Developing ARFID Pathways for Children and Young People

Stakeholder Engagement & Policy Recommendations Report

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IMPERIAL

Medical Research Foundation

ARFID® AWARENESS UK

Research team

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Lived experience advisors

ARFID Awareness UK supported the activities described in this report, providing testimony at each event about lived experience of receiving care for a child with ARFID, helping to formulate the recommendations and prepare this report.

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REPORT PURPOSE

This report summarises what we learnt from disseminating our research and stakeholder engagement, to support development of clinical pathways for avoidant/restrictive food intake disorder (ARFID) for children and young people.

Executive summary

Avoidant/restrictive food intake disorder (ARFID) for care for children and young people (CYP) remains highly variable across the UK. Workshop participants consistently identified fragmented commissioning, unclear clinical ownership, workforce pressures and lack of national guidance as the major barriers to safe, effective and equitable care.

Integrated multidisciplinary approaches involving paediatrics, mental health services, dietetics, occupational therapy, schools and families were viewed as the most promising models. Lived experience emerged as essential expertise, and parent-to-parent support was repeatedly identified as one of the most valuable interventions available.

National coordination, workforce development and knowledge-sharing networks were viewed as achievable mechanisms for reducing unwarranted variation before, and alongside, larger-scale investment.

Key messages

- ARFID care for children and young people remains highly variable across the UK.
- Workshop participants consistently identified fragmented commissioning, unclear clinical ownership, workforce pressures and a lack of national guidance as major barriers to care.
- Integrated multidisciplinary approaches involving paediatrics, mental health services, dietetics, occupational therapy, schools and families were viewed as the most promising models.
- Lived experience emerged as an essential source of expertise and parent-to-parent support repeatedly identified as one of the most valuable interventions.
- National coordination, workforce development and knowledge-sharing networks were viewed as achievable mechanisms for reducing unwarranted variation.

1. What was our aim?

We wanted to hear how services for CYP with ARFID are developing across the country, with a particular focus on how paediatric and mental health services were working together to meet the needs of CYP with different types of ARFID.

ARFID is characterised by a pattern of eating that avoids certain types of food or food groups entirely and/or eating small amounts due to feelings of fear or fullness. Unlike other eating disorders, people with ARFID don't restrict their food intake to lose or control their weight. Instead, food is often avoided because of the sensory features of food (smell, texture, appearance) or because of fear of the consequences of eating (such as being sick or choking). ARFID can occur at any age and can have severe medical consequences. Assessment and treatment needs to address both the mental and physical health of patients with ARFID, and it is also important that those who might benefit from psychological interventions are offered them.

In our research, we wanted to know how many CYP with ARFID a service was likely to see in a year and what types of problems, within the ARFID umbrella, were the most common. We also wanted to compare the type of ARFID, the treatment received, and the outcomes of CYP presenting to different sorts of services. We gathered data from paediatricians and child psychiatrists across the UK about CYP they had seen in clinic.

We found that CYP with ARFID get different care depending on where they are referred to, and that paediatric and mental health care often work separately rather than together. We also found that patients with ARFID in paediatric services were younger, were more often male, had more chronic symptoms, and were more likely to have sensory food avoidance and autism than those in mental health services. Child psychiatrists saw more patients with fear-based food avoidance, and with weight loss and anxiety. Most patients improved in their nutrition, despite receiving different types of intervention. However, those seeing mental health teams improved more with eating behaviours.

We wanted to share the findings from our research and to understand how to improve the care pathways for CYP with ARFID.

KEY INTERPRETATION

The central question was not simply whether ARFID belongs to paediatrics or mental health, but how services can build shared responsibility around children whose needs cross both systems.

2. What we did

We hosted four all day workshops in 2026, three in England and one in Scotland, inviting child and adolescent psychiatrists, paediatricians, other clinical multidisciplinary team members, the parents of young people with lived experience of ARFID, researchers, commissioners and managers, to talk about their local clinical pathways for ARFID.

The workshops included presentations about our research and from parents with experience of trying to access services for their child. This led into 'round table' discussions of what was working well and of the challenges faced in setting up care pathways for ARFID, and what might help overcome these. We hosted an online webinar in June 2026 to share what we learnt from these workshops.

3. What did we learn?

System-level service organisation

Discussion at the workshops focused heavily on **system level service organisation and pathway development**, with participants repeatedly describing difficulties creating integrated ARFID pathways across paediatric, mental health, dietetic, occupational therapy and community services. ARFID was consistentl y described as a condition that does not fit existing healthcare structures and that ARFID expertise remains highly dependent on local circumstances. Much ARFID work remains invisible within existing systems.

