

Oifig an Chomhairleora Chliniciúil Náisiúnta agus Ceannaire Grúpa do Mheabhairshláinte

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Deputy Sorca Clarke, Dail Eireann, Leinster House, Kildare Street, Dublin 2.

Date: 17.04.2024

PQ Number: 12604/24

PQ Question: To ask the Minister for Health if there are plans to develop a model of care for people with avoidant restrictive food intake disorder; and if there is a clinical lead within the HSE. –Sorca Clarke

Dear Deputy Clarke,

The Health Service Executive has been requested to reply directly to you in the context of the above Parliamentary Question, which you submitted to the Minister for Health for response. I have examined the matter and the following outlines the position.

In January 2018, the HSE published a National Model of Care for Eating Disorders (MOC) in partnership with College of Psychiatrists' of Ireland and Bodywhys. In the absence of a preexisting dedicated eating disorder infrastructure or strategy, this Model of Care document has been developed in order to guide the provision of high quality, accessible and value for money eating disorder services in Ireland. Key recommendations include the development of a national network of dedicated eating disorder teams embedded within the mental health service, a stepped model of outpatient, day patient and inpatient care provision based on clinical need, and the development of a skilled, trained workforce. In the context of the significant physical morbidity associated with eating disorders, this Model of Care also recommends a strong integration between primary care, mental health services and medical teams, including the bridging of the acute hospital and mental health service divide through mutual clinical commitments and shared pathways.

The NCPED aims to establish an ED network (8 adult teams and 8 CAMHS teams) in accordance with the agreed Model of Care 2018. These multidisciplinary teams provide specialist eating disorder assessment and treatment in the community and are the foundations of delivering quality eating disorder care across the stepped model of care. As of March 2024 there are 11 teams in places across the lifespan all at various stages of development.

Avoidant Restrictive Food Intake Disorder (ARFID) is an umbrella term that refers to a range of feeding and eating disorders without any weight or shape concerns. It is a term recently added

to diagnostic classifications: DSM -5 (2013) and ICD-11 (2022). ARFID is a new way of classifying feeding and eating disorders that have always presented in a wide range of settings depending on needs such as paediatrics, dietetics, speech and language therapy, mental health, developmental clinics and disability services.

ARFID is diagnosed when there is an eating or feeding disturbance that results in the persistent failure to meet appropriate nutritional and/or energy requirements and is associated with one or more of the following: significant weight loss, significant nutritional deficiency, dependence on enteral feeding or oral nutritional supplements and marked interference with psychosocial functioning. There are three profiles (anxiety related, sensory related, lack of interest) associated with ARFID and people of all ages can present with one or a mixture of these profiles or drivers.

There is a lack of research, best practice information and evidence based treatments for ARFID. As a consequence ARFID is not included in NICE guidelines for Eating Disorders (2017 or 2020 update). ARFID is also not included in APA American Psychiatric Association draft guidelines for eating disorders 2022. Treatment plans are best developed in a bespoke manner by treating teams and guided by the profile of the individual case. Treatment is likely to be multimodal, multidisciplinary and involve multiple settings (mostly outpatient). There is an absence of an evidence base for service models or formal treatments. Cases of ARFID can present across health care settings including primary care, disability services, paediatrics, adult medicine, mental health services, feeding clinics and eating disorder services.

A pilot outpatient ARFID service or feeding clinic was recently established in England during 2019 at the Maudsley Centre for Child and Adolescent Eating Disorders, and this is leading the development of clinical services, care pathways, training and research. Recommendations where services for ARFID best sit within health systems are awaited and currently not known. Domains of assessment need to include psychosocial, developmental, dietetic and medical. To date we are not aware of any evaluation or recommendations following the development of the pilot ARFID service in the UK. It is not yet known where services for ARFID should best sit within the health service. It would not be expected to solely lie within mental health services as management of children with ARFID in Ireland requires a collaborative working between a number of professionals and, depending on a person's needs and level of complexity. This will involve joint working between the acute hospital sector and HSE community healthcare divisions such as Primary Care, Disability and Mental Health. The lack of dietitians across primary care, outpatient paediatrics and community mental health services will be a challenges as effective treatment and care planning requires access to dietetics across these services.

The HSE National Clinical Programme for Eating Disorders and its Model of Care are focused on the following DSM-5/ICD-11 eating disorder categories: Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder. Feeding disorders fall outside the scope of the National Clinical Programme for Eating Disorders. ARFID is included only when there is a clinical indication and evidence base for mental health intervention. From 2018 to 2022 the NCPED teams completed 833 assessments, of which 48 (5.76%) had ARFID. It is likely many of these cases were referred initially with anorexia nervosa. The male: female ratio for ARFID was 30:70. In 2023 there were 21 cases of ARFID seen by ED teams.

The development of care pathways for ARFID will not be best led by the National Clinical Programme for Eating Disorders as it will require a collaborative approach with paediatrics, primary care, disability services and CAMHS/youth mental health. Direction will be required from these areas of the health service.

I trust this information is of assistance to you. Please do not hesitate to contact me if you have any further queries.

Yours sincerely,

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Dr Amir Niazi National Clinical Advisor & Group Lead for Mental Health Clinical Design and Innovation Health Service Executive