



**LEEDS PCF**  
P A R E N T C A R E R F O R U M

# **Leeds Parent Carer Forum ARFID Survey 2025 Report to Leeds Integrated Care Board (ICB), Leeds Health and Care Partnership (LHCP) and the West Yorkshire Integrated Care Board (WYICB)**

**February 2026**

## **Background**

The Leeds Parent Carer Forum (LPCF) was formed in January 2023. The forum is run by a group of parents who are passionate about making a positive difference to improve the quality of life for SEND families in Leeds.

The PCF represent the parent/carer voice of families of children and young people aged 0-25 years, who have special educational needs and/or disabilities in the whole of the Leeds area. The PCF works in partnership with the Local Authority, Education, Health and Social Care services and are recognised and supported by the Department for Education.

The PCF and Health colleagues have met on a monthly basis since 2025 to identify and discuss key areas of challenge for Leeds SEND Families. Working relationships are positive and key themes have focused on Neurodevelopmental Assessment and Support e.g. autism and ADHD, Sleep and Avoidance Restrictive Food Intake Disorder (ARFID). In 2025, Leeds PCF ran two workshops centred around ARFID, one in March at the Local Offer Live event in conjunction with CYMPHS, and another in September with Juniper Tree, a private provider of Occupational Therapy. Hard copy surveys were distributed in both workshops, and an online survey was open from June to the end of September 2025. A total of 55 surveys were completed. Both workshops were well attended evidencing the real need for support.



The purpose of this report is to formally capture and present the feedback gathered from families. By collating their experiences, challenges, and insights in a structured way, this report aims to provide Health colleagues with a clear evidence base to support future decision-making.

It is intended to inform commissioning discussions, highlight gaps in current provision, and ensure that the lived experiences of families directly influence the development of more effective, responsive, and sustainable support pathways across Leeds.

It should be noted that existing NHS colleagues are involved with projects/workstreams looking at diagnosed or undiagnosed eating disorder, disordered or selective eating an example is Avoidant Restrictive Food Intake Disorder (ARFID). It is recognised that early intervention could avoid acute hospital admissions and the longer-term complications because of poor nutrition. For example the West Yorkshire Provider Collaborative for Children and Young People Mental Health Inpatient Services has undertaken research, spanning across sectors, across West Yorkshire, to map, review and evaluate pathways for young people (up to the age of 25 years), when they experience eating disorders, disordered eating, or are described as 'complex' by services. The report was published in Summer 2025 and it stated with the exception of Leeds, that all areas were developing an ARFID pathway or some offer of support.

## Executive Summary

This report synthesises feedback from Leeds families regarding children's eating difficulties, with a particular focus on ARFID (Avoidant/Restrictive Food Intake Disorder) and sensory needs. The data reveal a landscape marked by significant challenges: high prevalence of sensory-related eating issues, profound impacts on daily life and family wellbeing, inconsistent school support, and widespread dissatisfaction with available services. Quantitative findings are reinforced by powerful direct quotes, highlighting the urgent need for tailored and sustained support from health and educational services.

More detailed findings are outlined in the sections below. The feedback has been grouped into key themes, including sensory needs, the impact on family life, levels of school support, and overall satisfaction with current services.

# Sensory Needs

## 1. Sensory Aversion to Food

- Many children exhibit strong aversions to smells, textures, and the appearance of food.
- *Direct quote:* “He has significant sensory needs related to taste, texture, smell, the look of food – also sensory issues with clothing, noise etc.”

## 2. Restricted Diets and Food Preferences

- Diets are often limited to specific, preferred foods, typically “beige” or dry foods.
- *Direct quote:* “Strong preference for dry, beige food of a uniform shape/appearance.”

## 3. Impact on Eating Habits and Mealtimes

- Sensory issues disrupt routines and social aspects of meals.
- *Direct quote:* “My child has never managed meal times. He’s a ‘grazer’”

## 4. Emotional and Physical Impact

- Anxiety, trauma, and health concerns are common.
- *Direct quote:* “My children associate food with trauma. 3 out of 4 of my children have major issues with food and have high anxiety because of this. They throw up food, often daily.”

## 5. Need for Support and Challenges with Services

- Families report difficulties accessing appropriate support.
- *Direct quote:* “It’s been 14 years of no help, no support or anything.”

## 6. Other Sensory and Interoceptive Challenges

- Broader sensory and interoceptive difficulties are also present.
- *Direct quote:* “No perception of hunger.”

