Eating, Feeding & Swallowing for children on the Autism Spectrum: Getting the info and figuring out what to do with it

Part 1: Assessment

Christie Raffaele, MSc(OT), OT Reg. (Ont.) Courtenay Mayowski, MSc, R.SLP (C) Rebecca Perlin, M.CI.Sc. SLP(C) reg. CASLPO Dr. Sharon Smile, MBBS, DM, MSc

Alberta Health Services

Pediatric Eating And Swallowing

Holland Bloorview Kids Rehabilitation Hospital

Welcome & Learning Objectives

- Discussion of important points to consider when assessing eating, feeding & swallowing with a child on the Autism Spectrum
- To understand how to bring together assessment information to form appropriate goals
- Case study presentation bringing together assessment details, synthesis of results and application to treatment



Dr. Sharron Spicer

LAND ACKNOWLEDGEMENT



Pediatric Eating And Swallowing We acknowledge that what we call Alberta is the land of Treaties 6, 7 and 8. We are living and working on the traditional and ancestral territory of many peoples.

We acknowledge the many First Nations, Métis Settlements and Inuit who have lived in and cared for these lands for generations. We are grateful for the traditional Knowledge Keepers and Elders who are still with us today and those who have gone before us. We make this acknowledgement as an act of reconciliation and gratitude to those whose territory we reside on or are visiting.

Holland Bloorview

Kids Rehabilitation Hospital

We are currently working on the traditional territories of the Missasaugas of the Credit First Nation, the Wendat Nation, the Petun Nation, and the Seneca Nation, also a part of the Haudenosaunee Confederacy.

When we think of our commitment to reconciliation, we think of Indigenous communities with food insecurity, health inequities and limited access to medical services. We do a Land acknowledgement to renew our personal and professional commitment to work towards dismantling health inequities within these communities and other marginalized communities.



Eating, Feeding & Swallowing for children on the Autism Spectrum | Oct 26, 2022



PEAS.Project@ahs.ca

Project Scope

The Pediatric Eating And Swallowing (PEAS) Project is a provincial **quality improvement** initiative with the purpose of developing a provincial eating, feeding, and swallowing **clinical pathway** to standardize and improve care for children with a **pediatric feeding disorder**.¹

Target population: Patients receiving care from provincial Outpatient Clinics, Home Care, or Community Rehabilitation

¹ Goday PS et al. *Pediatric Feeding Disorder: Consensus Definition and Conceptual Framework.* J Pediatr Gastroenterol Nutr. 2019 Jan;68(1):124-129.



Is Feeding a Struggle? Find Services Equipment & Supplies FAQs For Families For Providers Q



For families and care providers of children with an eating, feeding and swallowing disorder





Popular Resources for Families



peas.ahs.ca

Eating, Feeding & Swallowing for children on the Autism Spectrum: Getting the info and figuring out what to do with it

Part 1: Assessment

Christie Raffaele, MSc(OT), OT Reg. (Ont.) Courtenay Mayowski, MSc, R.SLP (C) Rebecca Perlin, M.CI.Sc. SLP(C) reg. CASLPO Dr. Sharon Smile, MBBS, DM, MSc



Pediatric Eating And Swallowing

Holland Bloorview Kids Rehabilitation Hospital

Presentation: Feeding issues in ASD







46% to 89% (Ledford & Gast 2006)

Variable presentation with variable prevalence: **13-95%**

Carbohydrates (William et al. 2005)

Crispy/crunchy snack foods (Schmitt et al. 2008)



Texture: 69%, Appearance : 58%, Taste 45% Smell: 36%, Temperature: 22%, Reluctant to try new foods: 69% (William et al. 2000) Fruits and vegetables (Aheam et al. 2001, Cornish, 1998; 2002)

Disruptive Mealtime Behaviours



Persistence of feeding challenges into adulthood- (Kuschner et.al. 2015)



5 times the odds for children without ASD (5.11 (95% Cl 3.74-6.97) (Sharp et al. 2013)

