Workshop Cycle 4

Special Thanks

Practical Approaches to Feeding Challenges & Maximizing Nutrition
for Individuals with DS-ASD

Dominica Nichols, PhD, RD, LDN

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MASSACHUSETTS GENERAL HOSPITAL

Disclosures and Speaker Intro

Dominica Nichols: Registered Dietitian (RD) licensed in MA.

- MGH Down Syndrome Program clinic Registered Dietitian-Nutritionist
- MGH Medical Genetics clinic Registered Dietitian-Nutritionist
- No other active professional affiliations, but I do attend Massachusetts Down Syndrome Congress events and am a member of DSMIG.
- No additional relevant financial or nonfinancial relationships to disclose

Tessa Kennedy: Speech Language Pathologist licensed in MA.

- MGH Down Syndrome Program and Feeding and Nutrition Center Feeding Therapist
- No additional relevant financial or nonfinancial relationships to disclose

Disclosures and Speaker Intro

I see approximately 500 patients a year with Down syndrome.

- Geneticist/Physician (Drs. Skotko, Santoro and Oreskovic)
- Social Worker
- MGH Down Syndrome Program clinic Registered Dietitian-Nutritionist
- +/- Pediatric or Pediatric-Adult Feeding Specialist (CCC-SLP)

- Youngest Patients: age 0-5 also see a Pediatric Therapy Team:
  - SLP (communication, feeding skill development)
  - OT (fine motor, sensory integration and feeding development)
  - PT (gross motor eval including specific orthotic supports)

I am the proud parent of two children with Autism.

- Charlie is a rising 11th grader and eats (almost) everything except soft-cooked carrots. When he was younger, he required all plates and bowls and cups to be yellow. He has multiple food allergies and Asthma.
- Bronwyn is a rising 9th grader and she survives mostly on milk and various shapes and forms of pasta with cheese (ravioli, stuffed shells, lasagna etc.) She used to eat everything including carrots. She eats much better when I am not around.
- Neither of my children have DS-ASD, but they have taught me a great deal, including:
  - practical challenges of meeting “basic” nutritional needs
  - opportunities associated with routines, schedules & “SMAR” goals
  - challenges associated with hypo- and hypersensitivity

Parenting has forever changed my feeding recommendations.

- My children have struggled with weight gain and selectivity from the beginning. They have taught me that sometimes pizza must be served upside for it to be acceptable, and that only eating vegetables when they are covered in ranch still counts as a win.

- Parenting two innately picky toddlers has allowed me to tap into flexibility and empathy as a clinician but has also helped me understand how we can effectively set boundaries and the importance of feeding routines.

- Most importantly, I have learned that nutrition and skill development are important, but family and cultural structures around food are just as crucial to understand.

Nutrition and Feeding are two sides of the same coin.

- **What** an individual eats and drinks is important
- **How** an individual eats and drinks is important
- **Maximizing** quality of life and health are also important

Clinical "Roadmap"


American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™

FROM THE AMERICAN ACADEMY OF PEDIATRICS

Guidance for the Clinician in Rendering Pediatric Care

Clinical Report—Health Supervision for Children With Down Syndrome

Marilyn J. Bull, MD, and the COMMITTEE ON GENETICS

DS-ASD clarification & diagnosis

JIDR Journal of Intellectual Disability Research
Published on behalf of mencap and in association with IASSID

