Marcus
AUTISM CENTER

NIH Autism Center
of Excellence

Food Selectivity, Nutrition Status/Intake, and Autism Spectrum Disorder

William Sharp, PhD
Director – Children's Multidisciplinary Feeding Program

Rashelle Berry, MPH, MS, RDN, CSP
Nutrition Manager – Children's Multidisciplinary Feeding Program

Children's Healthcare of Atlanta

EMORY UNIVERSITY

Learning Objectives

- Describe the relationship between food selectivity and autism spectrum disorder (ASD)
- Identify methods for screening, preventing, and treating nutritional deficiencies in ASD
- Discuss evidence-based principles of feeding therapy in partnership with medical nutrition therapy

Agenda – November 14, 2019

Sharp/Berry- 8:15 to 9:30 AM

- Introduction to Food Selectivity in ASD – Sharp (15 minutes)
- Nutrition and Food Selectivity – Berry (45 minutes)
- Treatment for Food Selectivity – Sharp (15 minutes)

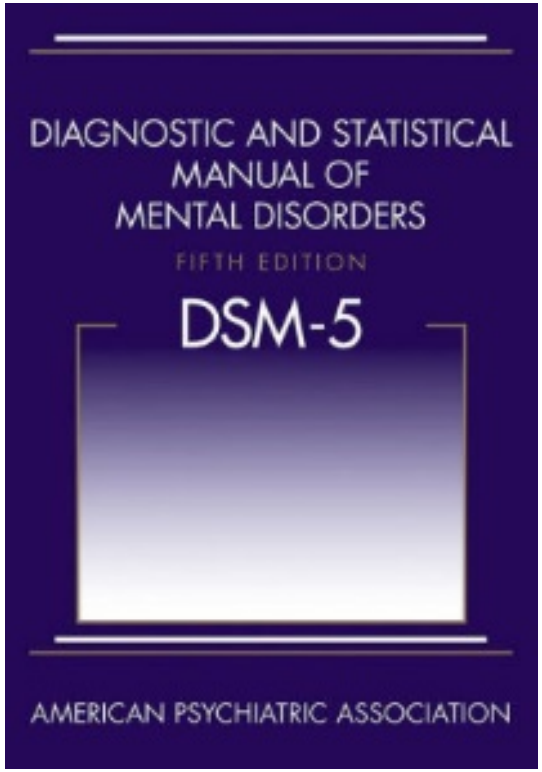
Q & A – 9:30 to 9:45 (15 minutes)

Autism Spectrum Disorder (ASD)

- DSM – 5:

Neurodevelopmental disorder(s) of unknown genetic origin where symptoms unfold over the first few years of life:

  - *Persistent deficits in social communication and social interaction*
  - *Restrictive, repetitive patterns of behavior, interests, or activities*



Pre-Treatment Video 1

Pre-Treatment Video 2

Food Selectivity in ASD

“A meta-analysis indicated that children with ASD have a fivefold increase in feeding problems compared with typically developing peers” – Sharp et al. (2018)

Take Away #1: Children with ASD Experience High Prevalence of Feeding Concerns

Qualification: Also high variability in available estimates

FOCUS ON AUTISM AND OTHER DEVELOPMENTAL DISABILITIES
VOLUME 21, NUMBER 3, FALL 2006
PAGES 153–166

Feeding Problems in Children With Autism Spectrum Disorders: A Review

Jennifer R. Ledford and David L. Gast

Many parents of children with autism spectrum disorders (ASD) report that their children have feeding problems. A body of literature targeted toward parents of children with ASD includes

ASD and that these problems represent a considerable challenge to parents and teachers. Schwarz (2003) concluded that most of these problems in children with ASD can be catego-

"Overall, the results of these quantitative descriptive studies indicate that problem feeding behaviors are present in 46% to 89% of children with ASD"

J Autism Dev Disord (2013) 43:2159–2173
DOI 10.1007/s10803-013-1771-5

ORIGINAL PAPER

Feeding Problems and Nutrient Intake in Children with Autism Spectrum Disorders: A Meta-analysis and Comprehensive Review of the Literature

William G. Sharp · Rashelle C. Berry · Courtney McCracken · Nadrat N. Nuhu · Elizabeth Marvel · Celine A. Saulnier · Ami Klin · Warren Jones · David L. Jaquess

"Prevalence rates varied depending on the content of the item or assessment method, with estimates as high as 95% of a sample describe as resisting trying new foods (Lockner et al., 2008)"

What about the internet?

GROW with Shield HealthCare

All Communities | GRO

Six Reasons Children with Autism Have Eating Issues

Amy Long Carrera, MS, RD, CNSC, CWCMS
Registered Dietitian Nutritionist

12/14/15 2:09 PM PST

Grow with Shield Link

- Home
- About GROW
- Ask the Dietitian

80%

ASD and Nutrition

Up to 80% of children with ASD are selective eaters. Your child may eat fewer fruits and vegetables and have less variety in his diet, putting him at risk for developing nutrient deficiencies. Long-term poor nutritional habits may increase the risk of developing chronic disease in adulthood, including hypertension, diabetes and obesity.

Why such variability?

- Need for better measurement and case definitions

- Past studies varied on how feeding issue was defined and measured:

Picky eater?

Eats a variety of foods?

Will eat only certain foods?

Fixated on recipes?

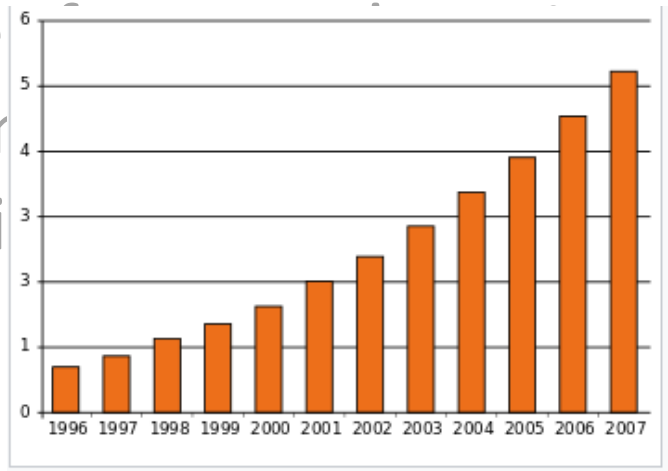
Prefers the same food?

Take Away #2: High Prevalence Corresponds with Unmet Need for Feeding Intervention

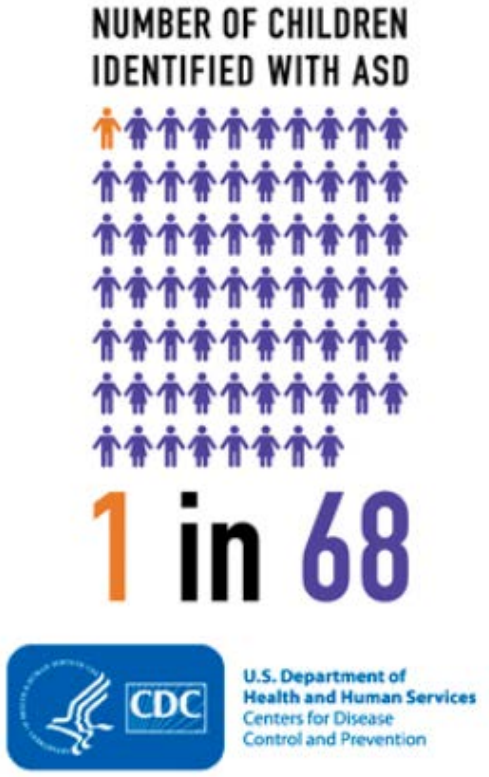
Take home message: Access to evidenced-based care is limited and no large scale movement to develop and evaluate effective treatments

Prevalence of ASD is increasing

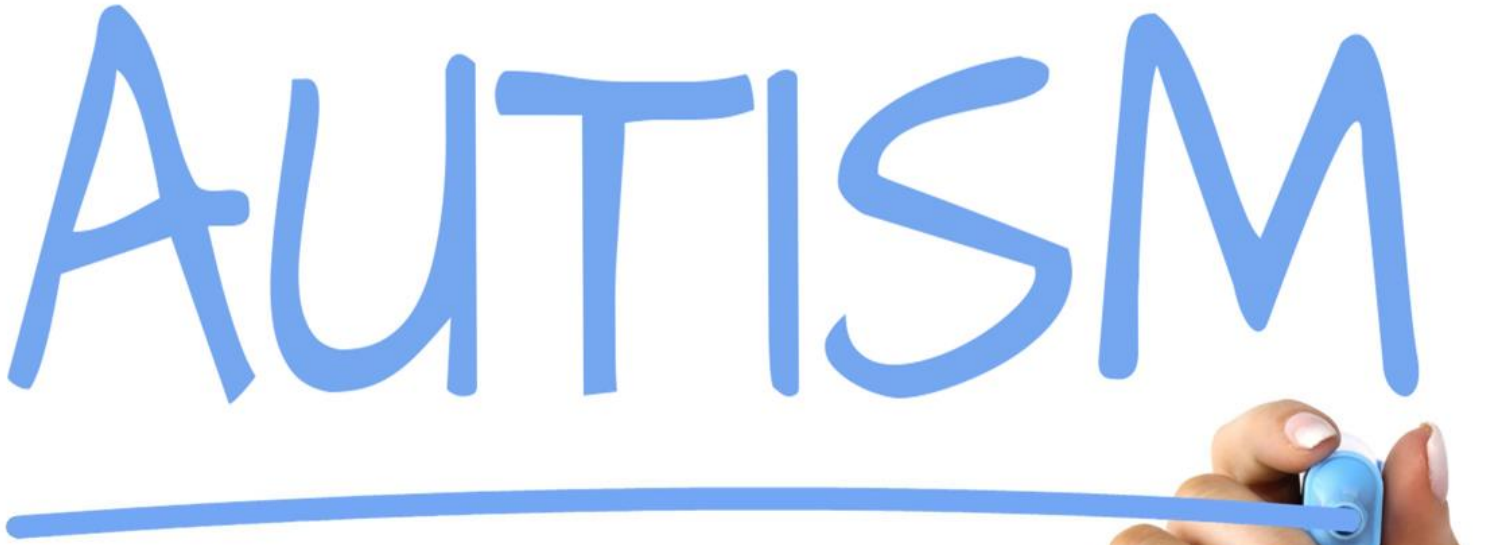
- About 1 in 59 children has been identified with autism spectrum disorder (ASD) according to estimate[illegible] and Developr Monitori (2014).



Reports of autism cases per 1,000 children grew dramatically in the U.S. from 1996 to 2007. It is unknown how much, if any, growth came from changes in autism's prevalence.[24]



Number of children identified with ASD: 1 in 68 (2010)



~ 1 Million Children with ASD in US with Feeding Concern

Math check……

- **73.7 million children below age of 18 in the US in 2017**
- **1 in 58 = 1,237,288 children (~1.2 million) with ASD in US**
- **80% = 989,830 children (~1 million) with ASD + Feeding Concern**

CBT Approach

1. The BUFFET Program: Development of a Cognitive Behavioral **Treatment** for Selective Eating in Youth with **Autism Spectrum Disorder**.

Academic Journal

(English) ; Abstract available. By: Kuschner ES; Morton HE; Maddox BB; de Marchena A; Anthony LG; Reaven J, Clinical Child And Family Psychology Review [Clin Child Fam Psychol Rev], ISSN: 1573-2827, 2017 Dec; Vol. 20 (4), pp. 403-421; Publisher: Springer; PMID: 28534237, Database: MEDLINE

Subjects: Autism Spectrum Disorder complications; Cognitive Behavioral Therapy methods; **Feeding** and Eating **Disorders** therapy; Program Development methods; Child: 6-12 years; All Child: 0-18 years

PDF Full Text PlumX Metrics

ABA Approach
*SOS

5. 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**.

Academic Journal

(English) ; Abstract available. By: Peterson KM; Piazza CC; Volkert VM, Journal Of Applied Behavior Analysis [J Appl Behav Anal], ISSN: 1938-3703, 2016 Sep; Vol. 49 (3), pp. 485-511; Publisher: Wiley-Blackwell; PMID: 27449267, Database: MEDLINE

Subjects: Autism Spectrum Disorder rehabilitation; Behavior Therapy methods; Caregivers psychology; **Feeding** Behavior physiology; Food Preferences; Sensation physiology; Verbal Behavior; Child: 6-12 years; Child, Preschool: 2-5 years; All Child: 0-18 years; Female; Male

Find It @ Emory PlumX Metrics

Intensive Approach

19. Improvements in Children's **Feeding** Behavior after Intensive Interdisciplinary Behavioral **Treatment**: Comparisons by Developmental and Medical Status.

Academic Journal

(English) ; Abstract available. By: Seiverling L; Hendy HM; Yusupova S; Kaczor A; Panora J; Rodriguez J, Behavior Modification [Behav Modif], ISSN: 1552-4167, 2019 Aug 06, pp. 145445519865170; Publisher: Sage Publications; PMID: 31387371, Database: MEDLINE

Find It @ Emory PlumX Metrics

Behavioral/ Nutrition Approach

6. The **Autism** Managing Eating Aversions and Limited Variety Plan vs Parent Education: A Randomized Clinical Trial.

Academic Journal

(English) ; Abstract available. By: Sharp WG; Burrell TL; Berry RC; Stubbs KH; McCracken CE; Gillespie SE; Scahill L, The Journal Of Pediatrics [J Pediatr], ISSN: 1097-6833, 2019 Aug; Vol. 211, pp. 185-192.e1; Publisher: Mosby; PMID: 31056202, Database: MEDLINE

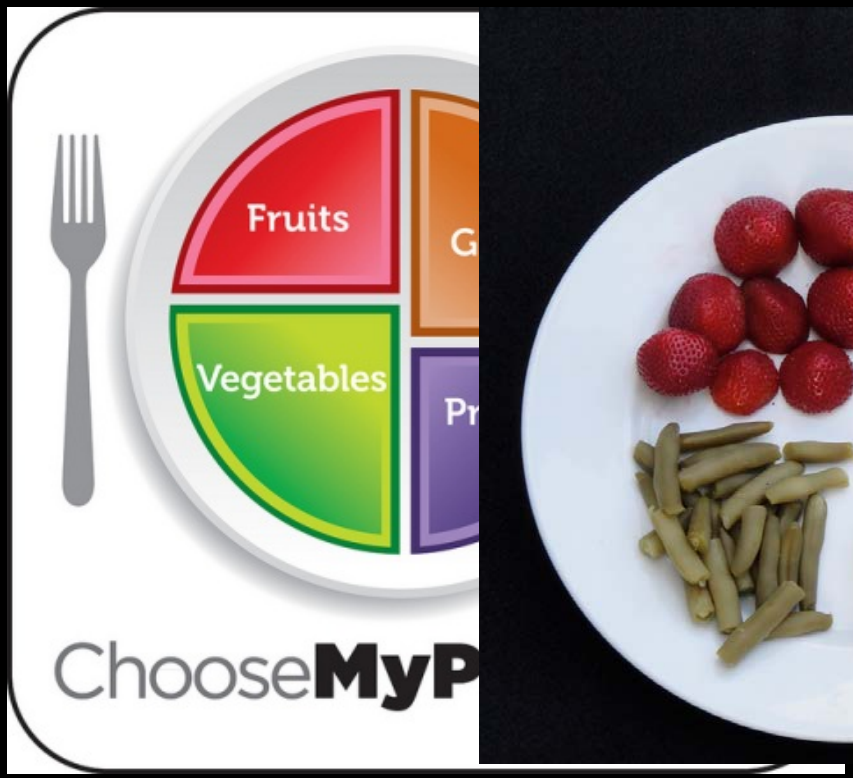
Find It @ Emory PlumX Metrics

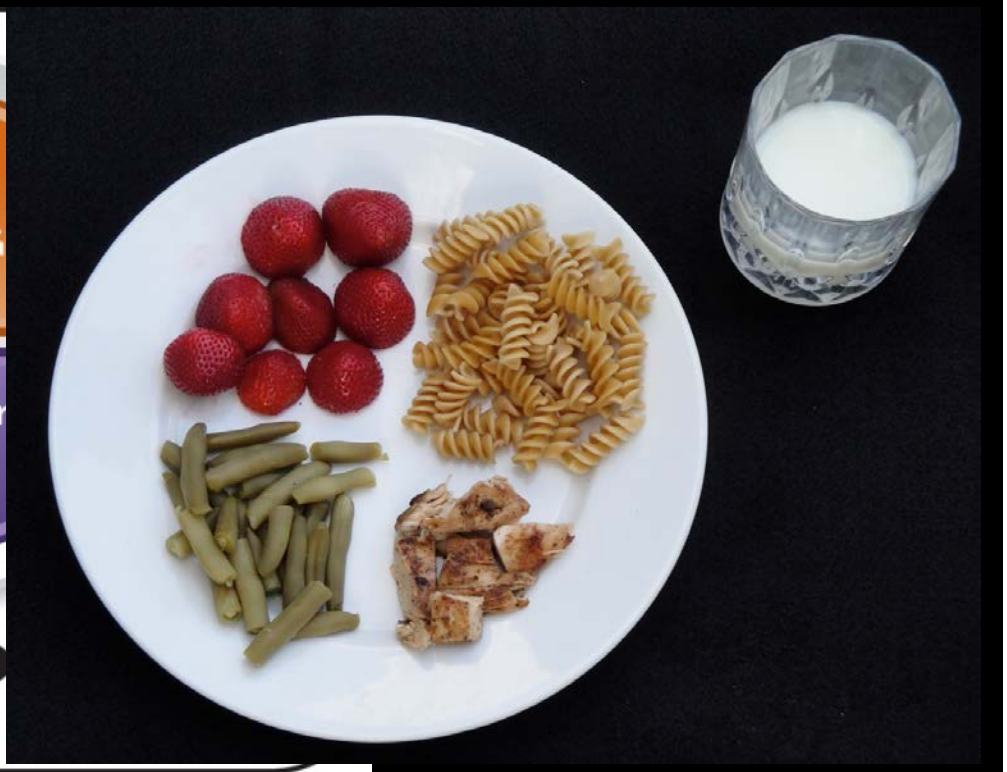
None are ready for widespread dissemination and adoption

