



A Community Approach to Avoidant/Restrictive Food Intake Disorder

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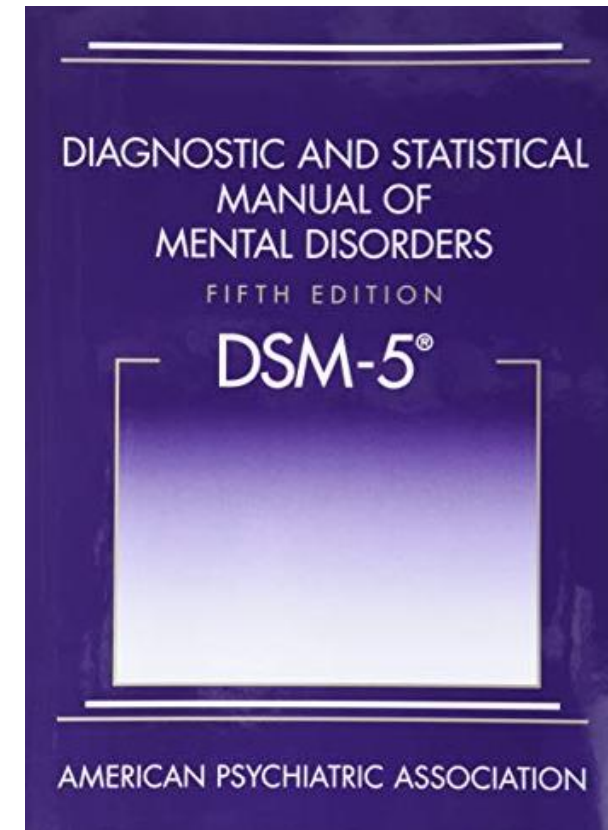
May 25th, 2021

Objectives

- Understand diagnostic criteria for ARFID
- Considerations for the community RD's care for kids with ARFID
 - What are the red flags?
 - When to suggest a referral for therapy or medical work up?
 - What is my role?
- Review of case studies

Diagnostic and Statistical Manual of Mental Disorders

- Published by American psychiatric association
- Gives common language and diagnostic criteria
- DSM-5 published in 2013
 - ARFID was defined and added for the first time.



DSM IV: Feeding disorder of infancy or early childhood

- Feeding disturbance manifested by persistent failure to eat adequately with significant failure to gain weight or significant loss of weight over 1 month
- The disturbance is not due to an associated gastrointestinal or other general medical condition
- The disturbance is not better accounted for by another mental disorder or lack of available food
- Onset < 6 years of age

DSM-V Avoidant/Restrictive Food Intake Disorder

- Eating/feeding disturbance as manifested by persistent failure to meet appropriate nutritional needs associated with one (or more) of the following:
 - Weight loss or unmet growth expectations
 - Nutritional deficiency
 - Dependence on nutritional supplements
 - Marked interference with psychosocial functioning
- Exclusionary criteria:
 - Not related to food scarcity or culturally sanctioned practice
 - Not related to body image or weight concerns
 - Not better explained by concurrent medical condition or another mental disorder

Pediatric Feeding Disorder (PFD)

A disturbance in oral intake of nutrients, inappropriate for age, >2 weeks + associated with 1 or more of the following:

1. Medical Dysfunction

- Cardiorespiratory problems, aspiration sequelae, GI process

2. Nutritional dysfunction

- Malnutrition, specific nutrient deficiency, reliance on nutritional supplements

Pediatric Feeding Disorder

3. Feeding skill dysfunction

- Need for texture modification, modified feeding position or equipment, modified feeding strategies

4. Psychosocial dysfunction

- Active or passive avoidance by child, inappropriate caregiver management, disrupted caregiver-child relationship

Absence of cognitive process consistent with eating disorders and oral intake is not due to lack of food or associated with cultural norms

Pediatric Feeding Disorder

- Used framework of the World Health Organization International Classification of Functioning, Disability and Health
 - Acknowledges that this is more than a disease state, it is a disability impacting various aspects of life
- Unifies medical, nutritional, feeding skill and/or psychosocial concerns associated with feeding disorder

ARFID vs PFD

	ARFID	PFD
Disordered eating	Yes	Yes
Avoids/restricts food	Yes	Possible
Poor appetite	Common	Possible
Malnutrition	Common	Possible
Traumatic or chronic experience	Possible	Possible
Comorbid anxiety or other MH disorder	Common	Possible
Frame as a disability	No	Yes

How does this happen?

- Medical problems, dysfunctional feeding relationship or other interruption promote conditioned food aversion
 - Eating is associated with pain, nausea fatigue, worry
- Once medical condition improves- aversion may not;
 - Infants and children will have persistent disruptive mealtime behaviors trying to avoid contact with food.

How does this happen?

- Problem persist due to negative reinforcement
 - Parents remove feeding demand and end meal early
 - Behaviors shaped and strengthened over time
 - Limited exposure → decreased sensory variability--> developmental, physiological, social processes → more stress
- Ultimately, child needs major intervention or ongoing artificial support

