

# 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







# Down Syndrome Growth Charts

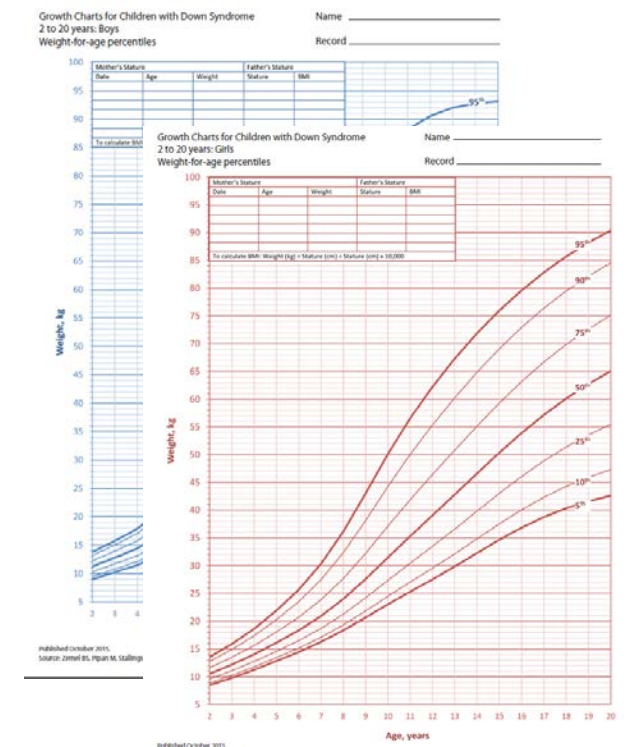
- 2015, Greater Philadelphia Area (637 DS children)
- Purpose
  - Screening Tool: compare against other children with DS – same sex and age.
  - “Are they following an appropriate growth pattern for someone with DS?”

- 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.





