Survey of Dietetic Service Provision to Individuals with Avoidant Restrictive Food Intake Disorder

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To understand current provision and gaps in dietetic services for individuals with Avoidant Restrictive Food Intake Disorder (ARFID), an electronic survey was distributed. Responses demonstrated dietitians are key professionals in ARFID services, often performing extended roles to include psychological and sensory support. However, formal pathways of care are lacking, with reports of isolated working and inadequately resourced multidisciplinary teams. Although areas of good practice exist, more resourcing is required, and multidisciplinary teamwork provides the best care.[1] Consequences of poor resourcing include compromised nutrition, leading to decreased physical and mental health and increased treatment times. The newly developed BDA ARFID Specialist Interest Group (BDA ASIG) supports the dietetic profession with its recently published position statement.[1]

Background & objectives

ARFID is characterised by extreme limitations in the amount and/or types of food consumed but does not involve distress about body shape or size.[2] Prolonged poor nutrition can result in significant health problems. Presentations are heterogeneous, requiring considerable dietetic expertise to manage effectively within a multidisciplinary team (MDT) approach. Evidence-based guidelines on dietetic interventions and management are not yet available and dietitians with varied skills and experience are supporting individuals in a variety of mental health, acute and community settings within adult and paediatric care.

The aim of the survey* was to acquire a deeper understanding of the current provision of dietetic services for children, young people and adults who have a confirmed or working diagnosis of ARFID across the UK and Republic of Ireland (ROI). More specifically, to investigate available dietetic resourcing, skills, training, care delivery and treatment approaches, and whether dietitians perceive their services to be adequate.

Methodology

An anonymous electronic survey was designed, with input from the BDA ASIG. Completion was requested during August 2022 by registered dietitians with experience in supporting individuals with ARFID. Participation opportunities were highlighted online by relevant BDA specialist groups and the Irish Nutrition and Dietetic Institute (INDI). Thirty-six questions scoped service demographics, management and resourcing, care delivery, dietetic approaches, perceptions of service provision, and training needs.

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Results

One-hundred dietitians participated, from England (81%), Scotland (9%), Northern Ireland (7%) and Wales (3%). There were no responses from the ROI. Across all settings, 83% worked with children (Paediatric, Child and Adolescent Mental Health Teams [CAMHS], and Children and Young People Eating Disorder Teams), 8% with adults and 9% in a combined service. The majority worked in acute or community-based services (some of which included mental health services) and 19% described their employers purely as a Mental Health Trust.

Service management & resourcing

Within services, 44% of dietitians reported often being the sole professional involved and 14% worked alongside only a community paediatrician. Where ARFID was handled by an MDT (23%), this was split almost evenly between CAMHS, Eating Disorder (ED) Teams and Feeding Teams. 19% worked alongside a non-medical supporting professional, (occupational therapist [OT], speech and language therapist [SLT] or psychologist). Dietitians working alone were based in community, primary care or hospital-based outpatient clinics. Mental Health Trusts were more likely to provide a multidisciplinary service (80%).

For 14%, a formal pathway for ARFID existed. This was not necessarily representative of the number of services, as more than one dietitian may have responded from a service. There was dietetic involvement in every formal pathway (see **Figure 1**). In acute and community services the pathway always included a paediatrician and often additional healthcare professionals (HCPs). Where private and mental health services had a formal pathway, this was always multidisciplinary.

Only 9% received designated dietetic funding, mostly in CAMHS, although one funded service was all-age. Posts were funded at Band 6 or 7, with approximately 20 patients/0.2WTE. Outcome data was collected by one funded service and nine unfunded services.

Traditional & extended dietetic roles

Figure 2 shows dietetic roles within formal pathways (n=14) compared to services with no pathway (n=50, non-mandatory answer). There were similarities (assessment of intake/status, dietary counselling, and nutritional support) but desensitisation, exposure therapy, cognitive behavioural therapy (CBT), family based therapy (FT) and diagnosis were more likely to be undertaken by dietitians working to a formal pathway. Micronutrient supplementation was more likely outside of a formal pathway.

Skills & training

Despite 41% of dietitians considering their roles 'extended', over half had not received formal training. Formal training included sensory, i.e. SOS course (21%), CBT (13%) or an ARFID short course; commonly Winchester University or the Maudsley NHS Trust (11%). Smaller numbers had undertaken behaviour change skills (8%), autism courses (4%), pica/ARFID/rumination disorder interview (PARDI) training (4%) or specialised supportive clinical management, care-coordination, decider skills, guided self help, and FT (all 2%). Colleagues and BDA specialist groups positively impacted dietitians learning. One third felt more research was needed to benefit their understanding of ARFID.

Care delivery & dietetic approaches

On the whole, the survey showed dietitians use poor growth or low BMI (60%) to escalate priority in ARFID, although CAMHS dietitians are less likely to use this criterion. Many consider clinical/biochemical signs of deficiency (42%) in addition or on its own. Less consideration is paid to poor dietary variety, or dependence on oral nutritional supplements (ONS). Only 3% felt obesity increases priority. Privately funded services accept all referrals without need for prioritising.

