

FEEDING YOUR INFANT AND TODDLER WITH DOWN SYNDROME: ADVOCACY AND ACTION

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AGENDA

Setting the Stage: Making Feeding Decisions

Evidence and Support for Feeding Decisions

- Breastfeeding
- Bottle/Formula Feeding
- Introducing Solids
- Nutrition in the Early Years
- Tube Feeding

Taking Action

- When to seek help with
 - Breastfeeding
 - Bottle feeding
 - Tube feeding
 - Solids
- Who Can Help
- Programs and Supports
- Advocating

MAKING FEEDING DECISIONS

A family survey

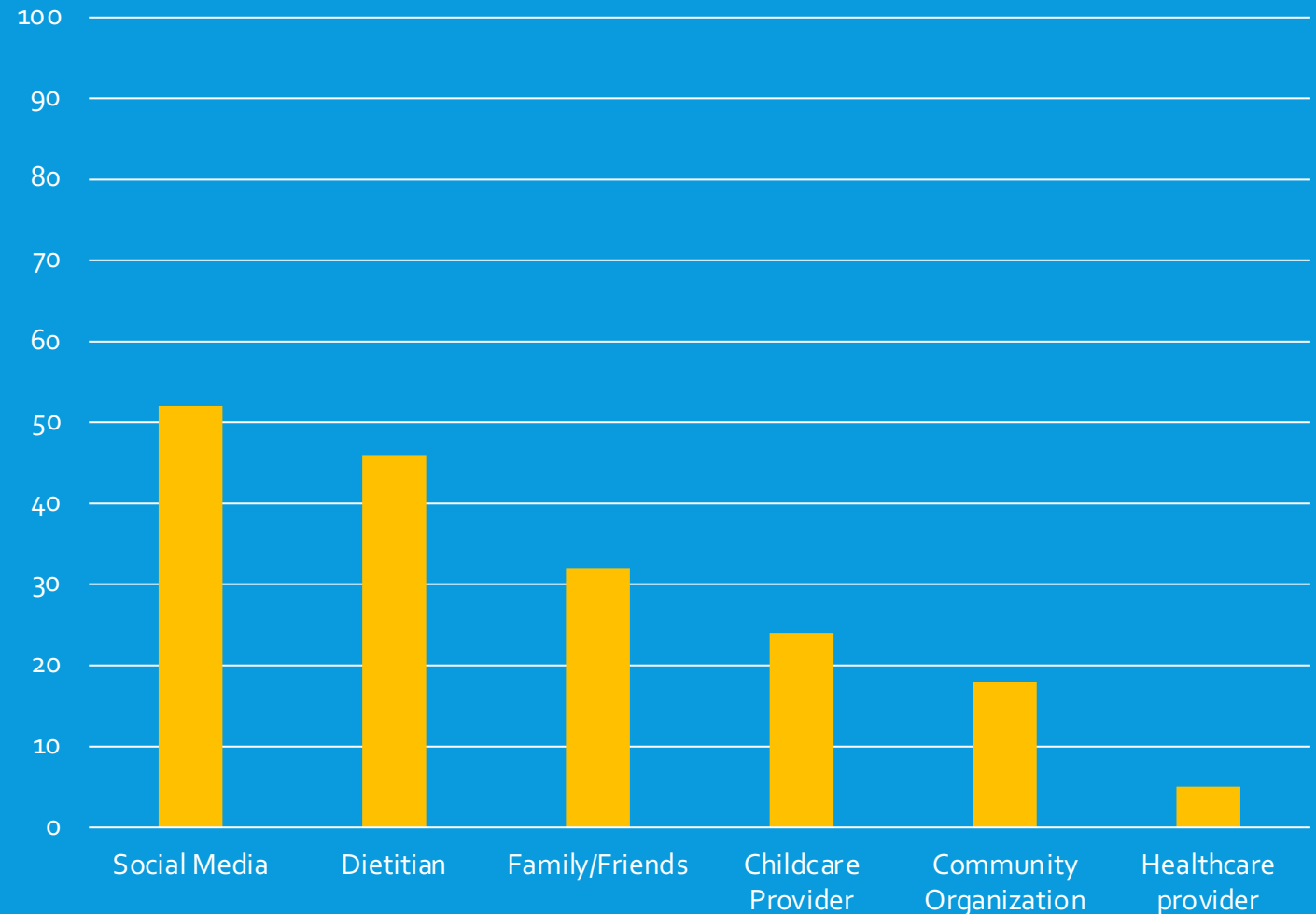
KEY FINDINGS - BREASTFEEDING



- Information about breastfeeding was received from:
 - Professional website (53%)
 - Lactation consultant (48%)
 - Family member or friend (41%)
 - Social media/blogs (40%)
 - Healthcare provider (26%)
 - Community organization (24%)
 - Childcare provider (21%)