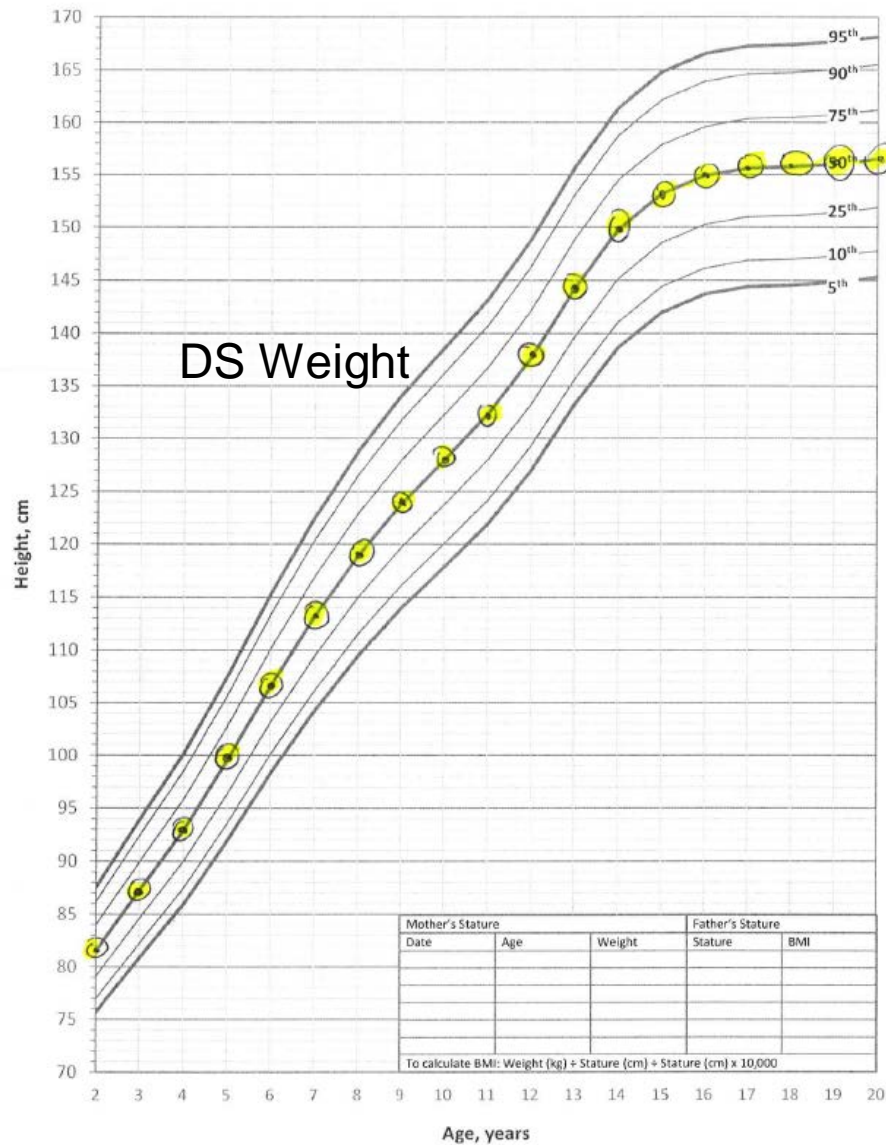


# DS Chart vs. CDC Chart (0 – 20 yrs)

Boy plotted on DS growth chart at 50%ile, same measurements on CDC

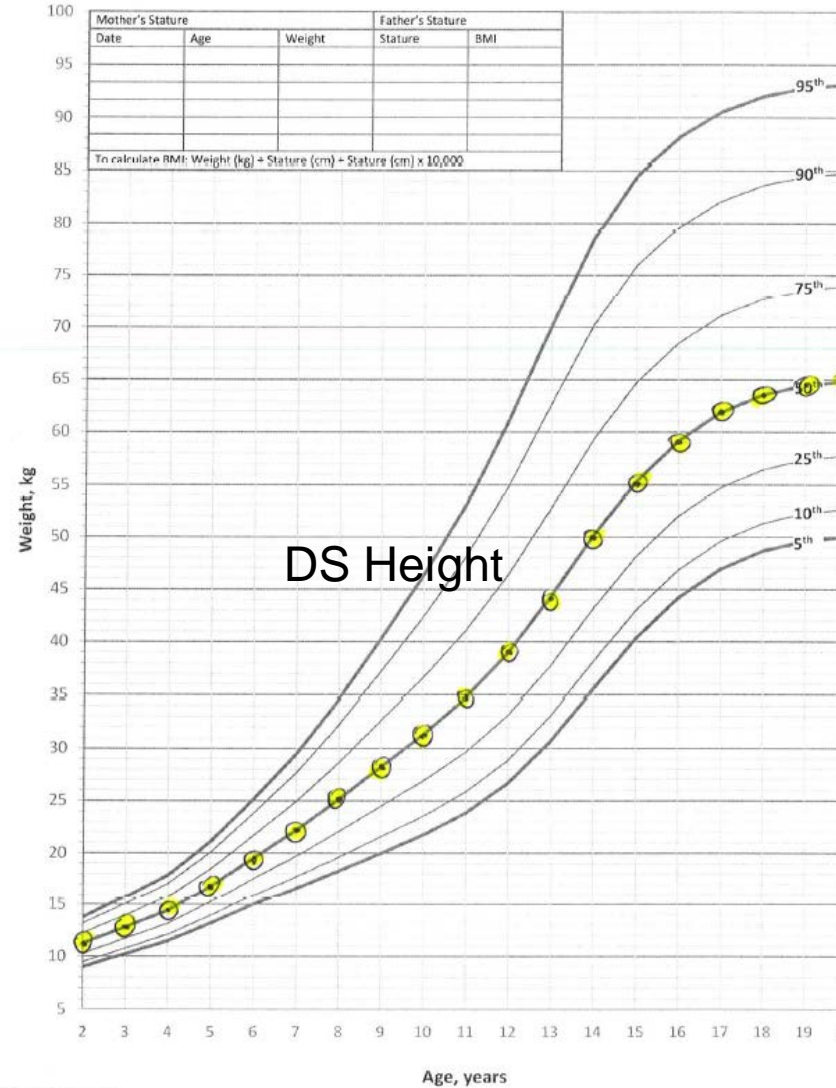
Growth Charts for Children with Down Syndrome  
2 to 20 years: Boys  
Height-for-age percentiles

Name \_\_\_\_\_  
Record \_\_\_\_\_



Growth Charts for Children with Down Syndrome  
2 to 20 years: Boys  
Weight-for-age percentiles