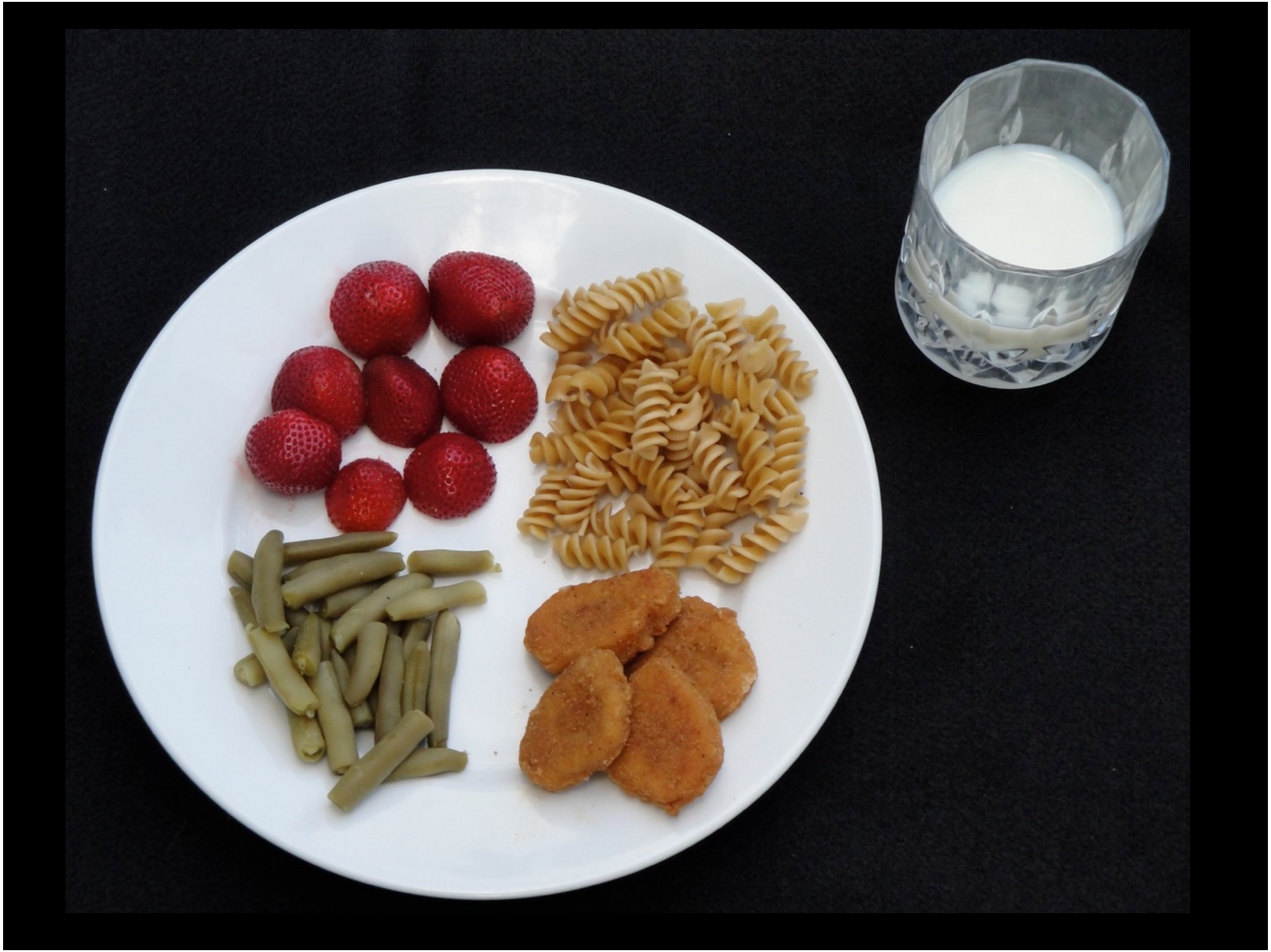
Take Away #3: Food Selectivity is Primary Feeding Concern in ASD

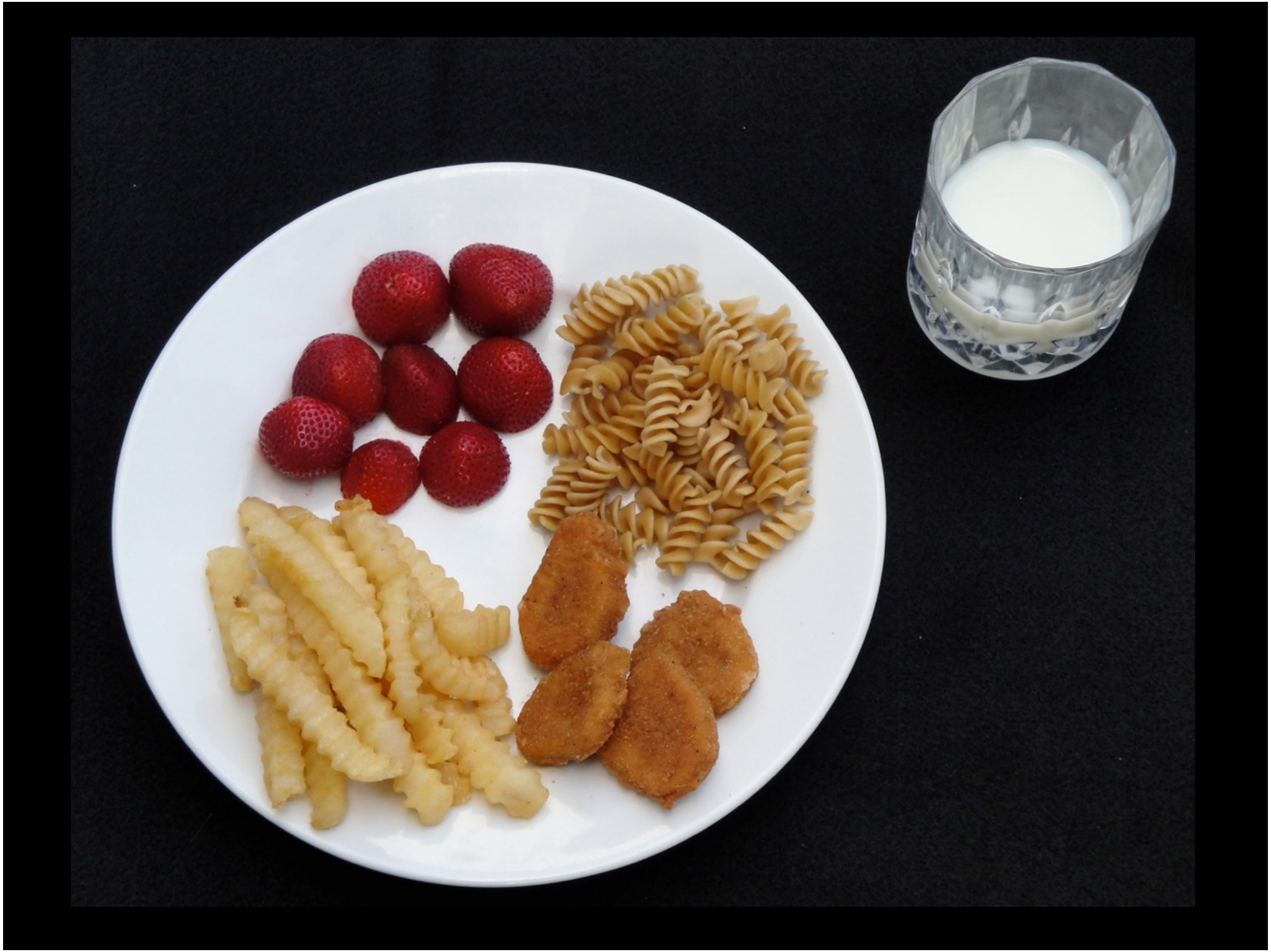
Qualification: Does not exclude other types of feeding concerns occurring in this population, but it is the primary concern

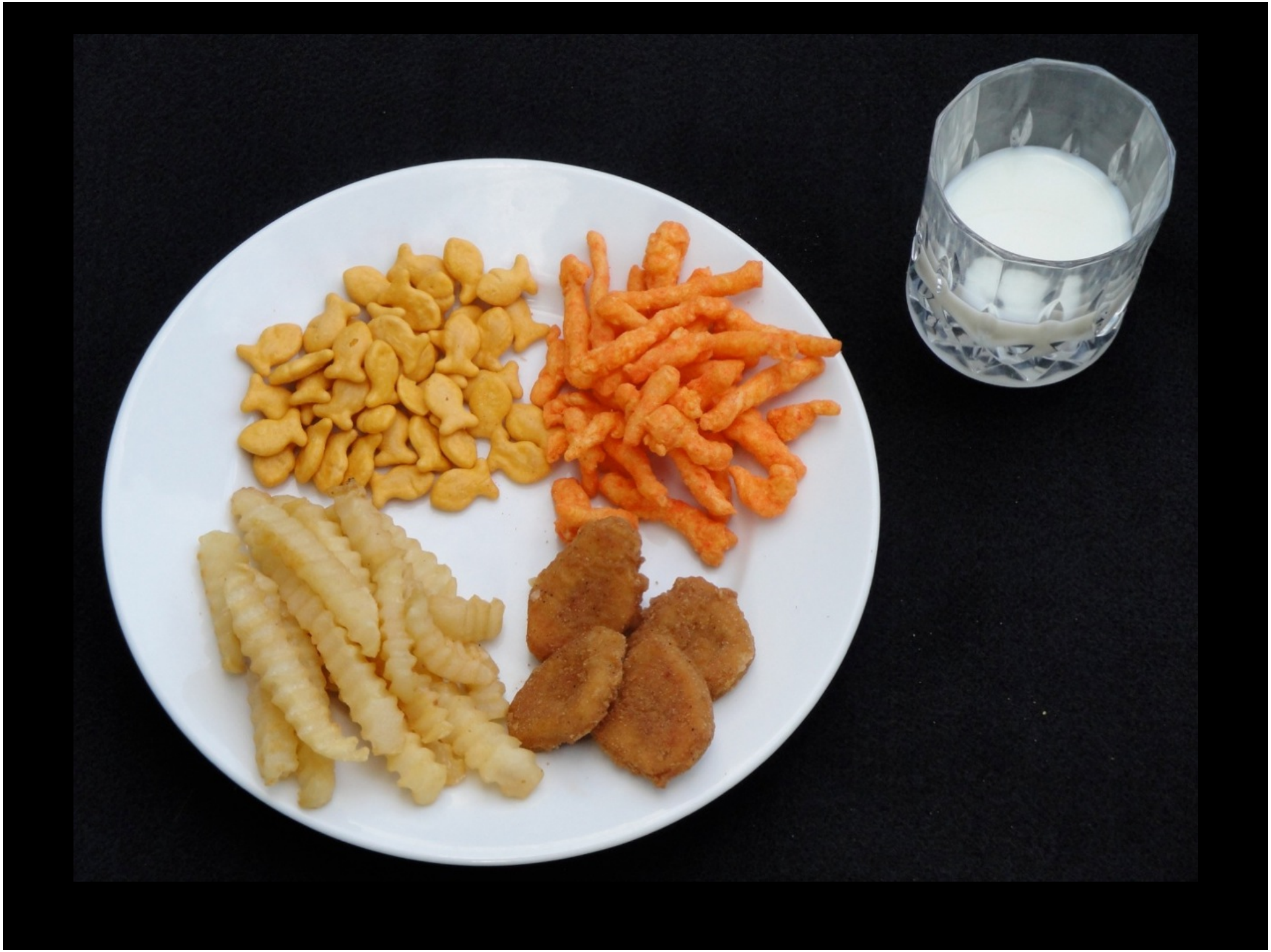
Recommended Goal for Food Intake











“The Autism Diet”

Table 4 Effect sizes, 95 % confidence limits and within-group tests for heterogeneity for studies included in the meta-analysis for feeding behavior problems by comparison groups

ASD versus subgroup	Number of contributing studies	Random effects model				Within-groups		
		SMD (SE)	OR	95 % confidence limits		*p* value	χ^2 test (Q)	*p* value
				LCL	UCL			
All groups	15	0.89 (0.08)	5.11	3.74	6.97	<0.001		
TD	13	0.94 (0.11)	5.49	3.77	7.98	<0.001	29.9	0.003
SB	3	0.98 (0.22)	5.89	2.73	12.71	<0.001	0.45	0.798
DD	2	0.67 (0.19)	3.36	1.69	6.67	0.001	0.012	0.913

TD typically developing, *DD* other developmental delay, *SB* siblings

Fivefold increase in the odds of having a feeding problem in ASD

Food Selectivity

Preference - carbohydrates, snacks, fats, and/or processed food

Rejection - fruits and vegetables

Sharp et al (2013). Feeding Problems and Nutrient Intake in Children with Autism Spectrum Disorders: A Meta-analysis and Comprehensive Review of the Literature. *Journal of Autism and Developmental Disorders,* 43(9): 2159 - 2173.

