

Objectives

- Introduction to the CDRC Feeding Clinic
- Typical food advancement. Expectations with developmental disability
- Define levels of acceptance and refusal and discuss strategies for each level.
 - Food selectivity, picky eating, problem eating
 - Pediatric Feeding Disorder
 - ARFID
- Tools and resources





Introduction to our clinic

- Multidisciplinary team specializing in complex pediatric feeding disorders.
- Simultaneous assessments, exploring multiple factors involved in feeding challenges: medical, psychosocial, feeding skill, sensory and nutritional origins.





Introduction to our clinic

Referral from medical provider

Average wait 3 months

Exceptions: higher risk, babies

- Medical review to triage
- We provide very limited therapy
- Follow up determined by need
 As frequent as every 2-4 weeks (baby, NGT)
 As infrequently as annually





Introduction to our clinic

Focus on medically complex feeding disorders

No classic eating disorders

Limited efficacy with autism

Limited efficacy with ARFID

Limited efficacy with sensory based feeding challenges

Generally declining referrals for non complex picky eating

Local feeding therapy is often best!

Frequent visits

Close to home

Establish a trusting relationship



M

Medical Team



Kevin Senn, M.D.



Sylvia Doan, M.B.B.S.



Karin M. Ide, CPNP, M.S.N.



Kelley Davis, DPN, RN, CPNP-PC

Feeding Specialists



Kristin Haines Mangan



Julia Farrell, OTR/L, IBCLC



Kelsey Frazier, MA, CCC-SLP

Dietitians



Sarah Sahl, RDN, LD



Melissa Nash, MPH, RDN

Psychologist

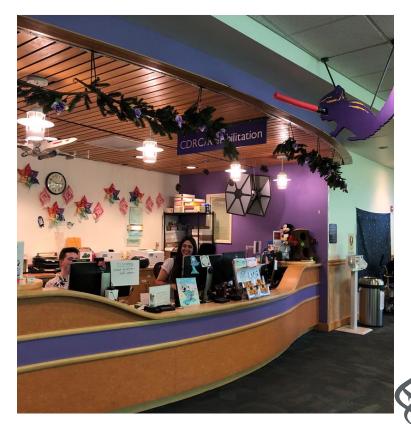


Darren Janzen, PsyD

Our space at Doernbecher







Interview and medical exam









Feeding observation

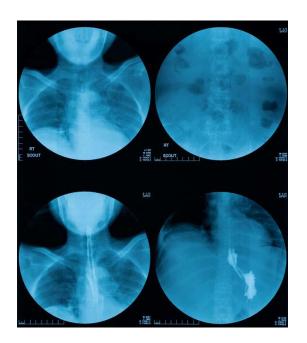






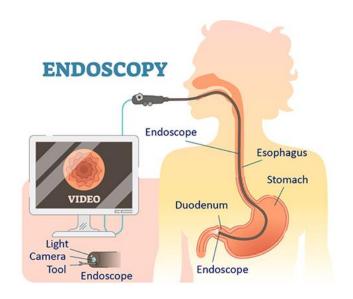
Instrumental Evaluations: Swallow Study







Instrumental Evaluations: Endoscopy, labs







What Parents Say:





What parents mean is

"Is my child ok? How worried should I be?"



Our roles:

Explore

- •Feeding Experience
- Medical picture
- Nutritional Risks

Understand

- Family goals
- Family struggles

Prioritize

- Discuss realistic goals
- Reset expectations
- Redefine success

Identify practices counterproductive to

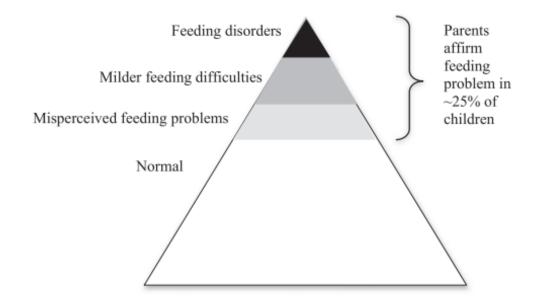
- •Formula use. Goal is to increase food variety
- TV for distraction. Goal of increased independence
- Exclusively feeding preferred foods. Goal is to increase variety