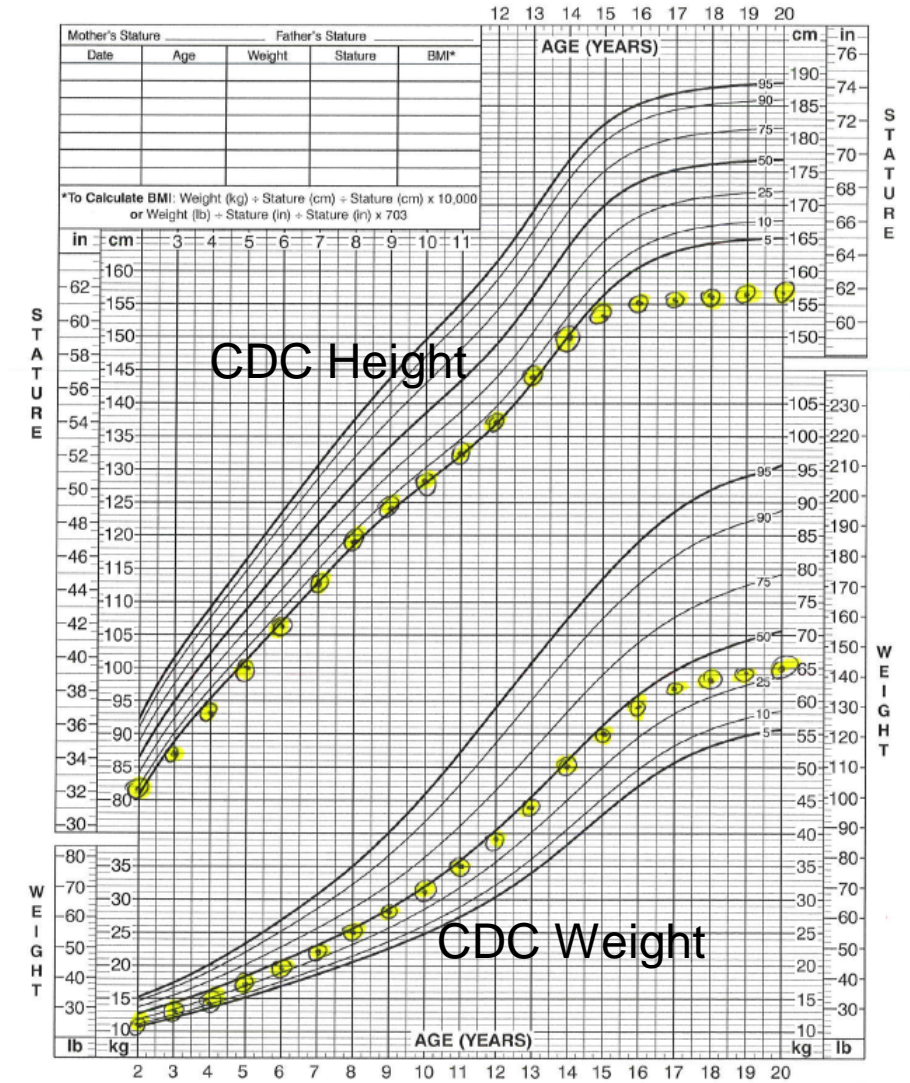
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Published October 2015.  
Source: Zemel BS, Pipan M, Stallings VA, Hall W, Schgadt K, Freedman DS, Thorpe P. Growth Charts for Children with Down Syndrome in the U.S. Pediatrics, 2015. CS260242-A

2 to 20 years: Boys  
Stature-for-age and Weight-for-age percentiles

NAME \_\_\_\_\_  
RECORD # \_\_\_\_\_



Published May 30, 2000 (modified 11/21/00).  
SOURCE: Developed by the National Center for Health Statistics in collaboration with the National Center for Chronic Disease Prevention and Health Promotion (2000).  
<http://www.cdc.gov/growthcharts>