Frequent Rejection of Fruits and Vegetables


New York Times
BESTSELLER
Fast Food
NATION
Eric Schlosser
The Dark Side of the All-American Meal
COOKING
GREAT
SINCE
Grinder
Breakfast Lunch & Dinner
cDonald's
BILLION
PLAYPLACE

This is NOT just picky eating

Picky eating

- Intensity: Mild preference; tolerance of other foods
- Impact: Minor accommodations required; annoying to parents
- Duration: Short; Early childhood

Food selectivity

- Intensity: Strong preference for certain foods/Extreme food restriction
  - Refusal behaviors to avoid
- Impact: Significant accommodations required on part of the family; places child at risk for nutritional deficiencies
- Duration: Chronic; Longstanding concern into adolescence and adulthood

Food neophobia part of childhood

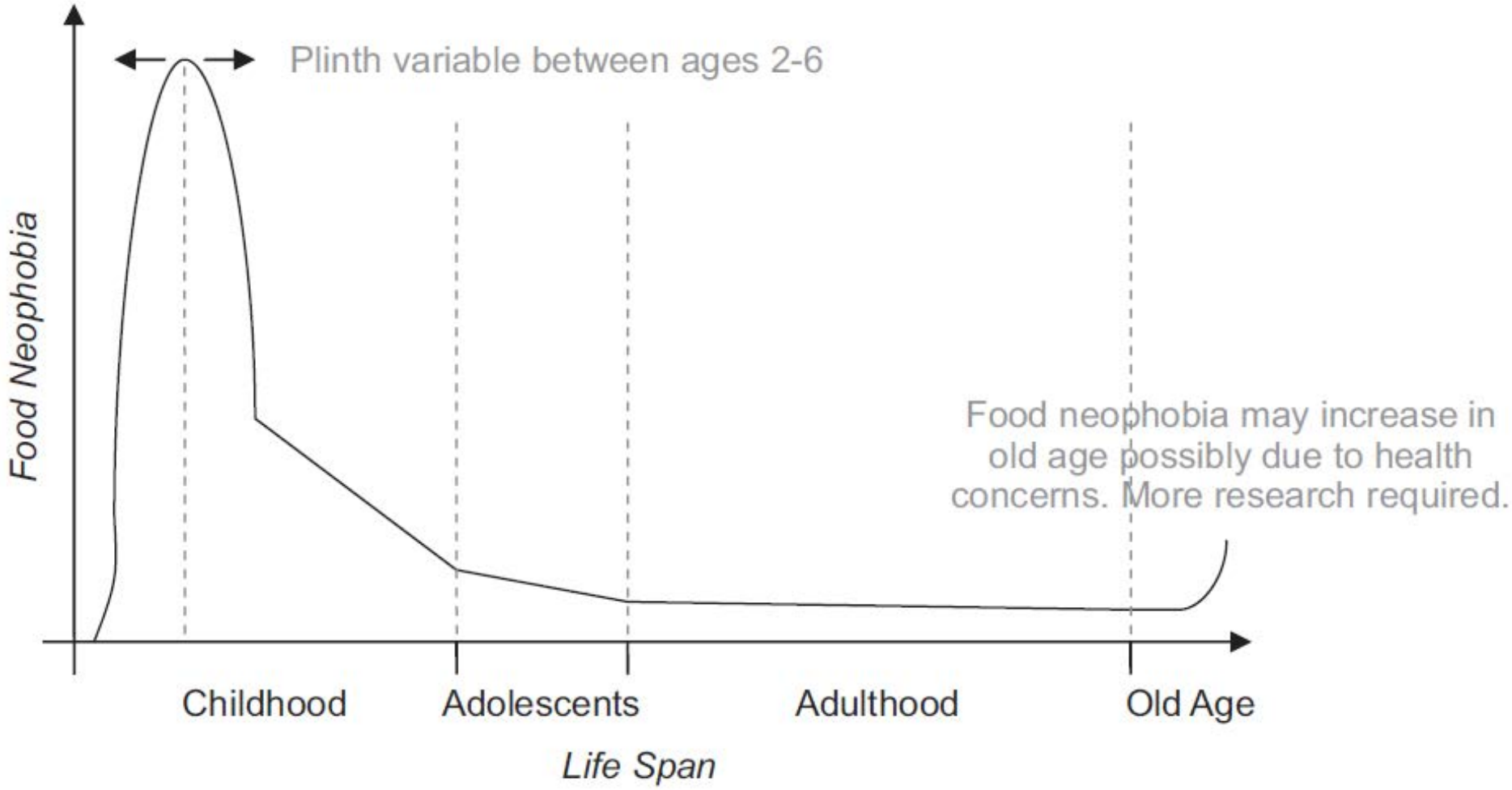


Figure 1: Life span model of food neophobia as proposed by Dovey et al. (2008)

Why?

GI Concerns

Behavioral Rigidity

Sensory Processing

Escape and avoidance of pain

?

Variety:: Detection Medical Solution

Impact beyond the child

J Dev Phys Disabil (2012) 24:19–33
DOI 10.1007/s10882-011-9252-2

ORIGINAL ARTICLE

Mothers' Challenges in Feeding their Children with Autism Spectrum Disorder—Managing More Than Just Picky Eating

Laura G. Rogers · Joyce Magill-Evans · Gwen R. Rempel

Daily Living and Quality of Life

Increased parental stress regarding health and development

Reduced opportunities to eat at restaurants or social occasions

Disrupted family meals & further limitations in social interactions

Required to prepare multiple menus for each meal

The Parent Experience

- Meals described as stressful, chaotic, and energy depleting
- Mealtimes lack positive interactions
- Child's food selectivity limited other family members' food choices during meals
- Caregivers reported ceasing family meals to avoid further worry, guilt, and stress.

Marquenie, K., Rodger, S., Mangohig, K., & Cronin, A. (2011); Suarez, Atchison, & Lagerwey (2016)

Take Away # 4: Symptom Severity Important when Assessing and Treating Food Selectivity in ASD

Qualification: No consensus definition on how best to quantify

Article

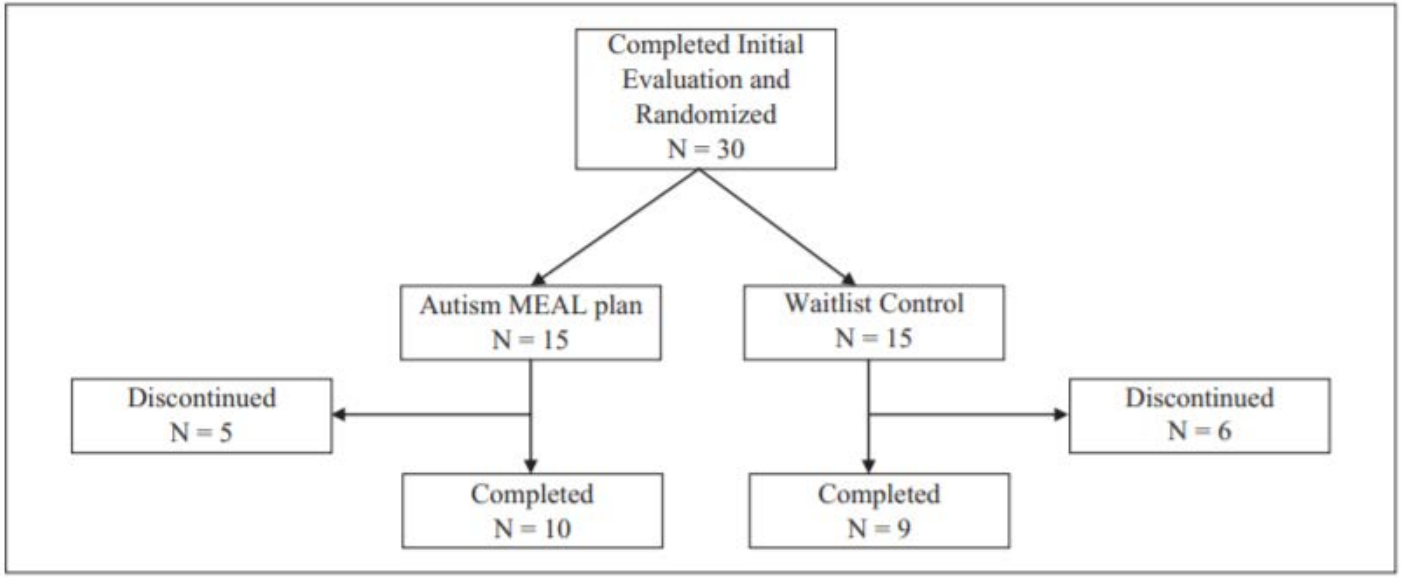
autism

Autism
0(0) 1–11

DOI: 10.1177/1362361313489190
aut.sagepub.com
SAGE

The Autism MEAL Plan: A parent-training curriculum to manage eating aversions and low intake among children with autism

William G Sharp[1,2], T Lindsey Burrell[1,3] and David L Jaquess[1,2]



Findings from MEAL Plan 1.0

- Enrollment criteria: ASD + Caregiver Concern RE: their child's mealtime behaviors or diet

- Results:
  - High social validity – Parents liked it!!
  - Parent perception of effectiveness – Parents thought it helped!!
  - Reduced levels of caregiver stress following – Parents felt supported!!
  - NO CHANGE in Food Selectivity or Mealtime Behaviors on a group level

- Research Lab Observations:
  - Highly variable response to intervention
  - Symptom severity also variable in terms of food selectivity and mealtime behaviors

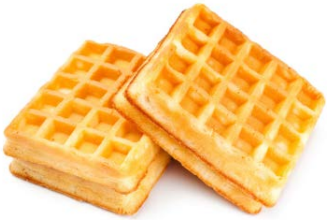
Food selectivity is not just a number

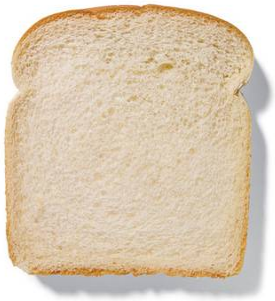
- Bandini et al. (2010): Children with ASD consumed 19 foods over three days







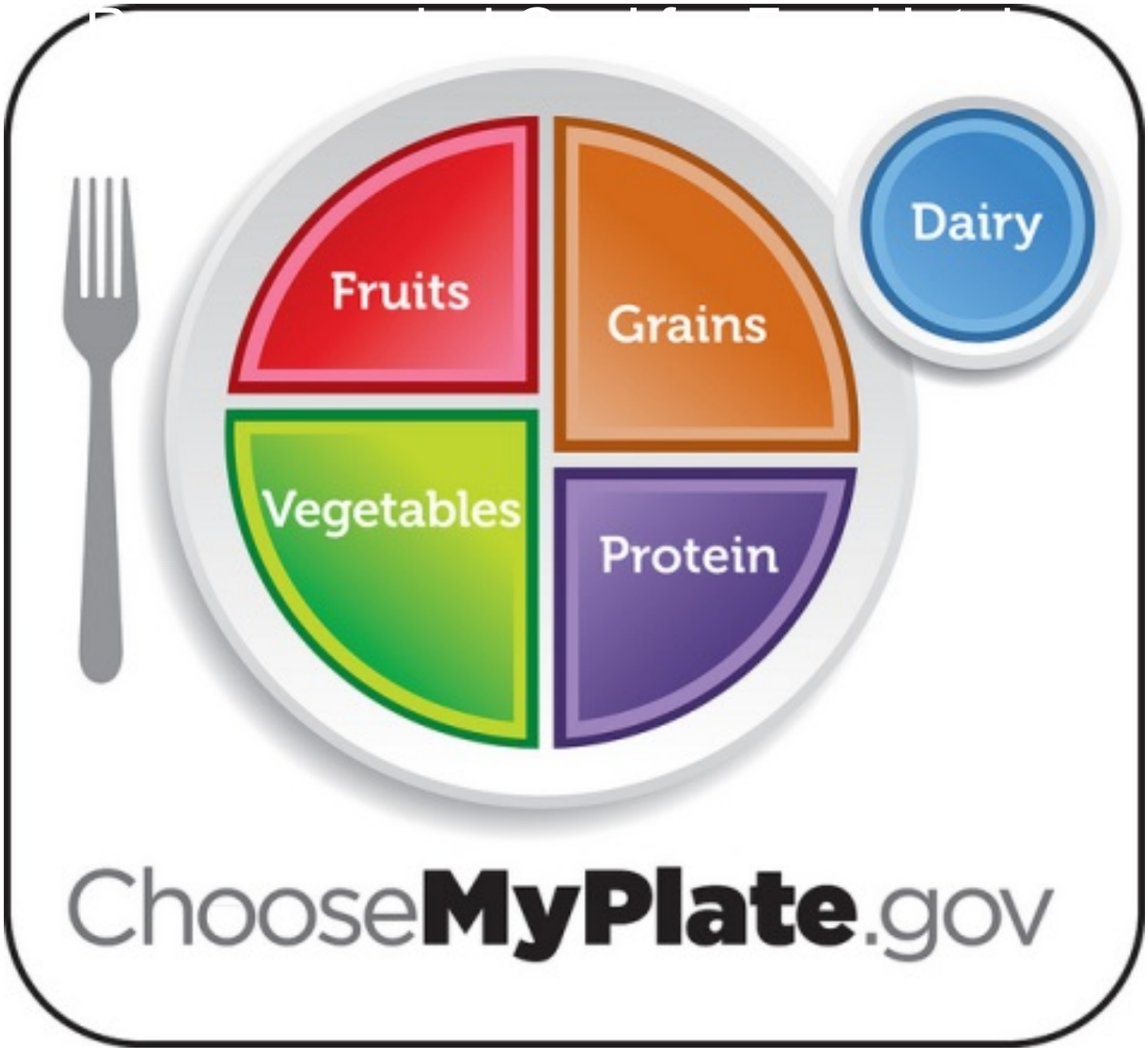






Toward Better Measurement

- A rigorous definition of food selectivity must account for both the breadth and quality of a child's diet.

- The most recent Dietary Guidelines for Americans provides a benchmark for ideal dietary intake - ***emphasizes the importance of consuming a wide variety of foods across all food groups***


Fruits
Grains
Dairy
Vegetables
Protein
ChooseMyPlate.gov

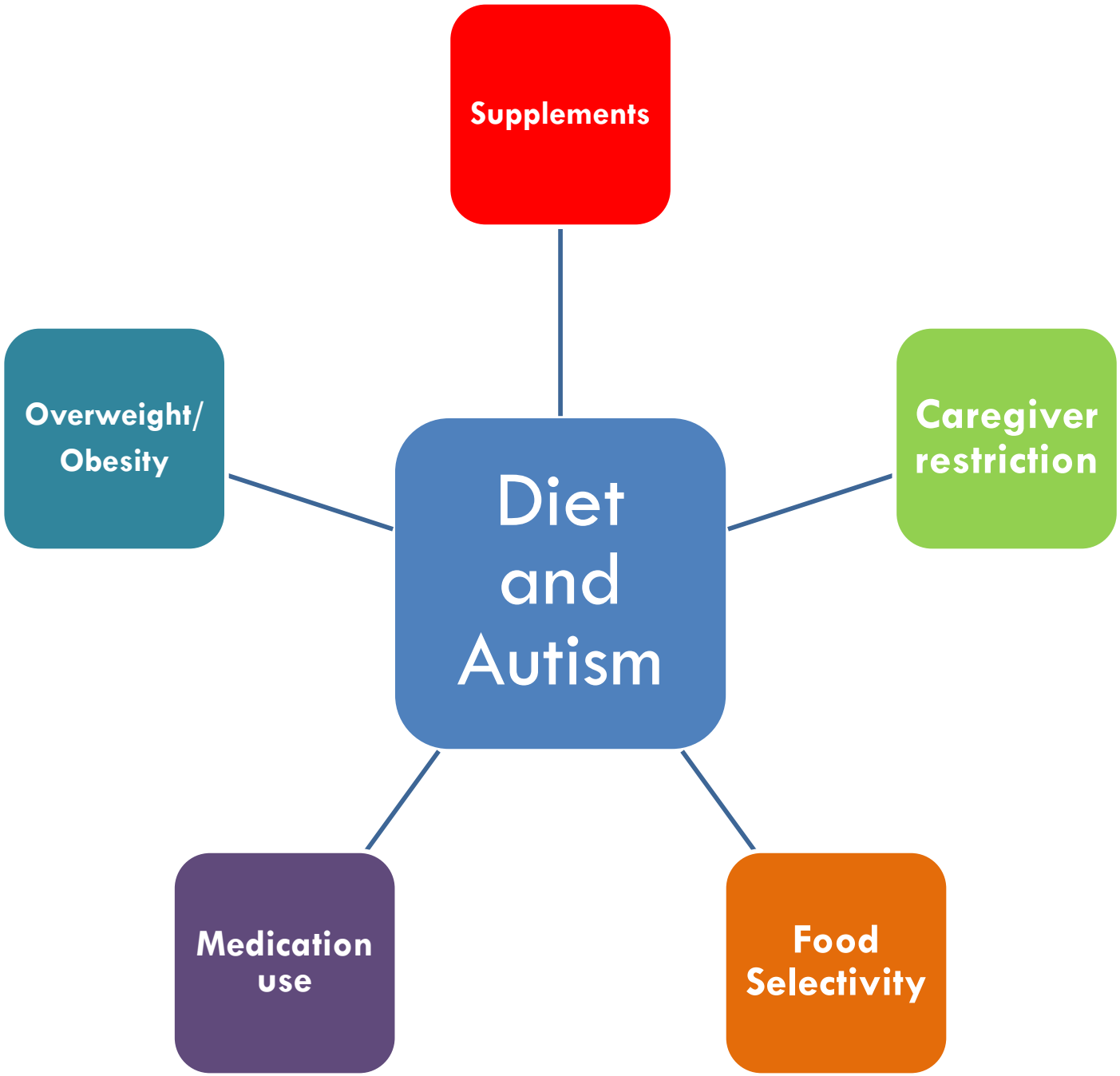
Framework for defining food selectivity by severity (Sharp and Postorino, 2017)

