Eating to Make a Difference
Why nutrition for Down Syndrome matters

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Outline

• Down syndrome specific growth charts
• Calorie needs
• Feeding skills
• Creating healthy eaters
• Physical activity
• Bowel movements
• Passing the baton
• Recommended resources
What's a growth chart?

CDC (2010)
1964 – 1994
~64,000 children
Down Syndrome Growth Charts

- 2015, Greater Philadelphia Area (637 DS children)
- Purpose
  - Screening Tool: compare against other children with DS – same sex and age.
  - “Are they following an appropriate growth pattern for someone with DS?”

- Observations
  - Comparable to UK DS Growth Charts, 2002 (1507 DS children)
  - Compared to previous DS charts (1988, USA) – improved growth!

- Nutrition Implications
  - Infancy – feeding difficulties/delays
  - Childhood and beyond – lower calorie needs, poor diets, inactivity, etc.

Boy plotted on DS growth chart at 50%ile, same measurements on CDC
DS Chart vs. CDC Chart (0 – 20 yrs)

Boy plotted on DS growth chart at 50%ile, same measurements on CDC
Tracking on the Growth Curve

“Following his/her lane”
“Tracking appropriately”

“Crossing lanes/percentiles”

Taken in context: Height/length, Parent’s height, medical issues, etc.
Down Syndrome and BMI

The graphs illustrate the Body Mass Index (BMI) growth patterns for girls and boys with Down Syndrome (DS) compared to the CDC growth charts. The graphs show BMI values from 2 to 18 years of age, with age on the x-axis and BMI in kg/m² on the y-axis. The lines indicate the 5th, 50th, 85th, and 95th centiles for both DS and CDC growth charts.
Down Syndrome and BMI

- BMI (body mass index) – compares weights vs. height

- DS population higher incidence of obesity (30 – 50%)

- DS Growth Charts for BMI merely describes the population – optimal?

- CDC BMI growth chart is good predictor of excess body fat
  - Goal = BMI <85%ile (correlated with excess body fat mass)
  - Greater >85%ile BMI = increased risk for heart disease and/or insulin resistance

Calorie Needs in Down Syndrome

• 2013 study compared calorie needs in children Down syndrome versus their siblings without Down Syndrome
  – 28 individuals with Down Syndrome vs. 35 siblings
  – Ages 3 – 10

• Results
  – Individuals with DS use 78 calories less per day (~5-10%)
  – Why?

• Probably not the main reason for higher BMIs
  – Definitely not the only reason

1 lb fat = 3500 calories

78 calories/day x 365 days/year = 28,470 calories/year

28470 calories/year ÷ 3500 calories/lb. = ~8 lbs/year

Dysphagia (Difficulty Swallowing) in DS

Signs and Symptoms

- Coughing
- Choking
- Arching/stiffening body during feeding
- Irritability or lack of alertness during feeding
- Refusing food or liquid
- Difficulty accepting different textures
- Increased feeding times (longer than 30 minutes)
- Decreased alertness during feedings
- Difficulty chewing
- Difficulty breast feeding and/or drinking from bottle or cup
- Loss of food/liquid from the mouth
- Increased stuffiness during meals
- Gurgly, hoarse, or breathy vocal quality
- Difficulty coordinating breathing with eating and drinking
- Frequent vomiting
- Recurring pneumonia or respiratory infections
- Less than normal weight gain or growth

American Speech-Language-Hearing-Association—“Pediatric Dysphagia”
Learning to Eat

• Can take longer for children with Down Syndrome…
  – Low muscle tone, difficulty with muscle/motor coordination, swallowing difficulties, sensory issues, medical complications

• Transitions and food textures based on skills and ability, not age

• Offering foods that match skill/ability level → better nutrition
  – Speech and/or Occupational Therapy

*Nutrition Focus. 26 (5). 2011.*
“Eating for pleasure or profit: the effect of incentives on children’s enjoyment of vegetables” (UK 2010), 2012 Cochrane Review
- 422 children, ages 4 – 6, United Kingdom
- Repeated exposure (Carrots, bell pepper, sugar snap peas, cabbage, cucumber, or celery)
- 12 exposures over 12 days, assess at last day, 1 month out, 3 months out
- Groups – tangible reward (non-food), social reward (praise), no reward, control

“Parent-Administered Exposure to Increase Children’s vegetable Acceptance a Randomized Controlled Trial” (UK 2014)
- 3-4 year old twins (442 children), mailed instructions - 14 exposures
How execute 15 – 20 exposures

- Meal Structure/Consistency
  - 3 meals, 2-3 snacks per day, ~2-3 hours apart, time limits
  - Only offer water in between meals/snacks, no grazing