Presentation: Feeding issues in ASD



Prevalence of obesity: up to **30.4%**

Gastrointestinal problems: 49.3 to 82%





Children 2-5yr: more likely to be overweight or obese

Children 6-11 yr: **underweight** than in matched cohort (Hyman et al. 2012) ASD consumed similar amount of nutrients/calories as control)



Iron deficiency: 24-32%, Iron deficiency anemia: 8-16%, Decreased bone mineral density

Low iron intake (Herndon et al 2009)

Low intake of Vitamin D, B12, protein and calcium (Zimmer et al 2012)

Vit C deficiency, Vitamin A deficiency, Rickets (McAlbee 2009, Stewart 2008)

> Holland Bloorview Kids Rehabilitation Hospital

Special Issue Article

The health status of adults on the autism spectrum

Lisa A Croen¹, Ousseny Zerbo¹, Yinge Qian¹, Maria L Massolo¹, Steve Rich², Stephen Sidney¹ and Clarissa Kripke³

OR, (99% CI)* Medical conditions Adults with ASD Controls Chi-square (N = 1507), N (%) (N = 15,070), N (%) value Gastrointestinal disorders 523 (34.70) 4139 (27.47) <0.001 1.35 (1.16-1.57) Constipation _ 67 (4.45) 210 (1.39) <0.001 3.11 (2.13-4.54) 79 (5.24) 510 (3.38) 0.002 1.41(1.02 - 1.95)Diarrhea Disorders of stomach or duodenum 20 (1.33) 220 (1.46) 0.68 1.00 (0.54-1.85) 0.97 Functional disorders 208 (13.80) 2075 (13.77) 0.96 (0.78-1.17) GERD 193 (12.81) 1161 (7.70) <0.001 1.77 (1.42-2.21) Gallbladder disorders 0.17 28 (1.86) 213 (1.41) 1.34 (0.79-2.28) Lower GI 50 (3.32) 242 (1.61) <0.001 1.92 (1.27-2.91) Other disease of esophagus 69 (4.58) 421 (2.79) < 0.001 1.66(1.17 - 2.35)Diseases of rectum and anus 39 (2.59) 295 (1.96) 0.09 1.26(0.80 - 1.97)Hepatic disease 33 (2.19) 228 (1.51) 0.04 1.58(0.96-2.60)Upper GI motility 114 (7.56) 593 (3.93) <0.001 1.85 (1.40-2.45) Sleep disorders 265 (17.58) 1446 (9.60) <0.001 1.92 (1.58-2.33) 0.005 1.54 (1.07-2.21) Organic sleep apnea 64 (4.25) 404 (2.68) Dyssomnia 236 (15.66) 1183 (7.85) < 0.001 2.05 (1.67-2.52) Nutrition conditions 561 (37.23) 2821 (18.72) <0.001 2.68 (2.29-3.12) Symptom concerning nutrition metabolism 524 (34.77) 2609 (17.31) <0.001 2.62 (2.24-3.06) and development Vitamin deficiency -75 (4 98) 344 (2 28) <0.001 2 35 (1 65-2 33)

Table 4. Prevalence of medical conditions among adults with ASD and controls.



Kids Rehabilitation Hospital



Autism 2015, Vol. 19(7) 814–823 © The Author(s) 2015 Reprints and permissions: sagepub.co.uk/journalsPermissions.nav DOI: 10.1177/1362361315577517 aut.sagepub.com

Think of feeding issues as a Medical issue **First**

"need for early and comprehensive medical investigation to determine if medical issues are contributing to the negative feeding behaviors for children with ASD" (Rogers et al. 2012)

> Holland Bloorview Kids Rehabilitation Hospital

Think of "feeding challenge" as a SYMPTOM not the problem

- When a child presents with a cough, we don't just treat the symptom of a cough, we complete a comprehensive assessment of possible underlying causes of the cough and systematically rule out or rule in, each possible cause
- Obviously the more successful we are at identifying the underlying cause of the cough, the more successful our treatment will be

This same approach should be applied to assessing feeding challenges in kids with ASD



The challenges:



There is currently no established method guiding clinicians to complete a comprehensive assessment of all of the underlying factors contributing to a feeding challenge in a child on the autism spectrum

Without an adequate framework for assessment, clinicians are left to guess how to proceed



Holland Bloorview Kids Rehabilitation Hospital

The current state of affairs:



For Example:

4 year-old boy with ASD presents with picky eating resulting in a limited diet of less than 15 foods. When new foods are presented, he cries and pushes the food away

He is referred to an OT who explains that the child has sensory feeding issues and designs an intervention to help desensitize the child to some target foods. After several months the child will touch and lick some new foods but has not added any new foods to his diet.