Category	Criteria	Rationale
Severe Food Selectivity	• Complete rejection of one or more food groups	Increases the risk of micro- and/or macronutrient deficiency (e.g., scurvy; iron deficiency anemia; kwashiorkor)
	• Accepts five or fewer total food items	Further narrowing of the diet would eliminate additional food groups
Moderate Food Selectivity	• Consumes two or fewer items in one or more food groups	Reflects a diet that may lack diversity of nutrient-dense foods; further restriction increases likelihood of nutrient deficiency
	• Regularly (weekly) accepts at least one item across the five food groups	Decreases likelihood of being diagnosed with a nutrient deficiency; however, intake may be limited to a handful of preferred items or involve high intake of a single food group
Mild Food Selectivity	• Diet involves at least three or more items from each good group (15 total foods); more than half of items fall into one food group	Suggests low probability of nutrient deficiency while recognizing child may show preference for a certain food group (e.g., grains)
	• Consistently (daily) accepts foods from all five food groups	Indicates the child maintains a consistent degree of dietary diversity

Nutrition Concerns in ASD

A story of restriction, poor dietary diversity, and potential medical consequences

TOWARD BETTER MANAGEMENT


Supplements
Overweight/ Obesity
Diet and Autism
Caregiver restriction
Medication use
Food Selectivity

"He was breast fed, with supplementary feeding, until the end of the eighth month; there were frequent changes in formula"

"He vomited a great deal during his first year, and feeding formulas were changed frequently with little success."

"She quit taking any kind of nourishment at 3 months. She was tube-fed five times daily up to 1 year of age."

Kanner L, Autistic Disturbances of Affective Contact, *Nervous Child*, 1943.

Nutritional Deficiencies

VS

- 380 calories
- 2 grams of saturated fat
- 10 grams of dietary fiber
- Key micronutrients:
  - Vitamin A
  - Thiamin
  - Riboflavin
  - Niacin
  - Vitamin B_{12}
  - Vitamin C
  - Vitamin D
  - Vitamin E
  - Folate
  - Calcium
  - Iron
  - Magnesium
  - Zinc

- 720 calories
- 8 grams of saturated fat
- 4 grams of dietary fiber
- Key micronutrients:
  - Thiamin
  - Riboflavin
  - Niacin
  - Vitamin C
  - Calcium
  - Iron
  - Magnesium
- No quantities of:
  - Vitamin A
  - Vitamin B_{12}
  - Vitamin D
  - Vitamin E
  - Folate
  - Zinc

Nutritional deficiencies are usually associated with poverty in developing countries

WIC

WOMEN · INFANTS · CHILDREN

Higher Risk Pediatric Populations

- Children on medical prescribed diets
  - Gluten-free
  - Allergen-free
  - Ketogenic
- Children with developmental/behavioral disabilities
  - Child mediated refusal behaviors
  - Parent mediated dietary restriction

Food and their nutrients

Nutrient	Primary Food Sources	Short term impact of deficiency	Long term impact of deficiency
Vitamin A	Vegetables	Impaired vision	Blindness, increased infection susceptibility, poor growth
Folic Acid	Fortified grains	Megoblastic, macrocytic anemia	Weakness, depression, and neuropathy
Vitamin B_{12}	Fish, meat, and poultry	Megoblastic anemia	Neuropathy, neurologic disorders
Vitamin C	Fruit, vegetables	Scurvy	Lesions, weakness
Vitamin D	Fortified milk	Poor bone growth	Rickets, Osteomalacia, Osteoporosis
Vitamin E	Vegetable oils, nuts		Neuromuscular disturbances
Calcium	Dairy products	Poor bone growth	Osteoporosis
Iron	Fish, meat, and poultry; fortified products	Poor growth, impaired muscle function	Iron deficiency anemia
Zinc	Fish, meat, poultry, eggs, dairy products	Loss of sense of taste and smell; poor immune function; poor growth	Acrodermatitis enteropathica

Scurvy

- "the patient had a very limited diet, eating only hamburgers, Wheat Chex®, Pop Tarts®, oyster crackers, and pancakes" (Cole et al. Scurvy in a 10-year-old boy. *Pediatr Derm* (2011) 28: 444–446.)

- "the child subsisted nearly exclusively on chocolate milk and that the parents did not supplement the child's diet with multivitamins" (Gongidi et al. Scurvy in an autistic child: MRI findings. Pediatr Radiol (2013) 43:1396–1399.)

- "He was subsisting on Honeycomb cereal and one type of Goldfish crackers. Although vitamin supplementation had been tried, [the] patient had either refused or vomited." (Harrington et al. Limping in a child with autism. Contemporary Pediatrics. April 1. 2007.)

Rickets

- “his current nutritional intake derived mainly from chips and gravy with a complete refusal of dairy products” (Stewart et al. Symptomatic nutritional rickets in a teenager with autistic spectrum disorder. *Child: care, health and development* (2008), 34(2): 276–278.)

- “Dietary history revealed a markedly altered intake consisting of only French fried potatoes and water for several years.” (Clark et al. *J Parenter Enteral Nutr* (1993) 17: 284-286.)

Iron Deficiency and Anemia

- Increased risk of iron deficiency in children with ASD shown by measuring serum ferritin levels
  - Latif et al. Iron Deficiency in Autism and Asperger Syndrome. *Autism.* (2002) 6: 103-114.
  - Herguner et al. Ferritin and iron levels in children with autistic disorder. *Eur J Pediatr*. (2012) 171(1):143-6.

"Scurvy was diagnosed in seven children at Boston Children's Hospital. All of the children had a developmental disorder and autism was the most common. They had a long-standing history of food selectivity with diets devoid of fruits and vegetables, and none of the children were supplemented with a multivitamin. They presented with limp, and an elaborate panel of tests and procedures were undertaken before the diagnosis of scurvy was made. Treatment with vitamin C led to rapid recovery of symptoms. This report emphasizes the importance of considering nutritional causes of musculoskeletal symptoms in children with autism and restrictive diets."

Ma NS, Thompson C, Weston S. Brief Report: Scurvy as a Manifestation of Food Selectivity in Children with Autism. J Autism Dev Disord. 2016 Apr; 46(4):1464-70.

Overweight and Obesity

MODERN FAMILIES + FRESH IDEAS
parenting

If Your Autistic Child Has a Weight Problem, He's Not Alone

According to the CDC, autistic or special needs kids have a higher risk of being obese.

Tags: Autism, Childhood Obesity

By Margie Wilson-Mars

SHUTTERSTOCK

Two of my autistic boys are overweight, and according to a new study by the Centers for Disease Control and Prevention (CDC), they're not alone. Children with developmental disabilities were already known to have a higher risk of obesity, but new research shows kids on the autism spectrum have *double* the risk.

The CDC and the government's Health Resources and Services Administration got the figures from parent-reported data from the National Health Interview Survey between 2008 and 2010 on 9,600 kids ages 12 to 17. Here is what the study found:

- Out of the total, 1,400 of the parents reported their children were autistic, had ADHD, an intellectual disability, a learning disability or some type of developmental disability.
- The children who have developmental disabilities were 50 percent more likely to be obese.
- When researchers looked specifically at kids with autism, they discovered their risk was more than double.

Why ASD?

Increased Calorie Intake due to Food Selectivity

Use of Edibles in Behavioral Intervention

Decreased Levels of Physical Activity

Medication for Problem Behavior

Disruptive Behavior

Overweight and Obesity

Other Notes

- On the Vineland Daily Living domain, obese children with ASD had lower scores than non-obese children
  - Need to explore interaction between disruptive behavior, adaptive behavior and obesity
- Prevalence of obesity in children with ASD and disruptive behavior (21.4%) higher compared with 18% reported in ATN two recent studies (De Vinck-Baroody et al., 2015; Hill et al., 2015)
  - Only 20.6% - 34.4% of ATN samples had disruptive behavior

Why Disruptive Behavior?

- May make it more difficulty to:
  - Limit carbohydrates
  - Introduce novel (& healthy) foods
  - Engage children in physical activity
  - More likely to be enrolled in behavior modification using reinforcement

Flopping

- Becomes a really effective….
- …. Especially if you are overweight or obese

Food Selectivity

- Parents often underestimate overall caloric intake due viewing the child's intake as "snacking"
  - Child may graze throughout the day
  - Not sit down for "meals"
  - But consume extreme amount of calories

Edibles as Reinforcers

- What makes a good edible reinforcer?
  - Easy to store and transport
  - Easy to delivery in units
  - Long shelf life
  - Relatively affordable
  - Item child is highly motivated to earn

Caregiver Initiated Restriction

Parents.

Home / Toddlers & Preschoolers / Health / Autism

8 Facts About the 'Autism Diet'

One of the most popular alternative treatments for autism is the gluten-free casein-free diet (GFCF). It has not been proven to work, and many doctors are cautious about it, but if you're wondering if it could help your child, read the facts below.

By Sally Kuzemchak, RD

Yunhee Kim

Gluten Free/Casein Free Studies

Early randomized clinical trials	Knivsberg et al., 2002 Elder et al., 2006	Small sample size Mixed Results Parent placebo effect?
Largest trial	Whiteley et al, 2010	Single blind Positive results with standardized measures No screening for intolerance/allergy
Later clinical trials	Hyman et al., 2010	Double-blind Small sample size Screened for wheat and milk allergy, celiac disease No improvement
	Johnson et al., 2011	3-month study Healthy diet comparison Improvements in both groups
	Hyman et al., 2016	All children placed on diet for 12 weeks, then given snack challenges Double-blind, placebo controlled No changes in symptomatology

Diet	Foods restricted
Elimination diets/elemental diet[22,23]	Elimination diet (6 foods): milk, egg, wheat, soy, peanuts/tree nuts, fish/shellfish Elemental: all foods except an amino acid–based formula
Fermentable oligo-di-monosaccharides and polyols[24,25]	Foods containing fructose (eg, fruit, high-fructose corn syrup), lactose (eg, cow's milk dairy), fructans (eg, wheat, onion, garlic), galactans (eg, legumes), and polyols (eg, sorbitol, cherries, avocados)
Food coloring/food additives avoidance[26,27]	Foods that contain food color additives (food dye)
Gluten-free, casein-free[28-30]	Foods containing gluten (eg, bread, pasta) and casein (eg, cow's milk, yogurt)
Ketogenic diet or modified Atkins diet[31,32]	Carbohydrate-rich foods, including sugar
Specific carbohydrate diet[29,33,34]	Cereal grains (eg, wheat, oats, rice), processed meats (eg, lunch meats, hot dogs), canned vegetables, canned fruits, most fruit juices, soy beans, chick peas, bean sprouts, mung beans, fava beans, yogurt, milk, processed cheese, tubers (eg, potatoes, yams), curry, onion powder, garlic powder

Figure 1. Possible caregiver-initiated restrictions in autism spectrum disorder (in alphabetical order).

Diet in ADHD

- Dietary interventions reviewed:
  - Omega-3 and -6 Fatty Acid Supplementation
  - Feingold Diet
  - Hypoallergenic/Elimination Diet
  - Food Antigen Desensitization
  - Sugar/Aspartame
  - Ketogenic
  - “Healthy” Diet Pattern

Millichap and Yee, *Pediatrics*, January 2012

Diet in ADHD

"Healthy" Diet (not associated with ADHD)	**Western Diet (associated with ADHD)**
Rich in:	Higher intake of total fat and saturated fat
Fish	
Vegetables	Higher intake of refined sugar
Fruits	Higher intake of sodium
Legumes	Deficient in Omega-3 fatty acids
Whole grain foods	Deficient in fiber
	Deficient in folate

Nutrition Treatment in ASD

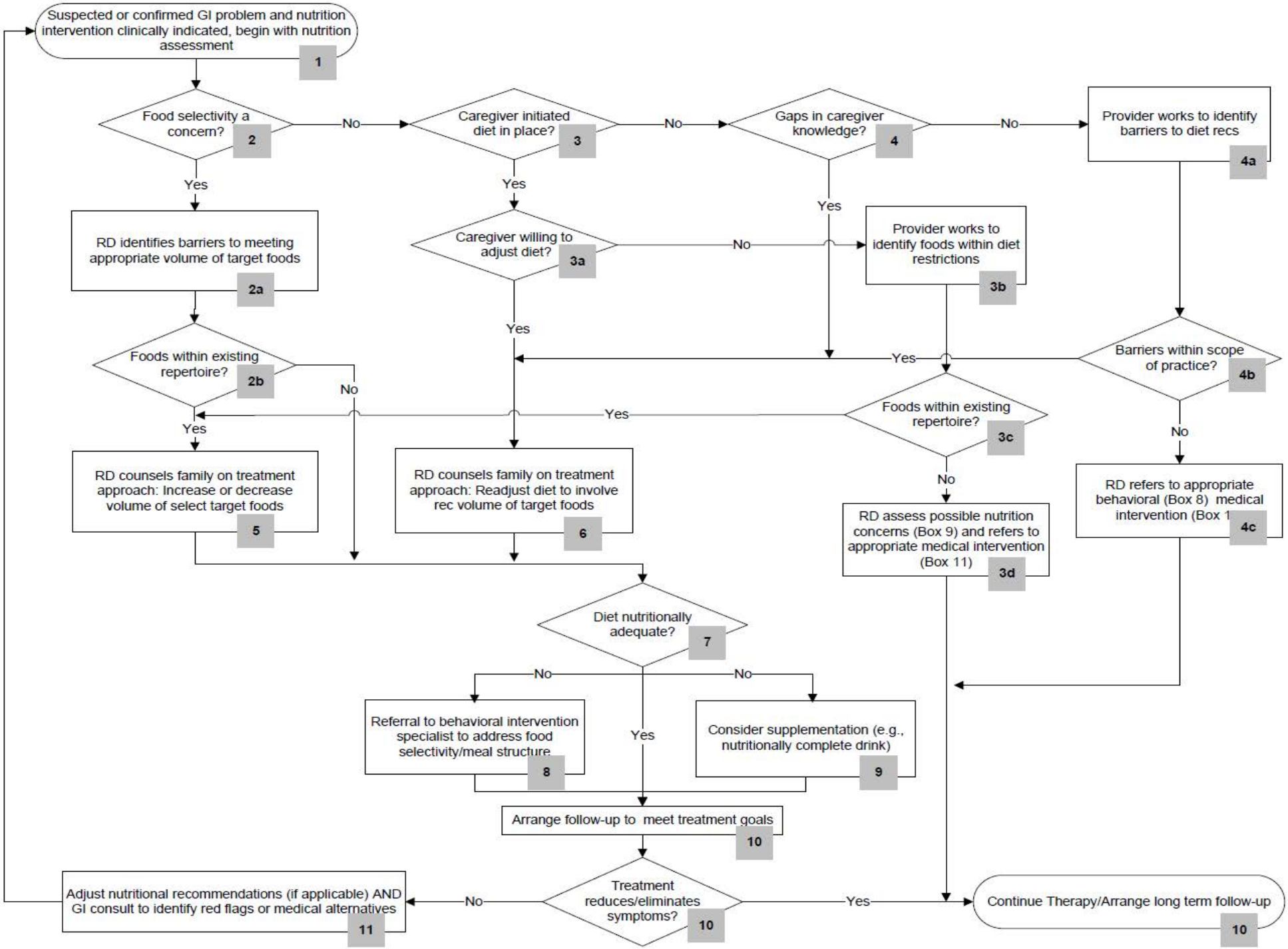
eat right.