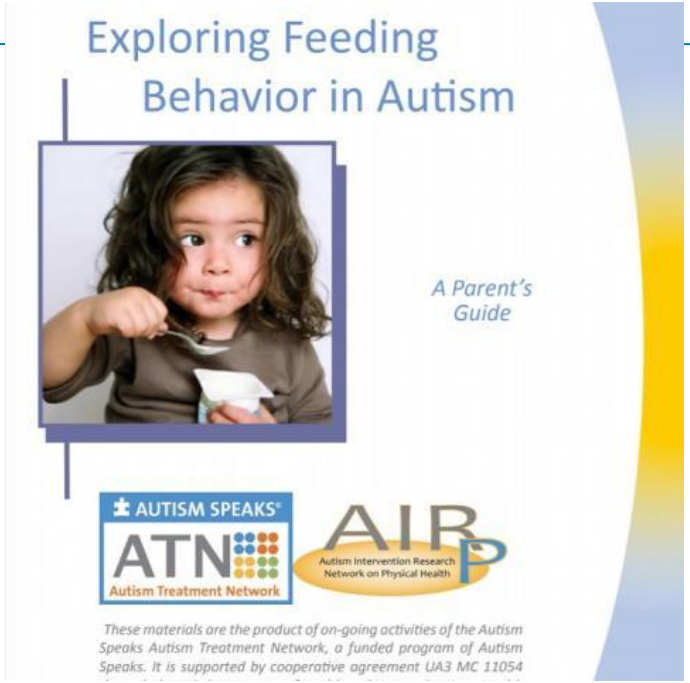
Journal of Intellectual Disability Research doi: 10.1111/j.1365-2788.2011.01465.x

Autism spectrum disorder in Down syndrome: cluster analysis of Aberrant Behaviour Checklist data supports diagnosis

N. Y. Ji,[1,2] G. T. Capone[1,2] & W. E. Kaufmann[1,2]

1 *Center for Genetic Disorders of Cognition & Behavior, Kennedy Krieger Institute, Baltimore, Maryland, USA*
2 *Johns Hopkins University School of Medicine, Baltimore, Maryland, USA*

- social communication
- social-emotional reciprocity
- repetitive behaviors
- hypo-sensitivities
- hyper-sensitivities
- not better explained by



Autism resources are a helpful place to start.

Nutrition Challenges and Opportunities

- “age-appropriate” nutrition and hydration
- desire for sameness, routine and “expected” outcomes
- competing priorities and various food environments (home, school, medical services, community, family)
- food as a motivator or a “threat”
- (in the setting of) medical co-morbidities (known or unknown)

Feeding Challenges and Opportunities

- “age-appropriate” feeding milestones and skill retention
- alternative modes of feeding
  - modified textures or consistencies
  - sensory-seeking behaviors or aversion

Dissecting the Details

Objective 1:

- Describe common nutritional concerns for individuals with Down syndrome and DS-ASD.

Objective 2:

- Describe the differences and similarities between **feeding** and **nutrition** for individuals with DS-ASD.

Objective 3:

- Identify relevant feeding strategies that can be used to support common nutritional problems for individuals with DS-ASD and how to get this support (other than just providing it yourself).

Common Nutritional Problems

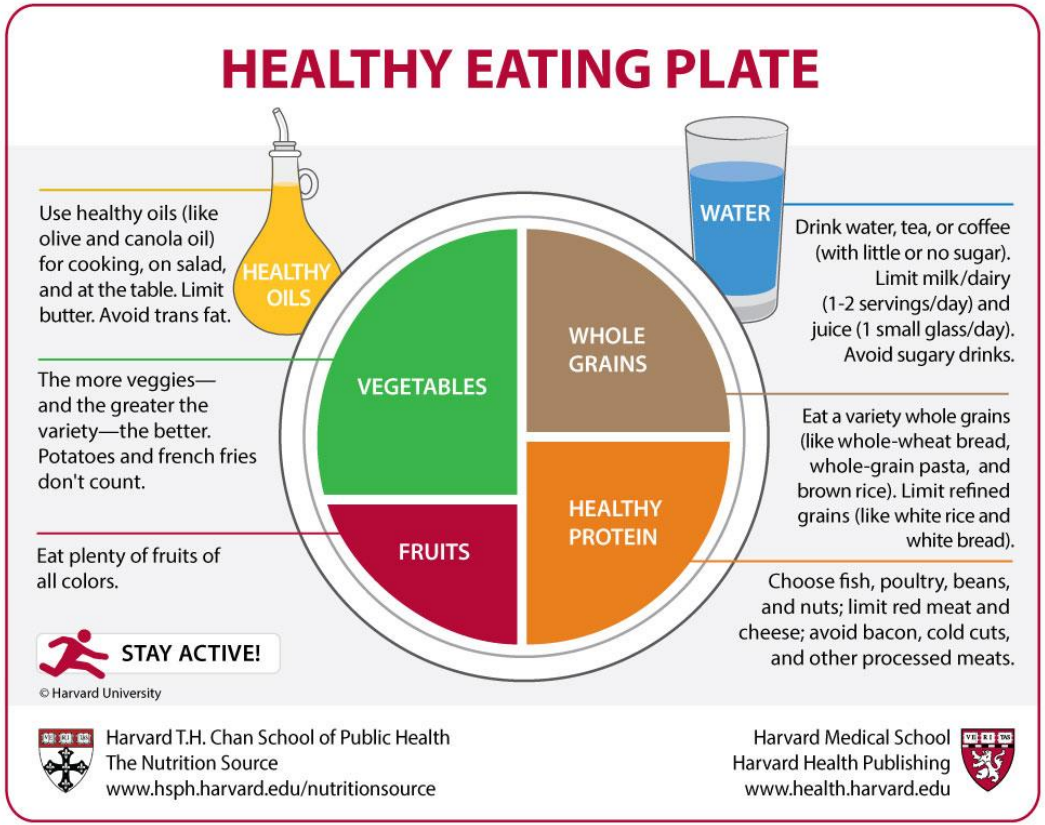
Nutritional Problem	Potential Consequences
Iron deficiency Iron Deficiency Anemia	Cognitive Change or Lethargy
Dietary Calcium Deficiency Excess Dietary Calcium	Osteopenia or Osteoporosis Drug-Nutrient Interactions, Constipation
Dietary Fiber Deficiency Inadequate Fluid Intake	Constipation, Diarrhea