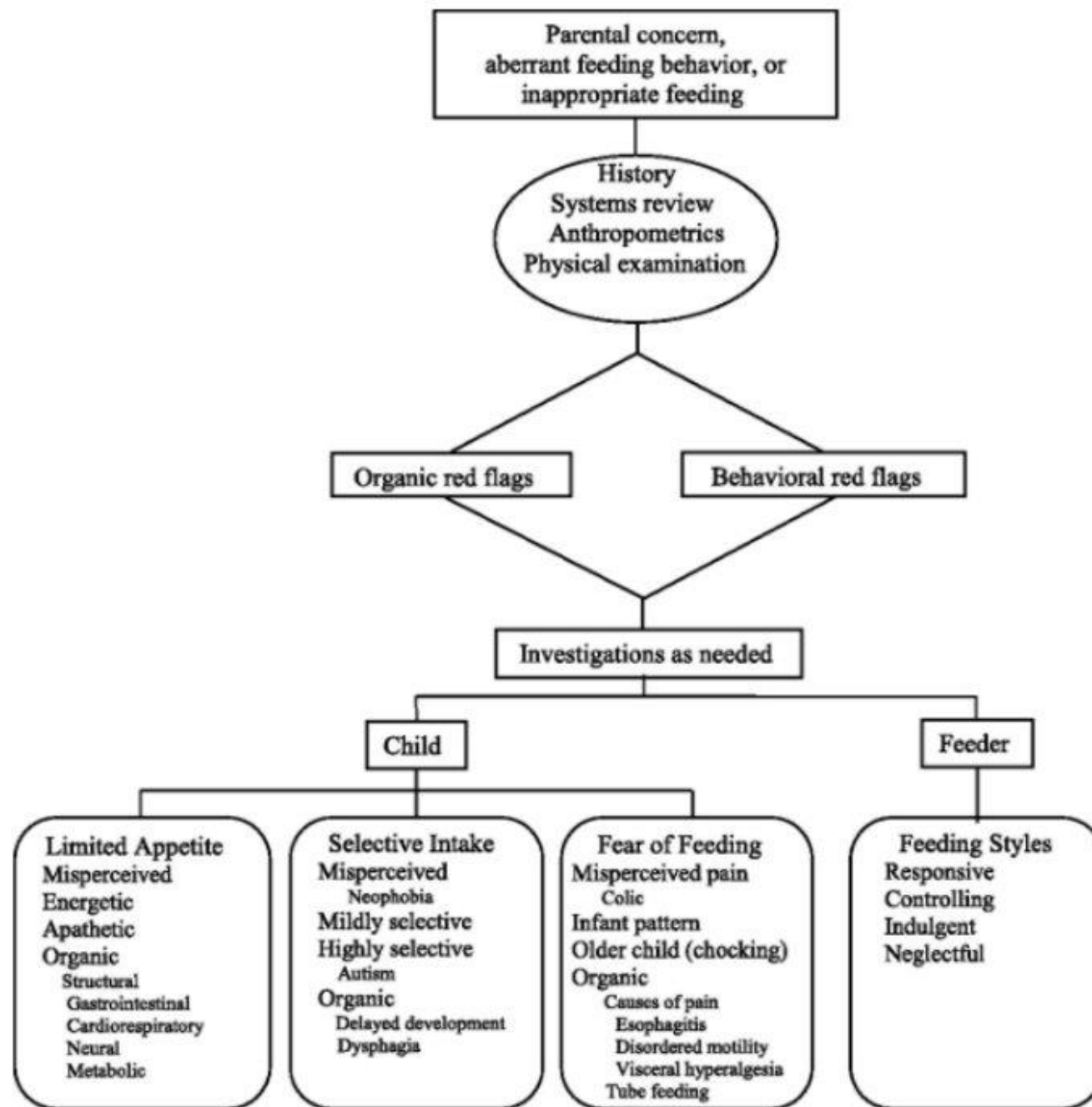
Before ARFID is Diagnosed Consider:

Medical conditions:

- GI: Atopic history and risk for food allergy, GERD, EoE, Celiac Disease, IBD
- Cardiac: fatigue with feeds
- Genetic condition: delay in skills and other milestone. Often dysmorphic features
- Mental Health Condition

Skill based deficits:

- Choking, gagging, color changes with feeds, inability to handle own secretions
- Oral structures, tongue tie, dental alignment and health
- SLP and OT can help
- A modified barium swallow study may or may not be warranted.



Approach:

The ARFID diagnosis is comes from the psychology and mental health arena

Pediatric Feeding Disorder is rooted in the medical and developmental realms

Even before medical work up is complete, behavioral and/or feeding therapy is recommended

Beneficial whether or not ARIFD is ultimately diagnosed

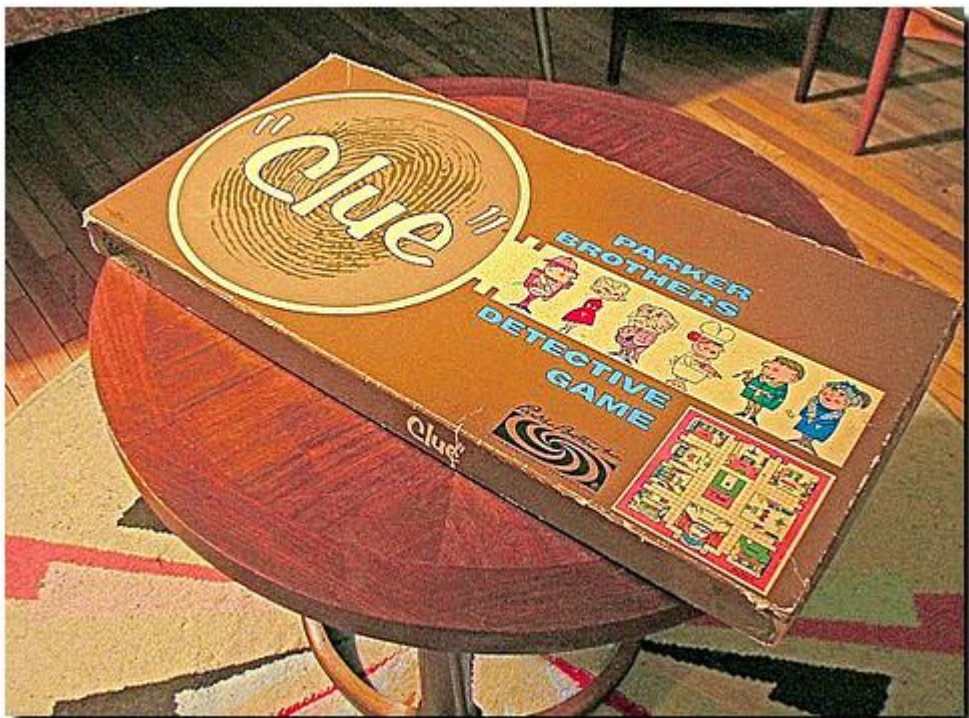
Consider the impact of parenting and feeding styles

Management

- Priority is safe eating, proper nutrition, manageable behaviors
- No standard treatment for ARFID. Approach depends on setting/resources
 - Medical: labs, disease screening management. Possible appetite stimulation
 - RD: Supplements as able, may consider nutritional supplements and even tube feeding if weight has dropped.
 - OT/SLP: Assess structures and skill. Then work on behavior, interactions, sensory properties.
 - PsyD: recognize and treat common co-morbid mental health conditions like anxiety or depression. Behavior modification and parent/child interaction
- Support/reinforce recommendation of mental health specialists and feeding therapists

Solving the Behavioral Mystery

*...and Helping
Skills to Build*



Who is vulnerable?

- Flavor preferences are partly genetic.
- “Supertasters” can be born with a high concentration of taste buds on the tongue and may be more prone to disliking bitter foods (e.g. vegetables).
- There may have been an evolutionary advantage to food preferences. *Foods like fruits, vegetables, and meats were more likely to be poisonous to our ancestors.*

Plus...

- Eating the same foods all the time makes new foods taste more unusual.
- Certain nutrition deficiencies can change the way foods tastes.
- Opportunities to learn about new foods is limited, if it’s hard to eat around others.