KEY FINDINGS – SOLIDS

- About half of families of children with Down syndrome were given information on:
 - When to introduce solids (45%)
 - Types of solid foods to introduce (40%)
 - Developmental readiness signs for starting solids (37%)
 - How to introduce solids (45%)



WHY?



- When it comes to giving advice about solid foods, providers feel unprepared to advise families of children with Down syndrome
 - Little education on Down syndrome
 - Unclear on guidelines
 - May give same advice as they do other families or no advice at all (Cochran et al., 2022)

THEREFORE, FAMILIES MAY NEED TO COME TO
THEIR HEALTHCARE PROVIDER WITH THEIR
OWN RESEARCH AND INFORMATION TO
ADVOCATE FOR THEIR CHILD AND FAMILY...

EVIDENCE & SUPPORT FOR FEEDING DECISIONS

BREASTFEEDING

BENEFITS OF BREASTFEEDING

- Breastfeeding was important to the mothers¹.
- If you can, WHO recommends exclusive breastfeeding is recommended during an infant's first 6 months¹
- Breastmilk content is individually composed and contains all the nutrition that a newborn infant needs during the first 6 months¹
- Protects the against various infections and sudden infant death syndrome (SIDS)¹
- Children with DS are at increased risk of infections, so, the protective qualities of breastmilk are important¹
- Strengthens tongue- and jaw muscles, and enhances facial expressions and language development¹

BARRIERS TO BREASTFEEDING

- Child with DS being singled out and treated differently to other children¹.
- Some healthcare professionals have negative attitudes about breastfeeding a child with DS, which could lead to them informing a mother that children with DS could not breastfeed¹. Stress hinders successful pumping
- More knowledge is needed to increase the frequency of breastfeeding¹. Mothers did not always receive the support they requested. Relied on their ability to find relevant knowledge and guidance, thus requested more person-centered care¹.
- Healthcare professionals focused on the feeding situation in its entirety and breast pumping according to the guidelines instead of supporting the initiation of breastfeeding based on the child's need¹.

OVERCOMING BARRIERS

- Mothers found an inner strength when their effort to initiate breastfeeding became strenuous¹.
- Breastfeeding their child with DS helped create a sense of normalcy in a situation that was difficult to grasp¹.
- Stress could also impact on their ability to lactate when they used the breast pump, which created a vicious circle of inadequate milk supply and further stress¹.
- The mothers also found support and information through peer support groups on social media¹

1. Jönsson, L., Olsson Tyby, C., Hullfors, S., & Lundqvist, P. (2022). Mothers of children with down syndrome: A qualitative study of experiences of breastfeeding and breastfeeding support. *Scandinavian journal of caring sciences*, 36(4), 1156–1164. <https://doi.org/10.1111/scs.13088>



- Finding a skilled lactation consultant is important
- Infants with DS can be successfully breast fed, and like with most infants, working with an IBCLC is very helpful
- Positioning is important, use pillows, hold your baby close, use a pillow to support your back
- Latching on, express some milk onto your nipple
- Ensure your baby has a mouthful of breast tissue to help draw out milk

BOTTLE/FORMULA FEEDING

BOTTLE/BREAST FEEDING

- Baby formulas may contain cow's milk, goat's milk or soy protein. The FDA requires infant formula to have 30 nutrients that your growing baby needs.
- Infants are interactive partners with bottle feeding¹
- Nearly all infant formulas have additional iron added. Iron-fortified formulas have reduced the rate of iron deficiency and iron-deficient anemia. Low iron formulas should not be used.
- Products labeled for older babies and toddler or "**follow-up formula,**" "**weaning formula,**" "**toddler milk**" or "**toddler formula**" are misleading and not necessary
- Sterilize all equipment for bottle feeding
- Do not use left over formula
- The U.S. Food & Drug Administration (FDA) reports that some babies fed homemade formulae been hospitalized for hypocalcemia (low calcium)



INTRODUCING SOLIDS

WHEN TO INTRODUCE?