Some participants conceptualised ARFID not simply as a disorder requiring specialist services, but as the visible end point of broader failures in feeding, nutrition, and developmental support systems. Prevention and early intervention were viewed as likely to be more cost-effective than crisis management and that integrated care should extend beyond health, to include social and economic support systems.

Fragmented ownership and commissioning

The dominant message was that **ARFID care is often fragmented** because responsibility is unclear. Participants described repeated experiences of services operating in silos, uncertainty regarding who should take clinical ownership, lack of confidence among professionals, and limited resources. Different commissioning streams prevent integrated care. Parental awareness is growing faster than service capacity; a specific concern was that the more successful and visible ARFID services become, the more referrals they receive, with the risk of services being overwhelmed.

Dietetic services appear disproportionately burdened within current pathways, while occupational therapy remained an underdeveloped resource. Tube feeding interventions represent a major pathway gap requiring further attention. Participants from areas without ARFID services described major concerns, reporting cases of blindness and scurvy secondary to nutritional deficiency, suggesting that the absence of pathways can result in preventable harm.

STAKEHOLDER VOICES

"Our links with paediatrics locally have been challenging."

"We're not equipped to provide physical health monitoring."

Referral processes and navigation

Professionals criticised referral processes, with **poor quality or multiple parallel referrals**, resulting in children appearing on multiple waiting lists. Referral quality directly affects access, triage decisions and waiting times. Meanwhile, families often struggle to understand which service does what, who to contact, what referrals mean and how pathways operate. Participants viewed navigation support and knowing when to escalate concerns as an intervention in its own right. In some areas of the country, participants described multiple services with overlapping roles.

STAKEHOLDER VOICES

"If only right at the beginning they had looked at the services that were already well established and really understood what the needs were."

Rather than assessing, discharging or referring elsewhere, participants described the value of holding cases jointly, **shared responsibility and ongoing collaboration**, creating partnerships between families, local clinicians and schools. Patient-Initiated Follow-Up (PIFU) models were suggested as a highly valued and efficient long-term support strategy, providing re-access without re-referral and faster access when deterioration occurs.

Diagnostic uncertainty, medical assessment and outcomes

A feature of many conversations was discussion around **diagnostic uncertainty**, with participants highlighting the challenge of distinguishing ARFID from underlying physical conditions and the need to avoid 'diagnostic overshadowing' [1]. Rather than asking whether ARFID is primarily a mental disorder, a feeding disorder, a neurodevelopmental problem, it should be conceptualised as potentially needing contributions from all three. Integrated care was repeatedly framed as preferable to service ownership debates. However, different types of ARFID presentation may have different needs and individualisation emerged as a core principle of ARFID care. A repeated theme was that clinicians should focus on "**treating the problem rather than the label**", while simultaneously recognising that diagnoses remain necessary because commissioning, funding, service access and intervention choices are all diagnosis-driven. Diagnosis helps research, commissioning, service access and treatment development while formulation helps individualised care, understanding mechanisms and treatment planning. Evaluation remains an important gap in ARFID pathway development, despite many services collecting substantial amounts of information.

Participants stressed the importance of **paediatric assessment before specialist ARFID intervention**. Key concerns were swallowing disorders, gastrointestinal disorders, genetic conditions, nutritional deficiencies and aspiration risk, emphasising that feeding difficulties rarely occur in isolation and arguing for more **holistic pathways** rather than narrowly focused feeding interventions. Underlying conditions that may be missed included coeliac disease, inflammatory bowel disease, hypothyroidism and type 1 diabetes. In addition, many CYP with ARFID have autism, learning disability, sensory difficulties and communication challenges and ARFID interventions often cannot progress unless broader neurodevelopmental needs are addressed. Consequently, families need support with, for example, sleep, challenging behaviour, educational needs, and family functioning.

[1] Diagnostic overshadowing is where clinicians mistakenly attribute a patient's new physical or mental symptoms to a pre-existing diagnosis

Participants also questioned **how risk and outcome should be measured** for ARFID given that traditional notions of recovery may not fit. A rich discussion centred on uncertainty about the domains of risk (nutritional, social, educational, developmental), recognising that weight is an inadequate indicator of risk and nutritional deficiencies may occur despite apparently adequate growth. Reliance on weight-based screening may delay referral. The aims of treatment are also complex: nutritional adequacy, reduced impairment, increased flexibility, improved participation (e.g. school attendance, social participation) or quality of life for the family as well as the individual. Neuro-affirming approaches may be needed, rather than attempts to achieve "normal eating." Participants often defined success in terms of family confidence rather than symptom elimination. Expectation management emerged as an important clinical task. Participants felt there was no shared conceptual framework regarding treatment goals, yet emphasised that the primary problem is often access, not treatment effectiveness.

