Honoring Ellen's Inspiring Legacy

https://p2p.onecause.com/bbch-diy/memorial/honoring-ellens-inspiring-legacy

1

1

Feeding and Eating issues in Autism Spectrum Disorders

Carol Hubbard MD MPH PhD FAAP

Maine Health Developmental Behavioral Pediatrics

2

2

Disclosures and Acknowledgements

- None of the planners or speakers for this event have any financial relationship to disclose.
- Special thanks to
  - Emma Cammann MD (MMC Pediatric PGY-1)
  - T Lindsey Burrell PhD & Caitlin Waddle MS RDN LD (SDBP)
  - Julia Fritz MD, Kay Mullin RD (MaineHealth Pediatric GI) Brock Libby MD (MaineHealth Adolescent Medicine)
  - Don Burgess MD, Victoria Dalzell MD and Samantha Dunn DO (MaineHeath Developmental-Behavioral Pediatrics)

3

3

Learning Objectives

- Be familiar with different feeding issues that occur in children with Autism Spectrum Disorders (ASDs)
- Know how ARFID (Avoidant-Restrictive Food Intake Disorder) is defined and how to distinguish it from picky eating and other feeding and eating disorders
- Be familiar with intervention and guidance for families of children with ASD and feeding issues including ARFID

4

4

Picky eating is common

- Up to 45% of all children experience some mealtime challenges
- Picky eating
  - Strong food preferences
  - Behavioral reactivity
  - Fluctuating hunger
  - Reluctance to self-feed

- Mild or transient feeding difficulties tend to resolve with low intensity intervention
  - Repeated neutral exposure to different and unfamiliar foods
  - Caregiver education about meal structure
  - Modification of food preparation or food presentation
  - Nutritional guidance
  - Avoidance of pressuring the child

5

5

Feeding and eating issues are particularly common in children with autism

- 62% (range 30-84%) have feeding difficulties
- Greater mealtime behavioral problems
- Increased food selectivity- taste, color, temperature, and in particular texture
- Behavioral rigidity and insistence on sameness limit food choices
- Children with autism consume
  - Fewer fruit and veggies
  - Less calcium and protein
  - More unhealthy, snacky, high-carb and sugar foods and juice
- Evidence of altered gut microbiome due to eating patterns

(Adams 2022)

6

6

Pediatric Feeding Disorder (PFD)

Goday et al (J Ped Gastroenterolgy and Nut 2019)

- Used the framework of the WHO *International Classification of Functioning, Disability, and Health (ICF)*, and proposed a unifying diagnostic term: "Pediatric Feeding Disorder" (PFD)
- Complex and heterogeneous disturbance in oral intake of nutrients that is not age-appropriate, and is associated with **medical, nutritional, feeding skill, and/or psychosocial dysfunction**, causing "functional limitations."
- Estimated to affect more than 1 in 37 children under the age of 5 in the US
- www.feedingmatters.org "For these infants and children, every bite of food can be painful, scary, or impossible, potentially impeding nutrition, development, growth, and overall well-being"
- Pediatric Feeding Disorder, Chronic is in ICD10 (R63.32)
- R63.__ is the ICD code for various feeding issues (feeding difficulties, behavioral, feeding difficulty unspecified etc)
- F50.82 is code for ARFID { "F" codes designate mental, behavioral, and neurodevelopmental disorders, while "R" codes represent symptoms, signs, and abnormal findings}
- PFD overlaps with ARFID has caused confusion among healthcare profs and families**. Both diagnoses exclude body image issues as a criterion.**

7

7

Avoidant-Restrictive Food Intake Disorder (ARFID)

- DSM 5 (2013)
- Replaced previous DSM-IV "Feeding Disorder of Infancy or Early Childhood" (which required onset before age 6y) and expanded to include individuals across the lifespan
- Added to ICD in 2019
- Defined as:

  An eating or feeding disturbance {apparent lack of interest in eating or food, avoidance based on sensory characteristics of food, or concern about aversive consequences of eating} as manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with one of more of the following:
  - Significant weight loss (or failure to achieve expected weight gain or faltering growth in children)
  - Significant nutritional deficiency
  - Dependence on oral nutritional supplements or enteral feeding
  - Marked interference with psychosocial functioning