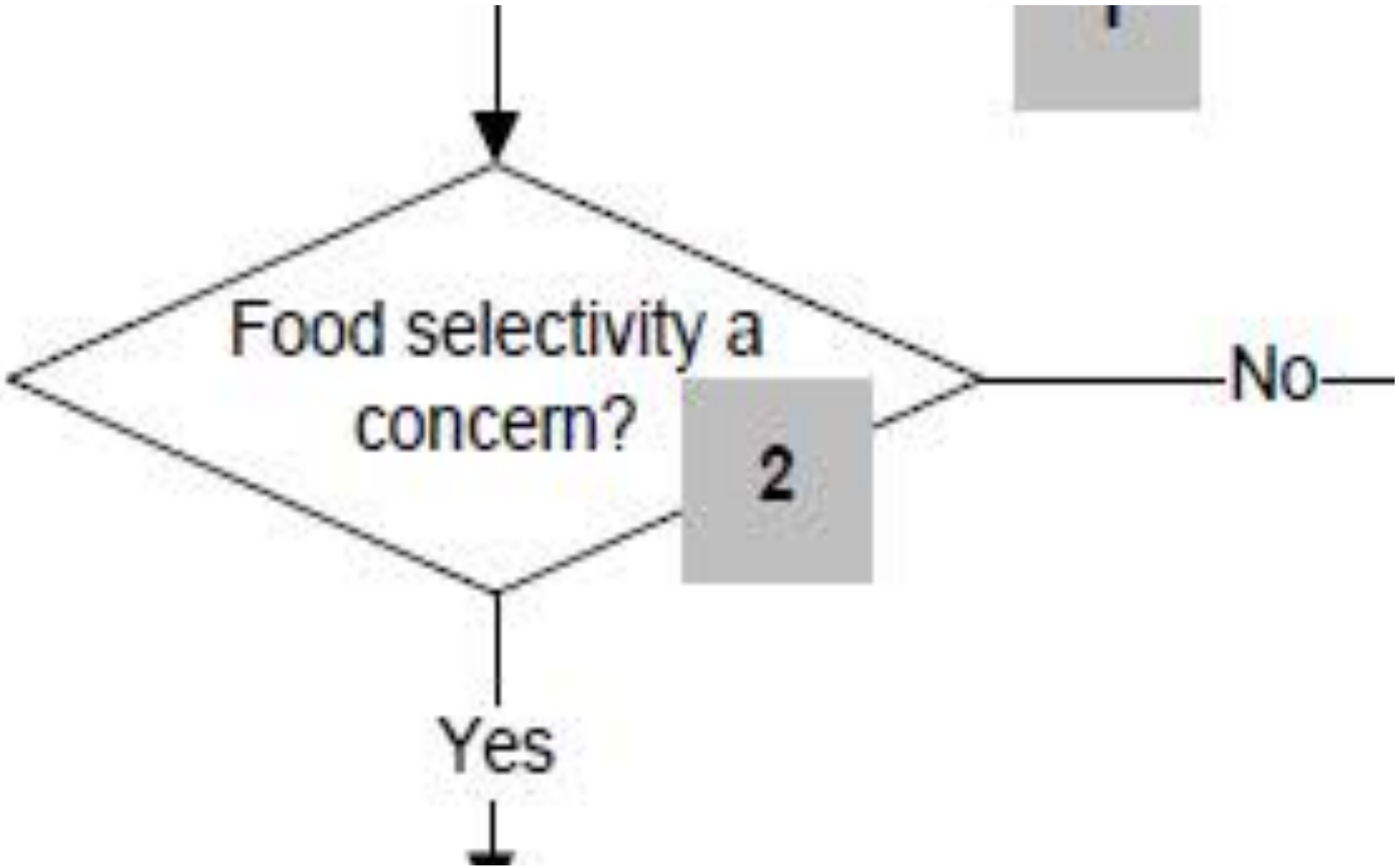
PRACTICE APPLICATIONS
Topics of Professional Interest

Nutrition Management of Gastrointestinal Symptoms in Children with Autism Spectrum Disorder: Guideline from an Expert Panel

AUTISM SPECTRUM DISORDER (ASD) is characterized by a core deficit in social communication with concomitant repetitive/perseverative behaviors and restriction in interests,[1] and individuals with ASD experience varying degrees of impairment.[2] The estimated prevalence of ASD in pediatric populations has climbed dramatically during the past decade, with approximately 1 in every 68 children currently meeting diagnostic criteria in the United States.[2] High prevalence occurs against a backdrop of increased health care costs[4] and social burden.[5] Medical comorbidities are significantly overrepresented compared with other pediatric populations, and children pediatric populations[9,10]; however, no guidelines are available for adapting existing practices for use among children with ASD. Current standards of care might be neither practical nor feasible, given the combination of behavioral, developmental, medical, and social deficits associated with the condition. For example, children with ASD often present with limited communication and, as a result, their symptom presentation may be unusual compared with that of their peers.[7,8,11,12] In many cases, GI

This article was written by ***Rashelle C. Berry,*** *MPH, MS, RD, CSP, lead nutritionist, Pediatric Feeding Disorders Program, Marcus Autism Center, Atlanta, GA;* ***Patricia Novak,*** *MPH, RD, EMPOWER project coordinator, Chil-*


Suspected or confirmed GI problem and nutrition intervention clinically indicated, begin with nutrition assessment
1
Food selectivity a concern?
2
No
Caregiver initiated diet in place?
3
No
Gaps in caregiver knowledge?
4
No
Provider works to identify barriers to diet recs
4a
Yes
RD identifies barriers to meeting appropriate volume of target foods
2a
Yes
Caregiver willing to adjust diet?
3a
No
Provider works to identify foods within diet restrictions
3b
Yes
Barriers within scope of practice?
4b
Foods within existing repertoire?
2b
No
Yes
Yes
Foods within existing repertoire?
3c
No
RD refers to appropriate behavioral (Box 8) medical intervention (Box 1
4c
RD counsels family on treatment approach: Increase or decrease volume of select target foods
5
RD counsels family on treatment approach: Readjust diet to involve rec volume of target foods
6
RD assess possible nutrition concerns (Box 9) and refers to appropriate medical intervention (Box 11)
3d
Diet nutritionally adequate?
7
No
No
Referral to behavioral intervention specialist to address food selectivity/meal structure
8
Yes
Consider supplementation (e.g., nutritionally complete drink)
9
Arrange follow-up to meet treatment goals
10
Adjust nutritional recommendations (if applicable) AND GI consult to identify red flags or medical alternatives
11
No
Treatment reduces/eliminates symptoms?
10
Yes
Continue Therapy/Arrange long term follow-up
10


Food selectivity a concern?
2
No
Yes

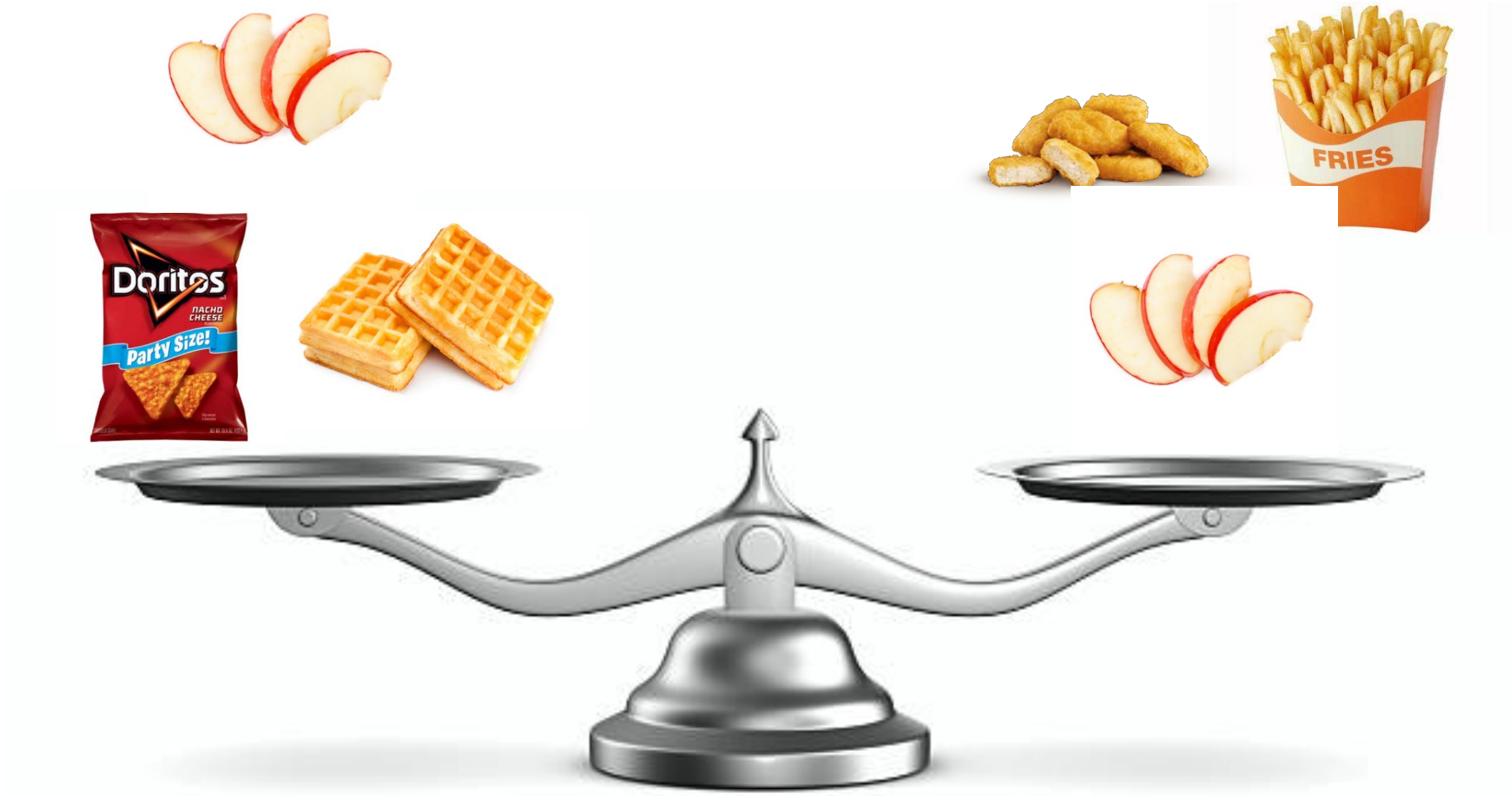
What is the child WILLING to eat?

Food Group	Foods Accepted
Fruits	
Vegetables	
Meats/Beans	
Grains	
Dairy	
Drinks	
Snacks/Sweets	

What is the child ACTUALLY eating?

Meal	Time	Place	Foods and Amounts
Breakfast			
AM Snack			
Lunch			
PM Snack			
Dinner			
Evening Snack			


Doritos
NACHO CHEESE
Party Size!
FRIES


Doritos
NACHO CHEESE
Party Size!
FRIES

Balancing the Diet

- Ideally, a meal contains foods from 3 food groups; a snack contains foods from 2 food groups
- Work with preferred food list, mixing most preferred with “will accept”
- If possible, each meal or snack should have a fruit and/or vegetable

Vitamin Supplementation

- Add multivitamin
  - Appropriate for:
    - Children with a medium level of rigidity
    - Children who chew
    - Children who will eat candy
    - Children who are selective only by texture NOT by type
    - Children who do not hoard food

Vitamin Supplementation

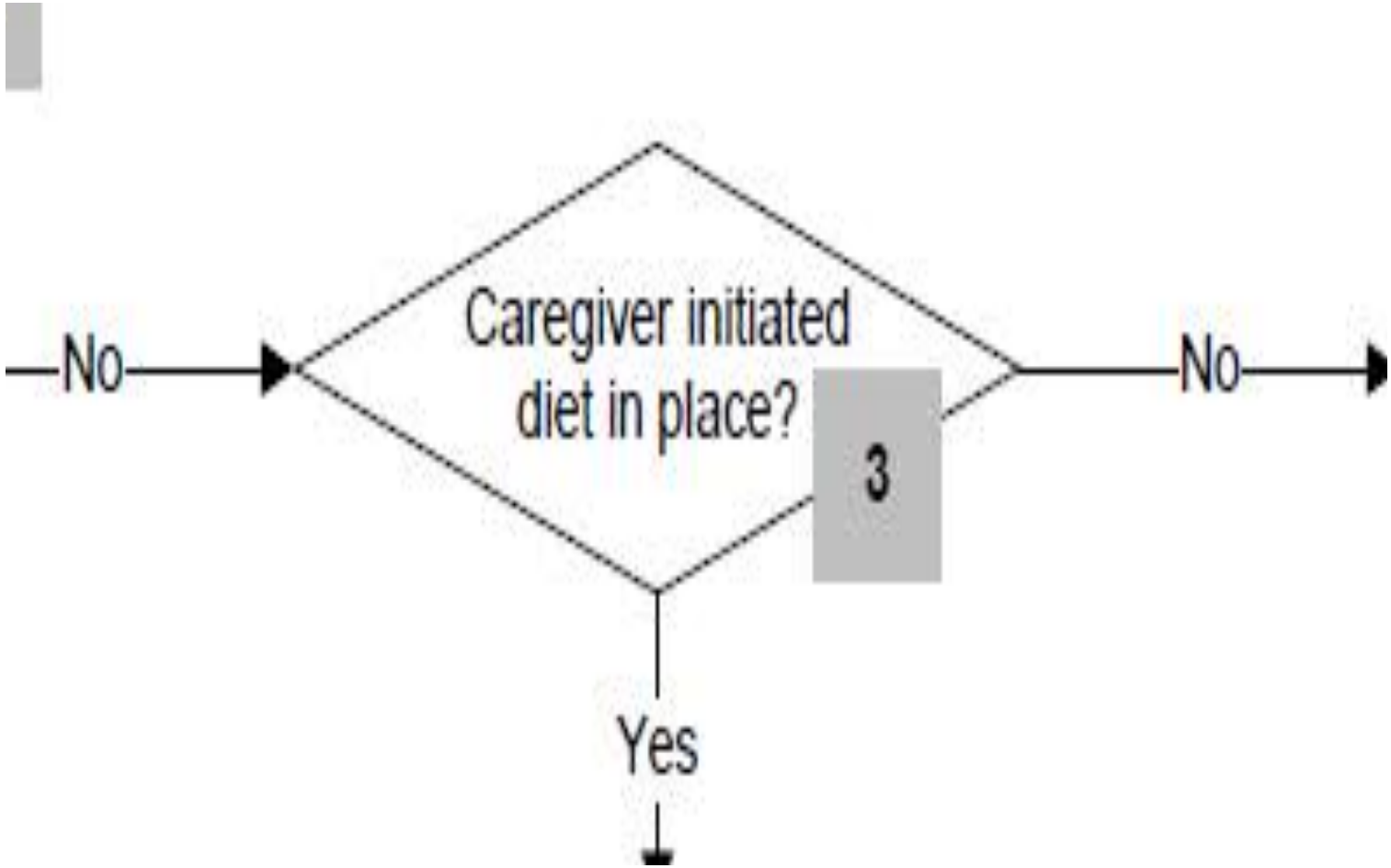
- CAUTION
  - Many children diagnosed with food selectivity will not take a multivitamin since it is not a preferred food
  - If the child is overweight due to hoarding, risk of overdose
  - Diet might be excessive in some nutrients; multivitamin could put some nutrients above TUL