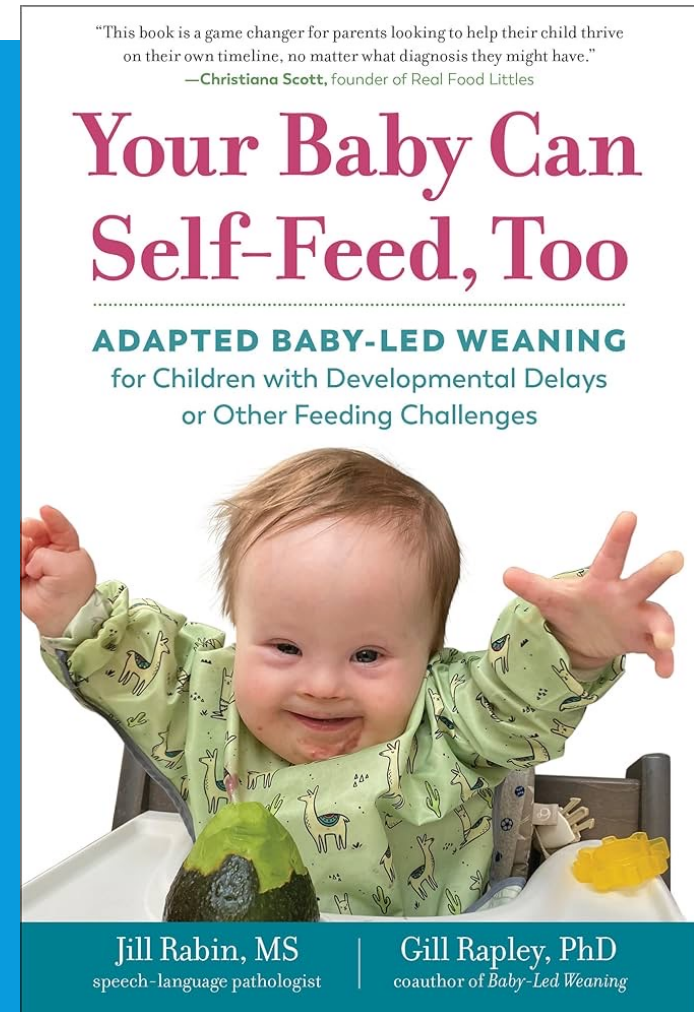
Developmental Readiness Signs:

- Good head and neck control
- Able to sit upright with support
- Interest in food/eating
 - Opens mouth when food is offered
 - Looks at others eating

HOW TO INTRODUCE?



Arslan et al., 2023; Bocquet et al., 2022; Campeau et al., 2021; Gomez et al., 2020; Martinon-Torres et al., 2021



Jill Rabin, MS
speech-language pathologist

Gill Rapley, PhD
coauthor of *Baby-Led Weaning*

POTENTIAL CHALLENGES – DELAYED ORAL MOTOR SKILLS

- Oral Motor Skills
 - Lips
 - Tongue
 - Jaw



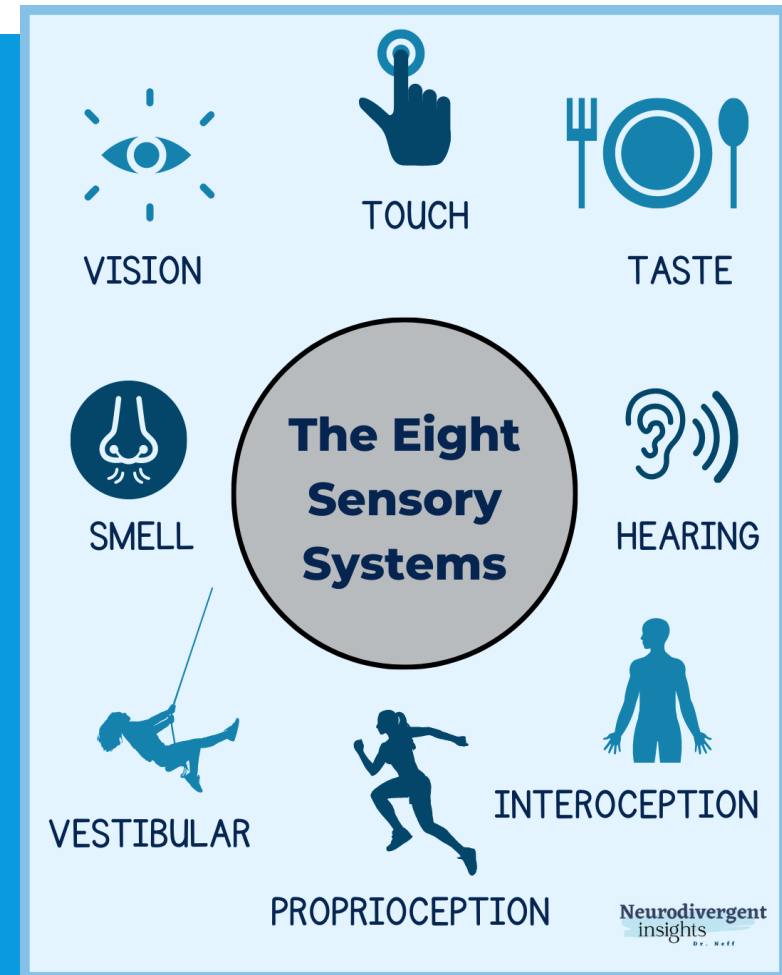
POTENTIAL CHALLENGES – DELAYED MOTOR SKILLS