Reassure

- •This is HARD
- Alleviate stress whenever possible
- Find areas to compliment









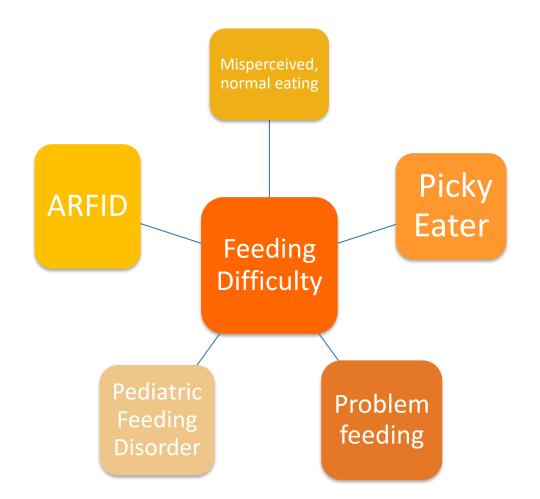
Pediatric Feeding Disorders: Prevalence

25%-50% of parents of neurotypical children report feeding problems.

Up to 80% of parents of kids with developmental differences report **feeding problems.**

1-5% meet diagnostic criteria for **pediatric feeding disorder**.







Definitions



Picky Eating

There is no uniform definition for picky eating.

...considered a developmentally normal behavior in young children that usually resolves by school age (Hagan et al., 2017) and does not affect growth.

Includes food neophobia, which is well defined as an unwillingness to try new foods, (Tan & Holub, <u>2012</u>) with a reported prevalence of 40–60% (Brown et al., <u>2016</u>; Faith et al., <u>2013</u>).

Some kids need 10-15 offerings to familiarize themselves with new food.



Picky Eating

Recommendations

Reassurance!

Stick with the basics that you know

Anticipatory Guidance

Consider therapy if concerns persist.



Problem Eating

No universally agreed up on definition

May require vitamin or mineral supplementation

Feeding therapy likely beneficial

Impacts on social life



Problem Eating

Recommendations

Reassurance

Stick with the basics that you know

Anticipatory Guidance

Vitamin and mineral supplement

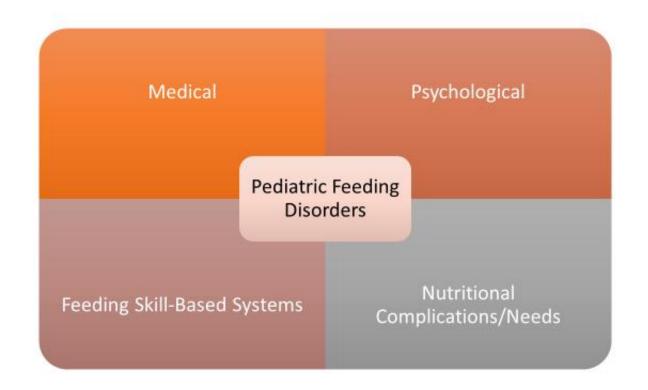
Consider labs

Feeding therapy likely recommended.



 <u>Definition</u>: Pediatric Feeding Disorder is impaired oral intake that is not age-appropriate, and is associated with medical, nutritional, feeding skill and/or psychosocial dysfunction.

 <u>Criteria:</u> A disturbance in oral intake of nutrients, inappropriate for age, lasting > 2 weeks, not due to the cognitive process consistent with eating disorders, a lack of food or normal cultural practices that is associated with 1 or more of the domains we will discuss.