Additives to food

- Add _____ to preferred food
  - Add… butter, instant breakfast, fiber, water, pureed vegetables, vitamins…
    - Add a very small amount at a time, starting as small as 1/8 teaspoon
- CAUTION
  - Run the risk of contaminating the food and further decreasing the number of foods accepted
  - Need to have a good idea of degree of selectivity

Reducing Volume

- Eliminate grazing
  - Appropriate for all children; especially overweight and underweight
  - Time with restricted access to food should be increased gradually
- CAUTION
  - Child might excessively tantrum, aggress, have self injurious behavior


No
Caregiver initiated diet in place?
3
No
Yes

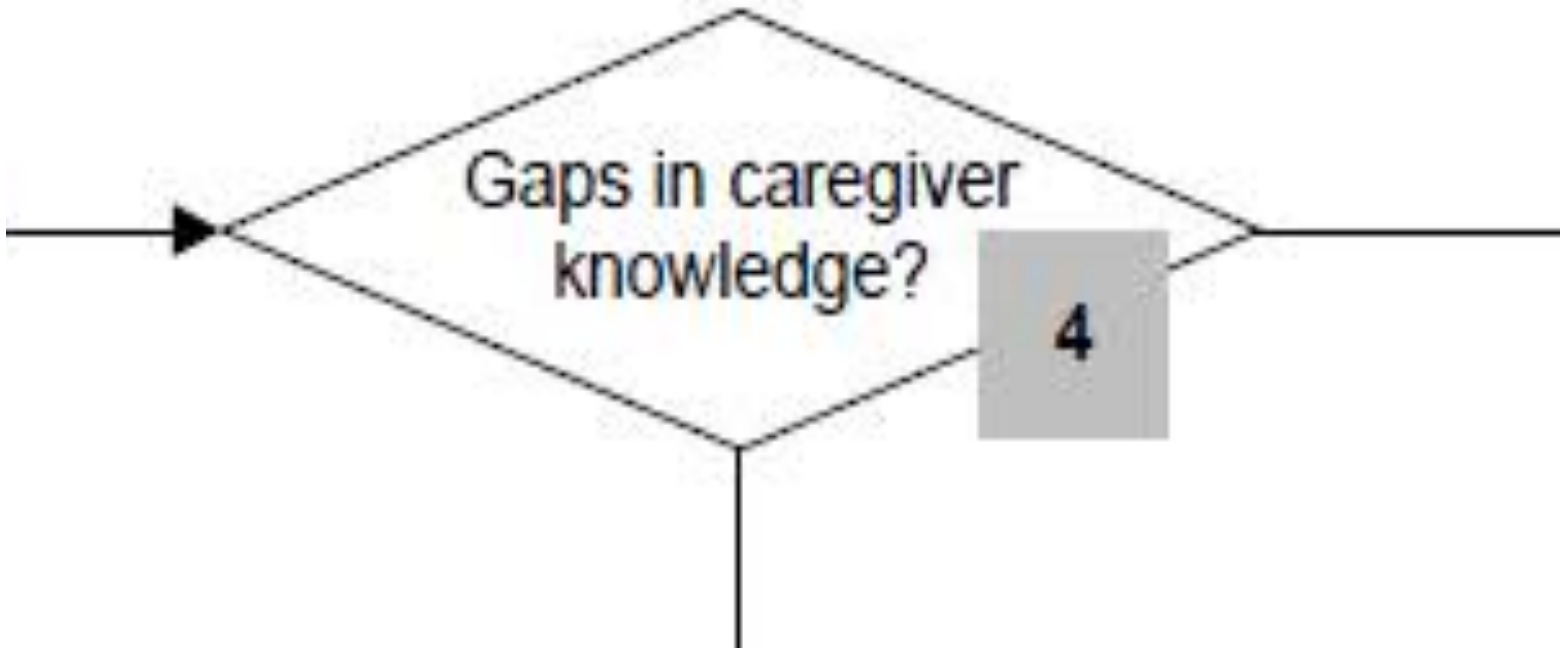
Questions to Consider

- What is the caregiver hoping to achieve with dietary restriction?
- Does the caregiver believe that the child is experiencing pain?
- Is the caregiver willing to see other medical professionals before beginning a diet?
- What foods does the child currently eat/not eat?

Danger of Use

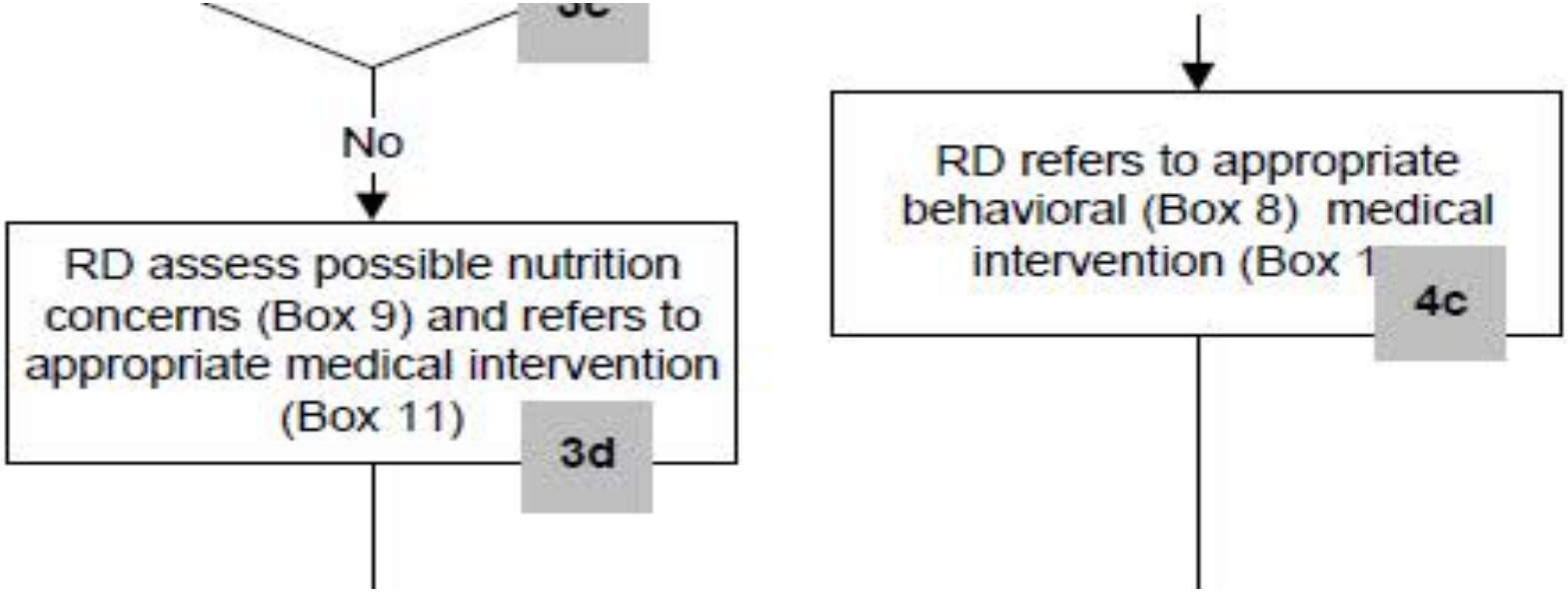
- May increase risk of nutritional deficiencies
  - Diet likely already compromised
- May involve removing preferred foods
  - Further restricting a child's diet
- May contaminate previously preferred food
  - Milk to soy milk
- May give caregivers a false sense of hope


it’s ok.


Gaps in caregiver knowledge?
4

Parent Consultation

- Regulate meal pattern
  - 3 meals + 2 snacks
  - Eat every 2 ½ to 3 hours
- Offer foods from at least 2 food groups at each meal and snack (if possible)
  - Ideal is 3 food groups for meals, 2 for snacks
- Slowly reduce or increase portions as appropriate
- Eliminate grazing
  - Start with 15 minutes no grazing, increase by 15 minutes every 3 days if no tantrums, work up to 2 ½ hours
- Eliminate juice or other sugary drinks
  - If juice is only drink accepted, dilute with water slowly, over time


No
RD assess possible nutrition concerns (Box 9) and refers to appropriate medical intervention (Box 11)
3d
RD refers to appropriate behavioral (Box 8) medical intervention (Box 1
4c

Change response checklist

Presentation of new and/or non-preferred foods		
Do you present your child with new and/or non-preferred foods?	YES	NO
Does your child have negative behaviors when presented with new and/or non-preferred foods?	YES	NO
Does your child have aggressions (hitting, kicking, scratching) or self-injurious behaviors (hitting self, biting self) when new and/or non-preferred foods are presented?	YES	NO
Are you able to manage your child's behaviors when new and/or non-preferred foods are presented?	YES	NO
Changes to mealtime routines (i.e. timing for meals, foods presented at each meal)		
Is your child flexible about mealtime routines?	YES	NO
Does your child have negative behaviors when mealtime routines are changed?	YES	NO
Does your child have aggressions (hitting, kicking, scratching) or self-injurious behaviors (hitting self, biting self) when mealtime routines are changed?	YES	NO
Are you able to manage your child's behaviors when mealtime routines are changed?	YES	NO
Denied or delayed access to food (limiting snacking/grazing)		
Have you ever limited your child's access to food or delayed the presentation of food?	YES	NO
Does your child have negative behaviors when food is denied or access to food is delayed?	YES	NO
Does your child have aggressions (hitting, kicking, scratching) or self-injurious behaviors (hitting self, biting self) when food is denied or access to food is delayed?	YES	NO
Are you able to manage your child's behaviors when food is denied or access to food is delayed?	YES	NO

Behavioral Intervention in ASD

A story of structure, realistic goals, and stimulus fading

IMPROVING MEALTIME INTERACTIONS

Take Away #5: Effective Interventions Available for Feeding Disorders, including Food Selectivity in ASD

Qualification: Need to Develop and Evaluate Treatments for Across Selectivity in ASD

www.jpeds.com • THE JOURNAL OF PEDIATRICS

A Systematic Review and Meta-Analysis of Intensive Multidisciplinary Intervention for Pediatric Feeding Disorders: How Standard Is the Standard of Care?

William G. Sharp, PhD[1,2], Valerie M. Volkert, PhD[1,2], Lawrence Scahill, MSN, PhD[1,2], Courtney E. McCracken, PhD[1], and Barbara McElhanon, MD[1,2]

Objective To assess models of care and conduct a meta-analysis of program outcomes for children receiving intensive, multidisciplinary intervention for pediatric feeding disorders.

Study design We searched Medline, PsycINFO, and PubMed databases (2000-2015) in peer-reviewed journals for studies that examined the treatment of children with chronic food refusal receiving intervention at day treatment or inpatient hospital programs. Inclusion criteria required the presentation of quantitative data on food consumption, feeding behavior, and/or growth status before and after intervention. Effect size estimates were calculated based on a meta-analysis of proportions.

“Results indicate intensive, multidisciplinary treatment holds benefits for children with severe feeding difficulties.”

Multidisciplinary Team: Psych, Nutrition, SLP, and Medicine

Includes Benefit for Severe Food Selectivity in ASD

Hammill Institute on Disabilities
Focus on Autism and Other Developmental Disabilities
XX(X) 1–12

DOI: 10.1177/1088357609349245
http://focus.sagepub.com

A Retrospective Chart Review of Dietary Diversity and Feeding Behavior of Children With Autism Spectrum Disorder Before and After Admission to a Day-Treatment Program

William G. Sharp,[1,2] David L. Jaquess,[1,2] Jane F. Morton,[1,2] and Aida G. Miles[3]

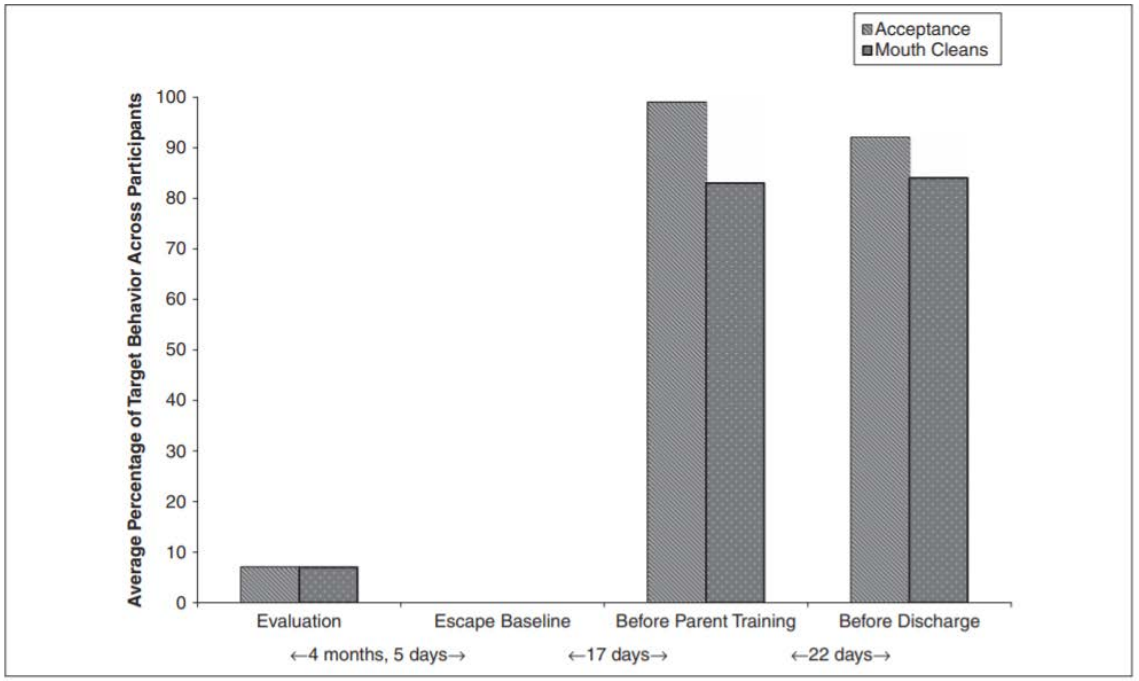
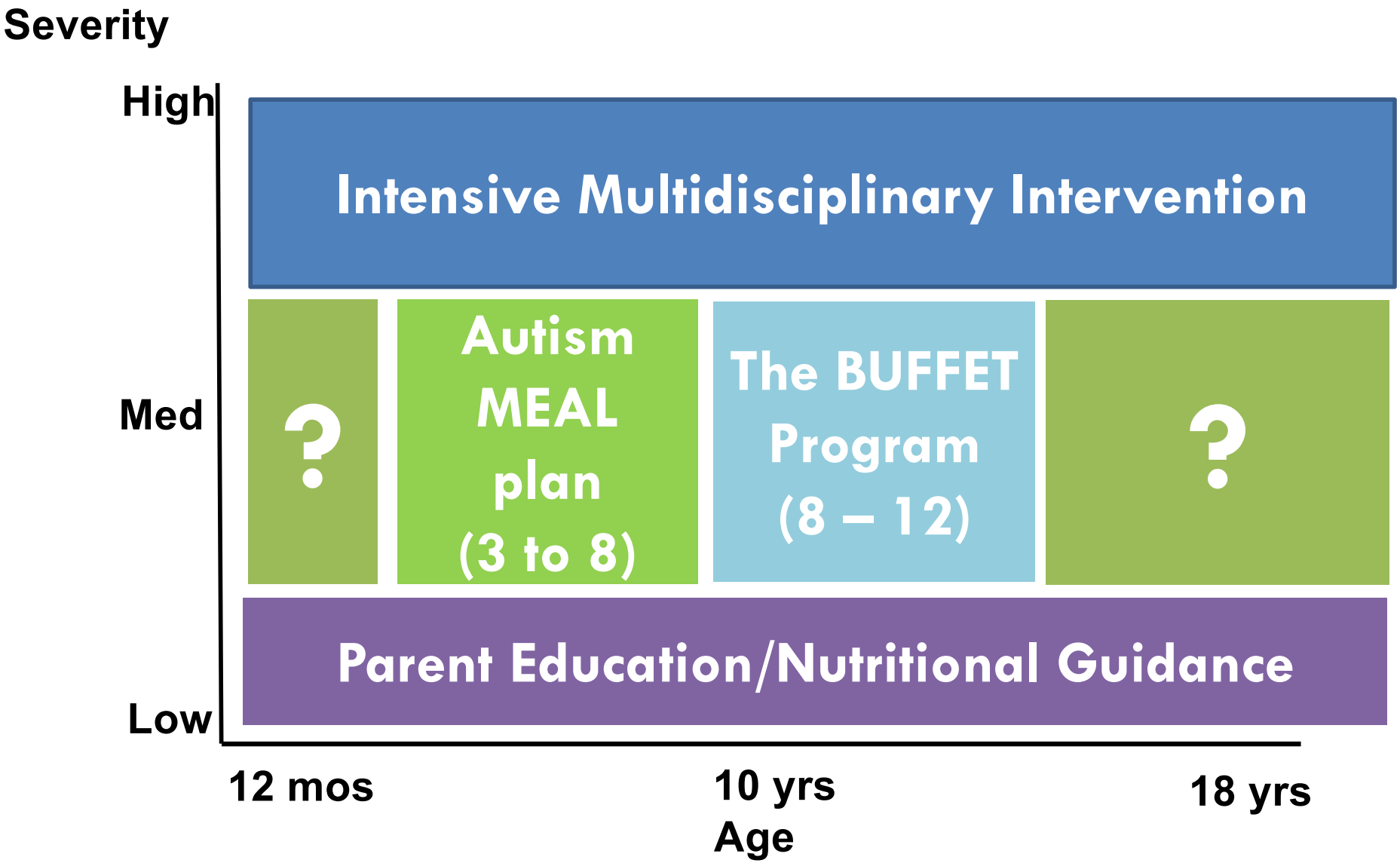


