

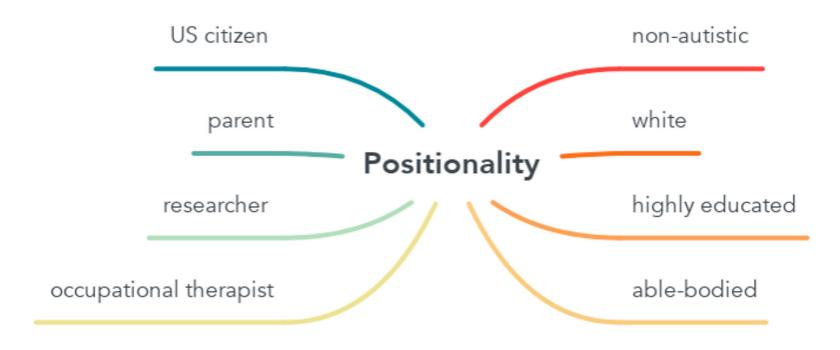
Supporting Autistic Children with Feeding Challenges using a caregiver-mediated approach



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Overview

- OT's and feeding-intervention
- How do feeding challenges present for autistic children?
 - Literature summary
 - Findings from my own work
- Caregiver-mediated intervention approach
- Case Studies and Discussion
- Questions & Discussion

OT's and Feeding

- Experts in daily activity and routine
- Skilled activity analyst
- Feeding is a complex activity of daily living
 - Child regulation +
 - Family context +
 - Parenting style:
 - Fine motor skills +
 - Positioning and oral motor skills +
 - Sensory tolerance and needs +
 - Properties of the foods
- Team Treatment is key

Autism & Feeding Challenges in the Literature

- Up to 84% of autistic children
- Complex and heterogeneous
 - Challenges include: food selectivity, sensory aversions to food properties, rigid mealtime routines, distressing mealtime responses, disruptive mealtime behaviors, and or difficulty participating in family mealtimes.
- Current published studies are focused on behavioral or sensory factors
- Impacts on development, nutritional deficiencies, and health
- Differential trajectories

Many improve with age

Clinically important group with severe and chronic challenges

Feeding Challenges & Families

Mealtime

- Context + needs of family members
- Structured for the needs of autistic child
- Limited family meal participation

Caregivers

- † stress and risk for poor health and wellbeing
- Mealtime is stressful and burdensome
- Actual mealtime vs. desired mealtime routine
- Also joy and meaning

Families

- Decreased social participation
- Limited choices for other family members



FEAST-US Survey

FEAST-US Survey

Online National Survey

Feeding and Eating in AutiSm Together (FEAST)
Assessment

Additional Measures:

Autism traits, sensory processing, mealtime behavior, caregiver stress, child adaptive skills

Participants

Caregivers (n=427) of autistic children

Average Age: 8.42 years Range: 2 to 12 years

82.9% male

88.52% white

31.6% >\$100,000 Household Income

61.4% Bachelor degree +

FEAST Assessment

Feeding and Eating in AutiSm Together (FEAST) Assessment

Part 1: FEAST Scores (items 1-34)

Total Score: Feeding Challenge Severity

Feeding Challenge Classification Subscales

Sensory

Behavior

Oral Motor

Gastrointestinal

Part 2: Clinical Utility questions (items 35-86)

Early Feeding Challenges

Independent Feeding

Family mealtime Routine

Caregiver Strategies and Responses

Mealtime Schedule and Length

Reported Sensitivities

Caregiver Feeding Priorities

Key Findings from the FEAST Survey

Feeding Challenges are Developing Early



33 % of families reported their child had at least one early feeding challenge.

Early feeding challenges predicted more severe feeding in later childhood.

For Many - Feeding Challenges Get Worse



44.5% of families report their child has continued to restrict their diet over time

Family Mealtime is Impacted



66% of caregivers reported they need to prepare a separate meal for their autistic child.