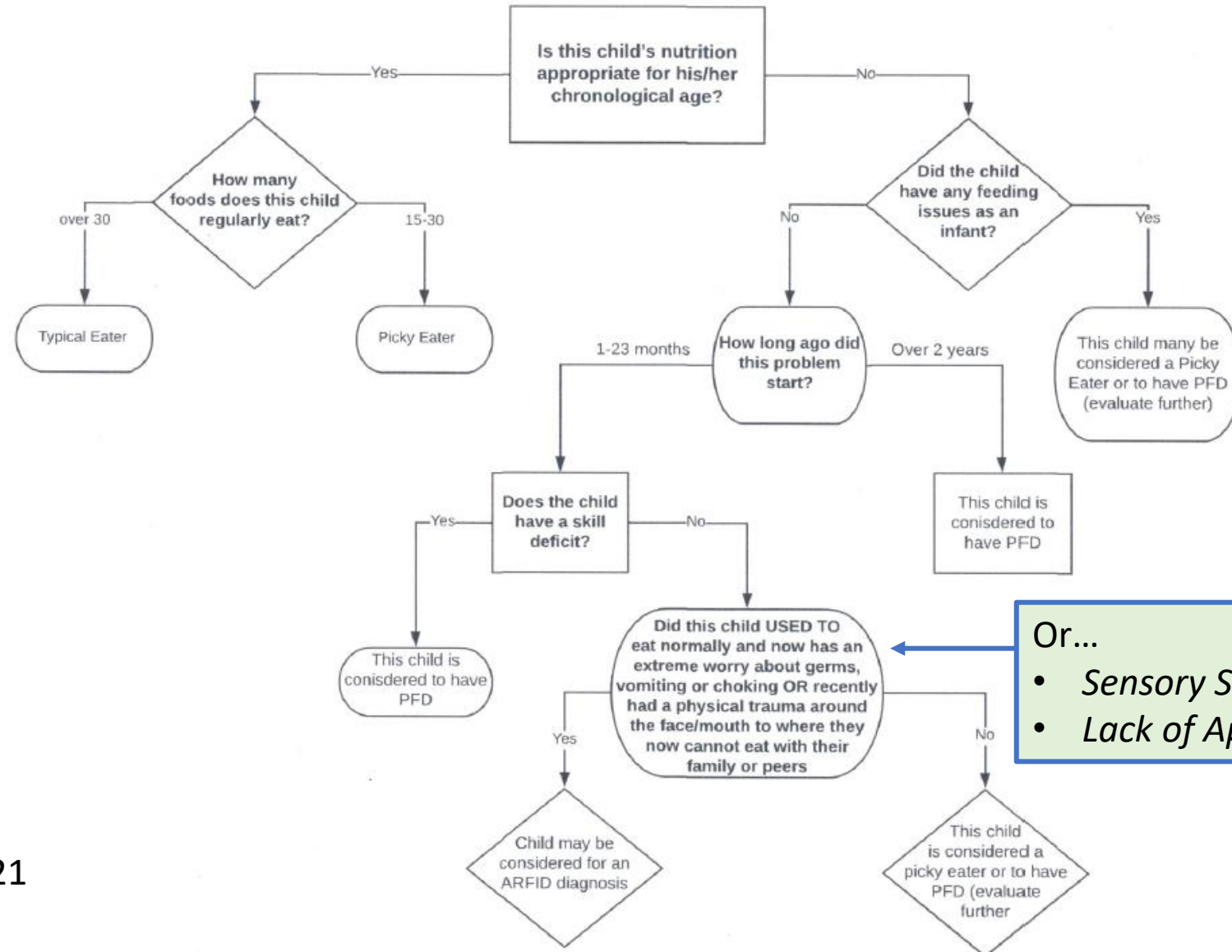


Thomas, J.J. and Eddy, K.T. (2019). *Cognitive-Behavioral Therapy for Avoidant/Restrictive Food Intake Disorder: Children, Adolescents, & Adults*. Cambridge: Cambridge University Press.

A Differential Diagnosis Decision Tree

Picky Eating, PFD, or ARFID?

“When the eating disturbance occurs in the context of another (medical or mental) condition or disorder, the severity of the eating disturbance exceeds that routinely associated with the condition or disorder”



Important Questions That Give Us Behavioral Clues



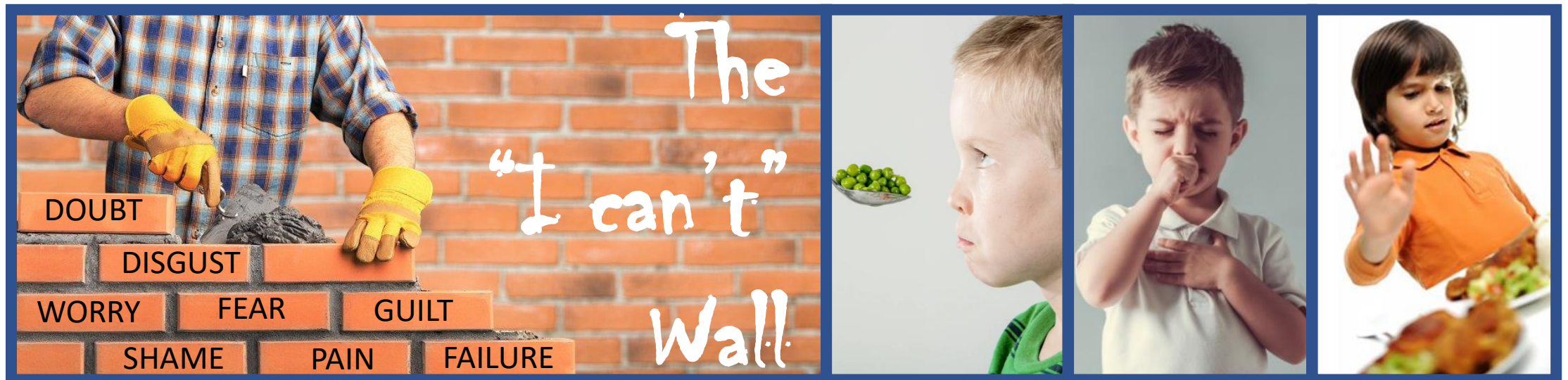
- 1) *How would you describe what happens during mealtimes?*
- 2) *What do you do when your child won't eat?*
- 3) *How anxious (or stressed) are you about your child's eating?*

These Q's can help to determine the parent's "feeding style":
Controlling - *Responsive* - Indulgent - Neglectful

The Barriers that Keep Patients Stuck

Avoidant/Restrictive eating patterns are maintained by:

- Sensory Sensitivity (e.g. tastes, textures, smells, looks, sounds)
- Fear of aversive consequences (e.g. choking, vomiting, disgust)
- Lack of appetite or low interest in eating



