

[REDACTED]
Sir John Robinson House
Sir John Robinson Way
Arnold
Nottingham
NG5 6DA
[REDACTED]
[REDACTED]

Miss Bower
Assistant Coroner Nottinghamshire

Date: 29 October 2021

Dear Miss Bower

Re: Regulation 28 – Report to Prevent Future Deaths

I am writing to provide you with a response to the above Regulation 28 report, dated 7 May 2021, in which you raised concerns that there is no specialist service commissioned to provide Autistic Spectrum Disorder (ASD) patients with long-term dietetic support for symptoms of Avoidant Restrictive Food Intake Disorder (ARFID).

NHS Nottingham and Nottinghamshire Clinical Commissioning Group (CCG) have liaised with Nottinghamshire Healthcare Trust (NHT) to understand the circumstances surrounding this case and the clinical pathways for autistic individuals with ARFID.

As a system we have developed an overarching action plan which describes our intention to develop an all-age pathway for individuals who are affected by ARFID. This pathway will ensure we are able to meet the needs of ARFID patients who are neurotypical and those who are autistic or who have other comorbidities.

To ensure pathways and services are patient centred we will undertake engagement with individuals and families whose lives have been affected by ARFID within childhood and adulthood. An All Ages ARFID working group will be established to lead the pathway development work and engagement, with this being complemented by a broader service transformation programme which aims to improve the lives of individuals with Learning Disabilities and/or Autism. The Nottingham and Nottinghamshire Integrated Care System (ICS) Mental Health and Social Care Partnership Board will oversee delivery of this work.

I hope the above, together with the action plan, provides you with assurance of our commitment to addressing the issues you have raised and am happy to provide regular updates regarding how this work is progressing. Please let me know if you require any further information.

Yours Sincerely,

p.p. 

[REDACTED]
Associate Director of Commissioning, Contracting & Performance – Mental Health and Community

Avoidant Restrictive Food Intake Disorder (ARFID) Pathway Development Action Plan

Objective	Actions	Timescales (By When)	Owner	Commentary
Develop All Ages ARFID Pathway	Review recommendations from regional CAMHS ARFID pilot and national work around ARFID	Nov '21	All Ages ARFID Task and Finish Group	Awaiting publication of regional reports.
	Undertake review of clinical cases to understand current provision and service gaps	Oct '21		Completed.
	Undertake needs assessment, including prevalence and impact of comorbidities such as ASD	Jan '22		
	Undertake literature review and understand evidence base for the treatment of ARFID	Jan '22		
	Review current service provision	Jan '22		
	Engagement with children, young people and families affected by ARFID	Apr '22		
	Develop preferred pathway with recommendations for service delivery	Jun '22		
	Obtain approval of preferred pathway and resources	Jul '22		
	Implementation of agreed pathway	Nov '22		
	Monitor and evaluation of agreed pathway	Ongoing		
Develop workforce capability across the All Ages ARFID pathway and relevant support services	Undertake skills audit and training needs analysis across specialist and non-specialist services to identify training requirements	Apr '22	All Ages ARFID Task and Finish Group	
	Explore development of expanded roles within primary care	Mar '23		

	Explore with Health Education England (HEE) the development of workforce competencies around ARFID	Mar '23		
Expand LeDeR reviews to include autistic people	Expand the learning from deaths mortality reviews to autistic people in addition to people with learning disabilities	Mar '22	Learning Disability Mortality Review (LeDeR) Steering Group	
	Identify themes from LeDeR reviews and embed processes to ensure that learning from deaths inform improvements in practice across the system	Oct '22		
Develop Annual Health Checks for autistic people	Incorporate the learning from the Learning Disability Annual Health checks and develop Annual Health Checks for autistic people, in line with the NHS Long Term Plan, and to include specific physical health requirements relating to ARFID and incorporating learning from the Primary Care Learning Disability Nurses	Mar '24	LD Annual Health Checks Group	