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The SAMIE

An Innovative Way to Screen Nutritional Risk in Autism Spectrum Disorder

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Disclosures

Nicole A. Withrow PhD, MS, RDN

- Employee
 - Assistant Professor and Dietetic Internship Coordinator at the University of Northern Colorado
 - Pediatric Dietitian Nutritionist at the Colorado Children's Hospital
- Research Support
 - The Research, Dissemination and Faculty Development Grant through the Office of Sponsored Programs, Suite #25, Kepner Hall at the University of Northern Colorado.
- Consultant
 - The Center for Discovery
- No other disclosures

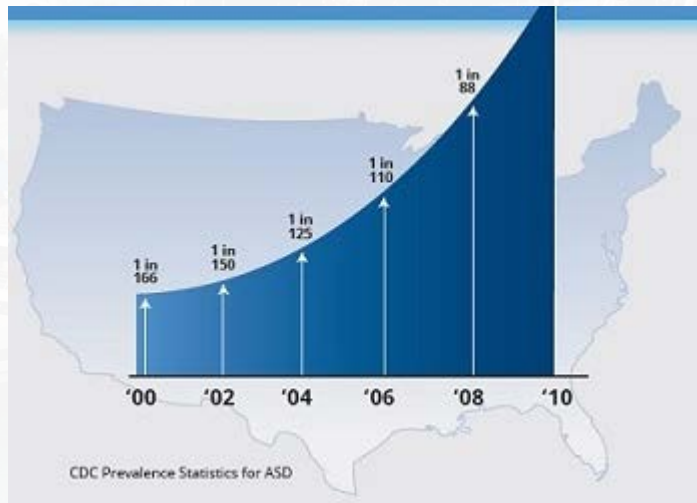
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Learning Outcomes

Participants will be able to:

- Better understand the medical conditions that affect dietary intake in individuals with an Autism Spectrum Disorder (ASD)
- Understand how sensory processing difficulties, aberrant mealtime behaviors, motor impairments, and dietary intake impact food selectivity in children with an ASD
- Describe the development of a new screening tool for identifying nutritional risk in individuals with an ASD and its utility in residential and community programs