- Head control
- Sitting
- Grasping food
- Bringing food to mouth
- Using utensils



POTENTIAL CHALLENGES – SENSORY SENSITIVITIES

- Hyposensitivity:
Decreased awareness of sensations
- Hypersensitivity:
Increased awareness of sensations



NUTRITION IN THE EARLY YEARS

START SIMPLE

Encourage

- Variety of foods from all food groups
 - Vegetables
 - Fruit
 - Protein foods
 - Whole Grains

Avoid

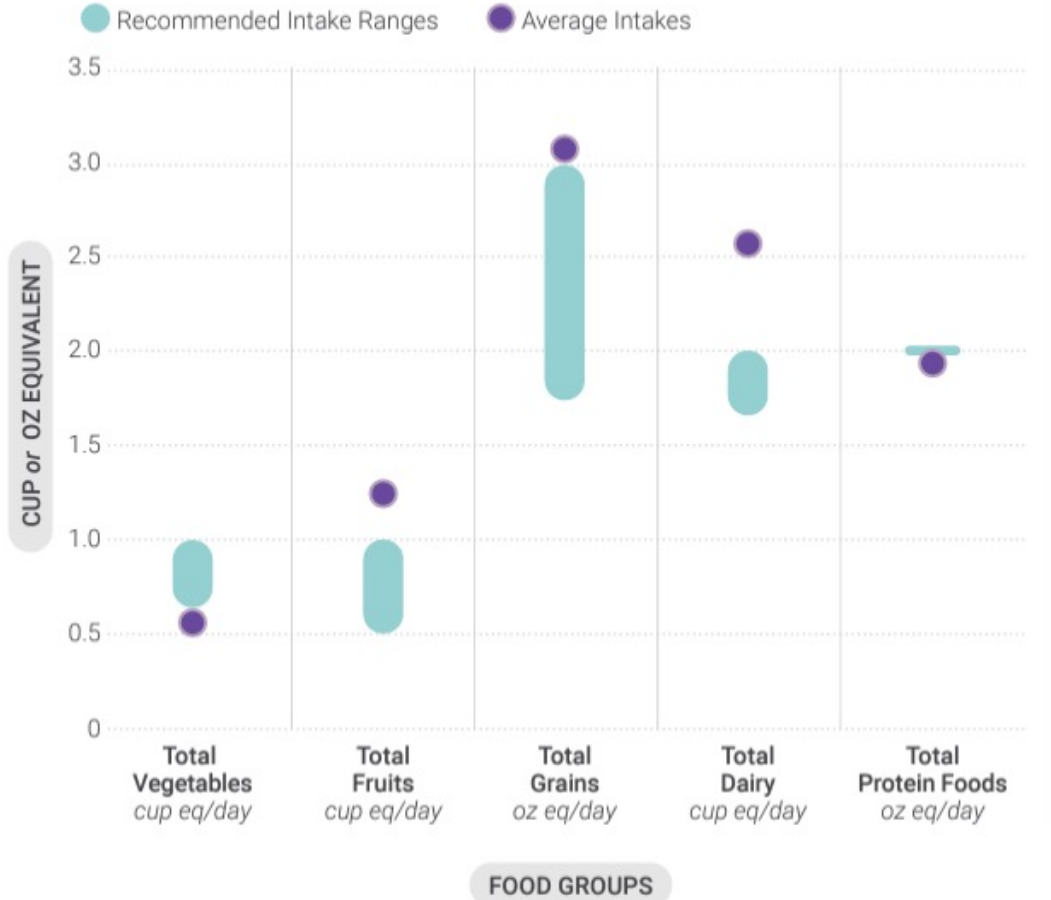
- High sodium foods
- Added sugars
- NO HONEY
- NO UNPASTEURIZED foods or beverages