Here's what we're missing:

- He has significant issues with constipation
- He grazes all day, eats a few bites at a time
- He is fed by others while walking around or while watching TV
- His parents struggle with his poor compliance in all areas (sleep, dressing, bathing etc.)
- Medical, environmental and other behaviour issues need to be addressed first

Medico-oral-behavioural-sensory approach – MOBS^E approach ©



The MOBS^E framework is designed to guide clinicians through each factor: medical/nutrition, oral-motor, behaviour, sensory and environment to help properly identify the aetiology(ies) of a child's feeding challenge.

The framework is grounded in the premise that the parent child relationship impacts all aspects of feeding and requires consideration as clinicians move through each element of the framework.

Factor	Description	Red flags	Resources/team members
Medical/ Nutrition	 Identify common medical factors that may alter feeding behaviours such as: constipation, GERD, food allergies, gastritis, dysphagia (coughing, choking or drooling with meals) and medication such as stimulants or antipsychotic agents. Identify the child's developmental age and acqui- sition of appropriate feeding skills. Determine if the child is nutritionally stable as indi- cated by: weight, height, BMI, growth curve, hydra- tion status, micro/macronutrient intake, HR, BP Document pubertal phase, peripheral stigmata of malnutrition or nutritional deficiencies 	 Pain with feeding Recurrent vomiting and/or diarthea Growth failure Pallor, lethargy Abdominal pain Hitting of abdomen (nonverbal child) H/O Aspiration Meets criteria for ARFID 	Feeding Handbook: See Buie et al. (2010) (16) and Smile (2019) (12) Consult a Dietitian and/or Gastroenterologist and/or Feeding specialist team as indicated
Oral-motor	 Identify any oral-motor challenges that may impact a child's feeding performance such as: anatomical differences (cleft, tongue tie, structure of mouth/teeth), delayed oral-motor skills (poor tongue lateralization, poor lip closure) leading to a mismatch of food offered not aligning with child's current oral-motor skill level. 	 Drooling H/O gagging or choking Difficulty advancing textures 	Feeding Handbook: See Barton et al. (2018) (17) Consult a Speech and Lan- guage Pathologist as indi- cated
Behaviour T	 Identify mealtime behaviours that may be contributing to a child's feeding performance such as: avoid- ance, refusal, tantrums, self-injurious behaviours Complete a functional behaviour assessment to determine the function of the disruptive meal- time behaviours 	 Self-injurious behav- iours at mealtimes Self-Induced Vomiting Inability to eat in dif- ferent environments 	Consult a Behaviour Analyst as indicated
^{Sensory} ଅନି	 Determine whether the child is experiencing sensory processing differences that may be impacting on their feeding performance such as: sensitivity to taste, texture, smell, appearance, sound of foods, challenges sitting, challenges sensing hunger cues 	 Anticipatory Gagging or Vomiting to certain scent or on seeing specific foods 	Feeding Handbook Consult an Occupational Therapist as indicated
Environment T	 Assess environmental factors that may be con- tributing to a child's feeding performance such as: mealtime schedule, distractions, positioning, different feeders, seating 	 Use of electronics to facilitate meal times Grazing 	Consult a Behaviour Analyst as indicated
Parent - Child Relationship	 Evaluate for parental anxiety around feeding Identify parent feeding style 	 Force feeding H/O Depression or Anxiety (parent or child) 	See Hughes et al. (2005) (18)



Conceptualized by Smile, S., Raffaele, C., Perlin R. 2017 ©

Medical / Nutrition



- Identify common medical factors that may alter feeding behaviours such as:
- Dental Caries
- Dysphagia
- GERD
- Gastritis
- Constipation
- Food Intolerances
- Food Allergies
- Medication