Sensory Matters but is Not the Whole Story



Reported sensitivities to the food and the mealtime environment were common (82% at least one)

Behavioral, oral motor, and gastrointestinal feeding challenges were also high among the sample.

Overlap between Feeding Challenges & ARFID

Significant Weight Loss or Faltering Growth



40.3% of caregivers report concerns about growth 18.0% report child has difficulty gaining weight

Significant Nutritional Deficiency



Diet is missing entire food groups

Primary concern for caregivers is nutritional variety

Dependence on Enteral Feeding or Oral Nutritional Supplements



Unknown overlap

Marked interferences with Psychosocial Functioning



Disrupted Family Mealtimes

Decreased Social Participation

Mealtime Distress and Dysregulation

Difficult School Eating Experiences

Summary



Complex and heterogeneous

Emerging early

Presenting across the family system and mealtime routine

Overlap significantly with ARFID criteria



Caregiver-mediated feeding intervention

- Families as partners
- Intervention in home context

- Strategies carried over during the week to increase consistency
- Mix of coaching, caregiver-education, collaboration, problem solving, intervention modeling

Engaged Eaters Program

Key Components:

- Ages 2 to 7 years old
- Direct intervention, modeling of techniques, caregivertherapist collaboration, & caregiver coaching
- Collaboratively set functional goals

Pre-Intervention
Assessment

EEP Intervention (~6 months) 24 intervention visits & 8 caregiver modules

Post-Intervention Assessment

- Intake Assessments (stress, efficacy, feeding challenge, demographics)
- Family mealtime observation
- Lab-based caregiver-child feeding interaction
- Caregiver interview
- Collaboratively set goals

- Repeat all assessments
- Evaluate progress on goals

Setting Goals

- Affirming of neurodiversity and child needs
 - Consider sensory needs and goals that might get you stuck
- Meaningful to the family
- Achievable based on child presentation and history
 - Ask about the child's history and set realistic goals and family expectations
- Zoom out from bite acceptance
 - Functional long term change (expanded diet, enjoyment during mealtime, increased skills)

Setting Goals

Child will accept 80% of new foods when presented

Child will demonstrate increased exploration of new foods (sight, touch, smell, etc) with necessary sensory supports available

Child will add broccoli to their diet

Child will add 3 new family foods to their diet OR

Child will identify 3 new foods that they enjoy eating to expand their diet

Child will sit at the table with family for dinner

Child and family will develop a consistent mealtime routine that supports child participation in eating and family engagement during mealtime.



Supporting Families



Get Regulated

Mealtimes should be regulated and relaxed

Regulation happens across a day and not only during mealtimes.

Build regulation routines as a part of mealtime routines.

Replace "Trying" Foods with "Exploring" Foods

Exploration ≠ Eating

Encourage:

Describing, touching, smelling, stirring, preparing, serving to others, drawing, talking about, etc.

Be Flexible in What is Offered

Everyone has red foods (foods they will never eat)

The goal is to find more foods your child enjoys, not make them learn to eat the foods they hate.

Stay flexible in what you offer to allow your child to explore and experience a wide variety and find the foods they like to eat.

Spark Curiosity

Curiosity is the best motivator for exploring foods.

Tie special interests to food exploration to bring in enjoyment and curiosity

Get curious about small changes to favorite foods

Lower the Pressure

Kids thrive with choice and control

Pressure to try foods will often backfire

Rewards/punishments tied to food exploration should be avoided

Increase choice by:

- Family style serving
 Child chooses how to explore food
 Children involved in meal prep/selection



Predictable Mealtime Routines

Family defines the mealtime structure and style

Encourage predictability through timing, practices, or other methods.

Predictability supports regulation



Set the Plate for Success

Consistent foods available, largest portion, close to child

Sometimes foods next largest portion

Small portions of new things

 Consider using separate small container or single bite on fork or toothpick to introduce a food

Child chooses what they eat on the plate



Be Descriptive

Expanded descriptive language builds opportunities for a child to identify which aspects of foods they enjoy and build curiosity around foods.



