consumed. Demands on the service and a limited understanding of how they could work to support children with disorders such as ARFID (nationally) meant that there was rarely regular input from dieticians.

As previously mentioned there has been the development of a new dietetic referral pathway for restricted eating which includes a tool to support parents who are concerned. The aim is to have a consistent approach to ensuring children are nourished if they do not have a varied diet. It clarifies who can refer to the dietetic service including health professionals, school nurses and GPs.

The referral pathway is currently being rolled out to GPs, Local Authority Children Services, community health services and schools. It was shared with Alfie's school prior to roll out to ensure this would support them to work with families and they have reported it has been effective as they have been able to sign post parents to the appropriate place to support a referral.

All children who are referred to Pediatricians with restricted eating are routinely referred into Dieticians.

ARFID, the Inquest was told, could lead to medical emergencies in eating disorders (MEED). The evidence given at the Inquest was that whilst this concept had been the subject of guidance amongst Psychiatrists it had been less publicised and there had been far less guidance by other Royal Colleges. In particular the Inquest was told that MEED needed to be far better understood by medical professionals in acute settings such as Emergency Departments and Paediatrics to avoid a situation where the impact of ARFID and the medical risk it posed was not understood until it was too late.

An action from the SSCP Learning Event was that all Stockport pediatricians be made aware of the recent Royal College of Child Psychiatrists published guidance in relation to ARFID” which was completed in February 2024.

As a system we are committed to learning from the sad death of Alfie and I can confirm that information / learning has been shared across NHS Greater Manchester ICB via the following:-

- DCO SEND GM Professional Network
- Pennine Care NHS Foundation Trust provided CEDS across Greater Manchester.
- CEDS are awaiting the publication of National CEDS Commissioning Standards expected in Spring 2024 which will develop a GM plan for restricted eating.
- Stockport NHS Foundation Trust Pediatricians have shared the learning across their professional Greater Manchester network.

I hope the above assures you and Alfie’s family that lessons have been learnt following the inquest into Alfie’s death and that there is now a clear plan in place to ensure that healthcare professionals recognise ARFID and have access to appropriate care pathways to best support any child with this condition.

If you require any additional information please let me know.

Yours sincerely

[Redacted signature]

[Redacted name]
Chief Executive and Place Based Lead
Stockport Metropolitan Borough Council/NHS Greater Manchester

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Interim Deputy Chief Executive Officer and Chief Nursing Officer
NHS Greater Manchester