Figure 2-2

Current Intakes: Ages 12 Through 23 Months

Average Daily Food Group Intakes Compared to Recommended Intake Ranges



INTAKES AND RECOMMENDATIONS

Data Sources: Average Intakes: Analysis of What We Eat in America, NHANES 2007-2016, day 1 dietary intake data, weighted. Recommended Intake Ranges: Healthy U.S.-Style Dietary Patterns . Dietary Guidelines for Americans 2020.

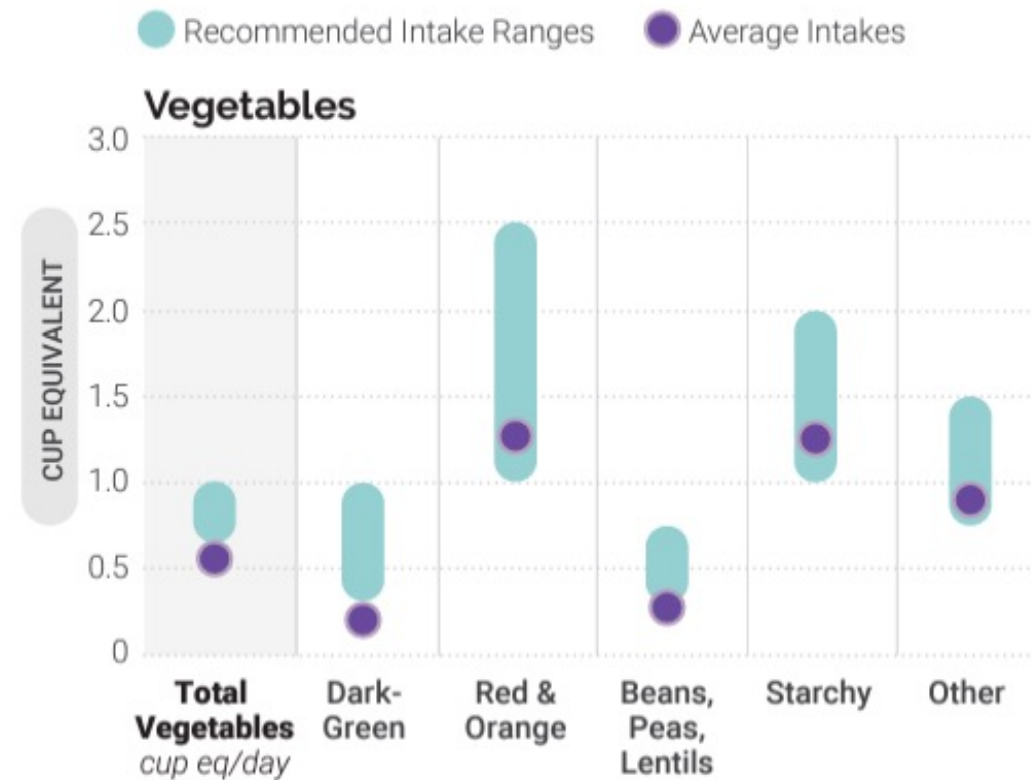
VEGETABLES

Recommendation: 2/3 -1 cup per day

- Offer 2-3 times per day
- Prioritize non starchy, deep colored vegetables
- Offer variety of textures, colors, preparation styles
- Don't pressure or bribe your child
- Expose, expose, expose!

Data Sources: Average Intakes: Analysis of What We Eat in America, NHANES 2007-2016, day 1 dietary intake data, weighted. Recommended Intake Ranges: Healthy U.S.-Style Dietary Patterns . Dietary Guidelines for Americans 2020.