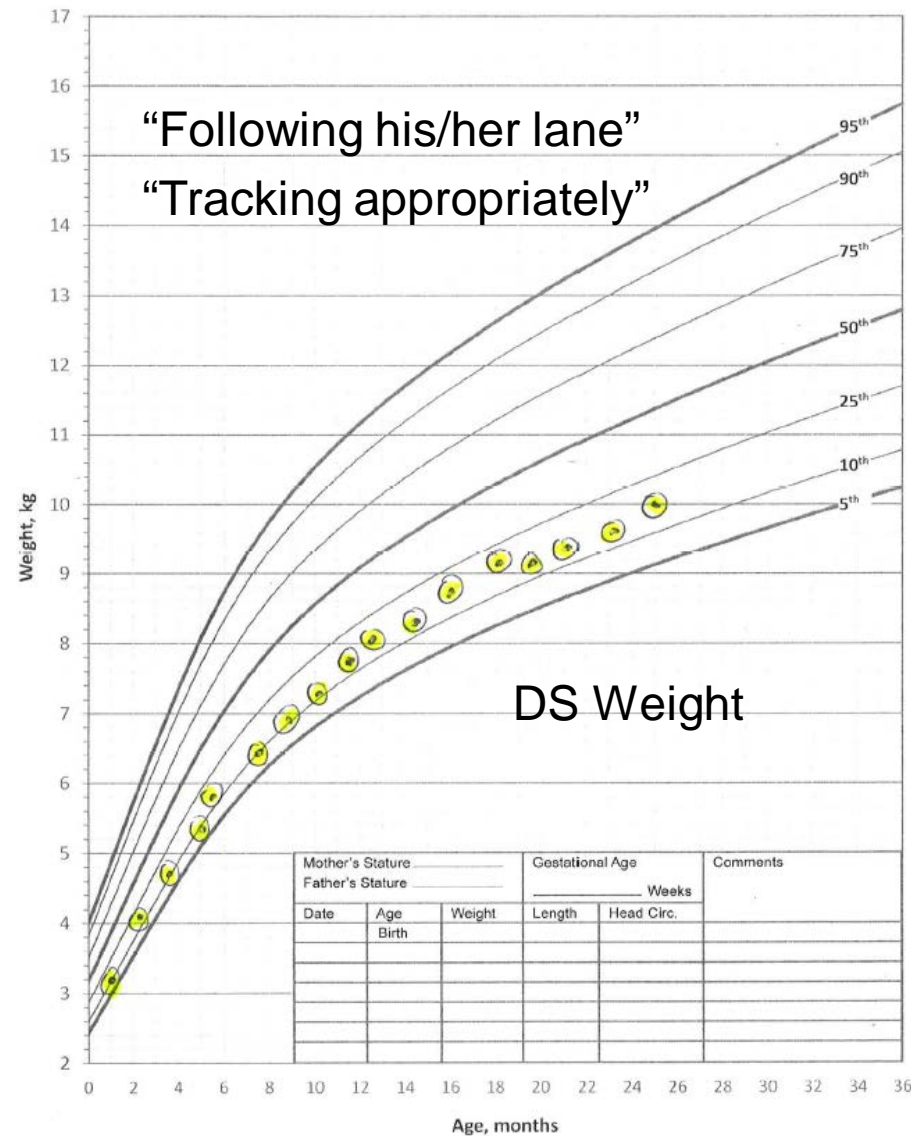
SAFER • HEALTHIER • PEOPLE™

# Tracking on the Growth Curve

Growth Charts for Children with Down Syndrome  
Birth to 36 months: Boys  
Weight-for-age percentiles