- Determine if child is nutritionally stable as indicated by:
- Weight/height
- BMI
- Growth curve
- Hydration status
- Micro/macronutrient intake
- HR, BP
- Pubertal Stage

Medical / Nutrition



Conceptualized by Smile, S, Raffaele C, Perlin R. 2018





- Identify oral-motor challenges that may impact a child's feeding performance such as:
- Anatomical differences (cleft, tethered oral tissues, structure of mouth/teeth)
- Delayed oral-motor skills (poor tongue lateralization, poor lip closure) leading to a mismatch of food offered not aligning with child's current oralmotor skill level





- Children with ASD reported to be later to transition to solid foods and to have more chewing difficulties than their matched peers (Nadon et al. 2011; Sahan et al. 2021)
- Some studies have reported higher prevalence of malocclusion in children with ASD compared to control group (Fontaine-Sylvestre et al. 2017) while others have found no significant difference (Barros et al. 2022)



Is it Sensory? Is it Motor?



- Is feeding difficulty really sensory based?
- Not accepting food (particularly gagging, spitting out) may not be sensory based rather:
 - Mismatch of child's mouth skills with food consistencies served
 - How fast they are being fed (pace)
 - How much they are being fed (volume)
 - Misunderstanding child's cues/behaviour

Is it Sensory? Is it Motor?

- A child accepting a wide variety of smooth pureed foods but refusing or spit/pull out harder solids
 - Suspect oral motor difficulties (ability) first before sensory or behaviour
- A child who willingly chews a selection of harder foods (e.g. skittles, smarties, gummies)

• Suspect behaviour and/or sensory, not oral motor





Is it Sensory? Is it Motor?

- Oral-motor delays can look like sensory issues-it is important to figure which is responsible for the challenges
- A child with oral motor issues needs to be fed foods that match their oral motor/developmental level, not necessarily their chronological age

If we offer foods that are too challenging we may see:

- Refusing food
- Refusing particular textures
- Coughing/choking
- Gagging/vomiting
- Swallowing foods whole
- Will chew on non food items/not food
- Putting foods in mouth-pulling/spitting out
- "feeding aversions"

•(Arvedson, 2013)

•Averse to "feeding"? or averse to foods that are too difficult for their motor skills?



bwc5610181 Barewalls @

How do we know if a child's oral skills may be affecting their eating?

- Assessment is important!
- Gather information on
 - history of development of feeding skills
 - What foods does the child eat well/willingly-WHY?
 - What foods does the child refuse or not eat well-WHY?
- Physical assessment should include **observing feeding** preferably in person or virtually/by video as needed to evaluate:
 - Child's overall developmental level/motor skills
 - Oral mechanism structure
 - Lip/Tongue/Jaw movement/skill when eating
 - Current chewing pattern
 - Oral movements during speech

Based on the results of assessment-what strategies will work best to help this particular child be ready to work on chewing and to transition to greater texture?

Myth Buster





- But we don't "SWALLOW" solid food!
- We chew foods thoroughly to almost a puree before swallowing
- If liquids/purees swallowed well, it is likely not a swallowing problem, but a "CHEWING" problem
- Children may avoid foods that they cannot handle, so they accept soft or pureed foods, rejecting foods that require chewing but often can't tell us why
- If this is the case, we need to assess their READINESS to work on chewing and determine a treatment plan
- Children can (if needed) continue to thrive nutritionally with purees/liquids

Myth Buster





- Spitting out foods could be sensory-but what if it is ORAL-MOTOR?
- Refusing particular textures, coughing/choking, gagging/vomiting, swallowing foods whole, chewing on non food items but not food, putting foods in mouth-pulling/spitting out
 - Can make the case for an oral motor origin.
- What if they are being force-fed?
- Mixed consistency (chunky) purees-PUREE SURPRISE!
 - puree elicits suckle-swallow pattern (Stolovitz & Gisel,1991) not chewing



Conceptualized by Smile, S., Raffaele, C., Perlin R. 2017 ©



- Identify mealtime behaviours that may be contributing to a child's feeding performance such as:
- Avoidance
- Refusal
- Tantrums
- Self-injurious behaviours
- Complete a behaviour assessment to determine the function of the disruptive mealtime behaviours
- Is the child having behaviour challenges in other areas?