Common Nutritional Problems

Nutritional Problem	Potential Consequences
Restrictive Diets for: - Allergy/Intolerance - GERD - EoE (Eosinophilic Esophagitis) - **Feeding Difficulties** or Swallowing Difficulties - ARFID (Avoidant/Restrictive Food Intake Disorder)	Meals require more planning. Meals may require ADL support. Feeding Difficulties are more common, often more intense, and more persistent in DS-ASD.

Common Nutritional Problems

Nutritional Problem	Potential Consequences
Poor growth Underweight	Can cause (or be the result of) co-morbidities like congenital heart disease, thyroid disease, Celiac disease, iron deficiency anemia or restrictive diets.
Rapid weight gain Overweight Pediatric Obesity or Obesity	


HEALTHY EATING PLATE
Use healthy oils (like olive and canola oil) for cooking, on salad, and at the table. Limit butter. Avoid trans fat.
HEALTHY OILS
WATER
Drink water, tea, or coffee (with little or no sugar). Limit milk/dairy (1-2 servings/day) and juice (1 small glass/day). Avoid sugary drinks.
The more veggies—and the greater the variety—the better. Potatoes and french fries don't count.
VEGETABLES
WHOLE GRAINS
Eat a variety whole grains (like whole-wheat bread, whole-grain pasta, and brown rice). Limit refined grains (like white rice and white bread).
HEALTHY PROTEIN
FRUITS
Eat plenty of fruits of all colors.
Choose fish, poultry, beans, and nuts; limit red meat and cheese; avoid bacon, cold cuts, and other processed meats.
STAY ACTIVE!
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Harvard T.H. Chan School of Public Health
The Nutrition Source
www.hsph.harvard.edu/nutritionsource
Harvard Medical School
Harvard Health Publishing
www.health.harvard.edu

Common Nutrition Problems

Metabolism is 10-15% “slower” in individuals with Down syndrome compared to peers of the same height, weight, age, gender.

No DS: 1000 kcal

DS or DS-ASD: 850-900 kcal

There is no difference in calories burned with exercise or activity. There is likely no difference in calories required for (medical) stressors.

Nutrient Density is important! We predict the same vitamin and mineral needs for healthy people with Down syndrome as other healthy people.

Adapted from slide by Caitlin Woglom, LDN

Common Nutrition Problems

Many challenges are similar for individuals with DS and DS-ASD.

- Mineral Deficiency or Excess (ie. calcium, iron)
- Macronutrient Deficiency (ie. fiber, water)
- Excess (or Inadequate) Energy Intake for current activity/stress level
- Co-occurring Gastrointestinal or Autoimmune Conditions
- Feeding Difficulties

Feeding Difficulties maybe more severe and persistent in DS-ASD.

