Parent & Carer Alliance C.I.C.

Press Release

For Immediate Release

14th January 2026

Parent and Carer Alliance C.I.C. calls for urgent national action on ARFID failures

Parent and Carer Alliance C.I.C. today releases new findings from a Gloucestershire-wide survey on swallowing difficulties and Avoidant/Restrictive Food Intake Disorder (ARFID). This exposes a severe lack of services, unsafe gaps in care, and the devastating consequences for children, young people, and their families.

Dr Benjamin Newton, Chartered Psychologist and author, who led the survey said:

As a parent carer myself, I am all too aware of the stress of looking after disabled children. The findings from this survey highlight a concerning pattern of parents fighting for services that aren't there, facing ridicule and disbelief from the professionals who are meant to care. I was quite concerned about the ongoing psychosocial impact on both the child and the wider family that restrictive eating and swallowing difficulties cause. The unresponsiveness of services was well illustrated by one of our survey respondents:

"*…imagine the stress if your dog stops eating and will only eat crisps. We take it to the vet, they get care, love, support, tests and no one just says "oh well their height is fine"…*"

Children and Young People Are Being Failed

ARFID is a serious eating disorder characterised by extreme food avoidance, sensory based restriction, or fear-based refusal. Despite its severity, families report a complete absence of a comprehensive pathway, specialist support, or coordinated care.

The situation is urgent. Children are suffering at home and at school. Some face life-threatening malnutrition. Many live with long term health consequences. Families report high levels of anxiety, isolation, and distress as they try to keep their children safe without professional support.

Key Findings from the ARFID Survey

1. High numbers of autistic children, but very few ARFID diagnoses

Families report that although many children have an autism diagnosis, ARFID is rarely recognised or formally diagnosed, which may hinder access to specialist help.

2. Difficulties linked to significant health risks

Children experience severe nutritional deficiencies, weight loss, and medical complications — yet support is inconsistent or absent.

3. Distress, isolation, and overwhelming carer burden

Parents describe feeling abandoned by services, forced to manage complex and frightening health needs alone.

4. Gloucestershire's service offer is "barely minimal"

Families report yearslong waits, blocked referrals, and no clear pathway. Many attempt to access specialist services outside the county but are prevented from doing so.

A System That Needs Fixing — Now

In the report, Dr Newton states: *“Commissioners must listen to the experience of parent carers in Gloucestershire and urgently work towards creating a service that parent carers and young people can access.”*

Call to Action

The Alliance is calling for immediate commissioning of a proper ARFID pathway and service, in Gloucestershire and across the UK, so families are no longer left navigating crises alone.

Parent and Carer Alliance C.I.C. urges national and local leaders to:

- **Create a dedicated ARFID pathway and specialist service for children and young people.**
- **Ensure families receive psychological and psychosocial support**, recognising the trauma and pressure they face.
- **Restore home-based support**, which previously helped children eat safely in their own environment but disappeared after COVID.
- **Build a compassionate system**, where families are met by professionals with understanding rather than barriers.

What Good Could Look Like

A functioning ARFID service could include:

- **Psychologist-led structured support groups for carers**, enabling shared learning and emotional resilience, with 1:1 support for those who need this.
- **Specialist staff providing practical help in the home**, where eating difficulties are most acute.
- **Clear pathways, timely assessments, and access to national expertise** when local provision is insufficient.

CEO and Founder of the Parent and Carer Alliance C.I.C. Lucy Fullard says:

“Too many children and families living with ARFID have faced unnecessary delays, confusion and distress due to the lack of a defined care pathway and services. This is not the standard of care our families should expect. The Parent and Carer Alliance C.I.C. stands ready to work with commissioners, clinicians, and policymakers to build the service families urgently need, and deserve.

Visit www.parentandcareralliance.org.uk to find out more about our work.

Based in Dursley, Gloucestershire the Parent and Carer Alliance Community Interest Company is a beacon of hope providing independent and practical advice for Parent Carers.

Contact: admin@parentandcareralliance.org.uk

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