Remember, there are two behaviours to consider




Conceptualized by Smile, S., Raffaele, C., Perlin R. 2017 ©





- Determine whether the child is experiencing sensory processing differences that may be impacting on their feeding performance such as:
- Sensitivity to taste, texture, smell, appearance, sound of foods,
- Difficulty staying seated for meals
- Challenges sensing hunger cues





- We know that children with ASD can process sensory information differently as it is one of the diagnostic criteria for ASD in the DSM-V
- We also know that eating can be a very intense sensory experience that involves processing information from many different senses at one time
- Therefore, it would be easy to assume that most children with ASD have feeding issues as a result of sensory processing issues



Is the problem REALLY Sensory??

Many things can look like sensory issues, but they may not be:

- Spitting food out
- Gagging
- Pocketing or holding food in mouth
- Only eating a few bites
- Difficulty staying seated while eating



Ensure the issue is not a medical, oral motor or behavioural problem that just looks like a sensory issue



What if it is a sensory issue?

- There is no strong evidence to support that we can change how our brain processes sensory information related to feeding (i.e. you can't make someone like a taste or smell)
- Despite the existence of "sensory feeding" treatments such as the Sequential Oral Sensory (SOS) approach (Toomey, K & Ross, E., 2011) there is no strong evidence to suggest that sensory interventions alone are effective for treating all children with feeding challenges.
- There IS evidence to suggest that we can use behavioural and anxietyreduction strategies to help kids learn to TRY new foods and to modify their reactions to unpleasant sensory input.

Interoception: A Hidden Sensory System • (• C 9 m

Interoception: A Hidden Sensory System

- Interoception is the awareness of our internal body states (Mahler, 2015)
- Interoception allows us the ability to "feel" the insides of our body including important sensations such as pain, body temperature, heart rate, hunger, thirst, sleepiness, need to use bathroom, and more (Craig 2002, 2003)
- The area of the brain that receives most of the information regarding interoception is the insular cortex (insula)

Several studies have demonstrated significant differences between the insula in autistic individuals and those without ASD (Garfinkel et al. 2016, DuBois et al. 2016)

Autistic adults report not feeling hungry, not attributing biological signs of hunger to needing to eat.

We can encourage kids to be hungry to encourage eating but can't rely on hunger as the sole treatment strategy

Myth Buster

Just stop giving him his preferred foods. When he gets hungry enough, he'll eat what you want him to. Kids won't starve themselves.



- Some kids with ASD may not feel hunger or may not connect the feeling of hunger with eating (differences with interoception)
- Some kids with ASD have extremely rigid behaviours that lead them to seek out familiar and fear anything new or even slightly different
- These children can restrict their intake to the point of becoming malnourished



Conceptualized by Smile, S., Raffaele, C., Perlin R. 2017 ©





- Assess environmental factors that may be contributing to a child's feeding performance such as:
- Mealtime schedule /grazing
- Distractions (tablet, TV, toys)
- Positioning
- Different feeders
- Different locations



Conceptualized by Smile, S., Raffaele, C., Perlin R. 2017 ©

Parent-Child Relationship

- Consider parental stress
- Consider parenting style with regards to feeding:



Parent-Child Relationship

- Be mindful of only gathering information from "parent report" (Vissoker et al. 2015)
- Important to gather information from parents/caregivers, preferably from multiple settings
- Also from child themselves if possible (Bitsika & Sharpley 2018)
- Observation is important to see the whole picture (Cermak et al. 2010)





Medico-oral-behavioural-sensory approach – MOBS^e approach ©



! Evaluate Parent- Child relationship/ Parental Anxiety !

Glenrose Ax Format







How do we take the assessment info and decide on treatment goals?