- Food Refusal or Texture Intolerance may lead to Vitamin or Mineral Deficiencies
- Food/Texture Refusal maybe represent reaction to a medical or environmental factor that cannot be otherwise communicated or resolved

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Nutrition and Feeding are two sides of the same coin.

- **What** an individual eats and drinks is important
- **How** an individual eats and drinks is important
- **Maximizing** quality of life and health are also important

Feeding (How) vs. Nutrition (What)

Feeding

Meal and Snacks
- -distinct pattern or grazing
- -slow eater or speed hunger

Mealtime Environment
- table or couch or floor
- plate, bowl, utensils, cup/nipple type

Mode of Feeding
- oral or tube or both
- fed or self-feeding

Textures and Consistencies

Nutrition

Water

Nutrients
- Carbohydrates and Protein
- Fats (omega-3 vs. omega-6 unsaturated saturated)
- Vitamins and Minerals

Flavors as a source of phytonutrients (spices are plants or minerals, ie. iodine)

Total Energy (IN and OUT)

Reasons I like Dr. Oz:

- He helps remind people to think about and work on their nutritional health and wellness.
- His YouTube Channel is entertaining and has helped some of my adult patients “get started”. Example: Dr. Oz says to put cinnamon not sugar in my coffee. This is a clear goal and is easy to follow.

Reasons I do not like Dr. Oz:

- He is **not** a Registered Dietitian with a license in your state. He is giving the masses “medical nutrition therapy” without an adequately comprehensive personal consultation.
- If I did this, I would not be following the Code of Ethics of my profession or the Licensure requirements in my home state of Massachusetts (or any other state).


BUT DR. OZ SAID...
HE'S NOT A DIETITIAN
Overgram

Reasons I like Instagram:

- Well-researched and vetted accounts can offer highly effective feeding strategies in easy-to-digest and helpful ways. They are far more accessible than trying to understand a complex research study.
- They can normalize the struggles that many families have with feeding difficulties and help them not to feel so alone. Many times they can offer great solutions to common problems.

Reasons I do not like Instagram:

- It is easy to propagate misinformation. Many accounts use fear-mongering or pseudo-science to scare parents in order to push certain ideas or products.
- Anyone can create an account and push information that is incorrect or dangerous. It is important to ensure that the creator is qualified to offer advice.

Have a Nutrition Concern?

Please find a Registered Dietitian.

- You want a Registered Dietitian with a license in your home state (or equivalent).
- For outpatient nutrition counseling, ask for someone who has recent experience with individuals with Intellectual Disabilities **and** at least one of your specific concerns.

- Communicate your expectations and goals for the visit ahead of time to ensure your time can be used effectively and efficiently. Share a diet and drink log but also share medical records and the timing of when you give medications.

Have a Nutrition Concern?

- If the first person you talk to says, “I am not sure I am a good fit for your needs,” **do not** give up! Ask them for a colleague’s referral or ask your trusted Primary Care Provider, SLP, OT, Developmental Pediatrician or Geneticist for the same.
- Please **do not** expect one consultation to “fix” the problem (unless it is quite minor). Registered Dietitians are most helpful when they can get to know your loved one, their/your family’s goals and how your loved one responds to recommendations.
- Depending on the concern or the format, you may want to see or check-in with your Registered Dietitian each:
  - 1-6 weeks
  - **quarter (2-3 months)**
  - **6-12 months**

Dissecting the Details

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Goal: Maximize Quality of Life while meeting all nutritional needs.

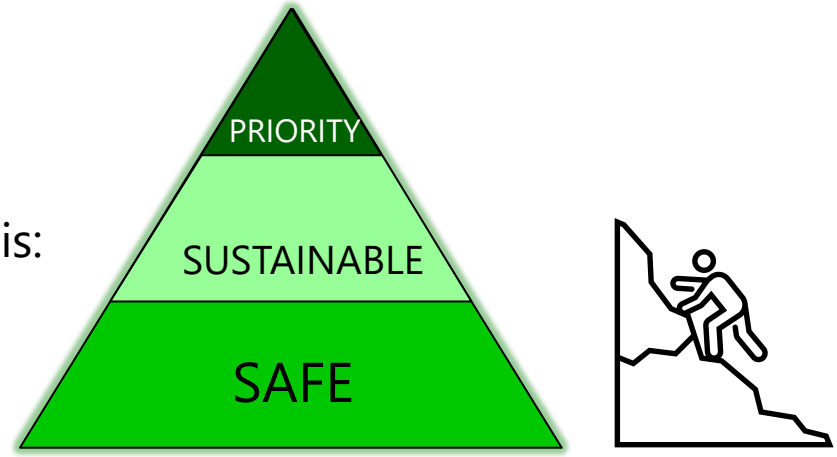
- Build a team and leverage your resources.
  - Family and direct Caregivers
  - Community
  - Staff
  - Medical Team