MEDICAL

- · labored breathing with and without feeding
- · color changes in lips or face when eating or drinking
- · sweating when eating or drinking
- · gurgle or squeaking sounds with and without feeding
- · reoccurring upper respiratory infections
- · crying, arching, coughing, grimacing when eating or drinking
- · suspected food allergies
- · multiple formula changes
- vomiting
- never seems hungry
- · physical discomfort when eating or drinking







FEEDING SKILL

Feeding Skill specific to ANY age

- labored, noisy breathing or gasping
- · coughing, choking, gagging or retching
- · gurgles or wet breaths
- · loud and/or hard swallows or gulping
- · unable to eat or drink enough for optimal growth
- · excessively short mealtimes (< 5 minutes)
- · excessively long mealtimes (> 30 minutes)
- · need for thickened liquids
- · need for special food or modified food texture
- · need for special strategies, positioning or equipment

Feeding Skill specific to an INFANT (12 months of age or younger)

- unable to latch to breast or bottle without help
- · weak suck
- need for pacing, flow management or rest breaks
- need for special equipment to breast or bottle feed
- often too tired to eat or quickly falls asleep when eating
- breast or bottle feeds best when asleep, i.e., dream feeds
- · unable to transition to solids
- unable to wean from breast or bottle

Feeding Skill specific to a CHILD (12 months of age or older)

- grazing between scheduled mealtimes
- refusal to eat, drink or swallow certain food textures
- needs distraction to eat such as screen time
- needs excessive praise/threats/bribes to eat
- difficulty chewing ageappropriate foods
- unable to eat in new or unfamiliar situations

NUTRITION

- · unable to eat or drink enough to grow or stay hydrated
- · insufficient or too rapid of a change in weight or height
- · lack of a certain nutrient, i.e., iron, calcium
- need for nutritional supplements
- · reliance on a particular food for nutrition
- · need for enteral feeds for nutrition-NG, GT, TPN
- · constipation
- limited dietary diversity for age
 - too few fruits and/or vegetables
 - limited or no protein source
 - too few foods eaten on a regular basis



PSYCHOSOCIAL

- · unable to come to or stay with the family at meals
- refusal to eat what is offered or to eat at all
- disruptive mealtime behaviors
- unable to eat with others present at mealtimes
- child exhibits stress, worry or fear during meals
- caregiver stress, worry or fear when feeding child
- · presence of bribes, threats, yelling at mealtimes
- need for distraction and/or rewards for eating
- · unpleasant mealtime interactions between caregiver and child



Recommendations

- Multidisciplinary team evaluations
- Identify and treat contributing medical conditions
- Identify and treat feeding skill deficits
- Identify nutrient gaps-address as able through food first,
- then supplements
- Stick with the basics you know
- Identify and address psychosocial challenges

Feeding therapy generally recommended.



ARFID- Mental Health Diagnosis

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: ARFID is NOT

- related to food scarcity or culturally sanctioned practice
- -related to body image or weight concerns
- better explained by concurrent medical condition or another mental disorder



ARFID

Recommendations

Multiple sessions of cognitive behavioral therapy RD goals: Identify nutrient gaps-address as able through food first, then supplements Stick with the basics you know

Feeding therapy (OT/SLP) generally less beneficial than behavioral therapy.



"How do I know if there's a problem?"

- 1. Screening tools
- 2. Triage tools
- 3. Nutrition assessment



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





All Feeding Problems: Nutritional Assessment

- Description of mealtimes
- Assessment of dietary intake
- Assessment of growth
- Consider medical diagnoses
- Description of mealtimes





- Assess Growth
- Determine Nutritional Adequacy
 (Protein, fat, fiber, fluid, vitamins, minerals)
- Address Feeding Tolerance
 (Allergy, EoE, Celiac disease, formula type)
- Manage tube feeding or oral formula
- Evaluate cooking and food selection skills
- Assess family dynamic and stress



Role of the Dietitian: Growth Assessment

Growth chart

- · Is growth adequate, poor,
- excessive? Trending OK? Altered growth expectation for any reason?