# Impact

## 1. Social and Family Impact

- Eating difficulties restrict social activities, holidays, and family routines.
- *Direct quote:* “It stops us going on holiday or to people's houses. We find it hard to have family round to eat.”

## 2. Emotional Toll and Stress

- High levels of stress, anxiety, and isolation are reported.
- *Direct quote:* “It has completely changed our lives. It is incredibly draining. It is very worrying. We have to think about it everywhere we go. We face judgement.”

## 3. Lack of Support and Resources

- Many families feel unsupported by health services and schools.
- *Direct quote:* “We have never been able to get any support for ARFID even when under CAMHS and dietician.”

#### 4. Routine, Control, and Sensory Issues

- Rigid routines and environmental factors are prominent.
- *Direct quote*: “Likes routine with eating 4x a day but unable to acknowledge when he is hungry.”

#### 5. Negative Reactions from Others

- Families experience judgement and misunderstanding from others.
- *Direct quote*: “Well meaning friends and family commenting on what he is eating and trying to encourage new foods can have a negative effect...”

#### 6. Nutritional Concerns and Health

- Concerns about nutrition, growth, and health are frequent.
- *Direct quote*: “He's underweight and not thriving. He's not able to learn as well as he could due to low energy levels.”

## School Support

- Only a minority feel their child's school provides definite support; most report partial or no support.
- **Personalised adjustments** (e.g., bringing own food, bespoke menus) and **supportive environments** (empathetic staff, alternative eating spaces) are valued.
- *Direct quote*: “Allowed to bring own breakfast to school, and quite relaxed about what's in the pack up.”
- *Direct quote*: “My son has a separate sitting area during his lunch where he can eat his food alone.”
- Gaps and inconsistencies in support are common, with some children not in school at all due to their needs.
- *Direct quote*: “School sometimes forgets. The cook offered to meet with her but due to her anxieties she didn't go, meaning for the first year she didn't eat in high school.”

## Overall Satisfaction

#### 1. Lack of Effective Support and Service Gaps

- Many families feel left to manage alone, with services either unavailable or ineffective.
- *Direct quote*: “There isn't any support. We're on our own.”

#### 2. Frustration with Referral Pathways and Service Navigation

- Families are often passed between professionals without resolution.
- *Direct quote*: “We just passed from dietician to another nothing is getting sorted my son survives on polycal powder.”

#### 3. Thresholds for Support Based on Weight

- Support is often denied if the child's weight is within a “normal” range, regardless of other concerns.
- *Direct quote*: “GP referred us to a dietician – we got one info pack and dismissed from the service without seeing / talking to anyone. All because his weight is on track.”

#### 4. Need for ARFID-Specific Services and Early Intervention

- There is a strong call for services that specifically address ARFID, with early intervention seen as crucial.
- *Direct quote:* “Having an ARFID pathway/support early on would have prevented my daughter's hospital admission (5 months NG tube fed) and follow on admission to Red Kite View.”

#### 5. Inadequate or Inappropriate Advice

- Advice given is often generic, unhelpful, or already tried.
- *Direct quote:* “Dietician – only support was a letter and a youtube video to watch. Paediatrician won't see us.”

#### 6. Discharge and Lack of Ongoing Support

- Rapid discharge from services with no ongoing support is a recurring frustration.
- *Direct quote:* “When support is given it is ok but you are then rapidly discharged – there is a need for an ongoing support eg a specialist nurse that you can access quickly for specific circumstances eg transition to secondary school.”

#### 7. Positive Experiences Are Rare but Valued

- A few respondents mention positive experiences with individual professionals.
- *Direct quote:* “We have had the support of a Paediatrician and Dietician within the growth and nutrition team. They are helpful when we need them and the nurses there have been absolutely fantastic when my daughter has had her bloods taken.”

## Conclusion

The data paints a consistent and concerning picture: children with ARFID and sensory-related eating difficulties, and their families, face significant daily challenges. Sensory aversions, rigid routines, and restricted diets are common, with profound impacts on social life, emotional wellbeing, and health. School support is inconsistent, and satisfaction with health and support services is low, with families frequently reporting a lack of tailored, ongoing, and ARFID-specific support.

The voices of families, captured in direct quotes, underscore the urgency for change, calling for earlier intervention, more individualised support, and greater recognition of the complexities involved.

A detailed breakdown of the data collated is provided below, along with the questions asked as part of the survey.