8

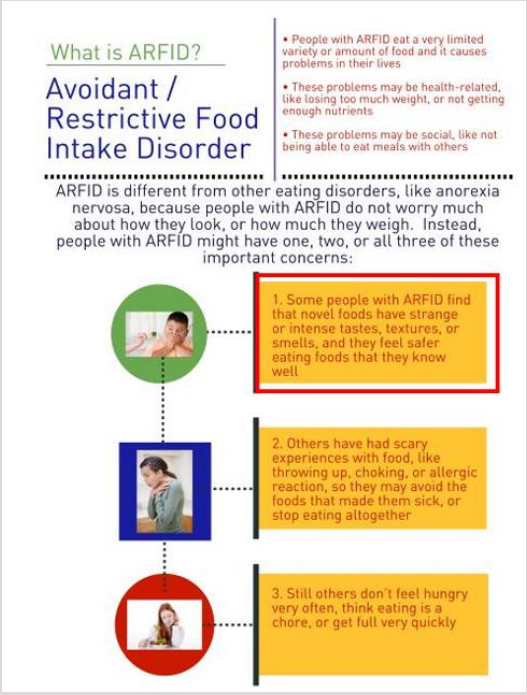
8

DSM5 ARFID (continued)

- Not better explained by lack of food or cultural practices
- Does not occur exclusively during course of anorexia or bulimia and **no evidence of a disturbance in the way body weight or shape is experienced**
- Not attributable to a concurrent medical condition or better explained by another mental disorder.
- When it occurs in the context of another mental disorder the severity of the eating disturbance exceeds that routinely associated with the other condition and warrants additional clinical attention

9

9



Three subtypes of ARFID

but increasingly acknowledged that they are not distinct and can co-occur

Sensory avoidance of food due to its sensory characteristics

Food avoidance due to fear of aversive consequences of eating

Food avoidance due to apparent lack of interest in food

10

10

Epidemiology of ARFID

- Estimated prevalence 0.5 to 5% of children and much higher in clinical settings (Nitsch et al 2021, Willmott 2023)
- Compared to other eating disorders:
  - Less common
  - Younger age of symptom onset
  - Longer duration of illness prior to diagnosis
  - Larger percentage of males
  - May have higher satiety-promoting cholecystokinin (then healthy controls) and lower appetite-stimulating Gherelin
- Symptoms may emerge in early childhood (before age 12) and overlap with symptoms of Pediatric Feeding Disorder
- Highly comorbid with neurodevelopmental/psychiatric conditions including anxiety and depressive disorders, OCD and ASD as well as functional GI conditions like irritable bowel
- More likely to have anxiety and less likely to have depression than for patients with anorexia or bulimia

- ARFID prevalence in ASD = 11.4%, ASD prevalence in ARFID = 16.3%
  (Meta-analysis, Sader et al, March 2025)

11

11

Picky Eating

- May or may not accept foods from all food groups
- Tolerates presence of other foods
- Willing to try new foods
- Diet likely provides adequate nutrition
- Prefernces are influenced by peers
- Will eat preferred foods across settings

ARFID

- Inflexible food preferences may change but variety remains restricted
- Consistently refuses 1 or more food groups
- Behavioral response to non-preferred foods is excessive
- Insensitive to social cues around eating
- Eating is disrupted across settings
- Will refuse to eat even when hungry

12

12

Impact of restrictive eating

MEDICAL

- Weight loss or obesity, impact on growth and puberty
- Electrolyte disturbances, hypoglycemia, vitamin and mineral deficiencies,
- Bradycardia, hypotension
- Low bone mineral density
- Amenorrhea
- Tube feed dependence

PSYCHOSOCIAL

- Avoidance of social activities that involve food-restaurants, parties
- Avoidance of family mealtimes, Interference with social relationships, isolation
- Impact on travel and vacations
- Depression and anxiety
- Impact on parents- increased stress, family diet restricted, impaired parent-child relationship

13

13

History and screening for restrictive eating

Medical History: relevant medical factors, growth, current nutrition, dietary diversity, evidence of nutritional deficiency (labs, dietary recall), current and previous therapeutic support, meal duration, diet texture and chewing concerns, any modification of food prep or administration, self-feeding, drinking liquids