- Division of Roles
  - Parent – what (this or that, don’t be short order cook), when (at the set meal time), where (at the table)
  - Child – how much (Don’t eat it? Still hungry? Have to wait until next meal/snack…)

- Developmentally appropriate foods (the right texture)


- Make meals social and positive, ↓ distractions

- Food Chaining = new foods similar to a preferred food (shape, color, taste, texture, etc.)
My Pizza Plate
My Ice Cream Bowl
Choose My Plate
Food Preparation

- Cut up fruits and vegetables when you get home from the store
- Make extra; freeze some for another time / freezer meals
- My favorite way of cooking vegetables = roasting
- Fresh, frozen, canned – I’m fine with it all
  - Canned Fruit – 100% juice, drain the juice
  - Canned vegetables – drain and rinse
  - Frozen = sometimes the best nutritional content
Quick Nutrition Tips

- Don’t drink your calories (except low fat dairy)
- My Plate = variety = complete nutrition
- Protein and fiber help with satiety
- We are designed to like Sugar, Salt and Fat (hedonism)
  - Keep it out of the house, it's difficult to fight nature
  - Moderation is key
- Supplements don’t replace food, at best, supplements are an insurance policy. First do, no harm. Let doctor know.
The Kid's Activity Pyramid

Be active everyday!

Group Play
Activities where you play and learn skills with others. Join a team, pick a club or go to a class.
- Dodge ball
- Gymnastics
- Ice skating lessons

Free Play
Activities you can do by yourself or with a friend anytime!
- Build a fort
- Four-square
- In-line skating

Choose to Move
- Help with chores
- Take the stairs
- Play with your pet
- Be active at recess
- Dance to music
- Play active games or videos
- Chase bugs, frogs and butterflies

Limit
Watching TV
Playing computer and video games
Sitting for more than 30 minutes

Have fun by trying different activities.

Family Play
Families who play together, stay healthy together. What will your family do?
- Take a walk
- Turn off the TV one day a week
- Play at the park

Free Play
- Skateboarding
- Sledding
- Fly a kite
- Water fights
- Hide-n-seek
- Jump rope
- Tag

Group Play
- Dance lessons
- Kickball
- Karate
- Soccer
- Baseball
- Capture the flag

Family Play
- Play catch or frisbee
- Bike rides
- Nature hikes
- Swimming
- Scavenger hunts
- Explore different playgrounds

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Physical Activity

• Goal = 60 minutes of physical activity (CDC)
  – I prefer “60 minutes of moving a day”

• Benefits for Exercise
  – Burn calories, helps maintain a healthy weight
  – Increase mitochondrial function
  – Helps build and maintain bone and muscle
  – Reduce risk for heart disease, insulin resistance/diabetes, cancer, and other conditions
  – Help with mood, self-esteem, stress
  – Improve cognitive performance in DS?
Constipation

• What is constipation?
• Constipation is common in DS – low tone, lower activity levels, poor fluid intake, low fiber intake
• What helps?
  – Fluid
  – Staying Active
  – Fiber (fruits, vegetables, whole grains)
  – Avoiding excessive amounts of dairy
  – Medical management (laxatives, softeners, fiber supplements)
    • Only with Doctor supervision
• Constipation =/= fun
Passing the Baton

• Grocery Shopping
  – I-spy, scavenger hunts
  – Grocery lists – cut pictures from grocery ad, shopping list with pictures
  – How to select good foods – appearance, expiration date, packaging intact

• Helping out with cooking
  – Adding the ingredients, mixing, measuring, setting timers, etc.
    • Occupation Therapy
  – Overtime, create their own cookbook of favorite recipes
  – Meal planning (pictures/flash cards) – calendar, grocery list

• MyPlate method
  – Learn portion control
  – How to make a balanced meal
  – Try activities on www.Choosemyplate.gov/kids
Take Home Points

• Individuals with Down Syndrome have different growth patterns
• Feeding difficulties during infancy put the child at risk for inadequate nutrition.
  – Seek help when appropriate.
• Excessive weight gain as individuals with Down Syndrome get older is a significant and relatively common concern.
  – Diets don’t work
  – Gradual, behavior and lifestyle changes
• Expanding the diet takes time, patience and persistence
• Healthy bowel movements are a big deal
Resources

- www.ChooseMyPlate.gov
- https://www.choosemyplate.gov/kids
- Down Syndrome Nutrition Handbook by Joan Guthrie Medlen
- Ellyn Satter (Child of Mine, How to get your kid to eat…, Secrets of Healthy Family)
- Food Chaining by Cheri Fraker
Questions/Share

- Ask a Question **OR**

- Share an experience
  - Increased variety/food selection
  - Manage weight issues
  - Transition with solids/textures
  - What physical activities have you incorporated
  - Promote fluid intake
  - Improved bowel movements
  - Transitioning responsibility of diet
  - Any other nutritional experiences