Additionally, participants, especially parents, highlighted that **diagnosis provides more than clinical categorisation**. Although participants advocated treating problems rather than labels, they simultaneously recognised the importance of diagnosis. Parents described diagnosis as opening doors that would otherwise remain closed, providing validation, access to services, educational accommodations and practical support. However, diagnosis can also prevent access to some services, with families becoming caught between services, and children who are chronically underweight, nutritionally compromised and medically vulnerable not meeting criteria for specialist services. Participants described situations where clinicians avoided diagnosing ARFID because doing so would reduce available support. The distinction between ARFID and Paediatric Feeding Disorder emerged as a major service-design issue.

Perceived training needs

There was a perceived need for a **national ARFID service specification**, containing guidance on team composition, referral pathways, required skills/disciplines, service responsibilities and clinical standards. Participants felt they were often adapting anorexia nervosa pathways, resulting in mismanagement, despite significant differences between conditions, and that current performance frameworks may inadvertently distort service delivery. Current pathways may also preferentially serve families with greater advocacy capacity, whilst disadvantaging some minority ethnic groups, non-English speaking families and socioeconomically disadvantaged families. Clinical practice continues to outpace research evidence and participants felt strongly that the lack of evidence base should not prevent pragmatic action. Given that ARFID may require a sustained rather than an acute-care model, **transition pathways to adult care** appear particularly underdeveloped and inconsistent. Participants repeatedly advocated for national networks, shared databases, service collaboration, stepped care approaches and outcome sharing.

National coordination was viewed as essential for advancing ARFID services. **Knowledge-sharing** was viewed as a highly achievable intervention with potentially large system-wide benefits. Examples included training packages, psychoeducational materials, pathway templates and assessment tools. Communities of practice and local ARFID champions emerged as an important implementation strategy.

Resource limitations and technology

These challenges were exacerbated by **resource limitations and workforce capacity**.

Many pathways appear to be shaped more by available resources than by clinical need.

Examples included: insufficient community occupational therapists, limited learning disability provision, overstretched paediatric services and lack of home-based services. This was particularly true when small specialist teams were covering large geographical areas. Consequently, services had long waiting lists and were often forced to ration care, resulting in restrictive eligibility criteria and fragmented provision. Consultation models were viewed as a practical way to increase reach despite limited resources. Local pathways were advocated in preference to reliance on tertiary specialist centres to keep care as close to home as possible.

Technology was viewed as a way **to increase capacity** without substantially increasing workforce requirements, as well as supporting continuity of care within and between services. Examples included triage (e.g. automated risk screening), dietary monitoring (e.g. photo food diaries, automated nutritional analysis), and growth monitoring (e.g. parent-entered measurements, risk flagging systems).

Training as a system intervention

Many professionals said they **lacked confidence or training**, leaving them feeling uncertain and exposed. Community clinicians felt unsupported and services worried about risk. The discussion also revealed a growing consensus that current systems create fear: fear among clinicians of holding risk, fear among services of accepting responsibility, and fear among parents that nobody is monitoring their child. Clinical fear appears to be a major driver of pathway fragmentation and the absence of guidance appears to contribute directly to clinician anxiety and service variability.

Training is increasingly viewed as a system-level intervention rather than simply professional development. **Key training needs identified** included clinical skills (e.g. assessment, ARFID treatment approaches, trauma-informed care, parent-focused approaches) and medical management (e.g. nasogastric or PEG feeding, tube weaning and nutritional rehabilitation).

STAKEHOLDER VOICE

“I think people are afraid.”


DEVELOPING ARFID PATHWAYS
FOR CHILDREN AND YOUNG PEOPLE
FROM EVIDENCE TO PRACTICE


Session 3
DEVELOPING ARFID PATHWAYS
FOR CHILDREN AND YOUNG PEOPLE

4. Lived experience, families and schools

Participants repeatedly argued that **ARFID awareness should extend beyond specialist services**. Target audiences include GPs, school nurses, teachers, health visitors as well as paediatricians, CAMHS clinicians and community teams. In particular, schools may play an under-recognised role in successful intervention.