Psychosocial/behavioral history: behavioral/developmental complexity, child avoidance behaviors, caregiver feeding strategies, impact on social function, impact on parent-child relationships

ARFID

- Good history including review of DSM criteria
- PARDI-AR-Q is a self/parent-report measure of the symptoms of avoidant restrictive food intake disorder (ARFID) see Feedingmatters.org
- Nine-item Avoidant/Restrictive Food Intake Disorder Screen (NAIS)

14

14

NIAS

Sensory: Items #1-3
Lack of Interest: #4-6
Anxiety: #7-9

Assign score of 0 up to 5 for each Likert response

Cut-offs: ≥ 24 overall ≥10, ≥9, and ≥10 on Picky eating, Appetite, and Fear subscales, respectively.

Validated for age 10 to adults

Zickgraf and Ellis 2018

Nine Item Avoidant/Restrictive Food Intake disorder screen (NIAS) - Child

		Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
1	I am a picky eater	○	○	○	○	○	○
2	I dislike most of the foods that otherpeople eat	○	○	○	○	○	○
3	The list of foods that I like and will eat is shorter than the list of foods I won't eat	○	○	○	○	○	○
4	I am not very interested in eating; I seemto have a smaller appetite than other people	○	○	○	○	○	○
5	I have to push myself to eat regular mealsthroughout the day, or to eat a large enough amount of food at meals	○	○	○	○	○	○
6	Even when I am eating a food I really like, it is hard for me to eat a large enough volume at meals	○	○	○	○	○	○
7	I avoid or put off eating because I am afraid of GI discomfort, choking, or vomiting	○	○	○	○	○	○
8	I restrict myself to certain foods because Iam afraid that other foods will cause GI discomfort, choking, or vomiting	○	○	○	○	○	○
9	I eat small portions because I am afraid of GI discomfort, choking, or vomiting	○	○	○	○	○	○

Individuals respond to each question on a scale from 0 (*Strongly Disagree*) to 5 (*Strongly Agree*). Subscales are each scored on a scale from 0–15, with higher scores indicating higher levels of each metric (picky eating, lack of interest, and fear). All items may also be summed to calculate a total score, ranging from 0–45, with higher scores indicating higher levels of avoidant/restrictive eating broadly.

Zickgraf, Hana F., and Jordan M. Ellis. "Initial validation of the Nine Item Avoidant/Restrictive Food Intake disorder screen (NIAS): Ameasure of three restrictive eating patterns." *Appetite* 123 (2018): 32-42.

15

Intervention for restrictive eating

Multi-disciplinary is best:
Medical, Nutritional, Behavioral

16

16

Address comorbidities

Medical conditions

- Dental conditions
- Referral to assess chewing and swallowing if needed (ENT, SLP)
- Constipation
- GI pain
- Reflux
- Eosinophilic esophagitis

(Refer to GI if needed)

Behavioral health- anxiety, mood, obsessiveness

17

17

Nutritional support

Family education on adequate nutrition

Support gradual expansion of food variety

Vitamin and mineral supplementation as needed

Labs: vit D, CBC, Iron, Ferritin, CMP +/- TSH, zinc, ESR celiac labs (specialists vary in labs they check)

Refer to dietician if needed

Tube feeds as last resort

18

18

Tips for families to support a restrictive eater

- Pre-meal ideas- get out energy, put on relaxing music, Pre-meal routine (heads-up, wash hands, help set the table etc)
- Scheduled meals and snacks, limit grazing
- "Meal hygiene:" eat as a family at the table, time-limits for meals, consider the meal environment (limit distractions like media), supportive seating
- Increase interaction with food, Engage child in process of preparing/eating food
  - Kitchen "experiments," non-mealtime exploration of new foods
  - Assistance with grocery shopping (option to choose which new food to try)
  - Provide developmentally appropriate choices ("Today we are trying carrots. Do you want 2 or 3 carrots on your plate?")
  - Look at cookbooks and help with cooking
  - Allow self-feeding whenever possible
  - Allow sensory exploration of new foods (touching, smelling, etc)
- Avoid pressure to eat- no clean plate rule
- Lots of positive reinforcement – though maybe not praise for eating food-rather praise specific positive mealtime behavior
- Introduce new foods carefully
  - Include "safe" foods as well as new foods on plate
  - Try not to overwhelm with new foods (i.e. one new food at a time)
  - Give new foods first when child is most hungry
  - Avoid having labels/brands of food visible
  - Use food chaining…