- Be confident with **slow and steady** progress through appropriate challenges. Do not compare to age-matched peers – compare to self.
- Ask for clarification and specific food ideas if you need them.

THEME 1: READINESS

- Caregivers, providers, and individual may all have different levels of READINESS to make a change, learn a skill, and/or remove a support.

What is:



- Remember SMAR goals: Specific, Measurable, Achievable, Relevant. Remain flexible on T (time) based on understanding of individual.

THEME 2: COMMUNICATION AND COLLABORATION

- Ideally, parents/caregivers, school, and medical team agree.
- What can be done if school has a view on nutrition and feeding that does not match family and/or providers?
- Example: Child is refusing to eat at school. We proposed that child was tired of the limited options offered at school (compared to home). When more flavorful options were provided, eating at school improved.
- Consider:
  - limitations of school-based services (supports vs. feeding therapy)
  - opportunities for school-based providers to practice in a safe and sustainable way
  - letters of advocacy, interim virtual visits, invite provider to IEP meeting

THEME 3: DEVELOPMENTAL FEEDING SKILLS vs GROWTH

- For individuals under the age of 20, growth charts are helpful tools to estimate nutritional status. They never tell the whole story.
- Growth trends may or may not be related to feeding status.

- Reviewing growth charts in detail can help support decisions of when to:
  - prioritize skill-building over catch-up growth (or vice versa)
  - rebalance between solid versus liquid nutrition
  - modify meal and snack pattern to allow adequate time between eating opportunities
  - add high calorie eating strategies
  - add nutritional supplementation

THEME 3: DEVELOPMENTAL FEEDING SKILLS vs GROWTH

- EXAMPLE: Child's failure-to-thrive/malnutrition started to resolve with a combination of feeding supports, mealtime schedule, and nutritional supplements. High calorie eating and supplements were weaned once catch-up growth was achieved and feeding supports started to yield more progress. No g-tube required.

- EXAMPLE: Child started to transition to less formula via g-tube and then needed to stop using the g-tube for hydration. Helpful supports included (a) close collaboration with school, (b) interim virtual visits with SLP/RD, and (c) regular review of growth chart to help parent remain confident.

THEME 3: DEVELOPMENTAL FEEDING SKILLS vs GROWTH

- EXAMPLE: Teen started to transition from most of their nutrition via g-tube to most of their nutrition from chewable solids and purees. Helpful supports included (a) outpatient feeding therapy, (b) outpatient nutrition counseling, and (c) regular review of growth chart at each feeding transition to show limited/no regression with decreased formula use.

- EXAMPLE: Adult became more accepting of oral exploration with purees after adjustments were made to their formula regimen. Helpful supports included (a) outpatient feeding assessment, (b) outpatient nutrition counseling, and (c) ongoing parent engagement.

THEME 4: TUBE FEEDING and WEANING TUBE FEEDS

- Feeding tubes can be important tools to help someone close gaps in their nutrition.
- Significant nutritional gaps can get in the way of developmental progress and make it harder to meet other goals.
- Feeding tubes can provide complete or partial:
  - nutrition
  - hydration
  - medication access
- Partial tube feeds can be a temporary support while other feeding skills are practiced and an opportunity (if medically necessary) to reduce stress on oral intake and make mealtimes more positive.