# Recommendations

## Establish Dedicated ARFID-Specific Support Services

Given families' consistent reports of inadequate and generic provision, specialist pathways should be created that offer:

- Dietetic support tailored to sensory aversions and restricted diets.
- Psychological interventions where appropriate.
- Occupational therapy input focused on sensory integration and tolerance-building.
- Ongoing, not one-off, support to monitor progress over time.

## Develop Early Identification and Intervention Pathways

Children with ARFID and sensory-based eating difficulties need support far earlier than they currently receive. Services should:

- Provide clear referral routes into specialist support.
- Equip frontline professionals with basic ARFID awareness to reduce mislabelling (e.g., "picky eating").

## Improve Training and Awareness Across Health, Education, and Social Care

To reduce inconsistency in responses and improve family experience:

- Deliver ARFID-specific training for GPs, school nurses, SENCOs, teaching assistants, paediatricians, and therapists.
- Provide practical guidance on safe feeding, sensory strategies, and how to talk sensitively with families.
- Embed this training within existing professional development programmes.

## Raise Public Awareness to Reduce Stigma

Families often face judgement and misunderstanding from communities and extended family. Public messaging should:

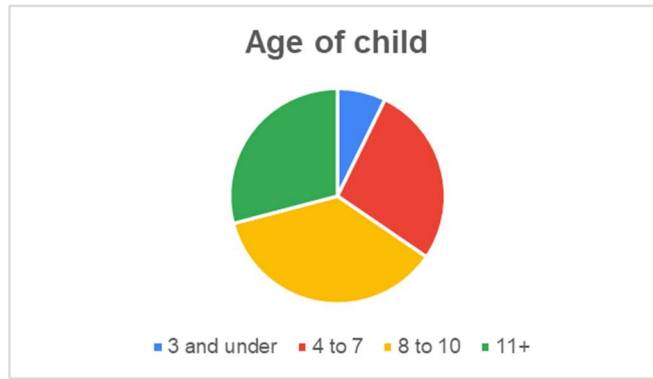
- Promote awareness of ARFID as a legitimate and serious eating disorder.
- Highlight the difference between ARFID and typical picky eating.
- Encourage supportive responses, not criticism or pressure.

**Thank you for taking the time to read this report. It will be shared with the families who contributed, as well as through Leeds Parent Carer Forum activity.**

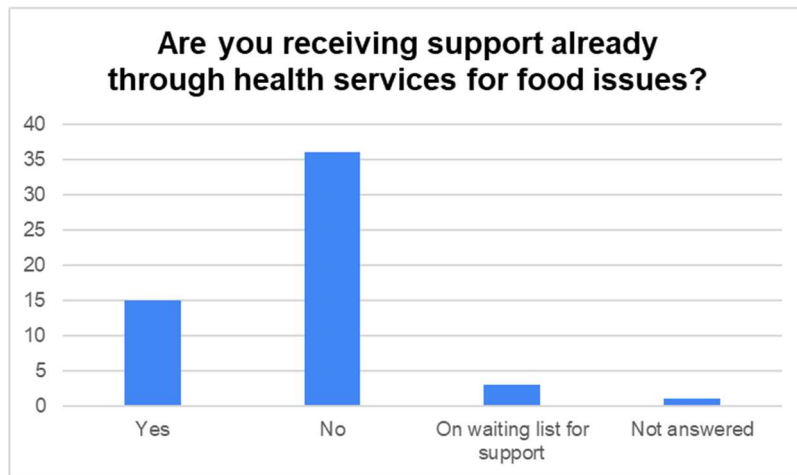
**In 2026, the Parent Carer Forum will provide funding for additional support sessions for SEND families in Leeds. This will provide much-needed help ahead of a more formalised ARFID support pathway being developed across the city.**