19

19

Food Chaining

- Start with preferred foods and gradually add new foods in very small amounts or mixed in with the preferred food
- Very gradually increase the amount and frequency of the new food
- Praise and encouragement for trying the new food

Lots of info and ideas are available on-line and in books

20

20

Addressing disruptive mealtime behavior

- Use previously-mentioned ideas to create a more positive, relaxed meal-time environment
- Increase positivity –conversation about easy topics or what is enjoyable about the meal rather than focusing on how much or what they are eating
- Avoid power struggles
- Teach good mealtime manners
- Use timer to delineate mealtime
- If tantrums occur-
  - Remain calm-understand that the child may feel overwhelmed
  - Explain that being upset is OK but disruptive behavior is not
  - Different expert opinions about child leaving the table Offer calm-down space and then return to the table- don't allow 'escape', vs once they leave the table they are done
  - Consider antecedents-is the child tired or 'hangry'

(https://nutritioninbloom.com/blog/2019/6/1/dealing-with-maladaptive-behaviors)

21

21

When more help is needed: Evidence-based therapeutic approaches

Applied Behavioral Analysis (ABA)-based therapy

- Focus on decreasing behaviors that make mealtimes challenging, food aversion seen as stemming more from generalized behavior that makes caregiver-child interaction challenging
- Usually reward-based

Sequential Oral Sensory (SOS) Approach to feeding (SOSapproachtofeeding.com)

- Reports to be evidence-based but some studies contradictory
- Play based introduction of foods along a sensory hierarchy – looking, smelling, touching, tasting, chewing, swallowing –work through 32 steps sequentially
- "Food Science" approach for older and/or more cognitively advanced kids to encourage engagement

CBT +/- Exposure therapy

- Cognitively able to engage (age 8-10 and up), eating by mouth, not on tube feeds
- ARFID-focused CBT: Focuses on psychoeducation and changing cognition and behaviors pertinent to ARFID, such as identifying and targeting thoughts and feelings underlying restrictive eating (eg fear of vomiting or of sensations related to food and eating), reducing avoidance, increasing exposure to food, helping patients to make plans to introduce new foods over time. Similar to other CBT for anxiety, phobias, etc.

22

22

Intervention: who can help?

Ideally a multi-disciplinary approach for children with significant symptoms

- Medical- GI, ENT, DBPeds, (all may say they do not assess ARFID)
- Psychiatry for inpatient management
- Nutrition
- Occupational and Speech therapy
  - May use SOS or other approaches (FOCUS for Mealtime Success or Beckman Oral Motor therapy), sensory desensitization, progressive exposure
- ??Psychologists/therapists

23

23

Possible feeding resources
(may not be a complete list)

- Adaptive Pediatric Therapy (Stratum NH)
- Saco Bay Kids (Portland, Saco, Kennebunk, Auburn): Saco location 207-439-5104, Auburn location 207-783-3450
- Kid O'Therapy (Topsham): 207-844-8287
- Mindful Mealtimes (Gorham): 207-776-1182
- Pediatric Development Center (Westbrook): 207-591-7210
- Holland Speech Therapy (Scarborough): (207) 229-0507 (In person and virtual)
- Voice and Swallowing Center of Maine (Belfast): 207-505-4409
- Lincoln Health (Emily Bloomfield) (Damariscotta, Booth Bay): 207-633-1928Speech and OT
- Waldo County General Hospital Speech Language Pathology and Speech/Swallowing Center (Belfast): 207-505-4409
- Pen Bay Rehab (Rockland): 207-301-6380
- Stephens Memorial Rehab Department (3 years and older) (Norway): 207-744-6506)

Boston Children's Hospital ARFID Program:

Patients 6 to 18 years old with a diagnosis of ARFID and one or more of the following criteria for severe malnutrition:

- no weight gain for six months or longer in a growing child
- body mass index (BMI) for age Z-score </= -2.0
- weight loss of >/=5 percent of body weight in the past three months.
- dietary intake assessed to be severely restrictive (e.g., consisting </=5 foods or diet devoid of key food groups)
- In addition, patients must:not be diagnosed with another restrictive eating disorder (e.g., anorexia nervosa) and must reside within New England (Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont) during the time of treatment
- ARFID-FEED@childrens.harvard.edu , 617-355-6341

24

24

Could it be possible to target outpatient ARFID therapy by subtype?