Feeding Progression Resources

Websites

- *MGH Down Syndrome Program, Patient Resources*:

https://www.massgeneral.org/children/down-syndrome/patient-handouts

- *Food Chaining:*

https://www.sensorysolutions.org/application/files/2214/9815/7292/Food_School_Handout-1.pdf

https://youngwomenshealth.org/wp-content/uploads/2018/09/Food-Chaining-for-ARFID.pdf

- *Autism Training Network (ATN), Tool Kits*:

https://www.autismspeaks.org/tool-kit?resource_type[606]=606&resource_type[606]=606

Feeding Progression Resources

Books

- *Broccoli Boot Camp*:

https://www.woodbinehouse.com/product/broccoli-boot-camp-basic-training-for-parents-of-selective-eaters/

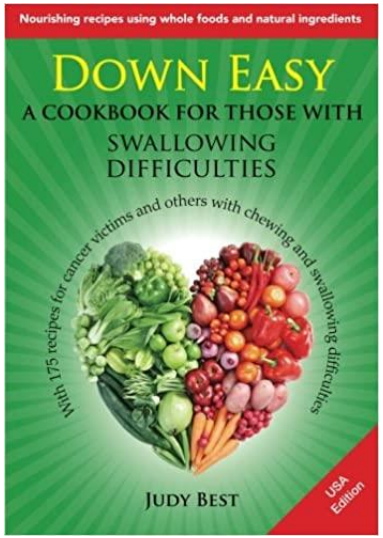
- *Food Chaining:*

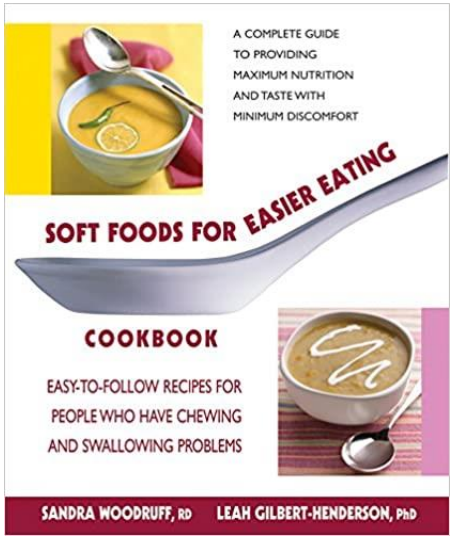
https://www.amazon.com/Food-Chaining-Proven-Feeding-Problems-ebook/dp/B009W6V6Q0

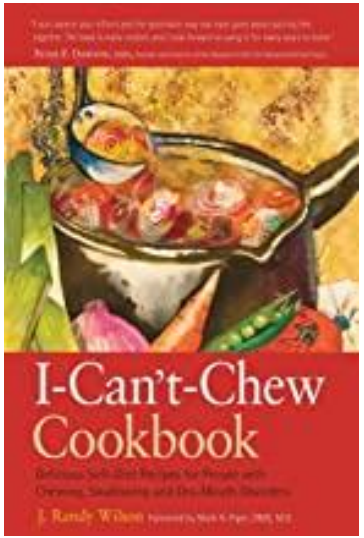
- *Helping Your Child with Extreme Picky Eating*:

https://www.amazon.com/Helping-Child-Extreme-Picky-Eating/dp/162625110X

- *Cognitive-Behavioral Therapy for Avoidant/Restrictive Food Intake Disorder: Children, Adolescents and Adults* by Jennifer J. Thomas and Kamryn T. Eddy


Nourishing recipes using whole foods and natural ingredients
DOWN EASY
A COOKBOOK FOR THOSE WITH SWALLOWING DIFFICULTIES
With 175 recipes for cancer victims and others with chewing and swallowing difficulties
JUDY BEST
USA Edition


A COMPLETE GUIDE TO PROVIDING MAXIMUM NUTRITION AND TASTE WITH MINIMUM DISCOMFORT
SOFT FOODS FOR EASIER EATING
COOKBOOK
EASY-TO-FOLLOW RECIPES FOR PEOPLE WHO HAVE CHEWING AND SWALLOWING PROBLEMS
SANDRA WOODRUFF, RD
LEAH GILBERT-HENDERSON, PhD


I-Can't-Chew Cookbook

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Take Home Messages

Aim for "age-appropriate nutrition" in the setting of medical complexity, communication differences and sensory sensitivity to novel experiences.