Figure 1. Acceptance and swallowing of nonpreferred food by time

Limitations of Extant Literature

- Intensive Model of Care
  - Not widely available in all communities
  - Not a level of intervention appropriate for moderate feeding concerns
  - Time and resource intensive

Matching Intervention to Severity



ARTICLE IN PRESS

THE JOURNAL OF PEDIATRICS • www.jpeds.com

ORIGINAL ARTICLES

The Autism Managing Eating Aversions and Limited Variety Plan vs Parent Education: A Randomized Clinical Trial

William G. Sharp, PhD[1,2], T. Lindsey Burrell, PhD[1,2], Rashelle C. Berry, MPH, MS, RD[2], Kathryn H. Stubbs, PhD[2], Courtney E. McCracken, PhD[1], Scott E. Gillespie, MS[1], and Lawrence Scahill, MSN, PhD[1,2]

Objective To assess the feasibility and initial efficacy of a structured parent training program for children with autism spectrum disorder and moderate food selectivity.

Study design This 16-week randomized trial compared the Managing Eating Aversions and Limited variety (MEAL) Plan with parent education. MEAL Plan (10 core and 3 booster sessions) provided parents with nutrition education and strategies to structure meals and expand the child's diet. Parent education (10 sessions) provided information about autism without guidance on nutrition, meal structure, or diet. In addition to feasibility outcomes, primary efficacy outcomes included the Clinical Global Impression - Improvement scale and the Brief Autism Mealtime Behaviors Inventory. Grams consumed during a meal observation served as a secondary outcome.

The Autism MEAL Plan

The Autism **M**anage **E**ating **A**version and **L**imited (MEAL) Plan is a parent-training curriculum designed to assist caregivers in improving mealtime behaviors and expanding dietary diversity among children with autism spectrum disorder (ASD). The program combines didactic material with role-play activities, interactive worksheets, video examples, live practice, and homework assignments with the goal of providing caregivers with the knowledge, skills, and support required to design and implement intervention in the home setting. The curriculum involves a *parent as therapist* model of intervention – with parents serving as the primary change agent with support provided during weekly therapy sessions.

Why treatment manuals?

17 Years

Research to Practice Gap

- Why manuals?
  - Accelerate evaluation and adoption

Treatment manuals

- Treatment manuals provide structure for the intervention and permit replication and eventual dissemination

- Why parents?

- Who's involved?
  - Psychology + Nutrition

MEAL 2.0: Revision and Clinical Trial Update

- Revised curriculum
  - Added content: 10 sessions (vs 8 sessions); 3 booster
  - Therapist and parent scripts to promote standardization
  - Hands-on practice, homework, and live coaching to enhance effectiveness
- Extended Follow-up Timeframe –
  - End of study: 12 weeks
  - Follow-up : 16 weeks (1 month); 20 weeks (2 months)
- More precise inclusion/exclusion criteria

Inclusion/Exclusion Criteria

- Eligible participants:
  - 1) Males or females between 3 and 8 years of age
  - 2) Diagnosis of ASD
  - 3) Living in a household with 1 parent or primary caretaker able to read and speak English.
- To be included, children had to exhibit moderate food selectivity defined as a diet involving the following:
  - At least 6 total food items
  - One item from all food categories (i.e., protein, grain, and dairy)
  - Two or fewer food items in 1 food category (i.e., fruit, vegetable, protein, grain, or dairy).

Study Design

- 16-week randomized controlled trial (RCT) of MEAL plan vs. PEP
- MEAL plan:
  - Structured treatment manual focused on parent training (PT) – combining behavioral and nutritional principles to target moderate food selectivity
  - 10, 90-minute group sessions delivered over 12 weeks
  - 1 Telephone Booster; 2 in-person boosters
  - Psychology led all sessions; dietitian co-led sessions 2 & 7
- PEP:
  - An active comparator that controlled for attention and allowed us to examine the extent to which information alone would decrease mealtime behavioral problems and improve dietary variety
  - Focused on ASD education (no feeding or nutrition)
  - 10, 90-minute sessions
  - Psychology led

Outcome Measures

- Primary Outcome Measures:
  - The Clinical Global Impression - Improvement Scale (CGI-I)
    - Scores range: 1 (very much improved) through 4 (unchanged) to 7 (very much worse). Scores of much improved or very much improved (i.e., 2 or 1) were used to define positive response
  - Brief Autism Mealtime Behaviors Inventory (BAMBI)
    - 15-item caregiver questionnaire designed to evaluate mealtime behavior in children with ASD
    - 4 factors (food selectivity, disruptive mealtime behaviors, food refusal, and mealtime rigidity)

CGI - Ratings

THE JOURNAL OF PEDIATRICS • www.jpeds.com Volume ■

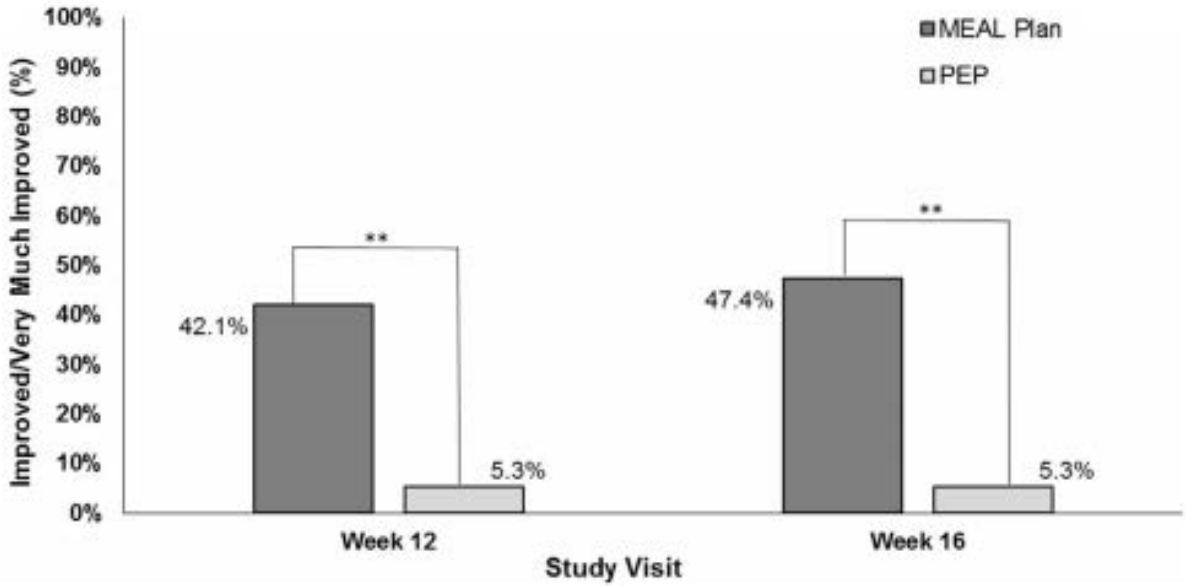
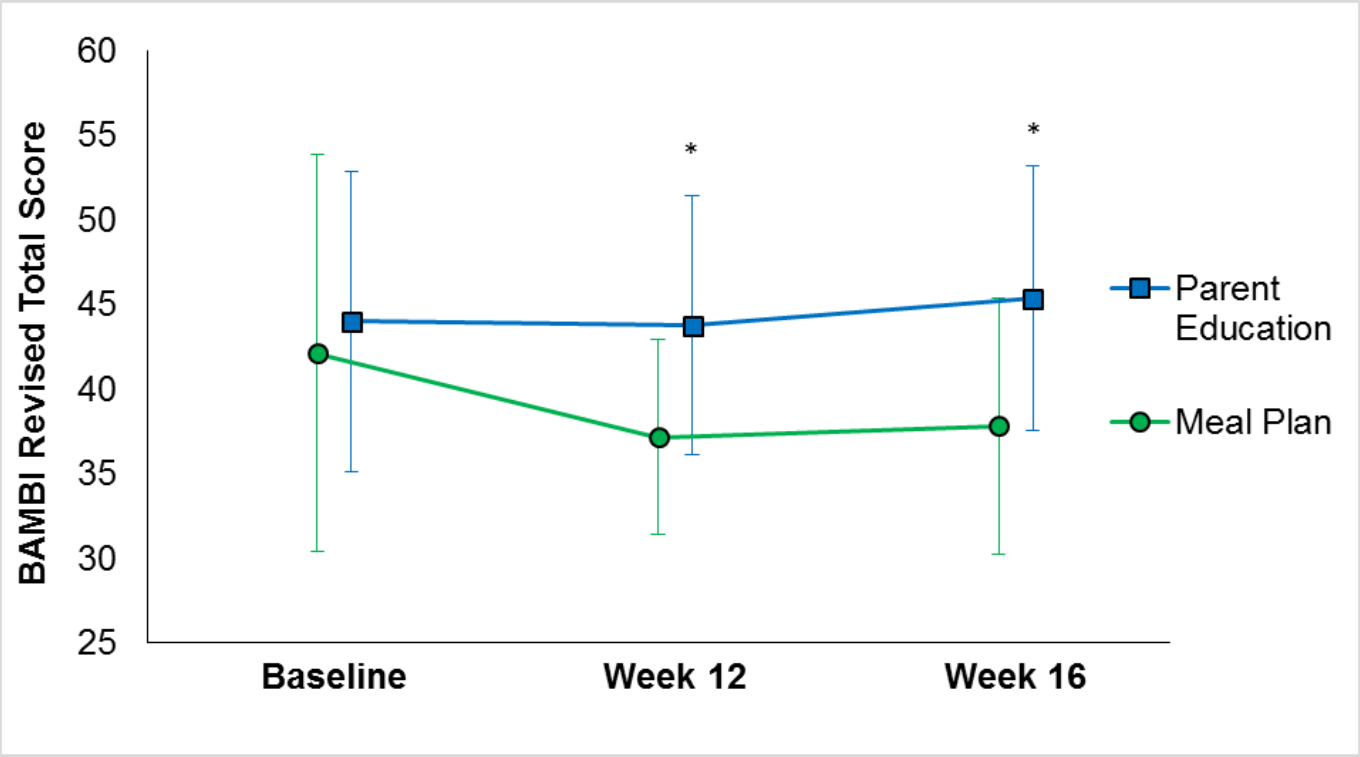
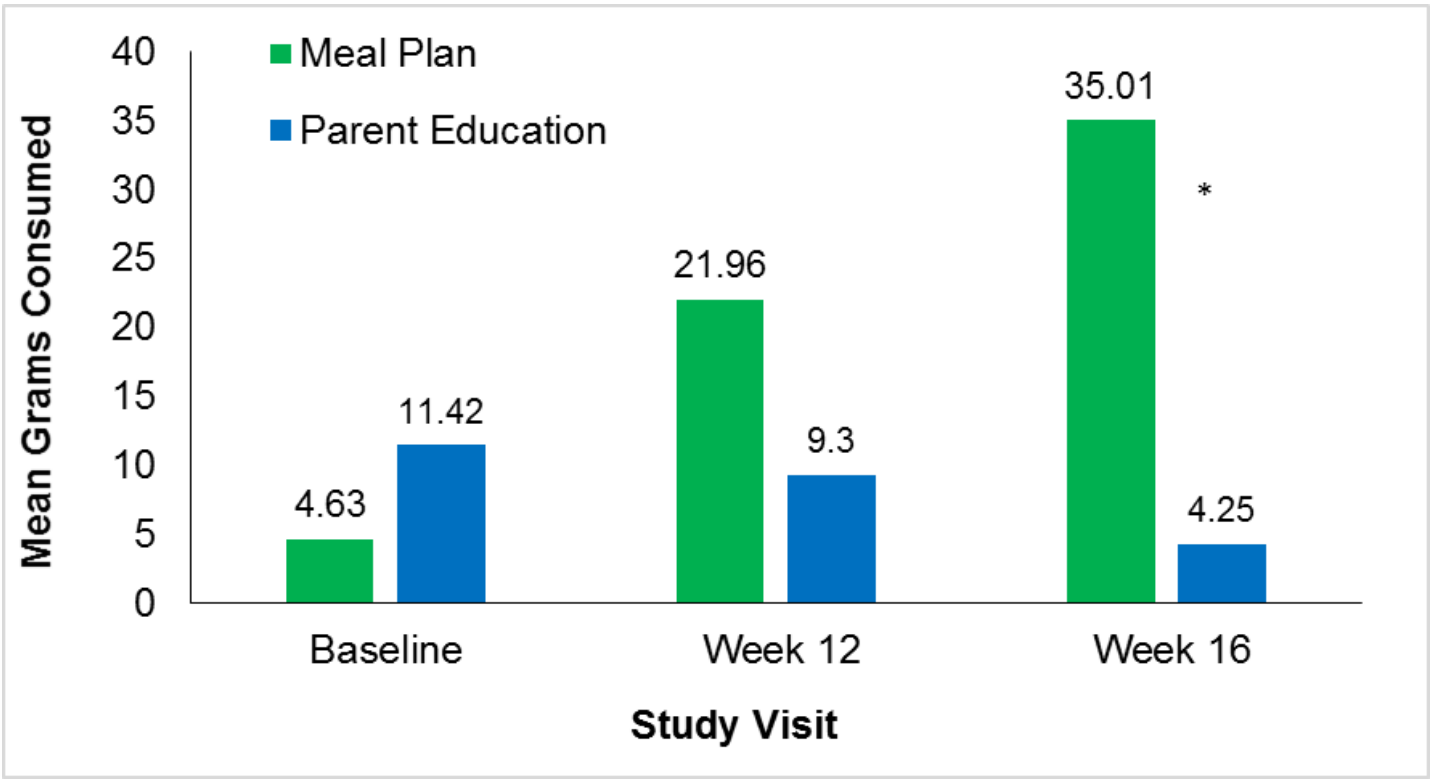


Figure 2. Percentage of participants who were rated as improved or much improved at weeks 12 and 16 based on CGI-I scores. The dark shaded bars represent the MEAL Plan participants and the light shaded bars represent the PEP participants. **Significant difference in response rate at the .05 level. Participants who dropped out or did not complete the assessment visit were classified as no improvement.



BAMBI Revised Total Score. * indicates a significant difference at 0.05 level. Error bars represent standard deviations.



Grams Consumed. * indicates a significant difference at 0.05 level.

