IMPROVING ARFID CARE:

LEARNING FROM EXPERIENCE

A report from a roundtable discussion hosted by First Steps ED.

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ABOUT THIS REPORT

This report draws on a roundtable discussion involving service users from four eating disorder charities: First Steps ED, ARFID Awareness UK, SYEDA (South Yorkshire Eating Disorder Association), and PEDS Eating Disorder Charity. Participants included young people living with ARFID, parents and carers. Two additional contributors provided quotes. All names are included with permission; quotes have been lightly edited for clarity. The discussion was structured around three questions: experiences of diagnosis and accessing care; what participants want to see change; and what good ARFID care looks like.

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WHAT IS ARFID?

Avoidant/Restrictive Food Intake Disorder (ARFID) is a feeding and eating disorder characterised by a persistent pattern of avoiding or restricting food intake. Unlike anorexia or bulimia, ARFID is not driven by concerns about weight or body image. Instead, it typically stems from one or more of three presentations: extreme sensory sensitivity to the taste, texture, smell or appearance of food; a fear of aversive consequences such as choking or being sick; or a low interest in food and eating.

ARFID is not fussiness. It causes genuine distress, can lead to serious nutritional deficiencies, and in the most severe cases can be life-threatening. It was only formally recognised as a diagnosis in 2013, which partly explains why awareness among health professionals and educators remains low.

There is no single profile of someone with ARFID. It can present from weaning age or develop later in life. It frequently co-occurs with autism, ADHD, and other neurodivergent conditions - but it also affects people with no such diagnosis. As one participant put it: "No two snowflakes are ever the same."

The care pathway for ARFID in England is fragmented. GPs are often the first point of contact but frequently lack the knowledge to recognise or refer appropriately. Most NHS eating disorder services do not treat ARFID. Where specialist support exists, it is patchy and often relies on individual professionals who happen to have taken an interest. Families are routinely told to manage privately, or to wait.

A NOTE ON WHO TOOK PART

The participants at this roundtable represent a cross-section of experiences:

- Madison from Doncaster, who was diagnosed at 16 after being misdiagnosed with anorexia at age seven
- Chloe from Peterborough, a 19-year-old managing ARFID alongside autism and Functional Neurological Disorder, and her mum, Amanda
- Kensi from Warwickshire, an 8-year-old who stopped eating at age two and a half, and her mum, Becki
- Emily from Derby, who is 13 and has had a positive experience of diagnosis and treatment, and her mum, Marian
- Liz from Derby, who has been fighting for 11 years for care for her 27-year-old daughter, who lives with ARFID, autism, and a learning disability
- Lucy from Stockport, whose son Alfie died aged seven - the first recorded case in England of a child dying as a direct result of ARFID.

Three further contributors submitted written testimony: Shikha, an adult with ARFID currently navigating pregnancy; Adam, an adult with ARFID; and Katrin, whose daughter has been under an eating disorder clinic in Leicester with no local provision for ARFID.

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THE EXPERIENCE OF GETTING A DIAGNOSIS

Getting a diagnosis is not straightforward for anyone with ARFID. The condition is not yet well understood by GPs, schools, or most NHS eating disorder services - and weight, which triggers concern and intervention for most eating disorders, is often normal in people with ARFID, meaning the usual alarm bells do not ring.

Becki, whose daughter Kensi stopped eating at age two and a half, described a four-and-a-half-year journey before getting a diagnosis: "The doctors don't know what it is. The school aren't helpful at all." It was one GP who happened to notice that Kensi's weight had remained consistent since early childhood, who eventually secured the right referral. Without her, the family would still be struggling without answers.

For adults, the barriers are different but equally frustrating. Madison had to explain the condition to her own doctor before she could self-refer to a service. "I had to physically tell my doctor what it was," she said. Shikha, who submitted written testimony, described being dismissed by her first GP as a "fussy/picky eater" before eventually finding a more receptive clinician - who had still never heard of ARFID. The NHS eating disorder clinic she was then referred to told her it did not treat ARFID: "It left me feeling like what I was experiencing wasn't important enough or worthy enough to deserve care."