# Data

Age of child	
3 and under	4
4 to 7	15
8 to 10	20
11+	16
<b>Total</b>	<b>55</b>

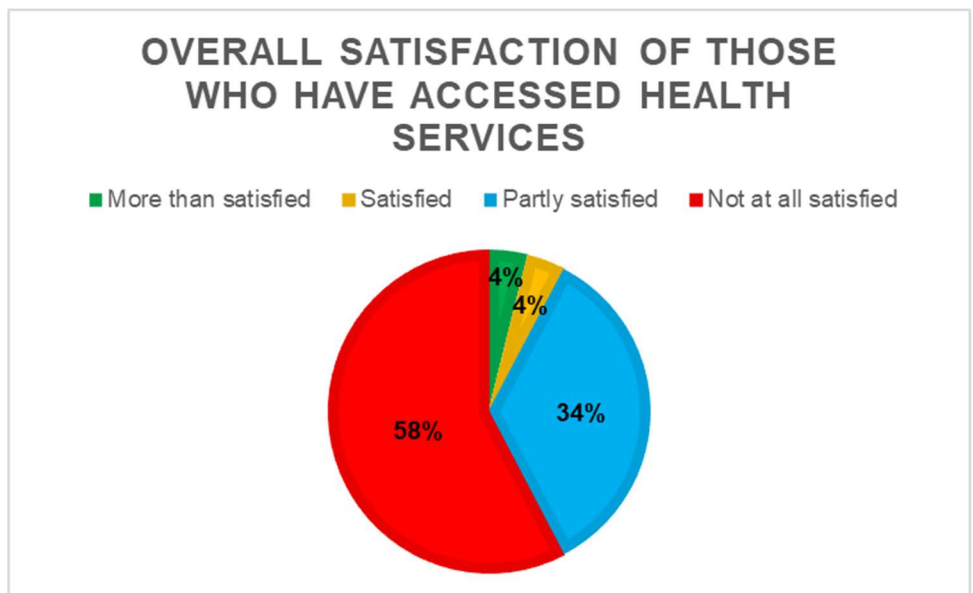


Are you receiving support already through health services for food issues?	
Yes	15
No	36
On waiting list for support	3
Not answered	1
<b>Total</b>	<b>55</b>



Satisfaction with Services Supporting Child's Eating		
<b>Satisfaction Level</b>		
More than satisfied	1	
Satisfied	1	
Partly satisfied	9	
Not at all satisfied	15	
Not applicable	26	*

\* 3 respondents did not answer



## Background position

Question	Yes definitely	To some extent	Not sure	No, not at all
1) Are you worried about how much food your child is eating and their weight and growth?	36	16	0	3
2) Does your child have difficulties with eating, involving avoidance or restrictions of certain food?	51	4	0	0
3) Are your child's eating habits related to them thinking they are too big or heavy?	2	2	4	47
4) Has your child's eating lead to difficulty maintaining a healthy weight?	19	20	4	12
5) Does your child's eating difficulty mean they can't gain enough weight to grow?	11	10	9	25
6) Does your child have any nutritional deficiencies?	16	7	26	6
7) Does your child depend on tube feeding or nutritional supplements?	6	4	1	44

## Sensory Needs

Question	Yes definitely	To some extent	Not sure	No, not at all	
8) Does your child struggle with smells related to food and cooking?	32	13	5	5	
9) Does this stop them from eating?	29	14	5	6	*
10) Does your child find trying or eating different textures difficult?	51	4	0	0	
11) Does your child prefer not to use regular feeding tools such as knives and forks?	30	16	2	7	
12) Do you have to physically feed your child?	5	10	0	39	*
13) Is your child's eating experience more positive when this is in a fixed routine very dependent on their needs?	25	16	5	9	