Name \_\_\_\_\_

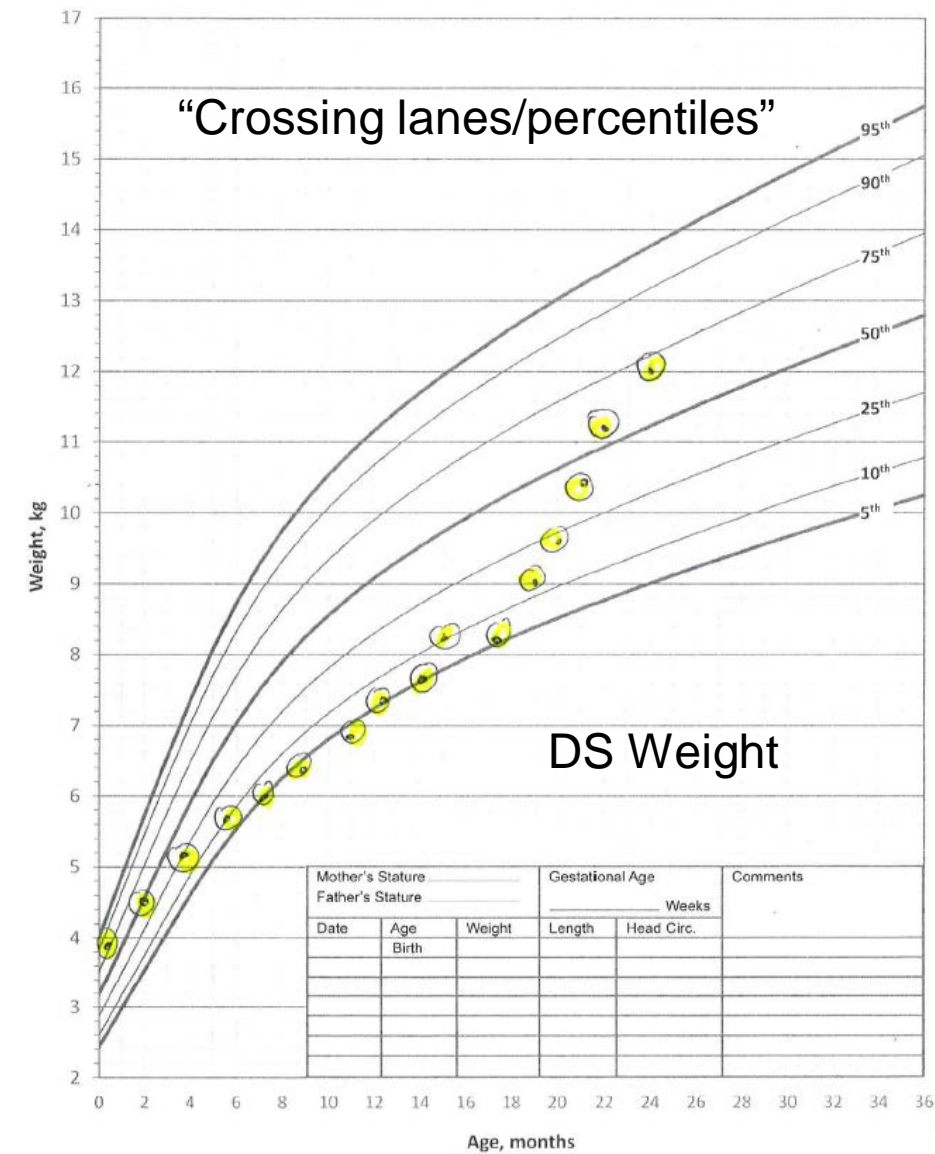
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Growth Charts for Children with Down Syndrome  
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