Introduction of ASD

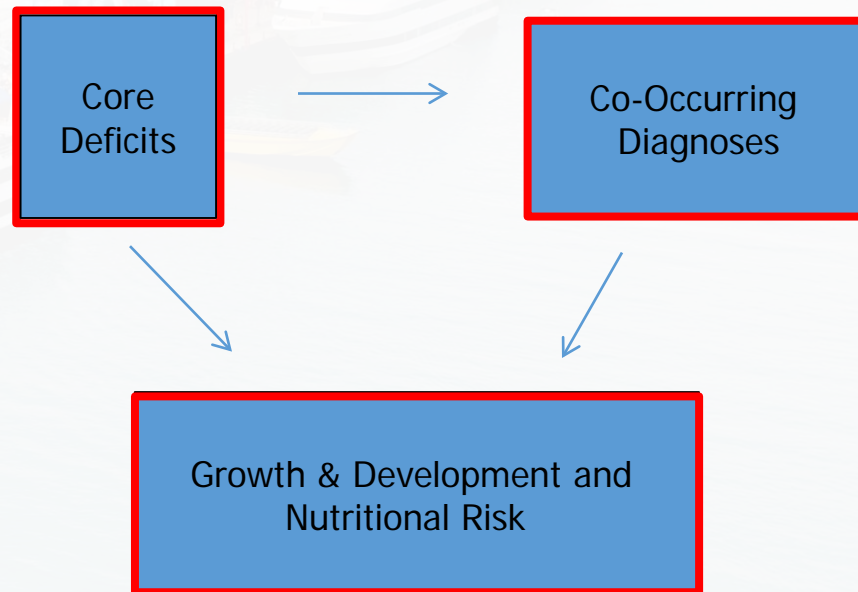


ASD affects approximately 1 in every 68 children in the US

Diagnosis is more common than pediatric cancer, diabetes, and AIDS combined

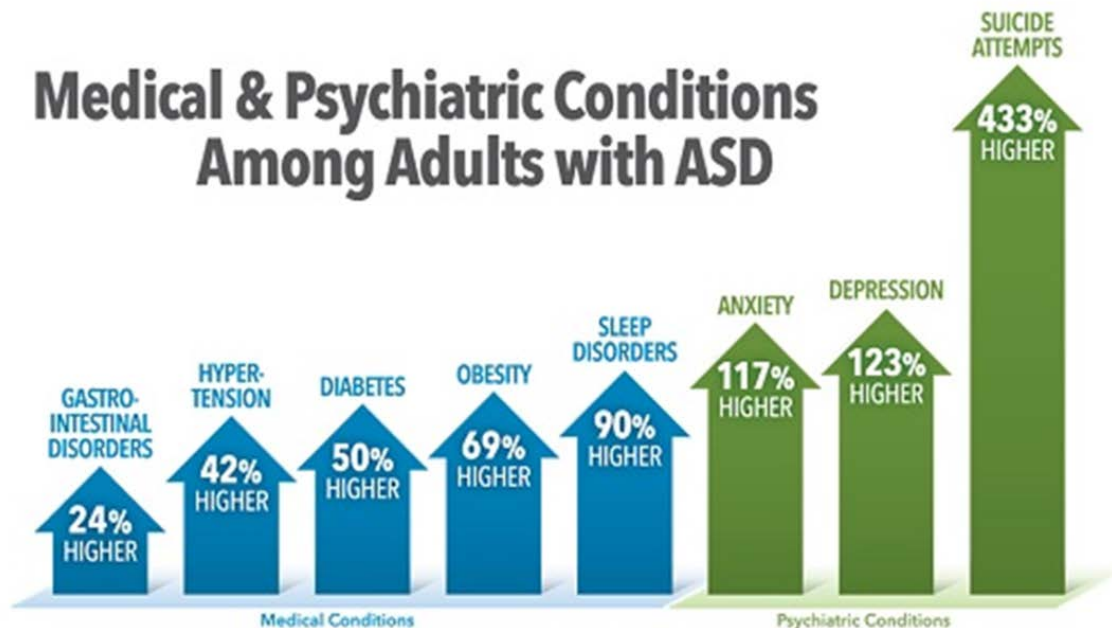
CDC, 2014; Autism Speaks, 2014

Complexities of an ASD in children



ASD in Adults

Medical & Psychiatric Conditions Among Adults with ASD

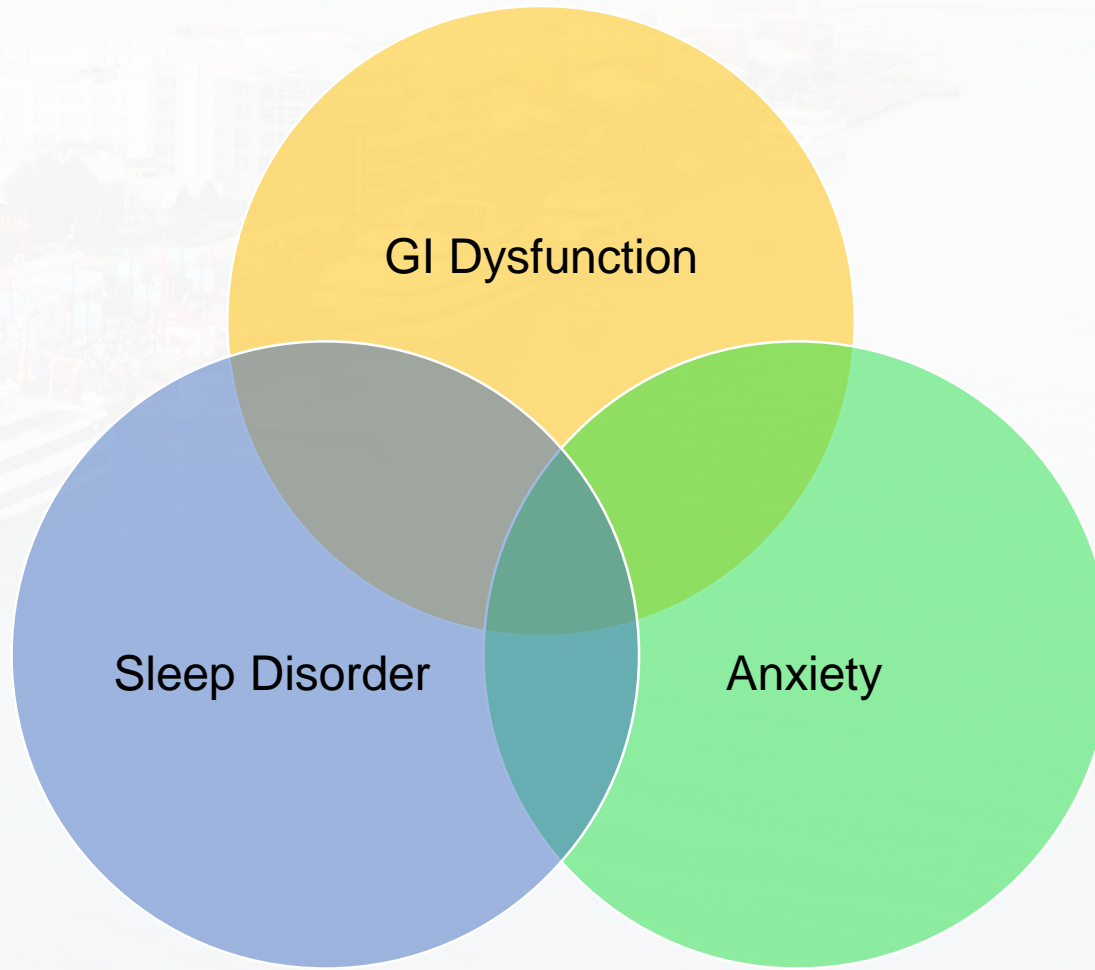


Figures as compared to adults without ASD.

DIVISION OF RESEARCH
AUTISM RESEARCH PROGRAM

ALL of these conditions can impact healthy eating

Most Common Medical and Psychiatric Conditions that Impact Eating in ASD





Anxiety

- 11-42 % of people with an ASD struggle with 1 or more anxiety disorders compared to 3-15% in general population
- These disorders include: social, separation, panic disorder and phobias
- Anxiety often increases in adolescence
- No medication has FDA-approval specifically for the treatment of anxiety in children with an ASD

Anxiety means an unsuccessful mealtime

Gjevik et al, J Autism Dev Disord 2011; 41 (6): 761-769. Kerns et al, Behav Ther 2015; 46 (1):29-39. Vaan Steensel et al, Clin Child Fam Psychol Rev 2011; 14(3):302-317; Vasa, 2016; White, 2009; Romero, 2016; Bellini, 2006

Sleep Disturbances

- Over half of children with an ASD have 1 or more chronic sleep problems
- **Potential Reasons:**
 - Undiagnosed Medical Conditions
 - Increased anxiety
 - Nutrient absorption
 - GI dysfunction
- **Signs and Symptoms**



Katz, 2016; <http://dx.doi.org/10.2147/CPT.S44806>; Pediatrics 2016; 137;S98; [Child Obes.](#) 2013 Apr;9(2):125-31; [Diabetes Care.](#) 2016 Mar 22; Yang, 2015; Cortesie, 2010; Vasa, 2016