Recent Findings for Patients with ARFID

- A retrospective chart review of patients with ARFID (N=59) found a co-occurrence of symptoms in over 50% of the sample. Patients with sensory sensitivities was the most common in the sample and frequently co-occurred with both lack of hunger and/or fear of negative consequences.
- Co-morbid conditions are often present... In reviewing these same Eating Disorders Day Treatment patients (N=59), it was found that:
 - 38.9% had *Autism Spectrum Disorder*
 - 10.17% had *Attention-Deficit/Hyperactivity Disorder*

(Reilly et. al., 2019)



Goals of Psychological Therapy for ARFID



1) Sensory Sensitivity:

- Systematic desensitization following the “Steps to Eating”

2) Fear of Aversive Consequences:

- Psychoeducation about how avoidance maintains anxiety and exposure decreases anxiety over time.
- Development of fear hierarchy with graduated exposure to situations in which choking, vomiting, or other fears occur.

3) Lack of Interest in Food/Eating or Limited Appetite:

- Interoceptive exposure to feelings of fullness or nausea (*testing to see if negative predictions are really as bad as they seem – “We can do hard things!”*).

Nutrition and ARFID

ARFID and Malnutrition

Nutritional Assessment in ARFID:

1. Description of mealtimes
2. Growth
3. Vitamin and mineral intake
4. Possible medical complications
5. Description of mealtimes

ARFID and Malnutrition:



Known:

Diet quality is poor

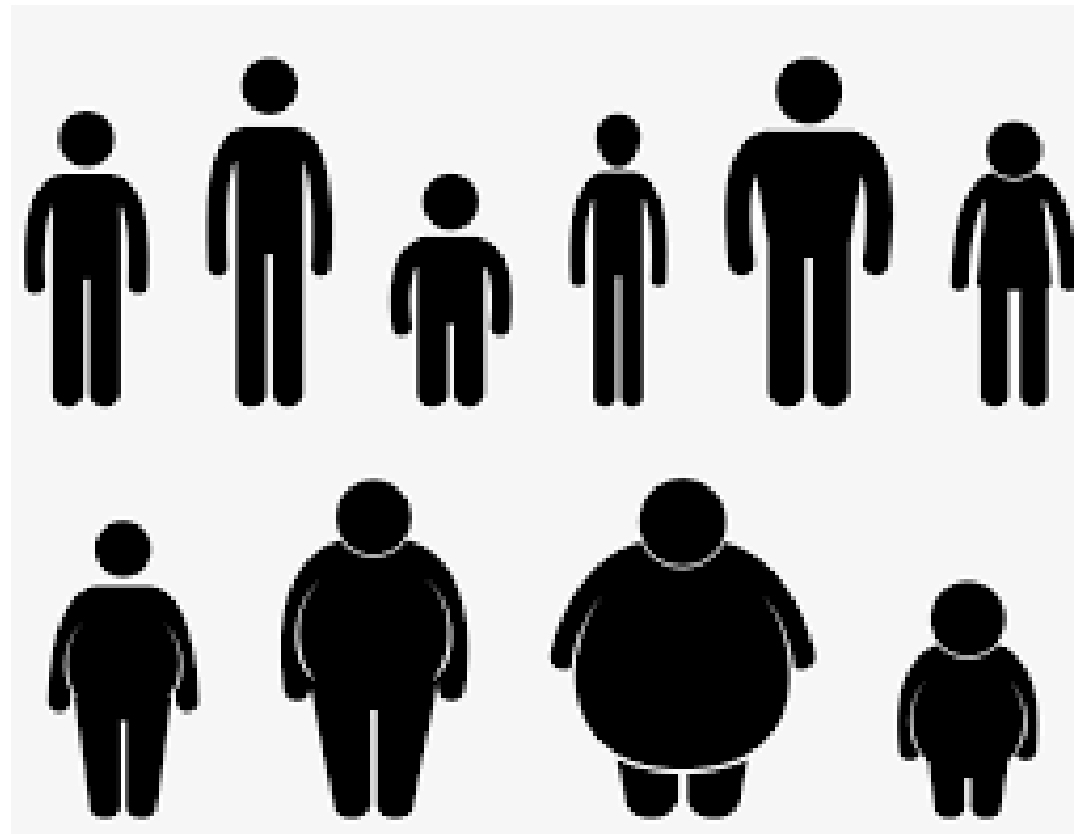
- Preference for refined carbohydrates, sugars, highly processed foods
- Low or no consumption of meats, veggies, fruits
- Major changes in dietary intake are very hard to achieve

Unknown:

- Which tools help us assess nutritional status in ARFID?
- How prevalent are complications related to poor nutrition in ARFID?
- Which nutrients should we be most worried about?
- Are there acceptable ways to fill these nutrient gaps?

ARFID and Malnutrition

Growth for people with ARFID looks like this:



ARFID and Malnutrition

- Variety restriction
 - Results in healthy weight or overweight status
- Volume and variety restriction
 - Low weight
- Post traumatic food restriction
 - Tends to result in rapid weight loss

A healthy BMI does not indicate whether or not feeding or behavioral supports will benefit a family.

ARFID and Malnutrition:

How does dietary intake in individuals with ARFID compare to same aged peers?

ARFID and Malnutrition:

Comparing Diets of Individuals with ARFID vs Controls

Population and Design:

- US, healthy weight individuals with ARFID, 52 4-day diet recalls compared to those of healthy controls

Findings:

Significant differences in intakes of :

Vitamin K
B12

Population and Design:

- Germany, low to normal weight individuals with ARFID seeking treatment. 20 3-day diet recalls and food preference lists compared to healthy controls

Findings:

Significant differences in intakes of:

Calories
B vitamins (Riboflavin, Thiamin)
Vitamin C
Vitamin K
Zinc
Iron
Potassium

Harshman, S. G., et al (2019). "A Diet High in Processed Foods, Total Carbohydrates and Added Sugars, and Low in Vegetables and Protein is Characteristic of Youth with Avoidant/Restrictive Food Intake Disorder." [Nutrients 11\(9\)](#).

Schmidt, R., et al (2021). "Macro- and Micronutrient Intake in Children with Avoidant/Restrictive Food Intake Disorder." [Nutrients 13\(2\)](#).

ARFID and Malnutrition:

Considerations:

- Comparative studies. How great were the diets of the controls?

ARFID and Malnutrition:

Healthy Eating Index Score

- Data-driven assessment quantifying diet quality.
- Used to see how well the what we eat aligns with Dietary Guidelines.
- A score of 100 suggests *all* foods reported align with the Dietary Guidelines recommendations. A score of 0 indicates that none do.