Assessment methods to define nutritional intake are shown in **Table 1**. A quarter use computerised analysis to gain a higher degree of accuracy to predict nutritional risk.

Table 2 explores dietetic approaches. Additionally, a few dietitians advocated disguising vegetables/fruit in accepted foods, not a recommended practice where high trust levels are required in the therapeutic relationship.

Micronutrient supplements are frequently recommended with drops/liquid, powders, and gummies most accepted. Several remarked on general poor acceptance and the expense of 'over-the-counter' supplements, with only 5% requesting a prescribable form. Patches are rarely recommended due to limited evidence. **Table 2** shows 89% offering ONS and 30% offering tube feeding as treatment, however, **Table 3** shows lower figures for perceived acceptance of ONS. Tube feeding was more common in Community Trusts compared to Mental Health Trusts (maximum of 25 vs 10 individuals on caseload), but many were supported by dietetic and community/feeding nurses only (77%) without psychological support.

Perceptions of knowledge and service provision

Most dietitians feel confident to recognise ARFID, yet do not have supporting multidisciplinary services or time needed. **Figure 3** gives further details.

Figure 4 expresses the main concerns for those who lack MDT support, with 'other' concerns including family disillusion and withdrawal from services.

Discussion of key findings

The survey captured valuable data due to high response rates across a broad geographical area (excepting ROI). Professionals agree ARFID is not a new diagnosis but gives clearer definition and improved guidance on identification, intervention and care, which demands multidisciplinary support.

Irrespective of funding or a designated pathway, **dietitians are key professionals** in ARFID services, but many work in isolation. Heterogeneous presentations necessitate thorough assessment; as a minimum, an MDT should include medical, mental health and dietetic professionals.[3] Assessment of sensory processing, oral-motor development, or swallow function may also be indicated, requiring occupational and speech and language therapists.[3] Uni-professional management could jeopardise care and increase stress in both the individual, family and professional. **Organisations rarely had dedicated clinical pathways or resourcing** and often dietitians recognised ARFID but had **no route for formal diagnosis and treatment**. An inexperienced dietitian may not recognise the unique sensory, psychological, and nutritional management strategies needed, giving potentially detrimental advice, and leaving treatment expectations unmet. Experienced dietitians may take extended roles following psychological and sensory training courses, but even appreciating resource limitations, this should not mitigate against multidisciplinary care; multidisciplinary opinion and support is required. Regarding banding, it is recommended that a lead dietitian in an ARFID service should be a minimum of Agenda for Change Band 7.[1] **Funded services were rare** and where funding existed, banding did not always follow this recommendation, but positively, dietetic time (whole time equivalents) met recommendations,[1] calculated from the BDA 'Safe staffing, safe workload guidance'.[4]

Priority is often escalated by poor growth or a low BMI, and less consideration is paid to obesity. However, obesity offers false reassurance; high intakes of processed carbohydrates put individuals within the expected weight range, but often with a very poor-quality diet.[5,6] Children with autism, commonly associated with ARFID, may in fact be more likely to be obese than children developing neurotypically.[7] Individuals of any weight who present with symptoms of ARFID benefit from early and frequent screening for micronutrient adequacy.[8] Although **dietary intake is often assessed using food diaries**, available time limits computerised assessment. As intake is restricted to very few foods, accuracy of recall may be more likely than in typical eaters and a skilled dietitian should be able to predict likely nutrient deficiencies. **Micronutrient supplementation** was seen as a proportionately greater role of dietitians working outside a formal pathway (see **Figure 1**), perhaps used as a 'safety net' when solely managing care. Food-first approaches to nutrition support are difficult; food fortification is virtually impossible as individuals will not accept any additions/changes to the limited food they do consume. Consequently, it has been anticipated that at least one third of children with ARFID will require an ONS[5,9] and 17% will require tube feeding.[9] **Although, when required, ONS seems a useful treatment option, the majority can only maintain ONS acceptance in under half their caseload**. Tube feeding is a last resort, but complex psychological support – always required where there is no physical reason for a child not to eat – was frequently not available, risking longevity of feeding.

Most dietitians were not at ease with their current service, quoting lack of time and limited access to mental health professionals. The BDA ASIG recommends an hour is needed for an appointment in the context of an MDT approach, with an ability for regular intense follow ups, which exceeds routine dietetic capacity. Dietitians should be embedded within an ARFID MDT, providing teaching, training, consultation, and supervision.[1] Overall, the survey demonstrated an inadequate structure to fully meet the needs of this patient population, echoed by the literature.[3]

Limitations and biases

The survey provides only a snapshot of the dietetic situation. Participation closed prior to the BDA position paper release,[1] so survey responses were not influenced. We chose to include dietitians using either a working or formal diagnosis (rather than only formally diagnosed ARFID), to capture dietitians who may be working outside an MDT, making assumptions of correct assessment.