GI Dysfunction

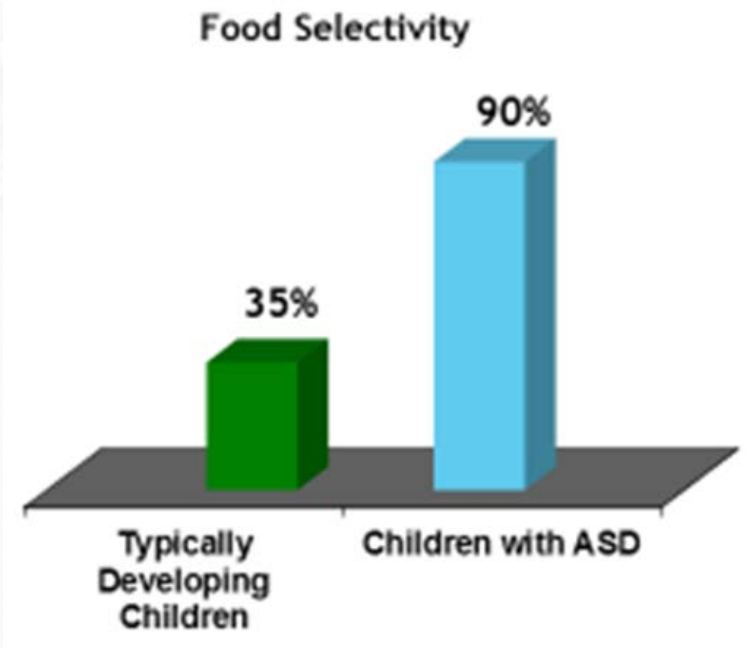
- Children with an ASD are nearly eight times more likely to suffer from 1 or more chronic GI problem compared to typically developing children
- Constipation – most common problem
- Peristalsis is affected
- Microbiome in ASD may be different
- **Signs and Symptoms**

Chaidez, 2013; Clinical Therapeutics, Vol 37: Num 5, 2015; Curr Psy Rep 2013; Feb: 15 (2): 337-350; McElhanon Bo, McCracken C, Karpen S & Sharp WG, 2014; Margolis, 2016

Primary Nutritional Concern in ASD: Food Selectivity

4 domains:

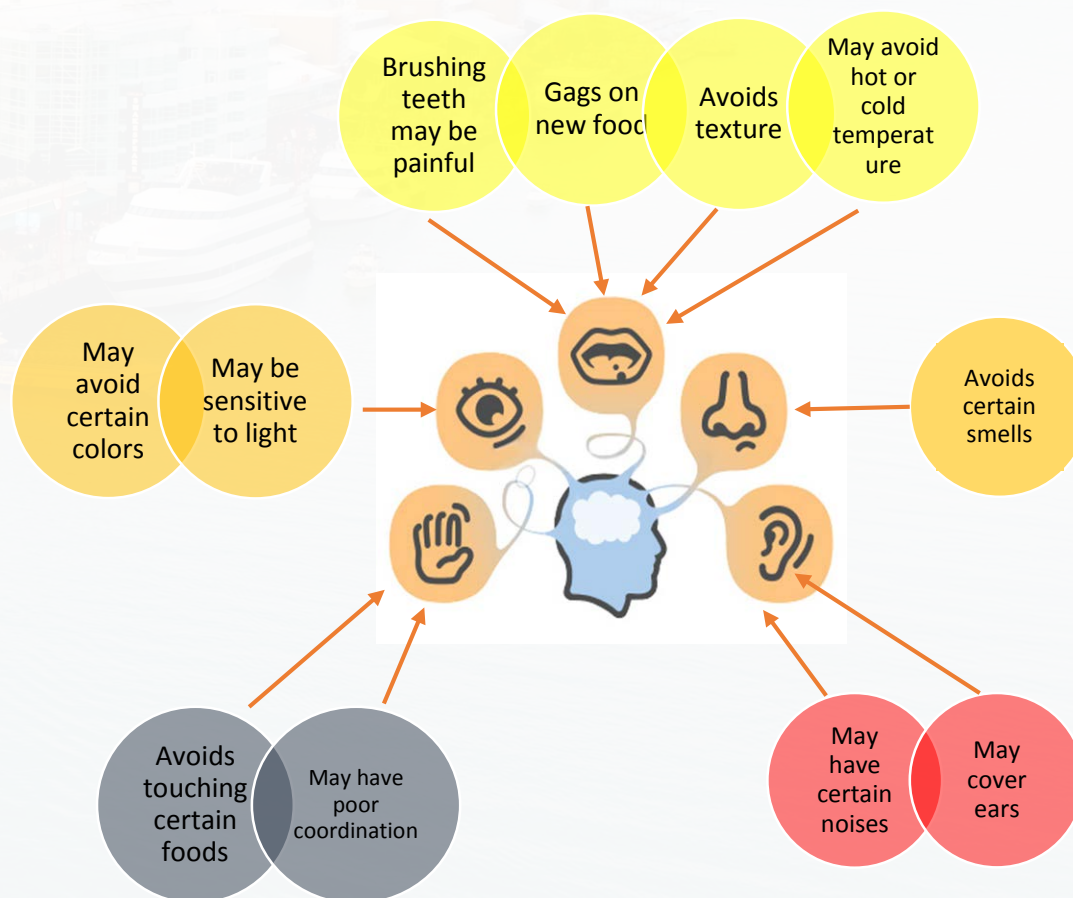
- Sensory Processing
- Motor Impairments
- Aberrant Mealtime Behaviors
- Dietary Intake
 - Dietary Interventions