Participants viewed **lived experience as a valuable source of expertise**. Parents described learning independently, developing effective strategies, experimenting with interventions and supporting other families. Participants repeatedly described families carrying responsibility for nutritional, emotional, and medical risks and acting as pathway coordinators in the absence of coordinated services.

PARENT VOICE

"No one will help me, so I have got to do this on my own."

We heard how parents had contributed through advocacy, service development, training, awareness raising and policy influence, making lived experience not only supportive but transformative and critical for maintaining momentum and accountability.

ARFID also creates a substantial hidden financial burden for families. Participants described ARFID as affecting the whole family system. Parents frequently felt judged by professionals and society and many reported withdrawing from social activities. Psychoeducation is the most scalable and universally applicable intervention available for ARFID, and acceptance and validation emerged as key mechanisms through which services reduce distress. Parents wanted collaborative partnerships rather than instruction and described frustration when professionals assumed they had not already researched extensively and tried multiple strategies.

Peer support also emerged as potentially underutilised in ARFID pathways, with parents consistently reporting that contact with others experiencing ARFID was among the most helpful interventions they had received. Participants reported positive experiences with parent groups/workshops such that some families no longer required therapy after attending.

5. Good practice and pathway principles

Several **examples of good practice** emerged, particularly where multidisciplinary relationships had developed organically, where **paediatric input was embedded** within ARFID services, where there were joint discussions of complex cases, and where consultation models enabled professionals to access specialist advice and skills such as dietitians, psychiatrists, OTs and specialist nurses. Participants repeatedly described how successful integrated pathways appear to be emerging in place of historical siloed care through informal collaboration, mutual trust, shared problem-solving and cross-service relationships. It was noted that the composition of the team often influences how ARFID is conceptualised and treated.

We heard that good care pathways often depended on motivated individuals and **strong clinical leadership** rather than formal structures, and that innovation and successful quality improvement initiatives were more likely where leaders explicitly supported experimentation. Participants discussed examples from other specialties (e.g. cancer clinics) where CYP see multiple professionals in a single appointment, and there are clear pathways and coordinated treatment plans. We heard many examples of well-functioning services which could be adapted elsewhere and small scale, evaluated, pilots emerged as one of the most realistic implementation strategies. A promising solution discussed was the development of **integrated neighbourhood teams**.

6. Summary of Findings

Positive practice examples

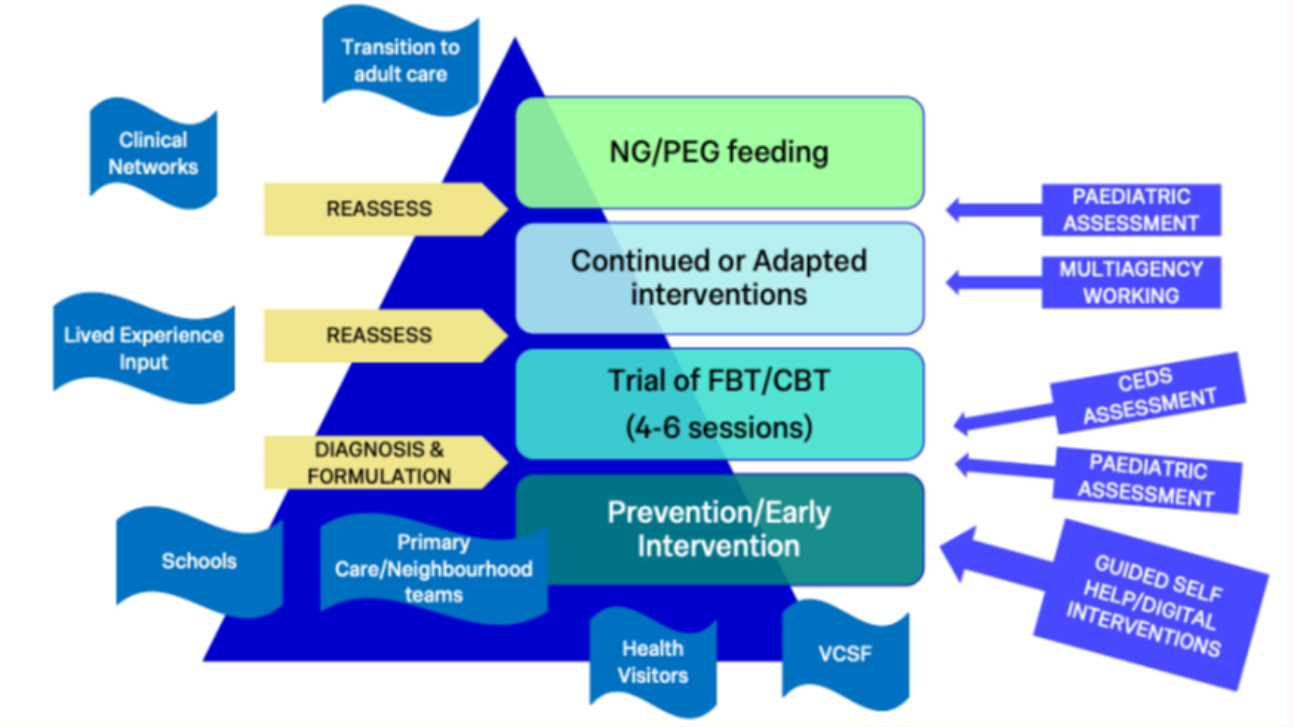
Positive practice	Why it works
Embedded paediatric clinics	Direct medical oversight
MDT ARFID teams	Shared expertise, holistic understanding and problem solving
Integrated paediatric-CAMHS working / neighbourhood teams	Access to specialist advice, cross-service collaboration, improved continuity and shared expertise
School collaboration	Better understanding of context
Parent support groups / peer mentoring	Peer learning, reduced isolation, increased confidence and empowerment
Lived experience involvement	Real-world insight and enhanced relevance
Step-care pathways	Resource efficiency
Pilot projects and quality improvement	Service development and reduced waiting times
Consultation and support to community teams	Capacity building
Technology-supported monitoring	Increased capacity