Anxiety-Mediated	Lack of Interest	Sensory Sensitivity
CBT +/- exposure therapy	Medical management (cyproheptadine)	ABA
FOCUS/PREP**	Reward-based system	SOS**

**Particularly mixed evidence regarding long-term efficacy of intervention

Thanks to Emma Cammann MD!

25

Medication

- Cyproheptadine- appetite stimulation, has the most data for ARFID, may work better if take breaks from it and then restart
- SSRIs: for anxiety (side effects can include GI symptom)
- Olanzipine: used judiciously at low-dose may facilitate appetite, weight gain and address OCD, anxiety, and depression
- ADHD meds for children with that diagnosis ADHD sx interfere with eating (be mindful of side effects- dyspepsia and decreased appetite for stimulants and bupropion, constipation for guanfacine)

26

26

Take-homes

- Restrictive eating is common in people with autism and vice versa
- Diagnoses can include pediatric feeding disorder (or other R63 __ codes) or ARFID if meet criteria
- Assess for medical causes
- Consider underlying reasons for restrictive eating (sensory, anxiety/avoidance, lack of interest, feeding skill deficit)
- PCPs can provide valuable family behavioral guidance and support
- Ideally intervention includes behavioral support, nutritional guidance, feeding intervention (speech or OT), and medication and further medical care (GI, ENT) if needed
- Evidence basis for different behavioral intervention is evolving

27

27

Practical ARFID Resources

Feeding, Eating and Emotional Disturbances in Children with Avoidant/Restrictive Food Intake Disorder: https://www.mdpi.com/2072-6643/12/11/3385

Avoidant/Restrictive Food Intake Disorder (ARFID): Its Medical Complications and Their Treatment - an Emerging Area: https://link.springer.com/article/10.1007/s40124-021-00239-8

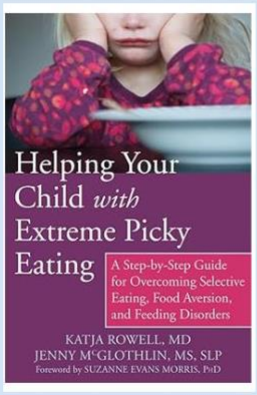
A US Based Consensus on Diagnostic Overlap and Distinction for Pediatric Feeding Disorder and ARFID: https://onlinelibrary.wiley.com/doi/10.1002/eat.24349

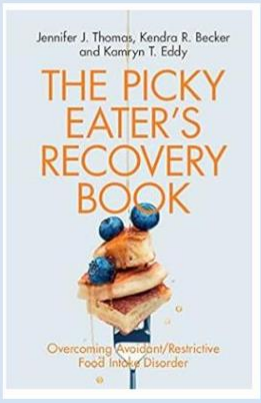
Assessment and Treatment of Avoidant Restrictive Food Intake Disorder: https://pmc.ncbi.nlm.nih.gov/articles/PMC10211369/

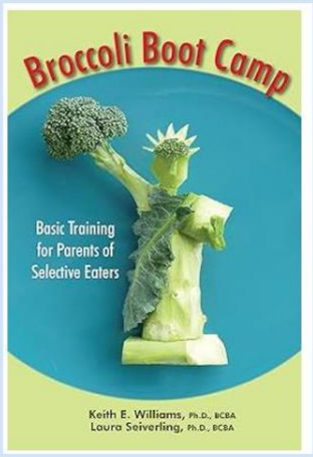
Strategies for Dietary Management of ARFID: https://pubmed.ncbi.nlm.nih.gov/35565707/