Babbitt et al., 2009; Bandini, et al., 2010; Zimmer et al., 2011; Raiten & Massaro, 1986; Ahearn, et al., 2003; Field et al., 2003; Levin et al., 2001; Cornish, 1998

Food Selectivity and Sensory Processing

- ▶ 30%-100% of children with an ASD experience some type of sensory processing dysfunction
- ▶ Sensory factors, such as smell, taste, texture, color and temperature can affect whether a child will consume food



Ayres and Tickle, 1980; Baranek and Berkson, 1997; Birch L.L., 1987; Greenspan, 1997; Cermak et al., 2004; Watling et al., 2005; Leekam et al., 2007; Bandini et al., 2010

Food Selectivity and Motor Impairments

- Up to 50-100% of children with an ASD suffer with motor skill impairments
- Children with ASD may have difficulty feeding because of oral motor impairments



Food Selectivity and Aberrant Mealtime Behaviors



- Core deficits of ASD may contribute to aberrant mealtime behaviors
- Problematic eating behaviors may have implications for nutritional risk in children with ASD

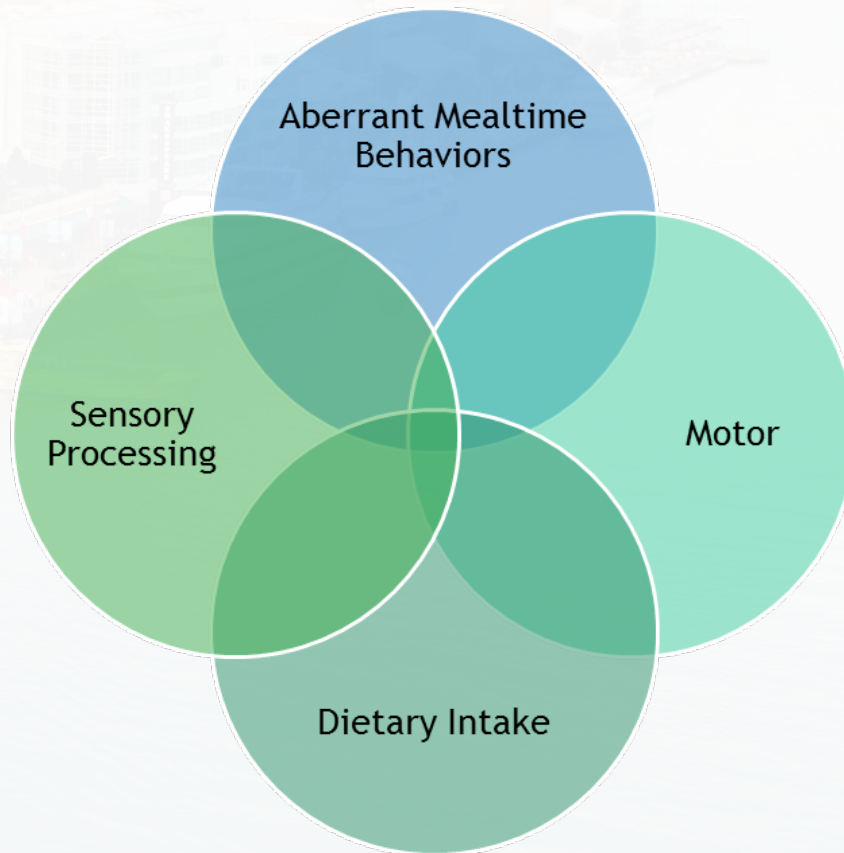
Schwarz, 2003; Curtin, Perrin, Tybor, & Must, 2005; Bowers, 2002; Herndon, et al., 2009