2 years 11 months

Referred for selective eating and limited food repertoire

Picky eating, nutrition concerns

Low dietary iron

Noted to have tongue tie

Not tolerating non-preferred foods on his plate

Recommendations:

- Tongue tie release
- Food Play for exposure
- Expanding Pediasure
- Iron supplement



3 years 10 months

Requested by parent **Recommendations:** Re-ax oral-motor skills & nutrition, Strategies for expanding diet Sensory exploration of non-preferred Working with community teams, good strategy use at home Introduce a reward system Improved tongue movement

Tolerating non-preferred on his plate, will touch dry nonpreferred





Parent Request

Nutrition concerns, OT requesting consult



OT working on food exposure, new GI concerns



Reduced tongue control, immature chewing pattern, drooling, low tone, dysarthric speech



Could tolerate some pudding on hands/arms but still hesitant



Recommendations:

- Referral to GI
- Refer for motor-speech
 Tx
- Work on OM control
- Continue diet expansion strategies





6 years old

Parent Request

Dropping foods



Taking some bites of new foods

) ? Mouth pain, difficulty with open cup



Exploring squishy texture with hands

Recommendations:

- Focus on spoonable foods
- Focus on goal foods, rather than general food play
- Refer to SROP for Feeding Treatment



Case Study Take-Aways

Dynamic Process
It's okay to back up and try something else
Ask What Else?



Eating, Feeding & Swallowing for children on the Autism Spectrum | Oct 26, 2022









Eating, Feeding & Swallowing for children on the Autism Spectrum: Getting the info and figuring out what to do with it Part 2: Treatment

Nov 2, 2022 | 10:30-11:30AM + Percolator 11:30-12PM

Joint Presentation by: Glenrose, and Holland-Bloorview Rehabilitation Hospitals



Pediatric Eating And Swallowing

Eating, Feeding & Swallowing for children on the Autism Spectrum | Oct 26, 2022

Contact Us PEAS.Project@ahs.ca





Q

FOR PROVIDERS

~

CLINICAL PRACTICE GUIDE

CLINICAL TOOLS & FORMS

COLLABORATIVE PRACTICE

PROFESSIONAL DEVELOPMENT

COMMUNITY OF PRACTICE

FAMILY RESOURCES



Community of Practice

We have just launched the Pediatric Eating And Swallowing Community of Practice (CoP) for healthcare providers who work with children with a pediatric eating, feeding and swallowing (EFS) disorder. This virtual CoP is an interdisciplinary community of healthcare providers across the continuum of care in Alberta. The goal of this CoP is to capture the spirit and harness the power of collaboration to enhance and improve interdisciplinary practice in EFS to attain the best outcomes for children and their families.

To join the PEAS Community of Practice:

- 1. You must be a healthcare provider with an AHS account. *See below for information on how to obtain an AHS account.
- 2. Go to the PEAS CoP website here: *https://extranet.ahsnet.ca/teams/CoP/PEAS/SitePages/Home.aspx* If prompted, enter your AHS account name and password.

3. Click "Join this community" as shown below. That's it!



Eating, Feeding & Swallowing for children on the Autism Spectrum | Oct 26, 2022

Thank you!



PEAS.Project@ahs.ca

https://survey.ahs.ca/peas.autism1

30 Min Percolator (optional) Eating, Feeding & Swallowing for children on the Autism Spectrum: Getting the info and figuring out what to do with it

Part 1: Assessment

Christie Raffaele, MSc(OT), OT Reg. (Ont.) Courtenay Mayowski, MSc, R.SLP (C) Rebecca Perlin, M.CI.Sc. SLP(C) reg. CASLPO Dr. Sharon Smile, MBBS, DM, MSc

Alberta Health Services

Pediatric Eating And Swallowing

Eating, Feeding & Swallowing for children on the Autism Spectrum: Getting the info and figuring out what to do with it Part 2: Treatment

Nov 2, 2022 | 10:30-11:30AM + Percolator 11:30-12PM

Joint Presentation by: Glenrose, and Holland-Bloorview Rehabilitation Hospitals



Pediatric Eating And Swallowing

Eating, Feeding & Swallowing for children on the Autism Spectrum | Oct 26, 2022

Contact Us PEAS.Project@ahs.ca



Thank you!



PEAS.Project@ahs.ca

https://survey.ahs.ca/peas.autism1