28

Practical ARFID Resources







29

- 2025 Mar;58(3):473-488

References

- Adams, SN, 2022. Feeding and swallowing Issues in Autism Spectrum Disorders, Neuropsychiatr Dis Treat. 18:2311-2321
- Białek-Dratwa A, Szymańska D, Grajek M, Krupa-Kotara K, Szczepańska E, Kowalski O. 2022. ARFID-Strategies for Dietary Management in Children. Nutrients. 22;14(9):1739. doi: 10.3390/nu14091739. PMID: 35565707; PMCID: PMC9100178.
- Cucinotta U, Romano C, Dipasquale V. 2023. A Systematic Review to Manage Avoidant/Restrictive Food Intake Disorders in Pediatric Gastroenterological Practice**.** Healthcare (Basel).):2245. doi: 10.3390/healthcare11162245. PMID: 37628443; PMCID: PMC10454601.
- Fisher M et al. 2014. Characteristics of avoidant/restrictive food intake disorder in children and adolescents: a "new disorder: in DSM-5. J Adol Health, 55(1):49-52
- Goday PS et al. 2019. Pediatric Feeding Disorder: consensus definition and conceptual framework, J Pediatr Gastroenterol Nutr. 68(1):124-129.
- Kambanis PE and Thomas JJ, 2023. Assessment and treatment of avoidant/restrictive food intake disorder, Curr Psychiat Rep 25 (2):53-64
- Kovacic K, Rein L, Kommareddy S, Szabo A Bhagavatula P, Goday PS. 2020, Pediatric feeding disorders: A nationwide prevalence study. J Peds. DOI:https://doi.org/10.1016/j.jpeds..07.04
- Peterson KM, Piazza CC, Volkert VM. 2016. A comparison of a modified sequential oral sensory approach to an applied behavior-analytic approach in the treatment of food selectivity in children with autism spectrum disorder. J Appl Behav Anal. 49(3):485-511. doi: 10.1002/jaba.332. Epub 2016 Jul 23. PMID: 27449267.
- Sader M, Weston A, Buchan K, Kerr-Gaffney J, Gillespier-Smith K, Sharpe H, Duffy F. 2025. The co-occurrence of autism and ARFID : a prevalence-based metanalysis, Int J Eat Disord, 58(3):473-488
- Thomas JJ, Eddy KT. *Cognitive-Behavioral Therapy for Avoidant/Restrictive Food Intake Disorder: Children, Adolescents, and Adults.* Cambridge, UK: Cambridge University Press; 2019.
- Thomas JJ, Becker, KR, Eddy KT. *The Picky Eater's Recovery Book: Overcoming Avoidant/Restrictive Food Intake Disorder.* Cambridge, UK: Cambridge University Press; 2021.
- Willmott E, Dickenson R, Hall C, Sadikovic K, Wadhera E, Miali N, Trompeter N, Jewell T .2023. A scoping review of psychological interventions and outcomes for ARFID, Int J Eating Dis, 57 (1):27-61

30

30

Thank you

Questions?

Answers?

31

Willmott et al, 2023 Scoping review of psychological interventions for ARFID

"Across a range of psychological interventions and modalities for ARFID, there were common treatment components such as food exposure, psychoeducation, anxiety management, and family involvement but studies characterized by small samples and high levels of heterogeneity, including in how outcomes are measured."

32

32

ARFID: new in DSM5 (2013)

Avoidant/Restrictive Food Intake Disorder

Diagnostic Criteria **307.59 (F50.8)**

A. An eating or feeding disturbance (e.g., apparent lack of interest in eating or food; avoidance based on the sensory characteristics of food; concern about aversive consequences of eating) as manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with one (or more) of the following:
   1. Significant weight loss (or failure to achieve expected weight gain or faltering growth in children).
   2. Significant nutritional deficiency.
   3. Dependence on enteral feeding or oral nutritional supplements.
   4. Marked interference with psychosocial functioning.

B. The disturbance is not better explained by lack of available food or by an associated culturally sanctioned practice.

C. The eating disturbance does not occur exclusively during the course of anorexia nervosa or bulimia nervosa, and there is no evidence of a disturbance in the way in which one's body weight or shape is experienced.

D. The eating disturbance is not attributable to a concurrent medical condition or not better explained by another mental disorder. When the eating disturbance occurs in the context of another condition or disorder, the severity of the eating disturbance exceeds that routinely associated with the condition or disorder and warrants additional clinical attention.