Play

Kids are more willing to explore and eventually try new foods when food exploration is playful

Examples:

- Pretend you are different animals and take bites in character
 - Tiny mouse bite, big tiger bite, bird peck, snake lick, etc.
- Mix favorite toys and foods
 - Use clean toys as utensils, decorate toys with foods, pretend a toy is eating with you and share foods together
- Use foods in new ways to make art or include in pretend play
 - Paint with yogurt or pudding on a plate, build a pokemon habitat in a pile of mashed potatoes, cut up vegetables to look like roblox characters



Considerations

- Families have likely tried many things ask them about what has worked
- Consider the food security of the family before recommending practices that increase food waste

 Many caregivers also have specific or selective eating preferences

lory

6 yrs

Selective eater since ~2

Diet:

Fruit/Veg: Strawberries, raspberries, blackberries

Protein: raw almonds, occasionally peanut butter

Grain: crackers

Rory

Goals:

- Comfort with food exploration Same room as family for meals Adding to her diet variety

Key strategies:

- Attending to regulation in every session
- Low pressure
- Imaginative play
- Sensory safety and clear expectations
- Curiosity for exploration without expectation of tasting

Hurdles

- Anxiety
- Illness



4 years

Unable to transition completely off milk bottle to solid foods

Diet:

- Milk in a bottle (1-1.5litre daily)
- nutter butter cookies
- pretzel sticks

Liam

Goals

- Transition to a new cup/drink vessel to drop the bottle
- Add foods
- Mealtime routine for mom and Liam

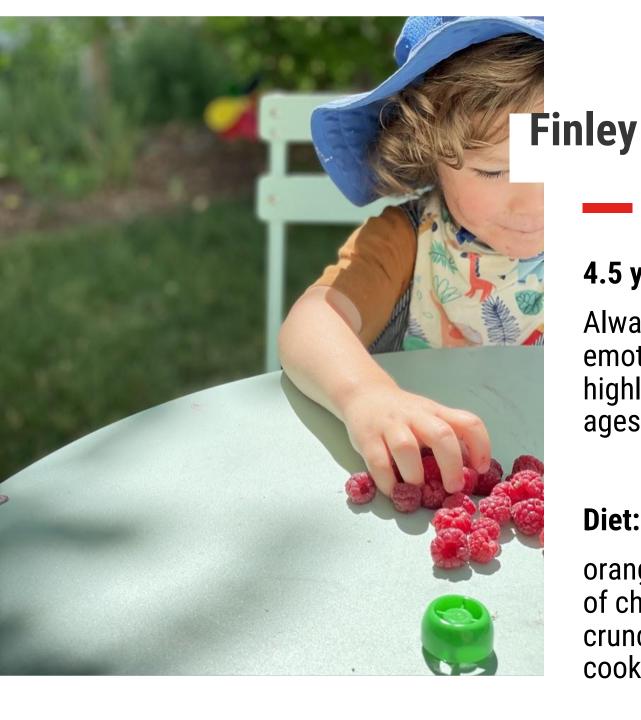
Key strategies:

- Following his sensory cues
 Reducing milk while offering alternatives
 Visual supports and variety
- Autonomy

Hurdles

- **Detail specificity**
- Sickness
- Mom's mealtime routines





4.5 years

Always had difficulty with foods, big sensory and emotional responses to any food that is not highly preferred. Continues to drop foods as she ages.

Diet:

orange juice, cheese toastie with a specific ratio of cheese to bread and cooked so the bread is crunchy, pretzels, one brand of chocolate chip cookies.