Barriers to service developments

Barrier	Frequency
Lack of integrated care/fragmented commissioning	Very high
Lack of National Guidance	Very high
Poor referral criteria	Very high
Unclear ownership of patients	Very high
Resource limitations	Very high
Workforce shortages	Very high
Lack of confidence/expertise	High
Diagnostic confusion/overshadowing	High
Poor referral information	High
Siloed services	High
Limited training and supervision	Moderate-High
Difficulty measuring outcomes	Moderate-High
IT and communication problems	Moderate

7. Clinical Recommendations Based on our Findings

A possible stepped care approach to ARFID support and treatment



FT = Family based treatment, CBT = cognitive behaviour therapy, NG = nasogastric, PEG = Percutaneous Endoscopic Gastrostomy, CEDS = community eating disorders service, VCFS = voluntary and community frontline sector

8. Policy Recommendations Based on our Findings

1. Establish a National ARFID Pathway to support commissioning

Agree standards for identification, assessment, and intervention, with alignment across Children and Young People's Mental Health Services/Community Eating Disorder Services (CYPMHS/CEDS), paediatrics, community, and education.

2. Invest in Early Identification and Intervention

Train universal services (schools, GPs, health visitors) in recognition and risk assessment for ARFID, and develop early triage models to prevent escalation and reduce admissions.

3. Fund Integrated MDT Models of Care

Develop services/pathways across paediatrics, CYPMHS, dietetics, and allied health professionals, using hub-and-spoke or networked models to reduce regional inequity.

4. Build Workforce Capability at Scale

Develop universal ARFID skills training beyond specialist services, with ongoing supervision, consultation, and clinical networks.

5. Prioritise Data, Outcomes and Cost-Effectiveness

Support routine outcome measurement (clinical + functional + family impact) and use data to demonstrate pathway impact (e.g. timely access, reduced admissions, shorter episodes of care).

9. Conclusion

Many services are already undertaking ARFID work, but often in disconnected ways. Innovation is occurring despite funding limitations. Improving communication and coordination is likely to produce substantial benefits to clinicians and families even before additional funding becomes available.

Despite high levels of motivation, the provision of ARFID care is variable and inconsistent. The urgent imperative is to move from local innovation to national coordination, ensuring that all children and families have access to safe, effective and equitable care.

FINAL MESSAGE

The future of ARFID care depends not only on raising awareness, but on building systems that work for children, families and professionals alike.

10. Acknowledgements

We would like to thank everyone who contributed to the development of this report and to the national conversations that informed its recommendations. We are particularly grateful to the clinicians, researchers, commissioners, service managers, allied health professionals, educators, those with lived experience, and voluntary sector colleagues who participated in the workshops and webinar, generously sharing their expertise, experiences and perspectives on ARFID pathway development across the United Kingdom.

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Finally, we would like to thank all children, young people and families affected by ARFID. It is our hope that the findings and recommendations presented in this report contribute to the development of more equitable, integrated and effective care pathways across the United Kingdom.