Post-Treatment Video 1

Post-Treatment Video 2

Next Steps

Can you purchase the MEAL plan?

No….and here is why…..

But….I can give you the overall structure…

The Curriculum

SESSIONS	TOPIC
1	INTRODUCTION TO FEEDING DIFFICULTIES IN ASD & MONITORING BEHAVIOR
2	NUTRITION PLANNING & STRUCTURING MEALS
3	METHODS FOR INCREASING APPROPRIATE MEALTIME BEHAVIOR
4	ANTECEDENT STRATEGIES FOR PRESENTING FOOD
5	MODIFYING MEALTIME INTERACTIONS & DESIGNING THE INTERVENTION
6	IMPLEMENTING THE INTERVENTION
7	FINALIZING A MEAL PLAN AND INCORPORATING NEW FOODS INTO MEALS
8	GENERALIZATION OF TREATMENT GAINS
9	WHEN TO TARGET NEW FOOD ITEMS
10	PROGRAM REVIEW AND SUMMARY OF KEY TREATMENT ELEMENTS

In plain speak, this intervention:

- Normalizes feeding difficulties in children with ASD
- Instructs caregivers how to interact with their child in a new way
- Teaches caregivers how to introduce foods
  - Which foods
  - Quantity of food
  - Texture of food
- Gives caregivers a method to measure progress using data and make decisions using data
- Provides guidance for incorporating these new foods into the daily schedule
- Empowers caregivers!!!

1. Introduce Meal Structure

- Meals should occur:
- 1) At the table (where)
- 2) On a schedule (when)
- 3) With preferred food items (how)

- And….sitting may need to be practiced

Table/Sitting Practice

How long will he/she sit?

2 minutes

Steps	Minutes
Start	1 min
1	2 min
2	3 min
3	5 min
4	10 min
5	20 min

Other Considerations:

1) Have preferred foods available, but only if sitting
2) Enrich the environment if aversive
3) Watch the transitions

What is sitting a challenge?

=

Make the meal a preferred food meal...

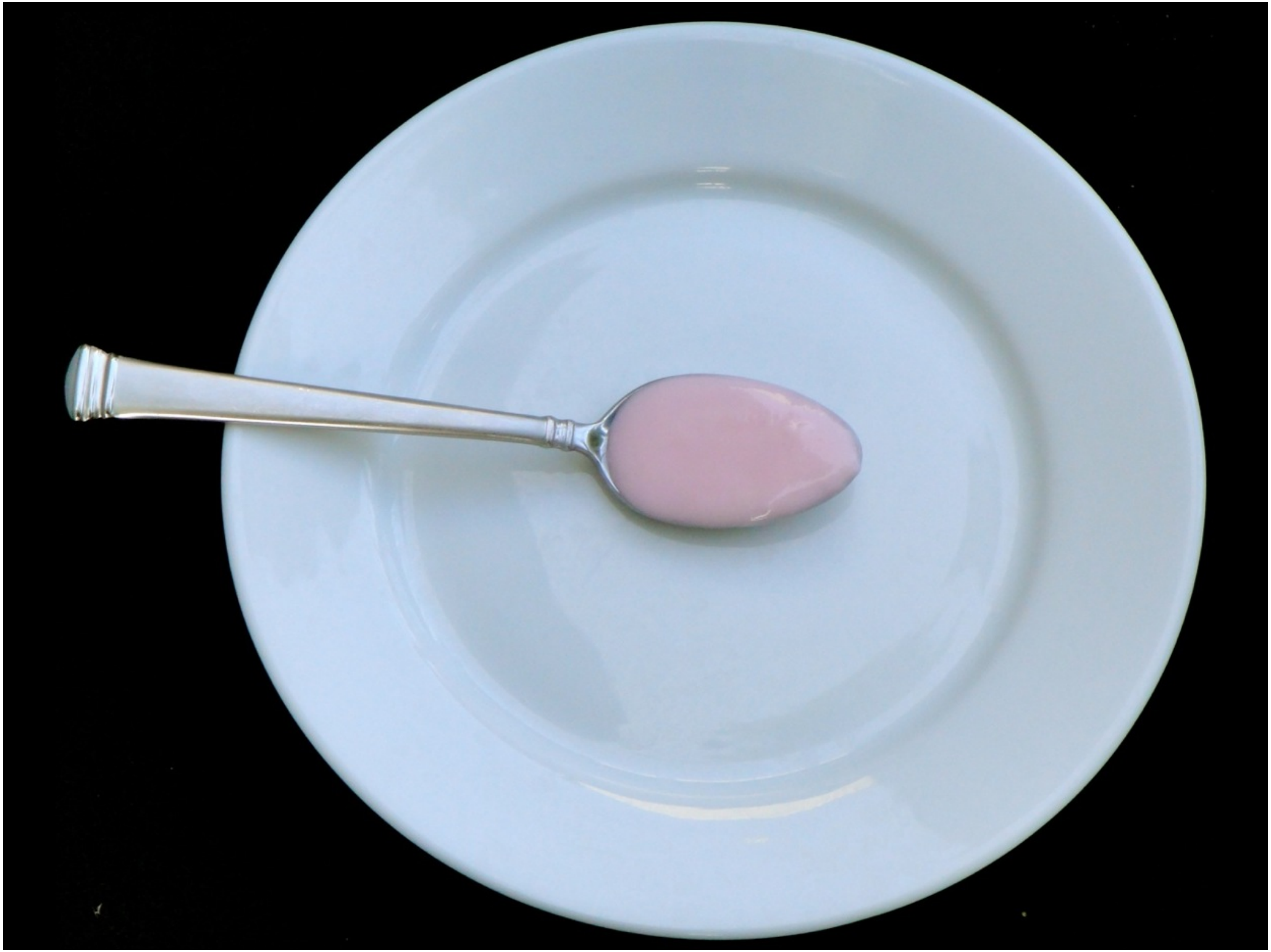
2. Shifting Caregiver Attention

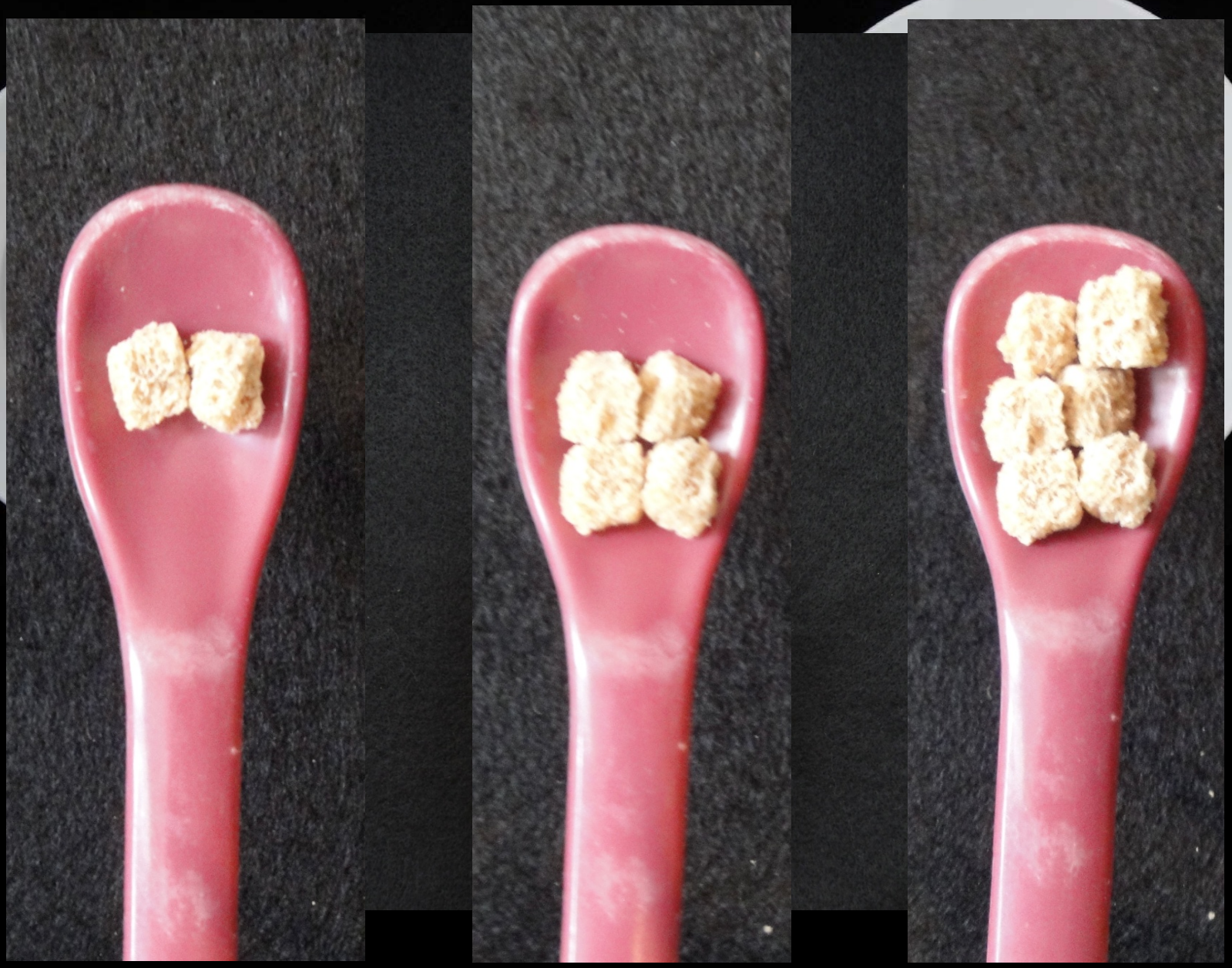
- General tendency to pay attention to problem behavior (we like to lecture)
- Tend to ignore children when behaving well (including when exploring/eating new foods)
- Differential Social Attention – Combined selective ignoring and labeled praise

3. Modifying How New Food is Presented

- We tend to present food items as if children like/eat them:

Portion Size and Variety Fading





The Power of Choice

- Why involve choice?
  - Provides sense of control
  - Increases motivation and engagement in task
- Choice during meals involves:
  - Modeling bite volume and allowing child to select starting point
  - Allowing the child to select what food to target during intervention
- May also require ignoring negative statements

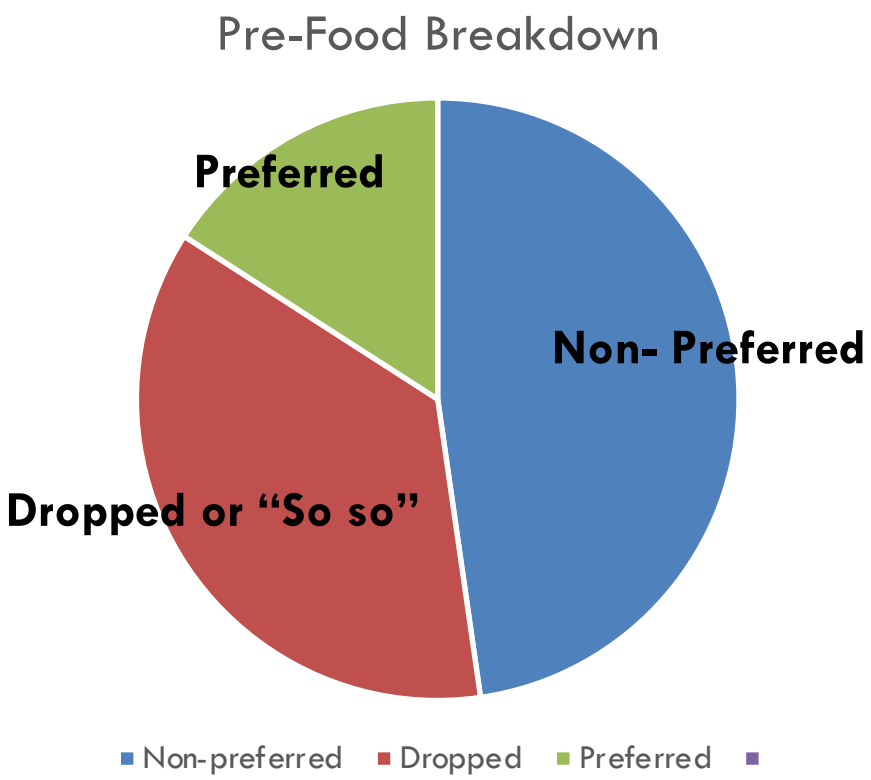
4. Resetting Targets

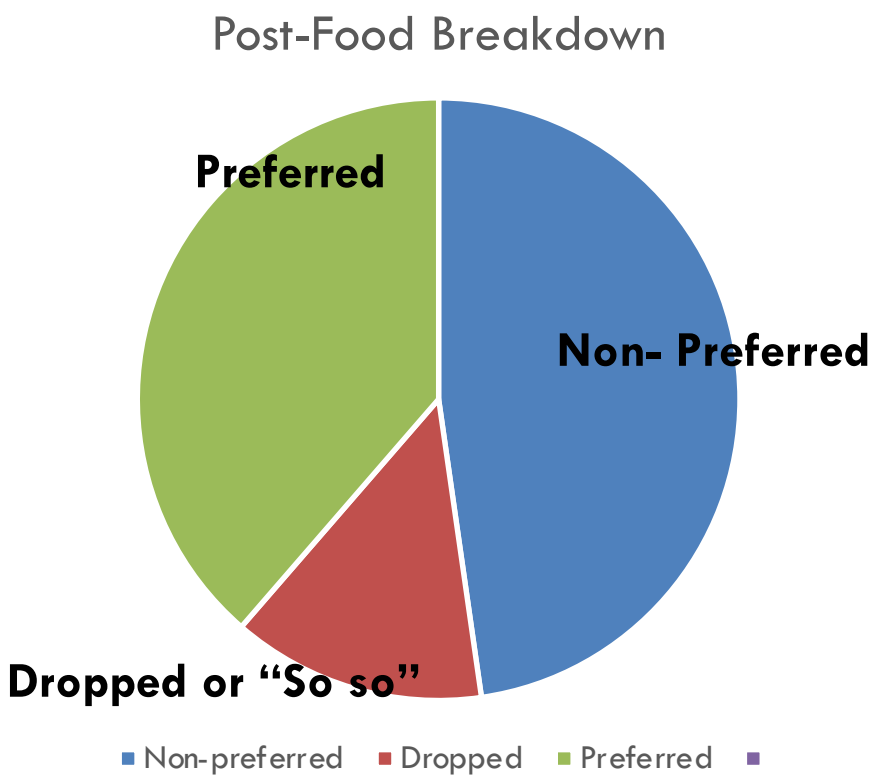
- Disgust begets disgust

FOOD LIST CHART

FOOD GROUP	CURRENTLY ACCEPTED FOODS	FOODS DROPPED/PREVIOUSLY ACCEPTED	FOODS THAT YOU WOULD LIKE TO INTRODUCE
Fruits (e.g., Apple, banana, oranges, berries, melon, peaches, pears, pineapple, mango)			
Vegetables (e.g., Green beans, peas, carrots, cauliflower, broccoli, eggplant, zucchini, squash, asparagus, lettuce)			
Meats/Beans (e.g., Chicken, beef, fish, turkey, nuts and nut butters, eggs, beans, tofu)			
Grains [e.g., Bread, dry cereal, hot cereal (oatmeal, grits), pasta, rice, waffles/pancakes, bagels, muffins]			
Dairy (e.g., Milk, yogurt, cheese)			

Focus initially on dropped foods….





5) Fading

- Steps + Decision Rules

Involves:

- 1) Child behavior as a guide
- 2) Stability criteria (e.g., 3 Meal Rule)
- 3) Tracking Performance - so you know when to move
- 4) Roadmap – so you know where to move and how quickly

6) Meal Length

- May involve:
  - 1) Meal duration (in minutes)
  - 2) Number of bites presented

- General rule:
  - When starting intervention….

The shorter the meal the better!

Conclusion

- Feeding problems common in ASD
- Assessment and intervention should include nutrition screen to determine severity and guide level of intervention
- Behavioral intervention is most well-supported intervention for food selectivity in ASD

Questions?