- · Doesn't account for tone
- Altered growth expectation (syndrome, Preemie, SGA)
- Reliant on accuracy

Body composition

Measures body fat stores

Measures:

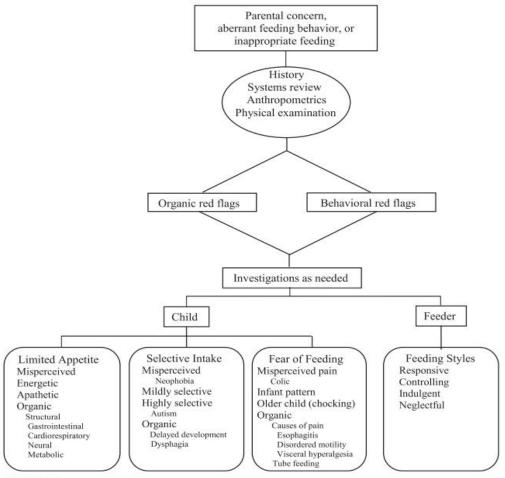
- Arm circumference
- Triceps skinfold
- Nutrition Focused Physical Exam

Limitations:

· Reliant on evaluator skill







Kerzner B, et al.A practical approach to classifying and managing feeding difficulties. *Pediatri cs*. 2015;135(2):344-353.

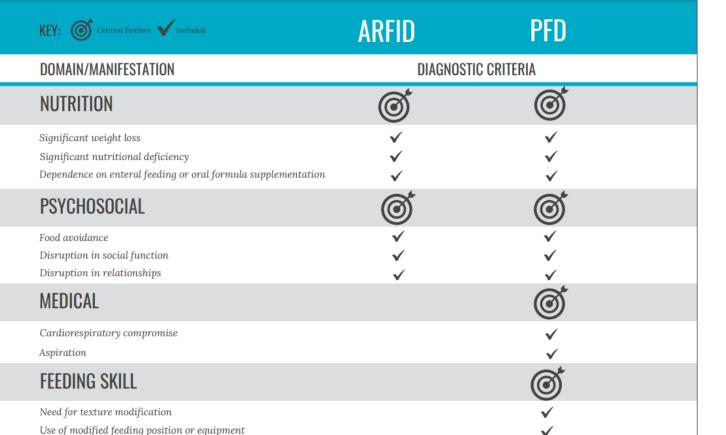
353. doi:10.1542/peds.2 014-1630

FIGURE 2

An approach to identifying and managing feeding difficulties.

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



Feeding Matters welcomes all families with children who struggle to eat and the professionals who serve them. Information and support is inclusive of all diagnoses related to feeding difficulties. If your family has an ARFID diagnosis, you too can find helpful information within the Feeding Matters community.

Use of modified feeding strategy







Avoidant Food Intake Disorder (ARFID) and Pediatric Feeding Disorder (PFD)

If a patient has a diagnosis of ARFID, it may be worth reassessing from the pediatric feeding disorder (PFD) perspective to see if the cause of feeding difficulties might include a medical or skill dysfunction, and not be purely behavioral.

-Dr. Richard Noel, Feeding Matters Volunteer Medical Director

	ARFID	PFD
THERAPEUTIC END USER	Psychiatric/behavioral	Multidisciplinary
DIAGNOSIS DEVELOPMENTAL ROOTS	Designed to replace and extend the DSM-IV diagnosis of feeding disorder of infancy or early childhood, also driven by desire to better represent patients' needs with EDNOS receiving treatment within eating disorder programs	Designed based on International Classification of Functioning, Disability, and Health (ICF) framework, recognizing that multidisciplinary care across four core domains represents the standard of care for PFD
TYPICAL AGE OF ONSET	Childhood and throughout the lifespan	Early childhood
PRIMARY ETIOLOGY	Psychiatric comorbidities, including anxiety disorders and obsessive- compulsive disorder	Complex medical and developmental conditions

https://www.feedingmatt ers.org/wpcontent/uploads/2021/1 0/PFD-ARFID.pdf



"How worried should I be?"



The Guidelines

Make every bite count with the Dietary Guidelines for Americans. Here's how:

Follow a healthy dietary pattern at every life stage.





atophotic beverages.

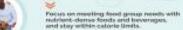
Limit feeds (C and beverages higher in added augura, seborated fat, and sodium, and limit











2020-25 Dietary Guidelines for Americans

Infancy:

First 6 moths:

- Exclusively feed human milk. Continue through at least 12 months, longer if desired
- If human milk isn't available, feed iron fortified infant formula through 12 months
- Start vitamin D supplement soon after birth

Around 6 months of age:

- Start nutrient dense complementary foods.
- Introduce potentially allergenic foods at this same time.
- Provide a variety of foods from all food groups.
- Pay special attention to rich sources of iron and zinc.
- Avoid added sugars and limit items higher in sodium.