Food Selectivity and Dietary Interventions

DIET	RESTRICTED FOODS
Elimination	Primarily 6 foods: milk, eggs, soy, peanuts/tree nuts, fish/shellfish
FOD MAP	Fructose (fruit, high-fructose corn syrup), lactose (dairy), fructans (wheat, onion, garlic), galactans (legumes), polyols (sorbitol, cherries, avocado)
Feingold	Foods that contain colorings/additives
Gluten and Casein Free*	Gluten (wheat, barely, rye, some oats) and casein (dairy, some soy, must read food labels)
Specific Carbohydrate (SCD)	Cereal grains, processed meats, canned vegetables, canned fruit, most fruit juices, soy beans, chick peas, fava beans, yogurt, milk, curry, tubers (potatoes/yams), bean sprouts, processed cheese
Ketogenic	Carbohydrate rich foods

Sharp et al., 2013; Autism Speaks, 2008; Elder et al., 2006

The Sensory, Aberrant Mealtime Behavior, Motor, Inventory for Eating Questionnaire (SAMIE)



The Development of the SAMIE

Lit Review/Expert Panel

- Literature Review and Clinical Practice
- 8 experts recruited to refine questions

Think Aloud Protocol

- 10 TAP were conducted

Pilot Study

- 4 participants (pilot-refine)
- 57 ASD and 105 TD participants completed the inventory via Qualtrics

Validation

- Confirmed fit of questions within each domain using a Cronbach Alpha $>.7$

Sample section of the SAMIE

Sensory, Aberrant Mealtime Behavior, Motor, Inventory for Eating (SAMIE) Questionnaire

FOR EACH ITEM BELOW, PLEASE USE THE FOLLOWING TO ANSWER THE QUESTIONS, SELECT THE NUMBER THAT BEST REPRESENTS



YOUR INDIVIDUAL'S INTAKE WITHIN THE LAST 3 MONTHS. ITEMS ARE RANKED ON A FIVE-POINT SCALE:

1	2	3	4	5
NEVER:	SOMETIMES:	ABOUT HALF OF TIME:	MOST OF TIME:	ALWAYS:
Has not occurred	25% of the time	50% of the time	75% of the time	100% of time

D. SENSORY PROCESSING	COLUMN A				
	NEVER	→			ALWAYS
	1	2	3	4	5
1. Gags easily after he/she sees and/or smells food	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Smells food that is new or different	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Avoids colorful foods	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Only eats specific brands of food (e.g., McDonald's french fries, PF Goldfish crackers, Danimals yogurt, GM Cheerios, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Avoids certain foods due to smell	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Prefers specific certain textures (e.g., crunchy, chewy, juicy, soft textures)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Prefers foods at certain temperatures (e.g., warm, cold, hot, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Eats new foods	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Key Points

- Developed due to an unmet need
- Validated Screening Inventory
- Intended use: during assessment of ASDs, community, private practice, residential facilities, research and any discipline who refers
- Currently, 3 residential facilities are using the SAMIE to identify nutritional risk and to guide interventions

Disclosures

Jennifer Franck MS, RDN

- Employee
 - Assistant Chief, Department of Nourishment Arts, The Center for Discovery
- Research Support
 - The Center of Excellence Grant
- Contributor
 - Autism and the Stress Effect, Hamlin 2016
 - Feeding the Heart, 2015
- No other disclosures



THE SAMIE IN RESIDENTIAL PRACTICE





N = 1

The Center for Discovery

- Schools and Residential Programs, Medical Clinic, Main Street Program, and Research Program
- Catskill Mountain region of New York and in Manhattan, NY
- Situated on 1500 acres of organically farmed land
- Employ more than 1,500 staff
- 320 residents (160 have autism spectrum disorders)
- 120 children with autism in the day school – non-residential program
- more than 700 outpatients through the Medical Clinic