Finley

Goals:

- Comfortable exploring foods to find new foods she likes
- Adding new foods to diet
- Communicating her food preferences to mom using her assistive communication device

Key Strategies

- Low pressure matched with highly preferred sensory experiences
- Regulating before mealtimes
- Cold & Pink foods

Hurdles

- Variable sensory regulation throughout the day
- interrupted sleep
- Availability of family time for meal prep or expanded exploration



Discussion & Questions

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Citations

Adams, S. N., Dadabhay, A., & Neille, J. (2021). An Exploration into Mothers' Experiences of Feeding Children with Autism Spectrum Disorder in South Africa. *Folia Phoniatrica et Logopaedica*, 73(3), 164–173. https://doi.org/10.1159/000507928

Ashley, K., Steinfeld, M. B., Young, G. S., & Ozonoff, S. (2020). Onset, Trajectory, and Pattern of Feeding Difficulties in Toddlers Later Diagnosed with Autism. *Journal of Developmental & Behavioral Pediatrics*, 41(3), 165–171. https://doi.org/10.1097/DBP.0000000000000757

Bonsall, A., Thullen, M., Stevenson, B. L., & Sohl, K. (2021). Parental Feeding Concerns for Children With Autism Spectrum Disorder: A Family-Centered Analysis. *OTJR: Occupation, Participation and Health*, *41*(3), 169–174. https://doi.org/10.1177/1539449220985906

Burkett, K., Haggard, M.-L., Van Rafelghem, D., & Harpster, K. (2022). Restricted Eating in Preschoolers with Autism: Mother Stressors and Solutions. *Journal of Autism and Developmental Disorders*, 52(6), 2589–2597. https://doi.org/10.1007/s10803-021-05078-6

Curtiss, S. L. (2018). Integrating Family Ritual and Sociocultural Theories as a Framework for Understanding Mealtimes of Families With Children on the Autism Spectrum. *Journal of Family Theory & Review*, 10(4), 749–764. https://doi.org/10.1111/jftr.12298

Fiese, B. H. (2021). Family mealtimes: Promoting health and well-being. In L. A. Francis, S. M. McHale, V. King, & J. E. Glick (Eds.), Families, Food, and Parenting: Integrating Research, Practice and Policy. Springer.

Leader, G., Tuohy, E., Chen, J. L., Mannion, A., & Gilroy, S. P. (2020). Feeding Problems, Gastrointestinal Symptoms, Challenging Behavior and Sensory Issues in Children and Adolescents with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 50(4), 1401–1410. https://doi.org/10.1007/s10803-019-04357-7

Ledford, J. R., & Gast, D. (2006). Feeding problems in children with autism spectrum disorders: A review. Focus on Autism & Other Developmental Disabilities, 21(3), 153–166.

Marquenie, K., Rodger, S., Mangohig, K., & Cronin, A. (2011). Dinnertime and bedtime routines and rituals in families with a young child with an autism spectrum disorder. *Australian Occupational Therapy Journal*, 58(3), 145–154. https://doi.org/10.1111/j.1440-1630.2010.00896.x

McAuliffe, T., Thomas, Y., Vaz, S., Falkmer, T., & Cordier, R. (2019). The experiences of mothers of children with autism spectrum disorder: Managing family routines and mothers' health and wellbeing. *Australian Occupational Therapy Journal*, 66(1), 68–76. https://doi.org/10.1111/1440-1630.12524

Page, S. D., Souders, M. C., Kral, T. V. E., Chao, A. M., & Pinto-Martin, J. (2022). Correlates of Feeding Difficulties Among Children with Autism Spectrum Disorder: A Systematic Review. *Journal of Autism and Developmental Disorders*, 52(1), 255–274. https://doi.org/10.1007/s10803-021-04947-4

Seiverling, L., Towle, P., Hendy, H. M., & Pantelides, J. (2018). Prevalence of feeding problems in young children with and without autism spectrum disorder: A chart review study. *Journal of Early Intervention*, 40(4), 335–346. https://doi.org/10.1177/1053815118789396

St. John, B. M., Hladik, L., Novak, P., Gartland, S., & Ausderau, K. K. (2022). Assessment and treatment of Feeding challenges in children with autism. In S. Marcus & S. Breton, *Infant and Child Feeding and Swallowing: Occupational Therapy Assessment and Intervention* (2nd ed.). American Occupational Therapy Association, Incorporated.