2020-25 Dietary Guidelines for Americans Toddlers and Children:

Offer a variety of foods from all food groups.

Offer foods with child seated in a highchair or at a table.

Age 6-12 months: focus on foods rich in iron, zinc, protein, choline, Vitamin D

Age 12-24 months:
additional effort to ensure
adequate calcium, fiber,
potassium. *Sugar and
sodium are already
overconsumed

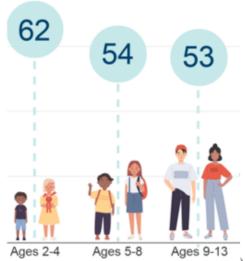
Aim to be a responsive feeder-recognize and respect signs of hunger and satiety.



2020-25 Dietary Guidelines for Americans

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.







Feeding Difficulty and Malnutrition:

Known:

Diet quality is often poor

- Often preference for refined carbohydrates, sugars, highly processed foods
- Low consumption of meats, veggies, fruits
- Major changes in dietary intake are very hard to achieve

Unknown:

- How prevalent are complications related to poor nutrition?
 - Which nutrients should we be most worried about?
 - Are their acceptable ways to fill these nutrient gaps?





Malnutrition in ARFID and Autism

Journal of the Academy of Nutrition and Dietetics

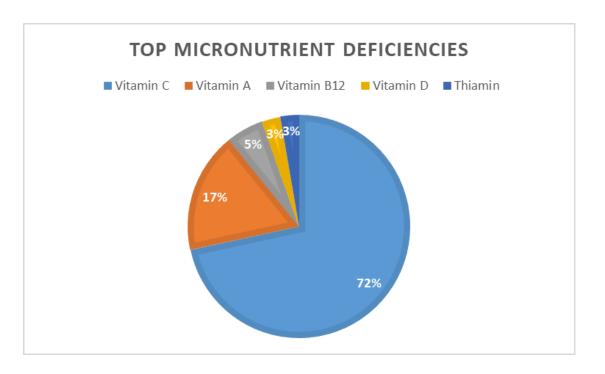
The premier source for the practice and science of food, nutrition, and dietetics

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

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.



Malnutrition in ARFID and Autism



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.



"What should I do?"



Family Centered Approach

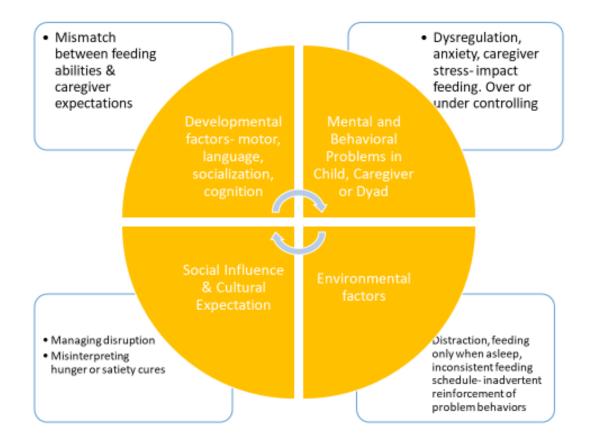
Meet the family where they are (culturally, emotionally, education level/style)

Recognize the challenges faced before getting to our clinic. What have they tried? How do confident are they to try again?

Use family-friendly language

Understand what changes a family can realistically make in a given timeframe

Recognize their family system (One household? Two parent household? Many siblings? Many generations?)





2018 Hospital for Sick Children prospective study:

Half of children experienced a feeding disturbance for **2** *years* before receiving a feeding evaluation.

Why does it take 2 years?