Co-occurring Conditions in TCFD Residential Students

TCFD n=88	
Seizure Disorder	62%
GI Issues	72%
Vit. D Deficiency	77%
Diarrhea	7%
Constipation	74%
Seasonal / Env. Allergies	82%
Food/Med Allergies	38%
Eczema	38%
Aggression	72%
Anxiety	86%
Self-Injury	68%
Sleep Problem	70%
Lack of Exercise/physical fitness	68%
Obese / Overweight	86%
Underweight	20%
* Prior to / At Admission	

Anxiety
86%



Health. Wellness. And Wonders.

www.thecenterfordiscovery.org

Gjevik et al, J Autism Dev Disord 2011; 41 (6): 761-769. Kerns et al, Behav Ther 2015; 46 (1):29-39. Vaan Steensel et al, Clin Child Fam Psychol Rev 2011; 14(3):302-317.

A New Paradigm



The Department of Nourishment Arts



Food Is Medicine



- Whole foods, plant based, seasonal diet
- Nutrient Dense HCHP Snacks
- Fruit Paste
- Lacto Fermented Foods
- Bone Broth



The SAMIE in Residential Practice

Sensory Processing:

- Smells new foods
- Only eat certain colors
- Foods must look same
- Try new foods
- Heats food during meal
- Uses hot sauce

Mealtime Behaviors:

- Only grazes
- Takes >30min to eat
- Comes easily to meals
- Needs distraction to eat
- Wiggles/bounces while eating.

Eating Skills:

- Vomits after meals
- Eats w/o gagging
- Chews food bf swallow
- Food spills from mouth
- Eats with hands

Dietary Intake:

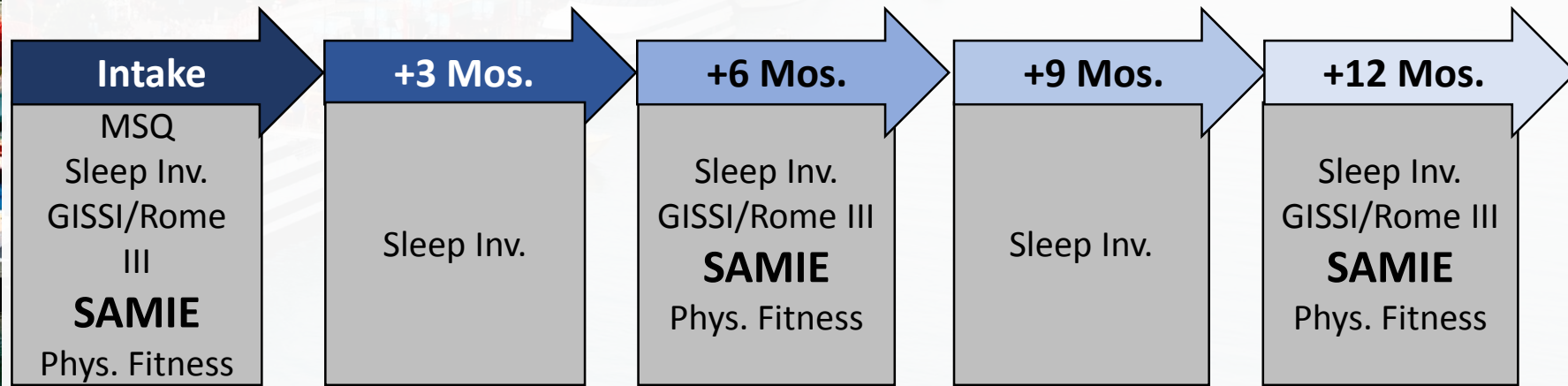
- Eats protein
- Avoids vegetables/fruits
- Drinks juice
- Eats restricted diet

