

Child and Adolescent Mental Health Unit



Castle Buildings
Stormont Estate
BELFAST, BT4 3SQ

Email: CAMHU@health-ni.gov.uk

Our Ref: STOF -0015 -2026

Date: 22 July 2026

Ms Zoe Connor

By email to: 220240505@aston.ac.uk

Dear Ms Connor

Preventable death from malnutrition in children and adults with selective eating – urgent national action required

Thank you for your letter to the Permanent Secretary, dated 8 July 2026, regarding the prevention, identification and management of nutritional risk in children, young people and adults with selective eating, including Avoidant/Restrictive Food Intake Disorder (ARFID). As policy lead for CAMHS, I have been asked to reply to you on his behalf.

I note the concerns raised in the open letter to NHS England, which accompanied your correspondence, regarding a number of Prevention of Future Deaths reports relating to malnutrition and ARFID.

I appreciate you taking the time to write about this important issue and to highlight the experiences of individuals and families affected by selective eating and ARFID. The cases referenced in your correspondence are deeply concerning and serve as a reminder of the potentially serious consequences that can arise when nutritional difficulties are not recognised or addressed at an early stage.

The Department recognises the serious impact that ARFID and other forms of restrictive eating can have on health and wellbeing. ARFID is a relatively new diagnosis, first introduced in 2013. It is characterised by restrictive eating patterns that result in significant health, nutritional or psychosocial difficulties. Unlike other eating disorders, food avoidance in ARFID is not linked to concerns about weight or body shape, but may relate to sensory considerations, low interest in food, or fears about adverse consequences such as choking.

The Department is aware of increasing concern regarding ARFID and the challenges associated with assessment and treatment pathways. Feedback received from Health and Social Care Trusts has highlighted increasing referral rates, limited specialist training, uncertainty regarding service responsibilities and significant gaps in provision. Trusts have also reported that presentations frequently overlap with autism spectrum disorder and that effective management often requires input from a range of professionals, including paediatric, dietetic, psychological and mental health services.

At present, there is no commissioned regional ARFID service or formally agreed regional assessment and treatment pathway in Northern Ireland. To address these challenges, officials have convened a regional multidisciplinary group involving representatives from community and acute paediatrics, Child and Adolescent Mental Health Services, Adult Mental Health Services, Autism Services and Psychological Services. The purpose of this work is to explore and develop an agreed regional pathway that reflects current evidence and best practice, supports earlier identification and intervention, and clarifies service roles and responsibilities. The work will also consider workforce training requirements, referral and triage arrangements, and the interface between relevant services.

I note the recommendation that a national review be undertaken to consider nutritional risk associated with selective eating across children and adults. The Department recognises the importance of understanding the issues raised and learning from emerging evidence and developments across the UK. Your correspondence has been shared with relevant officials involved in the ongoing regional work relating to ARFID and selective eating. Officials will continue to consider the issues raised, alongside emerging evidence and developments across the UK, as this work progresses.

Thank you again for writing and for drawing attention to this important matter. I hope the information provided is helpful and can assure you that the issues you have raised will continue to inform the Department's ongoing consideration of ARFID and related eating difficulties.

Yours sincerely

Carol Picton-Lynas
Head of CAMHS Policy Unit

Working for a Healthier People