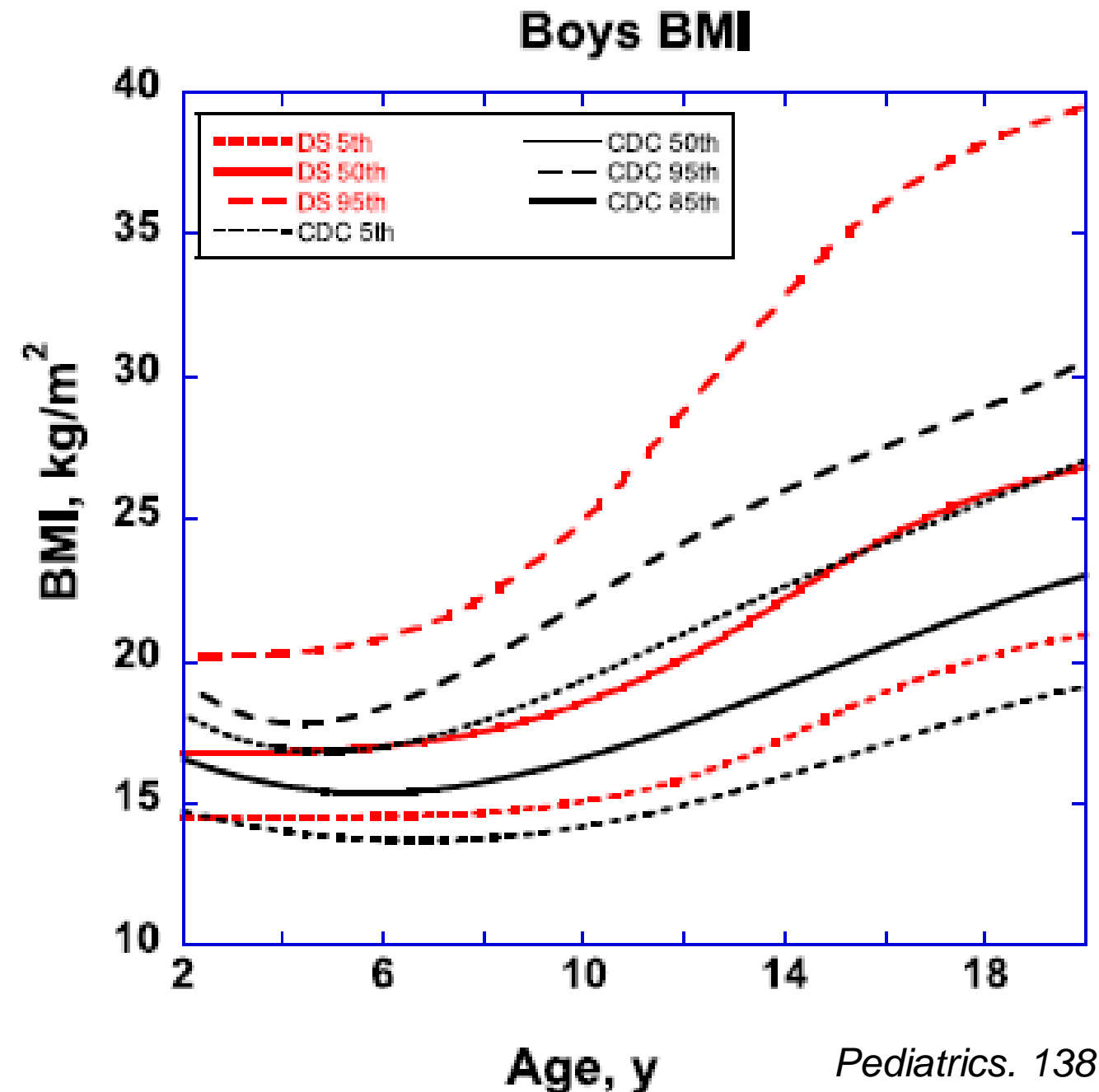
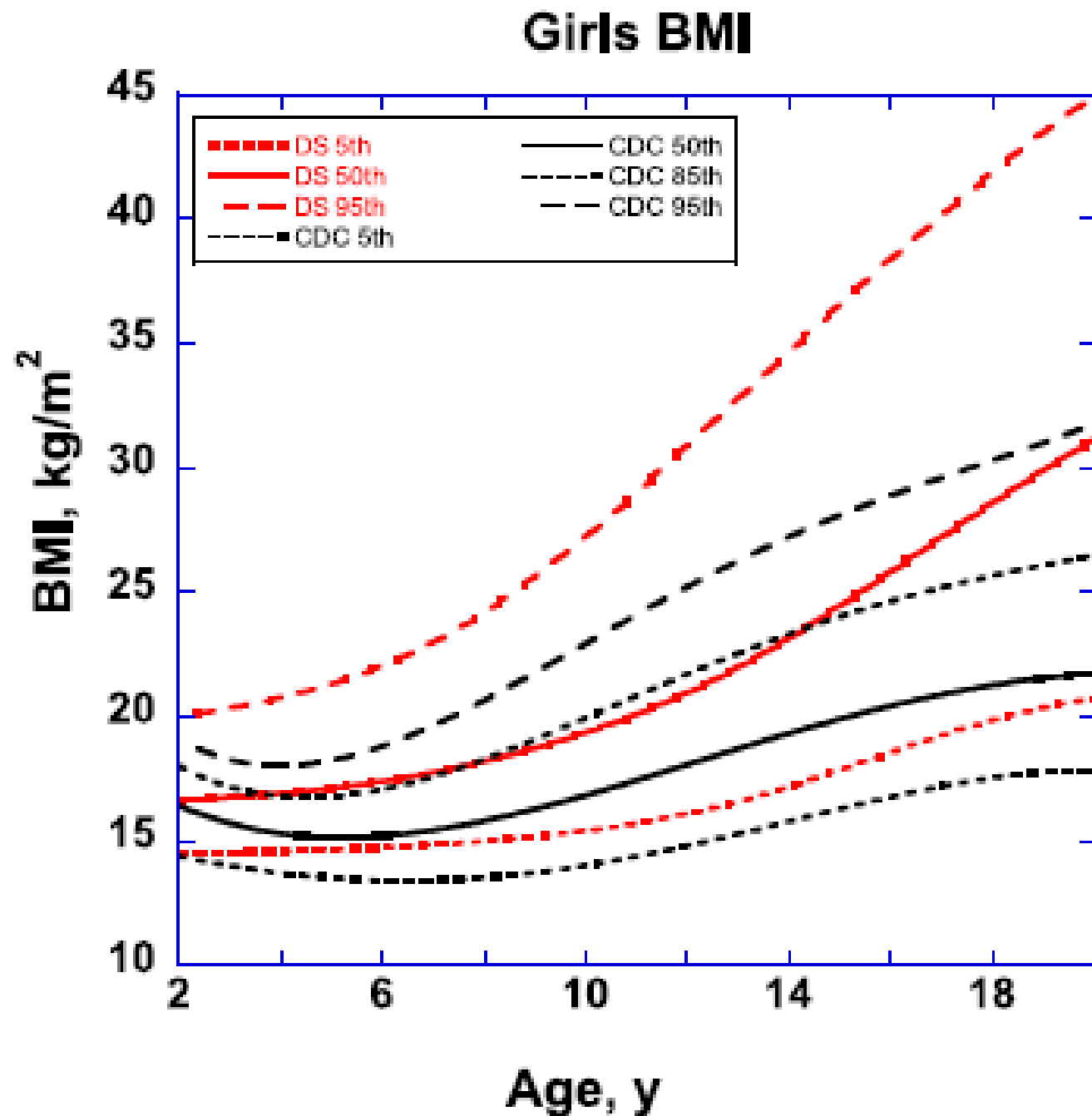
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Taken in context: Height/length, Parent's height, medical issues, etc.