Withrow 2016

The Centers of Excellence Grant

- Grant from New York State OPWDD to provide best practice for treatment and care of individuals with ASD
- 3 sites awarded with TCFD as lead site
- 5 medically related questionnaires:
 - Medical
 - GI
 - Sleep
 - Physical Activity
 - SAMIE**

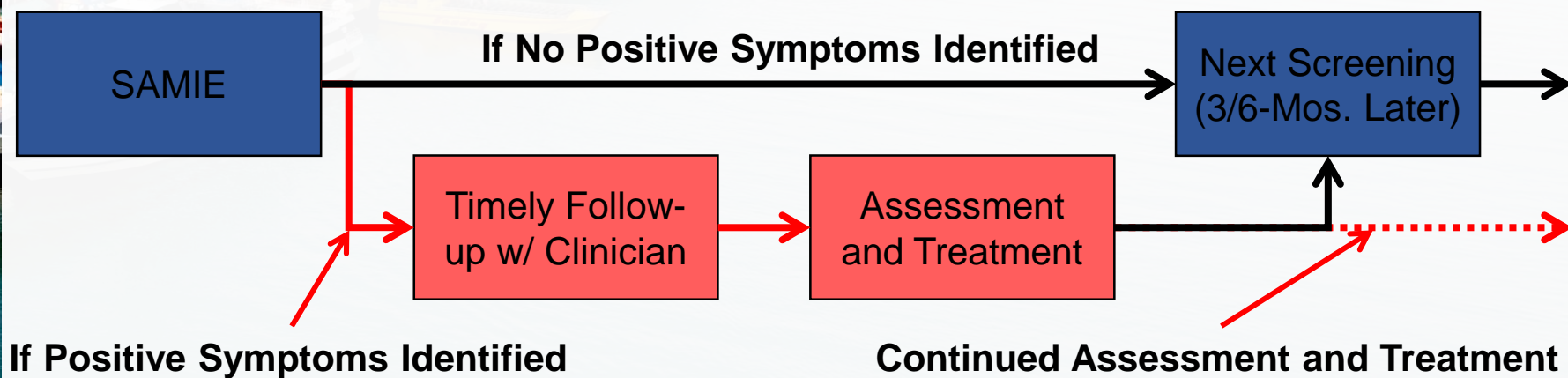
The SAMIE in Practice at TCFD



The Use of the SAMIE

- The SAMIE is intended for use within all pediatric program participants, including both CRP and day program participants
- The SAMIE is not age, gender, or diagnosis-specific
- Supply the provider with key information about the individual

The SAMIE in Residential Practice



Trial of SAMIE

- 3 sites including TCFD of residential pediatric population
- 20 residents from each site (n=60)
- Audit completed on 5 residents from each site (n=15)
- Dietitians from 2 sites completed SAMIE

Audit Results

- Out of the 15 audited files, 13 were felt to appropriately assess the individuals
- Preadmission use: good “snapshot” of feeding issues and intake especially as preadmission meetings do not allow for an extended discussion in one area
- Flagged questions important for identification of significant issues

Questions/Challenges in Residential Use

- Dietitian's role
- Should there be an overall scoring component?
- Better to not give as interview
- Not one caregiver so who knows best?
- Some questions might indicate an issue where there is none i.e. "Comes easily to meals/snacks" in ADHD
- Need a network of practitioners you can refer to



Future for the SAMIE in Residential

- Identify degree of feeding complexity
- Preadmission: snapshot and guide for multidisciplinary team
- N=1: to assess feeding progress in each individual historically
- Validated tool to prove success of food and nutrition program

Future Direction

- Additional validation of the SAMIE
- Dissemination of the SAMIE
- Determine use in other populations (teens/adults)

Please contact with questions and/or comments:
nicole.withrow@unco.edu or 303-638-8022 (cell) and
Jennifer Franck jfranck@tcfd.org or 845-707-8555.

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Practice Applications

Participants will be able to:

- Recognize the 4 domains that affect food selectivity in individuals with an ASD
- Discuss the utility of the SAMIE in Residential Facilities
- Use the SAMIE as a screening tool to identify nutritional risk and help direct referrals to the appropriate provider for children with an ASD

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