- Pediatricians frequently hear about feeding concerns
- Growth may be ok
- Developmental screening tools are not sensitive to feeding
- Time is limited, hard to tease out the true cases of disordered eating

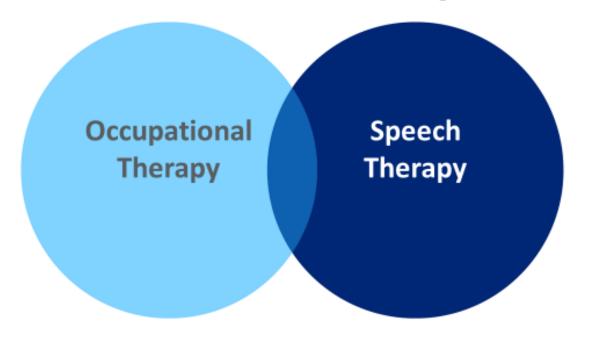


What waiting 2 years means

- Family has 3-6 meals per day
- They experience stress 3-6 times per day or 2,190-4,380 times in the two years while waiting
- In trying to reduce stress, they adapt and avoid.
- Or they overcompensate and force, damaging the feeding relationship.



Refer to Community Feeding Therapy





Therapy Outcomes:

Results vary

- Great with skill deficit or delayed development.
- Sensory based feeding issues may not improve without internal motivation to change
 - Desire to socialize outweighs the fear of trying

Autism and ARFID data: Following *intensive* treatment

- Parent satisfaction high
- Improved behaviors and interactions at meals
- Dietary changes: often <u>none</u> or <u>very insignificant</u>
 Occasionally ~20 foods, which must feel huge



Nutrition Tips for Picky or Problem Eating

Schedule

- Help kids tune in to appetite
- 3 meals, 1-3 snacks per day. Include caloric beverages only at meals
- · Avoid grazing
- Minimum of 2 hours between meals
- 15-30 minute meals
- Seek a calm, positive environment. No bribes, fights, or distractions

Mealtime environment and supports:

- Match texture to skill. Not age or desired skill.
- Are feeders attending to the child?
- Meals and snacks at the table
- Does the child have a supportive seat?
- Eating is social! Eat together!
- How pressured are meals? Stress decreases appetite.
- · Model what you want
- No TV or phones

Elmids

- Beyond 12 months of age, kids may displace food calories with excessive fluid intake.
- . 0-4 oz juice in 24 hours.
- 12-24 oz milk
- Ad lib water between

Appetite

- Are there acute changes in appetite or tolerance that should be addressed?
- New meds?
- New GI Process?
- Stress response?
- Increased distractibility?

irowth

- Malnutrition is not always a simple caloric deficit.
- Underlying medical condition? Work up or referrals needed?
- Does growth chart make sense? Does match what I see with my eyes?
- Is weight proportional to height?
- Does it match family's growth?

Nutrition Tips for PFD and ARFID

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Additional Tips

Rule of 3

- Kids need to feel they have something to eat at every meal
- Provide 3 separate foods:
 2 safe items and one
 challenge food
 - Safe foods are often rice, bread, rolls, noodles, fruit, yogurt.

Deconstruct meals

- · Divided plates
 - Not spaghetti. Plain noodles, sauce, veggies and meat separated
 - Not tacos. Tortilla, rice, beans, veggies separated
 - Not egg scramble. Eggs, sautéed veggies, shredded cheese
 - Not stir fry. Rice, meat and veggies

Fortified foods

- WIC cereals
- Milk
- Vitamin and mineral supplement



Nutrition Interventions:

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





Nutrition Interventions







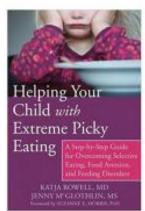
Family and Clinician Resources

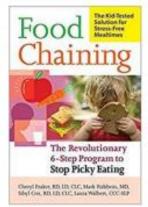
Books:

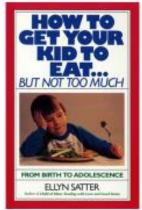
- Food Chaining-Fraker, Fishben, Cox, Walbert
- Helping Your Child with Extreme Picky Eating –Rowell, McGlothlin
- Getting your Child to Eat, But Not Too Much – Satter

Websites:

- www.feedingmatters.org
 - -Parent to Parent support.
 - -Parent questionnaire to identify problems.
 - -Working on advancing care for Pediatric Feeding Disorder.













Thank You