Chloe, 19, described the moment a dietitian said she thought her condition could be ARFID: "That's not a diagnosis. You have to go outside the NHS. It just shouldn't be such a hassle." PEDS recognised that her symptoms clearly matched the criteria for a diagnosis of ARFID.

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For those with learning disabilities, the route is even harder. Liz, whose daughter is 27 and has autism and a learning disability, has spent 11 years fighting for adequate care. Her daughter "doubly doesn't fit into services," Liz explained - too old for children's services, but not accepted by adult services equipped to deal with her needs.

> **“THEY WERE TREATING ME AS IF I’D PASSED MY EATING DISORDER TO MY DAUGHTER**
>
> - Liz

One of the most striking - and consistent - themes in the discussion was the experience of parents being treated with suspicion, rather than as partners in their child's care.

When Liz raised concerns about her daughter’s restricted eating, she shared her own history of an eating disorder to provide context. "It was the worst thing I ever did," she said. "It brought safeguarding, and it brought accusations. They were treating me as if I'd passed my eating disorder to my daughter."

Lucy Morrison described being labelled as having separation anxiety from her son Alfie, who was severely autistic and whose restricted eating was attributed entirely to his autism

throughout his short life. She was offered respite care when she raised concerns about his nutrition. "I don't want respite from my son. My son does not eat." When she was honest with professionals, it went against her. Alfie died aged seven. His ARFID was identified by the coroner, only two years after his death.

Becki described the experience from a wider angle: "When we are raising concerns, they bring welfare to your front door. It's like you're not doing enough - or you're doing too much, and you're treating them like a baby. People look at you as if to say you've done something wrong. Instead of saying how are you? " or " What can we do to help, they just say you're a bad mum."

This is not a minor well-being issue. Lucy described the system pushing families "not just to breaking point, but to suicidal." Her message to other parents: "This is not in your head."

WHAT SCHOOLS GET WRONG

Schools came up repeatedly throughout the discussion as lacking awareness and the skills to support pupils with ARFID.
One problem is that schools promote healthy eating in ways that are not safe for children with ARFID. When teachers tell a child that pizza is bad for them, or that sweets do not belong in a lunchbox, they are not being helpful - they are destroying safe foods.

Becki described what happened when Kensi's teacher made a comment about pizza: "Once they said that, she wouldn't touch it." Kensi's diet was already extremely restricted. Pizza had been one of her safe foods. After the teacher's comment, it was gone. Similarly, Becki described repeated conflict with the headteacher over the contents of Kensi's lunchbox - crisps, sweets, chocolate, "because that's all she will eat." The school treated this as a parenting failure rather than a medical reality.

> **"THE MESSAGE NEEDS TO BE: ALL FOOD IS GOOD FOOD**
>
> - Lucy

This is not about lowering standards of nutrition education. It is about recognising that for children with ARFID, any food they will eat is good food. A school that removes a safe food from a child's diet - however well-intentioned - has made that child's health worse.

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THE FINANCIAL COST

ARFID is expensive. This came up repeatedly, although it is rarely discussed among professionals. Parents often purchase large amounts of specific foods, only for them to refuse items when the packaging or taste changes. For Chloe's family, takeaways are the only reliably accepted food, costing around £200 a month. Amanda, her mother, prioritises Chloe's eating over personal expenses.

The issue of supplements provoked a particular feeling. Lucy described how, during Alfie's inquest, it emerged that she had been sprinkling vitamins into his food - something she did because she needed to get nutrition into him somehow. "It was highlighted in the inquest that parents should not be buying vitamins. It should be coming from the NHS."

Liz noted that provision varies hugely: some areas fund supplements, others do not. "There needs to be national guidelines." And the guidelines need to address both consistency and availability: when a pharmacist substitutes a cheaper version of a supplement or medication, changing the colour, shape, or packaging, a child with ARFID may refuse it entirely.