Data source for Healthy Eating Index scores: What We Eat in America, National Health and Nutrition Examination Survey (undated data are from 2013-2014).

	Mean Intake ^a			% (n) Not Meeting Dietary Reference Intakes ^b		
	Full or Subthreshold ARFID	Healthy Controls	<i>p</i> -Value	Full or Subthreshold ARFID	Healthy Controls	<i>p</i> -Value
	<i>n</i> = 52	<i>n</i> = 52		<i>n</i> = 52	<i>n</i> = 52	
Vitamin A (mcg) ^c	699 ± 32.5	807 ± 32.3	0.16	70 (37)	63 (33)	0.09
Vitamin C (mg)	348 ± 88.3	90.4 ± 4.8	0.45	62 (32)	49 (25)	0.08
Vitamin D (mcg) ^d	5.4 ± 0.2	6.2 ± 0.3	0.11	93 (48)	92 (48)	0.38
Vitamin E (mg)	10.0 ± 0.4	9.8 ± 0.4	0.65	86 (45)	84 (44)	0.95
Vitamin K (mcg)	55.8 ± 1.9	162 ± 12.3	0.01 *	78 (40)	55 (28)	<0.001 *
Vitamin B6 (mg) ^e	1.6 ± 0.04	1.9 ± 0.04	0.09	38 (20)	27 (14)	0.07
Folate (mcg) ^f	560 ± 17.2	569 ± 14.5	0.44	41 (21)	32 (17)	0.14
Vitamin B12 (cobalamin, mcg)	3.9 ± 0.1	4.7 ± 0.2	0.01 *	36 (19)	32 (17)	0.12
Calcium (mg)	1096 ± 29.1	1037 ± 26.7	0.78	63 (33)	72 (37)	0.75
Iron (mg)	14.5 ± 0.3	15.7 ± 0.4	0.14	45 (24)	46 (24)	0.38
Magnesium (mg)	248 ± 4.8	299 ± 6.6	0.05	90 (47)	76 (39)	0.002 *
Zinc (mg)	9.4 ± 0.2	11.0 ± 0.3	0.03	65 (34)	52 (27)	0.01 *

ARFID and Malnutrition:

Comparing Diets of Individuals with ARFID vs Controls

Table 2. Achieved percentage of recommended vitamin and mineral intake in avoidant/restrictive food intake disorder (ARFID) and controls.

	Controls		ARFID	
	<i>M ± SD</i>	Range	<i>M ± SD</i>	Range
% of vitamin intake ¹				
B1	60.9 ± 52.4	14.6–238.5	19.4 ± 21.8	0–67.8
B2	41.5 ± 23.8	13.0–96.9	18.7 ± 18.6	0–67.8
B6	61.2 ± 48.0	11.1–199.7	24.3 ± 21.4	0–79.2
B12	42.7 ± 31.9	3.8–123.0	29.1 ± 62.8	0–269.2
C	143.6 ± 138.1	21.1–491.4	42.7 ± 36.1	0–133.4
D	5.3 ± 8.6	0.5–38.6	8.0 ± 17.1	0–67.1
E	33.6 ± 23.0	8.7–94.5	25.0 ± 28.8	0–101.2
K	64.5 ± 45.0	13.5–152.6	23.8 ± 18.6	0–65.1
Folate	39.7 ± 21.7	13.0–95.9	18.7 ± 27.0	0–118.7
% of mineral intake ¹				
Zinc	52.5 ± 28.7	11.4–122.6	21.1 ± 30.9	1.2–134.9
Calcium	47.4 ± 32.2	13.1–116.6	51.0 ± 60.3	3.0–210.5
Iron	30.6 ± 16.5	8.9–79.8	17.4 ± 22.8	0.2–102.2
Magnesium	71.5 ± 38.8	22.1–154.9	68.8 ± 70.1	11.8–251.2
Potassium	42.3 ± 24.3	13.1–116.6	20.3 ± 15.7	0.5–56.0

¹ Reference values are based on German age- and sex-specific recommendations for energy and nutrient intake.

ARFID and Malnutrition

What is the prevalence of severe medical complications related to self restricted eating?



Journal of the
Academy of Nutrition
and Dietetics

The premier source for the practice
and science of food, nutrition, and dietetics

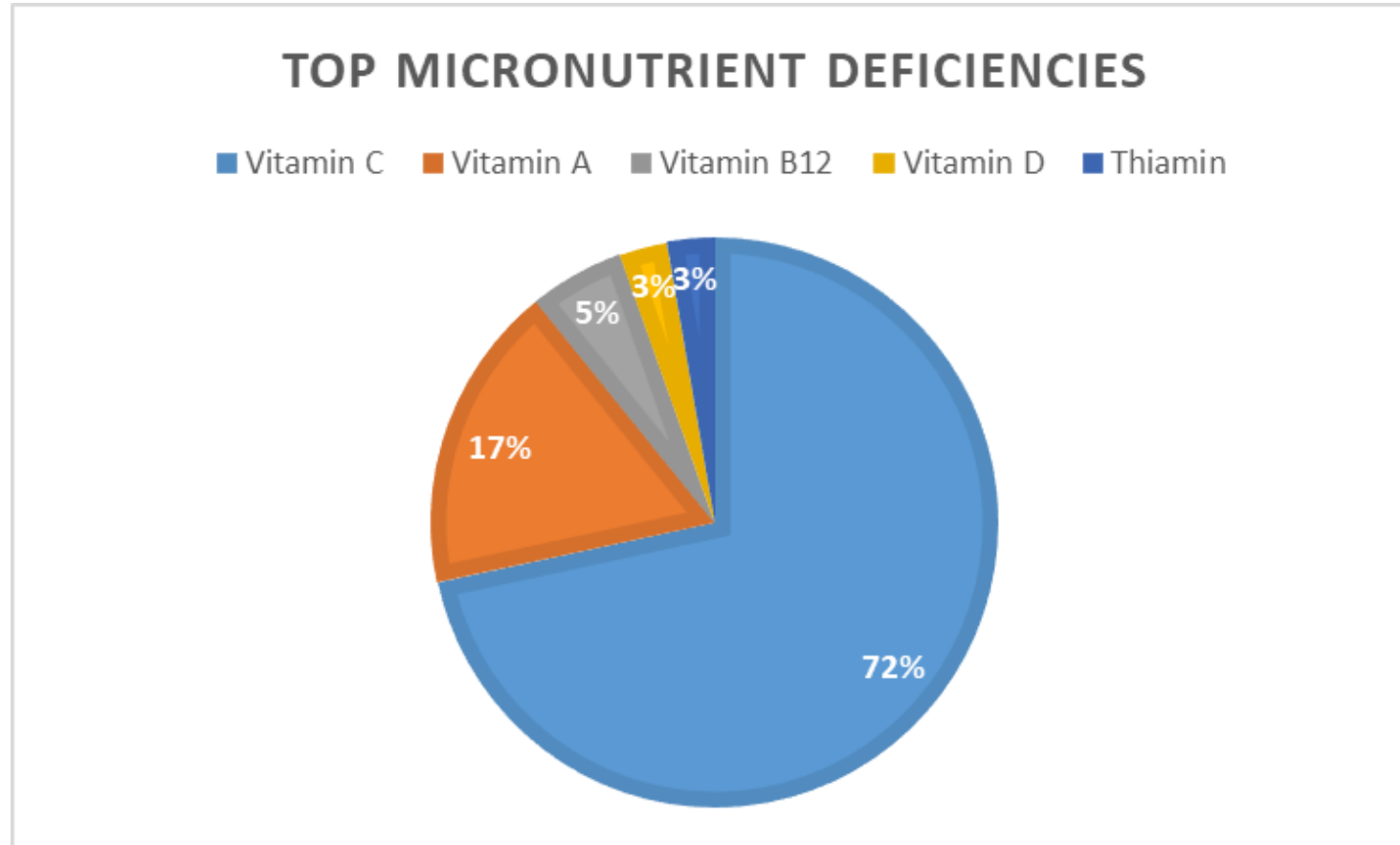
ARFID and Malnutrition:

- Systematic review of Case Reports and Case Series from 1957-2019
- 76 case studies from developed countries over 65 years

The majority were from 2009-2019

Yule, S., J. Wanik, et al (2021). "Nutritional Deficiency Disease Secondary to ARFID Symptoms Associated with Autism and the Broad Autism Phenotype: A Qualitative Systematic Review of Case Reports and Case Series." J Acad Nutr Diet **121**(3): 467-492.

ARFID and Malnutrition



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ARFID and Malnutrition:

Considerations:

- Extreme cases involving hospitalization
- Remember common nutritional deficiencies:
 - Vitamin D
 - Iron
 - Calcium
 - Zinc

Interventions Nutrition and ARFID

What screws us
up most in life
is the picture
in our head of
how it is
supposed to be.



Interventions Nutrition and ARFID



Interventions Nutrition and ARFID

Following *intensive* treatment findings include:

- Great parent satisfaction
- Improved behaviors and interactions at mealtimes
- Dietary changes: often none or very insignificant

Occasionally increase ~20 foods, which must feel huge

Zeleny, J. R., et al (2020). "Food preferences before and during treatment for a pediatric feeding disorder." [J Appl Behav Anal 53\(2\): 875-888.](#)

Interventions Nutrition and ARFID

Labs

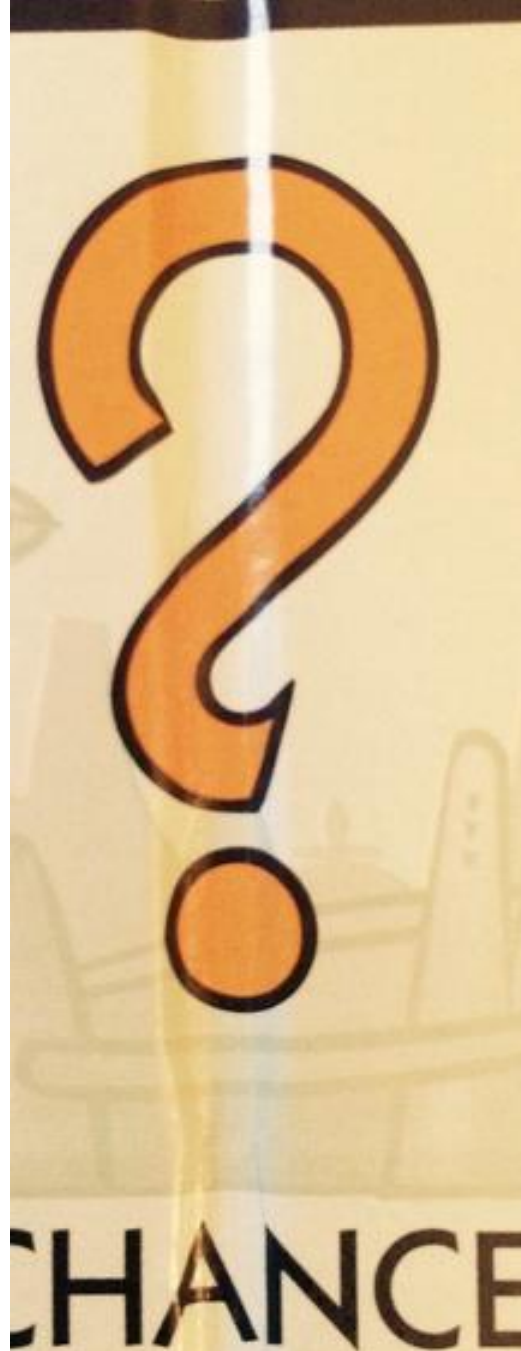
- Chemistry, CBC, Ferritin, 25(OH) Vitamin D
- Consider: Vitamin C, Vitamin A, Zinc, B12