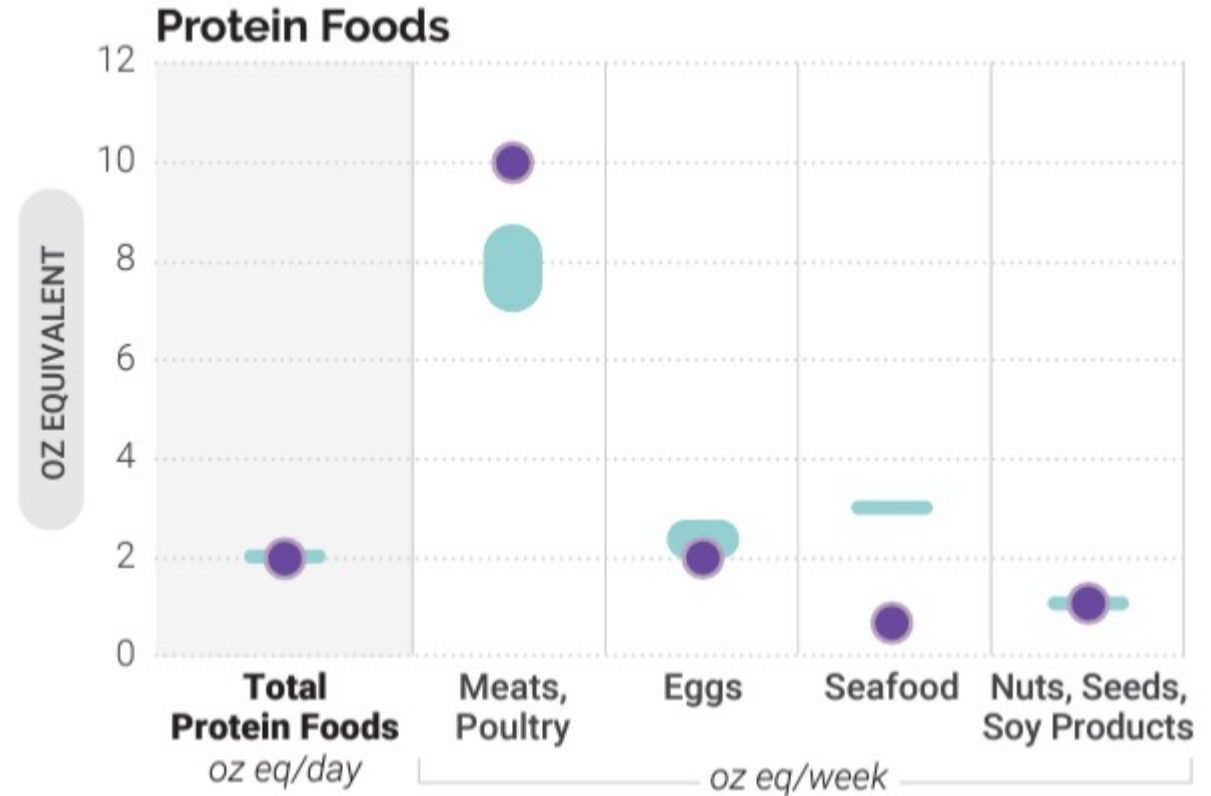
Figure 2-3
Average Intakes of Subgroups Compared to Recommended Intake Ranges: Ages 12 Through 23 Months



PROTEINS

Recommendation: 2 oz/day

- Offer 2-3 times per day
- Most American children consume adequate protein
- Variety is key