Madison pointed out that travelling to access specialist support adds further cost to a situation that families are already funding privately.

> **"PARENTS SHOULD NOT BE BUYING VITAMINS. IT SHOULD COME FROM THE NHS**
>
> - Lucy

THE PROOF PROBLEM: LIVING WITHOUT RECOGNITION

One of the more practical dimensions of low awareness is the absence of any formal documentation that confirms an ARFID diagnosis. Unlike an allergy - where a card, a medical alert, or a restaurant's legal duty of care creates a framework for accommodation - ARFID leaves people with nothing to point to.

Madison described the experience of eating out: "When I try to tell the people taking orders that I have ARFID, they look at me blankly. Have you got proof?" The answer, in most cases, is no. A diagnosis may exist on a clinical record somewhere, but there is no card, no letter, no standard document a person can carry. "It's not something we can physically get proof of having. You can get a card stating it, but that's not proof as such - not the way they need."

The practical consequences are significant. Madison described eventually finding a solution at an Indian restaurant that served food in separate bowls - a small adjustment that made the meal manageable. But getting there required explaining ARFID from scratch, hoping to find a member of staff willing to listen, and accepting that the next visit might go differently depending on who was working. That is the daily reality for many people with ARFID: each new situation requires a fresh case to be made, with no guarantee of being believed.

This links directly to the training issue. As Madison put it: "If the manager of the restaurant doesn't know what it is, they're not going to be able to train the staff." Awareness at the top filters down - or doesn't. The same applies to schools and GP surgeries.

There is also a subtler harm in the absence of formal recognition: it compounds the feeling, familiar to almost everyone in the room, of having to justify yourself. "You shouldn't have to prove to anyone that you've got ARFID," said Chloe. "If you're an adult and want to order off the kids' menu, you shouldn't have to share your whole life story." Madison added that many people struggle to accept a diagnosis that no piece of paper confirms: "A lot of people are not accepting of disability of any kind - and if there's nothing that says this is real, it makes that harder."

A standardised recognition document - issued at the point of diagnosis and accepted by services, schools, and hospitality venues - would not solve the awareness problem on its own. But it would give people something concrete to stand behind, and shift the burden of proof away from the individual every time they sit down to eat.

This should also extend to awareness when searching for information, as many participants found it challenging to find information from trusted sources. Katrin, whose daughter has ARFID, explained through a written contribution: "As an eating disorder I think it should come under the larger umbrella of eating disorders. So when people are searching on the NHS web site there is more information and detailed explanation, advice and links. Good care also means having access to information through public bodies such as doctors, schools, libraries and sports centres."

WHAT GOOD CARE LOOKS LIKE

Despite the clear calls for change, the discussion was not without hope. Participants were specific and constructive about what had worked and what needs to change.

Group peer support came up as transformative, particularly online group therapy of the kind offered by PEDS. Chloe described it as the only way she came to accept her ARFID. "I was literally like, I don't feel as bad." Kensi's mother described the same effect - being able to speak to other children with ARFID helped Kensi understand and articulate her own experience. The online format also removed a real barrier: the fear of eating in public. "You faced the fear," Chloe said, "but you weren't necessarily with someone in person."

Consistency of care was described as essential and frequently absent. Liz put it directly: "Every time you go round the mountain, it might be a different person. How many times are you telling the story? You can't keep starting from the beginning."

> **"I FELT EXTRA PRESSURE. LIKE I'D ONLY GOT THIS MANY SESSIONS TO FIX MYSELF. THEN I WAS JUST LEFT ON MY OWN**
>
> - Maddison

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Adam added to the case for longer-term support: "I don't think I could be 'cured', but I believe in a safe environment with the right counsellor, I could find the safe foods within each nutritional area to help me live longer and be healthier. The step to get there would be the funding. The pressure of knowing it's x sessions then you're done is immense and made me rush and then when I failed, it was a huge blow. Since finishing my sessions with First Steps ED, I've flatlined, not trying anything new for ages and seeing a small decline in terms of safe foods again."