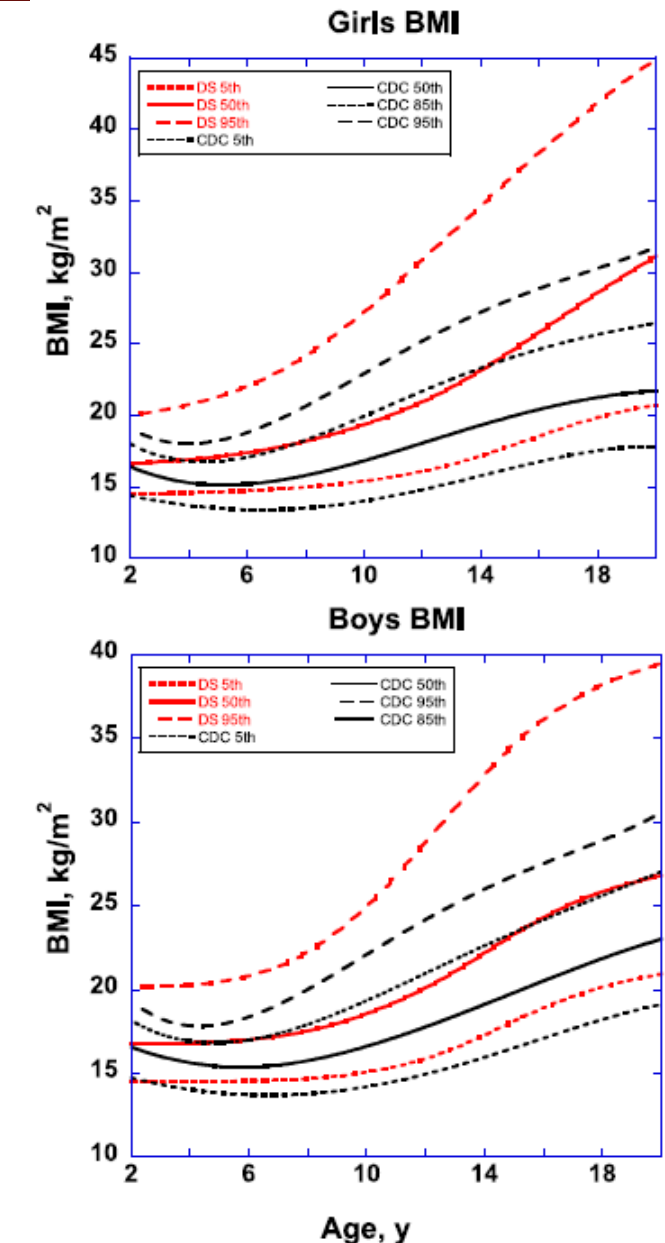
# Down Syndrome and BMI





# 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?



*Pediatrics. 138 (4). 2016.*

# 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

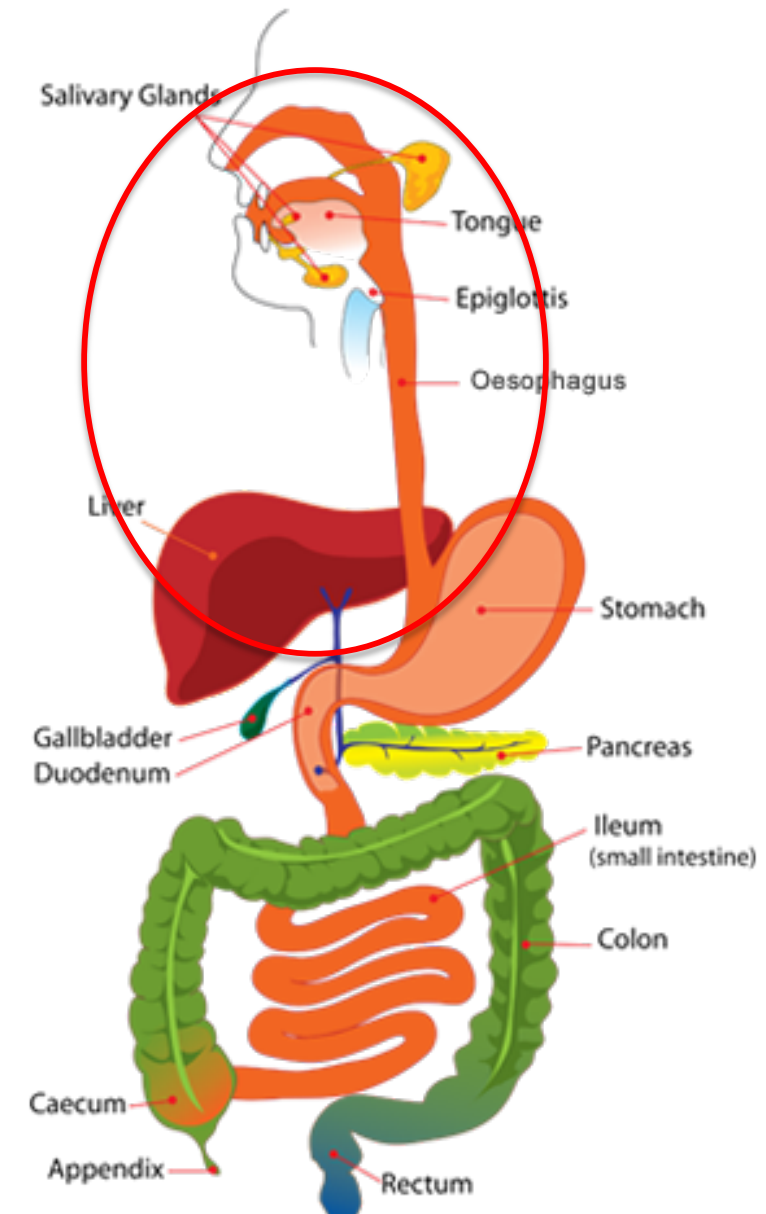