Diet

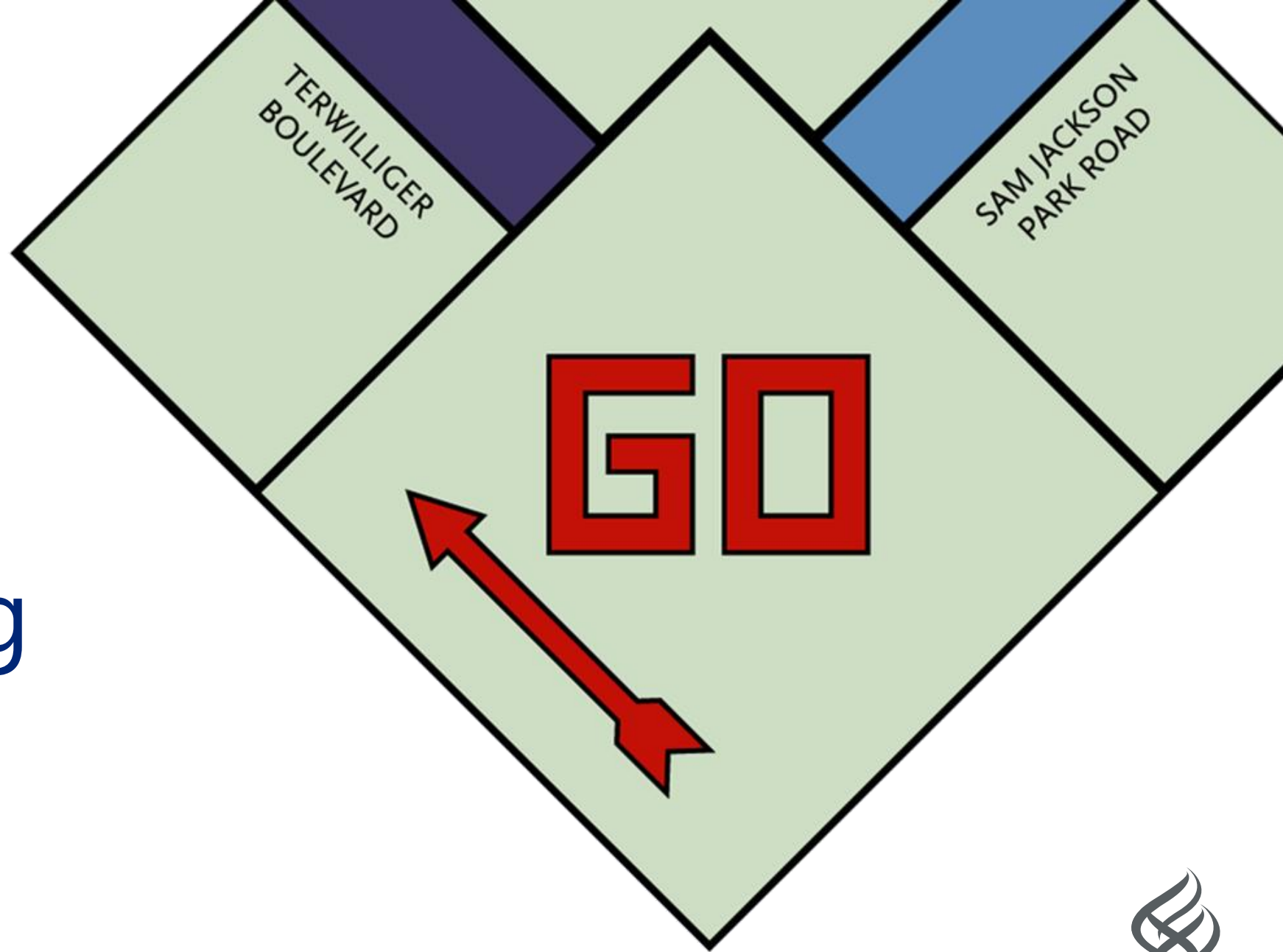
- Provide reassurance
- Vitamin and mineral supplements, fortified foods
- Consider oral nutritional supplements if weight *and* micronutrient intake are poor

Goals

- Refer to therapy
- Provide reassurance
 - Nutritional intake will not improve until medical contributors to ARFID, stress and anxiety are addressed



Let's go
back to
the
beginning



Data from 2018 Hospital for Sick Children prospective study:

46% of children had been having a feeding disturbance for approximately **2 years** before they received an evaluation.

Why does it take 2 years?

- Pediatricians hear about feeding concerns frequently.
- Growth may be ok.
- Developmental screening tools are not sensitive to feeding difficulties.

What does this waiting mean for the family of a child with PFD or ARFID?

- Family is having meal 3-6 (or more) times per day.
- They are experiencing stress 3-6 or more times a day or 2,190-4,380 times in the approximately 2 years while waiting for an evaluation.
- In trying to reduce the stress, they adapt and avoid.

What can you do?



ICFQ

- Free
- 36 months and under
- If over 36 months it will send families to another questionnaire
- Available online FeedingMatters.org



THE INFANT AND CHILD FEEDING QUESTIONNAIRE SCREENING TOOL

Feeding Matters' innovative Infant and Child Feeding Questionnaire® (ICFQ®) was authored in partnership with internationally renowned thought leaders representing multiple disciplines related to feeding. The ICFQ® is an age specific tool designed to identify potential feeding concerns and facilitate discussion with all members of the child's healthcare team.

According to a seminal study published in the 2020 Journal of Pediatrics*, the ICFQ® has been shown to accurately identify and differentiate pediatric feeding disorder (PFD) from picky eating in children 0-4 years of age based on caregiver responses to 6 specific questions. This 6-question quick screener continues to undergo research as Feeding Matters strives to promote the early identification of PFD.

6-QUESTION SUBSET

Does your baby/child let you know when he is hungry?	YES	NO	
Do you think your baby/child eats enough?	YES	NO	
How many minutes does it usually take to feed your baby/child?	<5	5-30	>30
Do you have to do anything special to help your baby/child eat?	YES	NO	
Does your baby/child let you know when he is full?	YES	NO	
Based on the questions above, do you have concerns about your baby/child's feeding?	YES	NO	

Red flag answers are in orange. If 2 or more of your answers are orange please contact your pediatrician.

Concerned? Take the full questionnaire:
feedingmatters.org/questionnaire



WHO IS FEEDING MATTERS

Feeding Matters, a 501c3 nonprofit, is the first organization in the world uniting families, healthcare professionals, and the broader community to improve the system of care for children with PFD through advocacy, education, support, and research. Use of this screener tool brings us one step closer to a world where children with PFD will thrive.

EARLY IDENTIFICATION

Expediting the identification of PFD may prevent the development of conditions that negatively impact a child's cognitive, physical, emotional and social development. Feeding is an intricate and complex skill that develops within a feeding relationship. Earlier detection and treatment of PFD also may reduce adverse effects on caregiver- child relationships. By completing the ICFQ® screening, children can be directed to appropriate specialists for more formal assessments and management. The first step in reducing the risk of increased symptom severity is identification.

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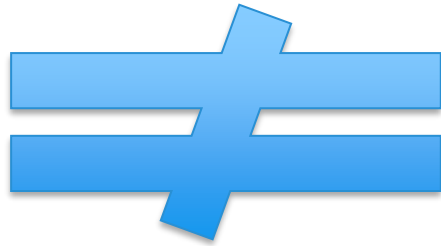
*Silverman AH, Kristoffer BS, Linn C, et al. Psychometric Properties of the Infant and Child Feeding Questionnaire. Journal of Pediatrics. 2020 August;223:81-86.e2. DOI: 10.1016/j.jpeds.2020.04.040.