Shikha described what good care had looked like for her: working with a therapist to reframe the goal from recovery to management. "I was able to see that the sensory difficulties I had around food are part of me - not a fault of mine. I feel more confident in managing the ARFID that I live with and will always live with." For those whose ARFID is rooted in autism, recovery is not the right goal. Framing it that way causes harm.

Good care does exist - and when it does, the difference is clear. Marian and Emily attended the roundtable having had an experience that stood apart from almost everyone else in the room. From their first contact with First Steps ED, they found understanding, practical advice, and a quick offer of support - a choice of group or one-to-one sessions, with barely any wait. The counselling worked. When Marian showed Emily what the meeting was about beforehand, Emily's response was: "But they can't get better at anything - everything was great." That is not a small thing to be able to say about eating disorder care. It matters precisely because it shows what is possible when the right expertise, the right approach, and the right resourcing come together. The problem is not that good ARFID care cannot be done. It is that too few people can access it.

FOUR RECOMMENDATIONS

1. Train educators, hospitality staff and healthcare professionals, and make "all food is good food" a standard message in schools

ARFID cannot be well managed without basic awareness among the people children and families encounter most: GPs, school nurses, SENCO staff, headteachers. The Oliver McGowan Mandatory Training model - which introduced standardised learning disability and autism training across health and care - offers a precedent for what is possible. Something comparable is needed for ARFID. Within schools specifically, healthy eating messaging must be adapted for pupils with ARFID. Hospitality and food service staff should also be made aware of ARFID so requests are accommodated where possible without people being made to feel like they need to prove their condition.

2. End the blame culture around parents

Parents of children with ARFID are routinely treated with suspicion at the point of seeking help. Welfare concerns are raised; parents are labelled as anxious or overprotective; honesty is penalised. This has to change.

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3. Introduce consistent national guidelines for supplements and nutritional support

There must be national guidelines for the prescription and funding of nutritional supplements for people with ARFID. Families should not be paying out of pocket for supplements that are clinically indicated. And when supplements or medications are prescribed, pharmacists and GP surgeries must understand that substituting a cheaper version - with different packaging, colour, or format - can undo weeks of difficult progress.

4. Fund and scale existing peer support, and remove the time limit from ARFID therapy

Short-term, time-limited therapy does not work for ARFID. Six to eight weeks with no follow-up pathway leaves people without the tools to manage setbacks. The specialist knowledge and the models that work - including online group therapy and the one-to-one support delivered by charities - already exist. What is missing is the funding for these organisations to reach everyone who needs them. Commissioners should be looking to these charities as delivery partners, not waiting for NHS services to develop equivalent expertise from scratch. People with ARFID and their families deserve consistent access to the right professional over time, and a support offer that does not end abruptly when a short course concludes or a charity's funding runs out.

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A FINAL WORD

The charities involved in this Roundtable discussion want to thank the participants for giving their time and their honesty in the hope of improving ARFID care. ARFID has been recognised as an eating disorder since 2013, but this discussion highlights that people affected by it are navigating a system that has not yet caught up with what they need.

The recommendations in this report are not ambitious or expensive in themselves. They require will, training, and a small number of policy changes. They also require commissioners and funders to recognise what the voluntary sector has already built - and to back it. What they would prevent - years of misdiagnosis, family distress, avoidable nutritional harm, and in the worst cases, death - is not small at all.

High-quality, specialist ARFID expertise already exists - in organisations like First Steps ED, PEDS Eating Disorder Charity, SYEDA, and ARFID Awareness UK, among others. These charities are already delivering the kind of person-centred, knowledgeable, responsive support that participants described as life-changing. The problem is not a lack of solutions. It is a lack of sustained funding to make those solutions available to everyone who needs them, regardless of where they live or what they can afford.

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