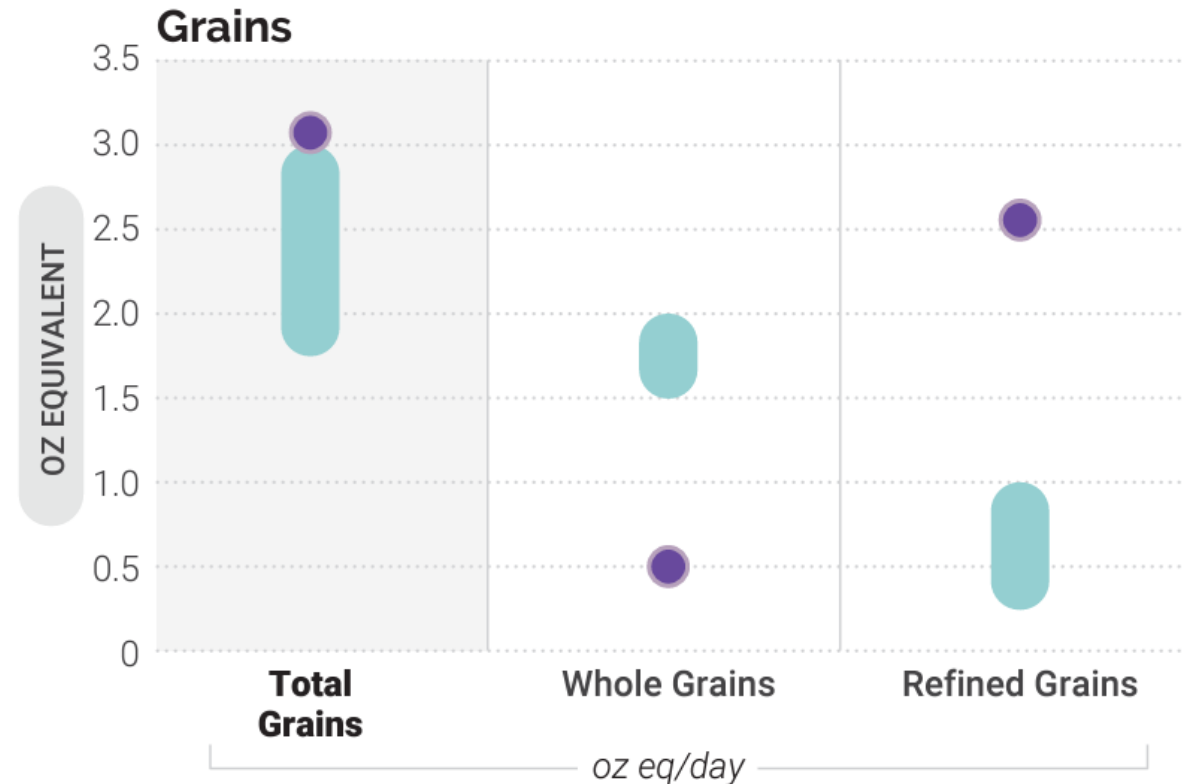


Data Sources: Average Intakes: Analysis of What We Eat in America, NHANES 2007-2016, day 1 dietary intake data, weighted. Recommended Intake Ranges: Healthy U.S.-Style Dietary Patterns . Dietary Guidelines for Americans 2020.

GRAINS

Recommendation: 1 ¾ - 3 oz/day

- Offer 2-3 times per day
- Whole grains are under-consumed
- Refined are over consumed



Data Sources: Average Intakes: Analysis of What We Eat in America, NHANES 2007-2016, day 1 dietary intake data, weighted. Recommended Intake Ranges: Healthy U.S.-Style Dietary Patterns . Dietary Guidelines for Americans 2020.

WHAT ABOUT GLUTEN?

- Gluten intolerance and/or celiac disease is much more common in children with Down syndrome
- Lentil or chickpea pastas aren't grains, but make good substitutes for fiber
- Gluten free whole grains:
 - Oats
 - Quinoa
 - Farro
 - Barley
 - Rice



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Ostermaier KK, Weaver AL, Myers SM, Stoeckel RE, Katusic SK, Voigt RG. Incidence of Celiac Disease in Down Syndrome: A Longitudinal, Population-Based Birth Cohort Study. *Clin Pediatr (Phila)*. 2020 Oct;59(12):1086-1091. doi: 10.1177/0009922820941247. Epub 2020 Jul 15. PMID: 32664755; PMCID: PMC8108108.

RECOMMENDED BEVERAGES

0-6 Months

- Breastmilk of iron-fortified formula
- Supplemental water is not typically needed in healthy infants

6-12 Months

- Breastmilk or iron-fortified formula
- Plain, fluoridated water can be provided in small amounts after starting complementary foods

1 Year and Beyond

- Breastmilk if desired
- Plain, fluoridated water
- Unflavored cows milk or fortified plant milk

NOT-RECOMMENDED BEVERAGES

- Flavored milk (contains added sugar)
- Toddler milks (unnecessary, typically contain added sugar)
- Sports drinks
- Sugary drinks
- Juice drinks
- 100% Juice*

NUTRIENTS OF CONCERN

FIBER	IRON	ZINC	CALCIUM	VITAMIN D
<ul style="list-style-type: none">• Whole grains• Fruit• Vegetables	<ul style="list-style-type: none">• Red meat• Beans• Greens• Fortified cereals• Oats• Enriched pastas• Shellfish• Fish• Quinoa• Tofu	<ul style="list-style-type: none">• Fish• Beef• Shell fish• Oats, cereals• Pork• Lentils	<ul style="list-style-type: none">• Dairy• Fortified plant milks• Greens• Shellfish• Tofu• Edamame	<ul style="list-style-type: none">• Speak to medical provider about vitamin D drops for infants• Fortified milks• Salmon• Egg yolk• Fortified cereals