Conclusions/Recommendations

More is needed to ensure the dietetic profession is adequately trained and supported to support individuals with ARFID. This need has been identified within the BDA position paper – *'The Role of the Dietitian in the Assessment and Treatment of Children and Young People with Avoidant Restrictive Food Intake Disorder'*[1] – now available for dissemination to commissioners and care providers.

Table 1: Dietary assessment methods

Assessment method	% of dietitians using method (n=100)
24 hr food recall	66
3 day food diary	47
4-7 day food diary	34
Food frequency questionnaire	18

Table 2: Dietetic treatment approaches used in the management of ARFID

Assessment approaches	% of dietitians using method (n=100)
Exposure training	3
Cognitive Behavioural Therapy	13
Group sessions for parents/carers	13
Division of responsibility	19
Offering tube feeding	30
Graded exposure, i.e. SOS, steps to eating	55
Familiarisation through play/cooking	70
Food chaining	78
Offering oral nutritional supplements (ONS)	89
Ensuring dietary adequacy through food/meals of current accepted food	96
Multivitamin/mineral supplementation	97

Table 3: Perceived ONS acceptance in the management of ARFID

Percentage of individuals with ARFID on caseload who accept ONS	% Dietetic responses (n=100)
None	8
Between 1% and 25%	54
Between 25% and 50%	30
Between 50% and 75%	8
100%	0

Figure 1: Professionals involved in a formal ARFID pathway

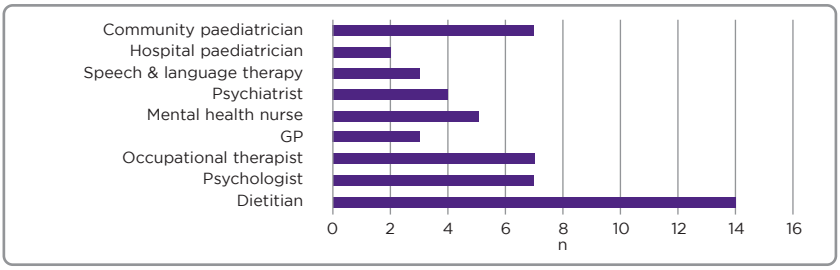


Figure 2: Dietetic roles in formalised ARFID pathways compared to no pathway

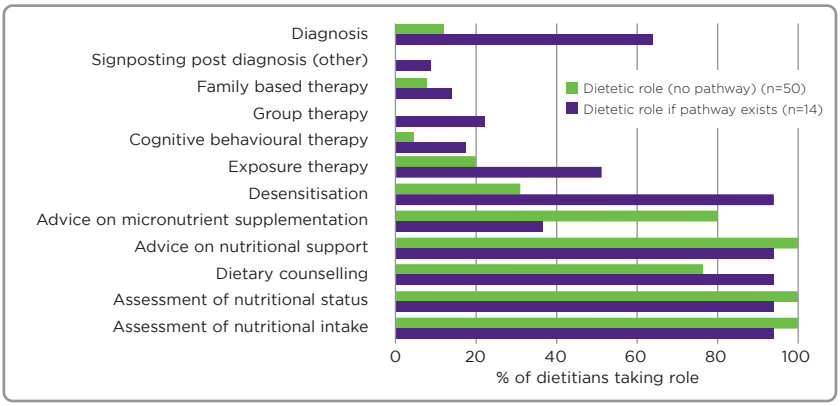


Figure 3: Confidence, time, knowledge and capacity of dietitians to manage individuals with ARFID

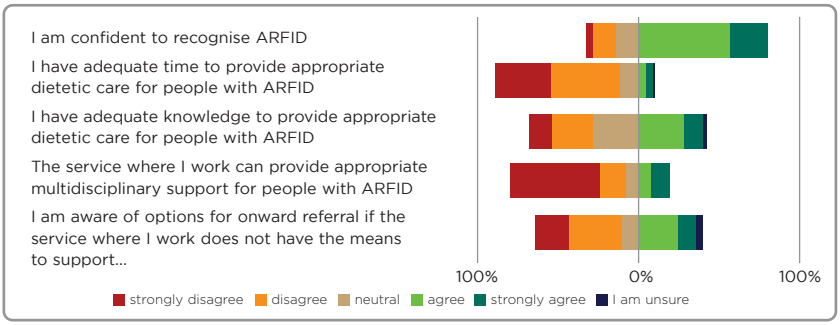
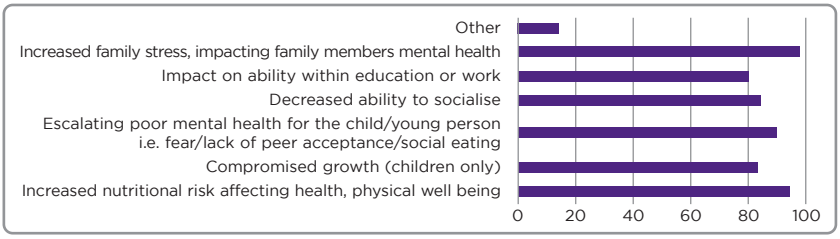


Figure 4: Dietitians perceptions of consequences of unavailable multidisciplinary care



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