FEEDINGMATTERS.ORG | 800.233.4658



Consider:

adequate weight gain and growth



functional eating patterns and mealtime participation

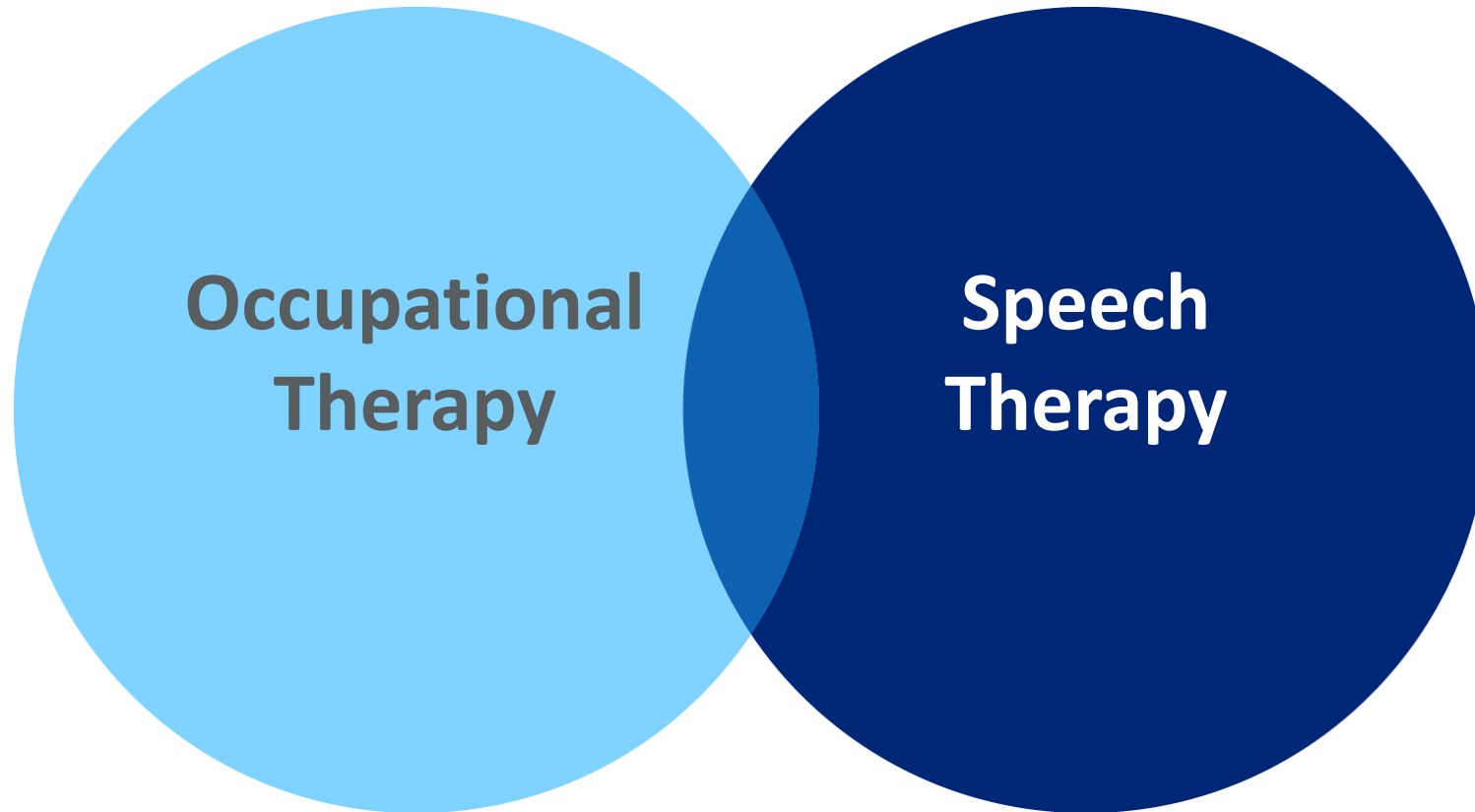
Pay special attention to kids with:

- History of nursing difficulty
- Slow weight gain in infancy
- Difficulty making transitions –to purees, weaning from breast or bottle (over 18 months), solid food transitions
- Any other motor, language or social skill delays

Questions:

- Does the family have set meal and snack times?
- How long is mealtime lasting?
- Is it causing significant parent stress?

Refer to Community Feeding Therapy



Feeding Therapy Evaluation

Medical history

Development

Oral motor

Dysphagia

Sensory processing

Family + Child



Mealtime participation

Behavior

Family-child
interactions

Family stress

Family goals

Feeding Therapy

POSITIONING
TRUST
Practice Family Education
Supportive Language

Play
CONSENT
Supports
Behavior
Motor Skills
Respect
Sensory
Exploration

“You can’t go back and change the beginning, but you can start where you are and change the ending.” –C. S. Lewis

Thoughts Into Action...

*Best practices towards seeing
improvements in our patients*

Case Study: 7-year-old Cisgender Male

History:

- He has been diagnosed with asthma, eczema, ADHD, sensory processing issues. More recently, anxiety and dysphagia have been occurring in the last 6 months.
- He has always been a picky eater, with preferred foods becoming more limited over the past year. Weight is stable (but lower with BMI at 5.24%), but he relies on significant nutritional supplementation.
- Patient is from a single-parent household and has two older siblings with significant neurodevelopmental and behavioral differences.

Clinical Findings:

- Normal EGD and MBSS

Approaches to Help: 7-year-old Cisgender Male

Medical-

- Evaluate for co-existing or underlying medical etiology of feeding difficulty and refer to appropriate specialty services.
- Support and reinforce recommendations of mental health providers and feeding therapists.

Behavioral-

- Increase meal/snack structure (3 meals and 2-3 snacks with the same time, place, and routine), Follow the “Rule of 3”, and Model pleasant/healthy eating behaviors.
- Establish a meaningful Positive Reinforcement system (consider the “Matching Law” in order to help their reason “*why to*” be higher than their “*why not*”). Also, help parents understand the importance of ignoring negative behaviors.
- Help the child to get involved with the selection and creation of family meals, even if they don’t taste the final product. Becoming a “*food scientist*” can facilitate systematic and low-stress exposures. Exposure is the key!

Approaches to Help: 7-year-old Cisgender Male

Nutrition-

- The growth chart isn't a very effective tool in identifying PFD or chronic ARFID.
- Micronutrient deficiencies can happen, but serious consequences are fairly rare.
- Well-balanced vitamin and mineral supplements, along with fortified foods such as breakfast cereal and milk are great at combatting serious nutrient deficiencies.
- Food variety and nutrient intake will not improve until medical conditions and stress contributing to ARFID are managed.

Feeding Therapy-

- Evaluation of oral motor and oral sensory processing skills.
- Evaluation of mealtime participation.
- Treatment - Family coaching to reduce stress for mealtime participation.
- Treatment - Sensory and play-based exploration of food to reduce worry and increase practice.

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Thank You