DON'T OVERTHINK IT

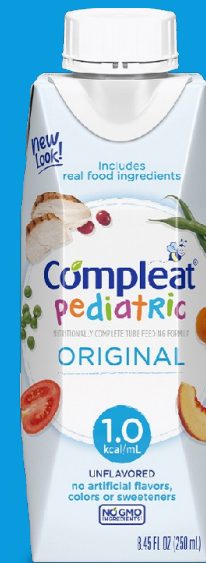
- Offer vegetables, fruits, whole grains, lean protein often
- Limit added sugar, sodium, highly processed foods, juice
- Avoid sugary drinks completely
- Avoid honey completely under 1 year old

Kid's Healthy Eating Plate



TUBE FEEDING

- Inquire about real-food based formulas for tube feeding
- Maintain positive oral experiences as allowed
- Involve child in age-appropriate sensory and food-related activities
- Offer tube feeding to mealtimes as you are able
- Experience the social aspect of mealtimes



QUESTIONS?

TAKING ACTION

WHEN TO SEEK HELP

BREASTFEEDING



Signs to Look For

- Uncomfortable after feeding
- Throws up during feeding
- Sounds gurgly/like they need to cough during feeding
- Exhausted during feeding and unable to finish
- Breathes harder/faster during feeding
- Needs to rest during eating to catch their breath
- Can only suck a few times before needing to take a break
- Holds breath while eating
- Gets bloated (big/hard tummy) after eating
- Gags in between feedings when there is nothing in their mouth

Who to Contact

- Early Intervention
- Lactation Consultant
- Speech language pathologist

BOTTLE FEEDING



Signs to Look for

- Uncomfortable after feeding
- Throws up during feeding
- Sounds gurgly/like they need to cough during feeding
- Exhausted during feeding and unable to finish
- Breathes harder/faster during feeding
- Needs to rest during eating to catch their breath
- Can only suck a few times before needing to take a break
- Holds breath while eating
- Becomes upset during feeding
- Gags on bottle nipple



TUBE FEEDING

Signs to Look for

- Child gags or vomits during or just after feeding
- Brushing child's teeth (or rubbing gums with cloth) is difficult
- Washing child's face is difficult

Who to Contact

- Registered dietitian
- Physician
- Feeding Team



SOLIDS



Signs to Look for (6-15mo)

- Prefers to drink instead of eat
- Gags with textured foods or smooth foods
- Sounds gurgly/like they need to cough or clear throat after eating
- Coughs during or after feeding
- Burps more than usual while eating
- Moves head down toward chest when swallowing
- Throws up during mealtimes
- Throws up between meals
- Has food/liquid come out of nose while eating

Signs to Look for (15-30mo)

- Gags with smooth foods
- Sounds gurgly/like they need to cough or clear throat after eating
- Coughs during or after feeding
- Burps more than usual while eating
- Gets watery eyes while eating
- Moves head down toward chest when swallowing
- Throws up during mealtimes
- Arches back during or after meals
- Needs to take a break during the meal to rest or catch their breath
- Sounds different during or after a meal (voice becomes high pitched, hoarse or quiet)

WHO CAN HELP?

- Speech language pathologist (SLP): Oral motor skills, sensory differences, and managing alterations to diet
- Occupational therapist (OT): Oral motor skills, sensory processing, and fine motor skills
- Physical therapist (PT): Positioning/physical support for feeding
- Lactation Consultants (LC): Breastfeeding and pumping support
- Registered dietitian (RD): Ensuring nutritional adequacy
- Psychologist/Social Worker: Managing behavioral aspects of feeding, family supports
- Physicians: Medical aspects of feeding, care management

PROGRAMS/SUPPORTS

- Feeding Matters
- Children's Developmental Services Agency
- Feeding Flock



ADVOCATING

SPEAKING WITH YOUR MEDICAL PROVIDER

- 1) Write concerns down before the appointment. It's easy to forget in the moment.
- 2) Say, "I'm concerned about my child's _____. Can we have a referral to _____"
 - Feeding therapy
 - A Registered dietitian
 - An occupational therapist
 - A physical therapist
 - CDSA



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SPEAKING WITH YOUR MEDICAL PROVIDER



3) If your referral doesn't go well...

Say: "I don't think our therapist/lactation consultant/etc. has had much experience with our challenges. Can you help me find a provider who has experience supporting children with Down syndrome specifically?"

THANK YOU!