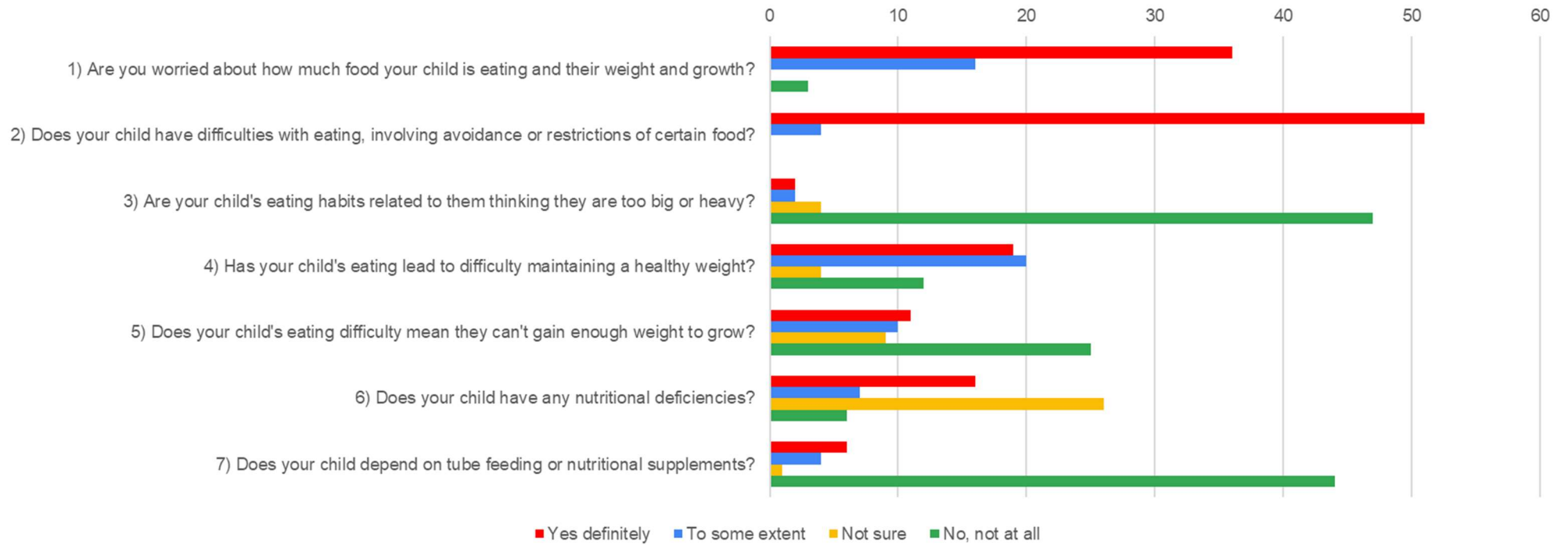
\* 1 respondent did not answer

## Impact

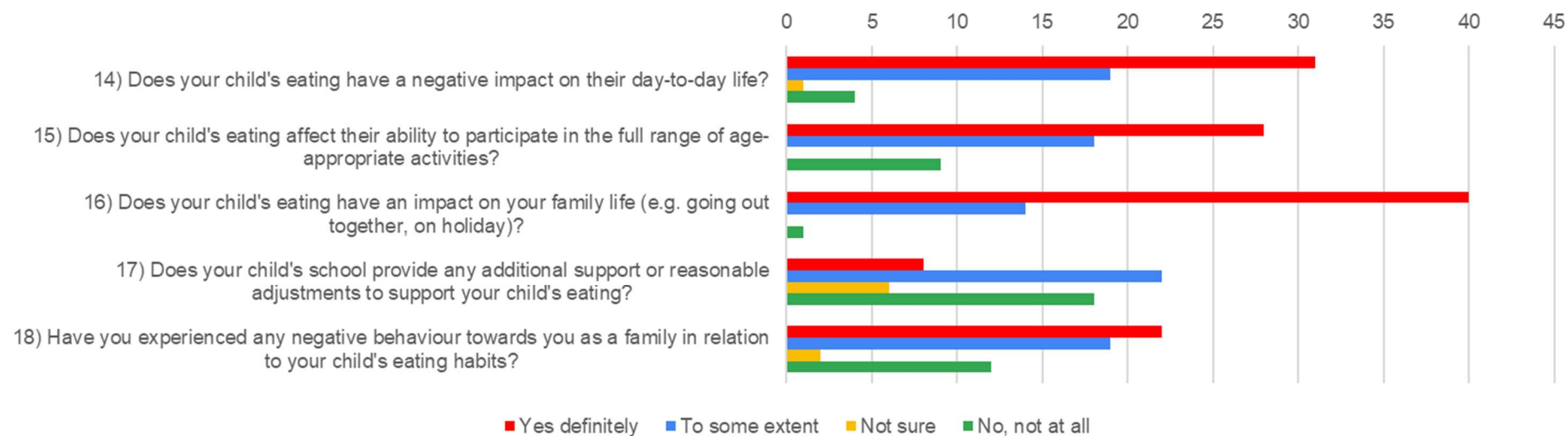
Question	Yes definitely	To some extent	Not sure	No, not at all	
14) Does your child's eating have a negative impact on their day-to-day life?	31	19	1	4	
15) Does your child's eating affect their ability to participate in the full range of age-appropriate activities?	28	18	0	9	
16) Does your child's eating have an impact on your family life (e.g. going out together, on holiday)?	40	14	0	1	
17) Does your child's school provide any additional support or reasonable adjustments to support your child's eating?	8	22	6	18	*
18) Have you experienced any negative behaviour towards you as a family in relation to your child's eating habits?	22	19	2	12	

\* 1 respondent did not answer

## Background position



## Impact of food/eating issues



## Sensory Needs