"Age-appropriate" changes as your loved one grows up and ages. Adequate nutrition are the basic building blocks that help your loved one have the fuel to thrive.

Feeding Skills are "how" and can be just as important as "what" someone eats and drinks. Making progress with Feeding can open the door to "age-appropriate" in partnership with a Registered Dietitian.

Strategies may be individualized but most nutrition goals do not change because of diagnoses (DS vs dual diagnosis of DS-ASD).

Looking for More Information?

Frequently Asked Questions

(A) When Do I Ask for Help with Feeding and Who Do I Ask?

(B) What Could be Different for my Loved one with a Dual Diagnosis?
(C) How do I get support at my child's school? (DS or DS-ASD)

(D) I am looking for a Feeding Therapist. Who is Qualified?
(E) I am looking for a Feeding Therapist. Who is Qualified?

Practical Approaches to Feeding Challenges & Maximizing Nutrition
for Individuals with DS-ASD

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When Do I Ask for Help with Feeding and Who Do I Ask?

Individuals with DS are generally more prone to Feeding Difficulties.

- Consider risk factors: oral motor delays and hyposensitivity (reduced sensitivity) due to low muscle tone
- Consider “time” tables: “wait-and-see” vs. “refer now”
- Consider “biggest” goals:
  - preventing pneumonia or other acute illness from aspiration
  - eating and drinking safely with peers or other caregivers (not just parent or not just favorite PCA)
- Next steps:
  - initial evaluation with SLP or OT should be covered at hospital that is “in network” (regardless of findings)
  - follow-up “feeding therapy” may need LOMN (letter of medical necessity) from MD

What Could be Different for my Loved one with a Dual Diagnosis?

Individuals with DS-ASD may need more intensive Feeding Therapy to resolve these challenges.

- It may take longer to progress through each step of feeding progression due to Food Aversion, Food Refusal or Avoidant/Restrictive Food Intake Disorder (ARFID).
- It maybe more challenging to decipher medical co-morbidities (like GERD) due to communication differences or differential experience of “pain” (hypo-/hyper-sensitivity). These could be getting in the way of making progress.
- Next steps:
  - outpatient evaluation and follow-up therapy (or Early Intervention)
  - consider local “food school” or intensive program like Kennedy Kreiger

How do I get support at my child's school? (DS or DS-ASD)

Most schools do not do "Feeding Therapy".

- Early Intervention can provide Feeding Therapy from OT or SLP.
- Most schools do not offer Feeding Therapy despite having OT and SLP on staff. This is due to liability concerns.
- Next steps:
  - initial evaluation with SLP or OT should be covered at hospital that is "in network" (regardless of findings)
  - follow-up "feeding therapy" may need LOMN from MD
  - ask outpatient to document need for 1:1 "mealtime supports" and what is required of the person providing this support
  - ask for school to add it to IEP before child enters the building

I am looking for a Feeding Therapist. Who is Qualified?

This the time to ADVOCATE, ADVOCATE, ADVOCATE.

- Depending on your loved one's needs for feeding, Occupational Therapist with feeding expertise or Speech Language Pathologist with feeding expertise is needed.

FOR YOUNG CHILDREN

- Early Intervention can provide supports (OT or SLP) but may have a long wait list. Look for an "in-network" hospital to start the evaluation process if able.
- Advocate for specific feeding goals to be added to care plan and IFSP. These should not take the place of time spent with your child on communication, gross motor or fine motor skill development.
- If you get pushback, advocate for consult ASAP and consider "regional consultation service" if local agency is unable to support your child.

I am looking for a Feeding Therapist. Who is Qualified?

This the time to ADVOCATE, ADVOCATE, ADVOCATE.

- Depending on your loved one's needs for feeding, Occupational Therapist with feeding expertise or Speech Language Pathologist with feeding expertise is needed.

FOR OLDER CHILDREN or ADULTS

- Look for an "in-network" hospital to start the evaluation process if able.
- Advocate for specific feeding goals to be added to IEP or IPP. These should not take the place of time spent with your child on communication, gross motor or fine motor skill development and will need to be called "mealtime supports" if they are school-age.
- If you get pushback, advocate for consult ASAP (outpatient) and consider more intensive services as appropriate.