28470 calories/year ÷ 3500  
calories/lb. = **~8 lbs/year**



# 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**





# 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.*



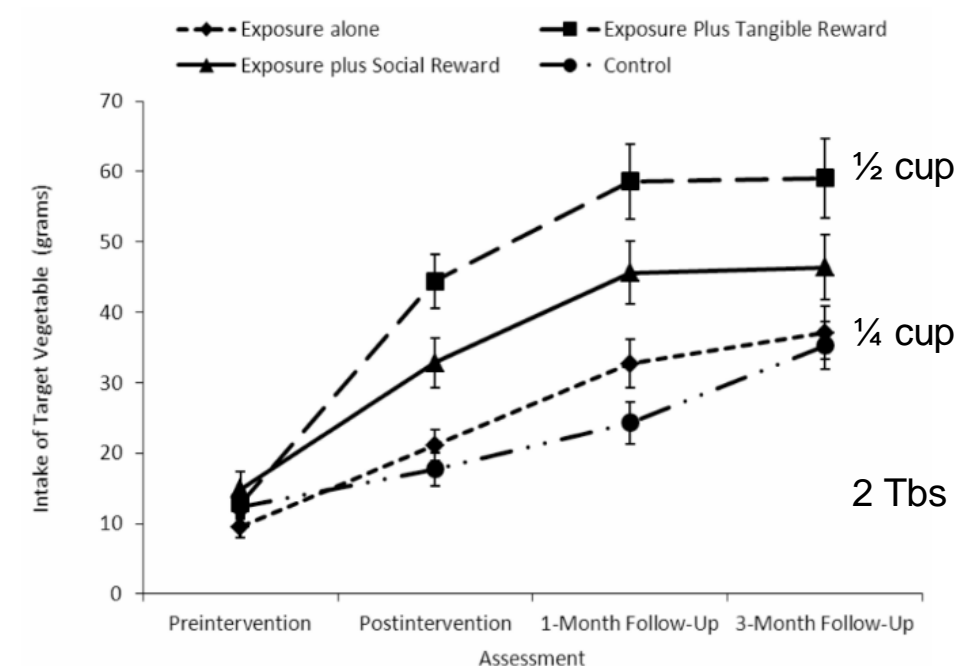
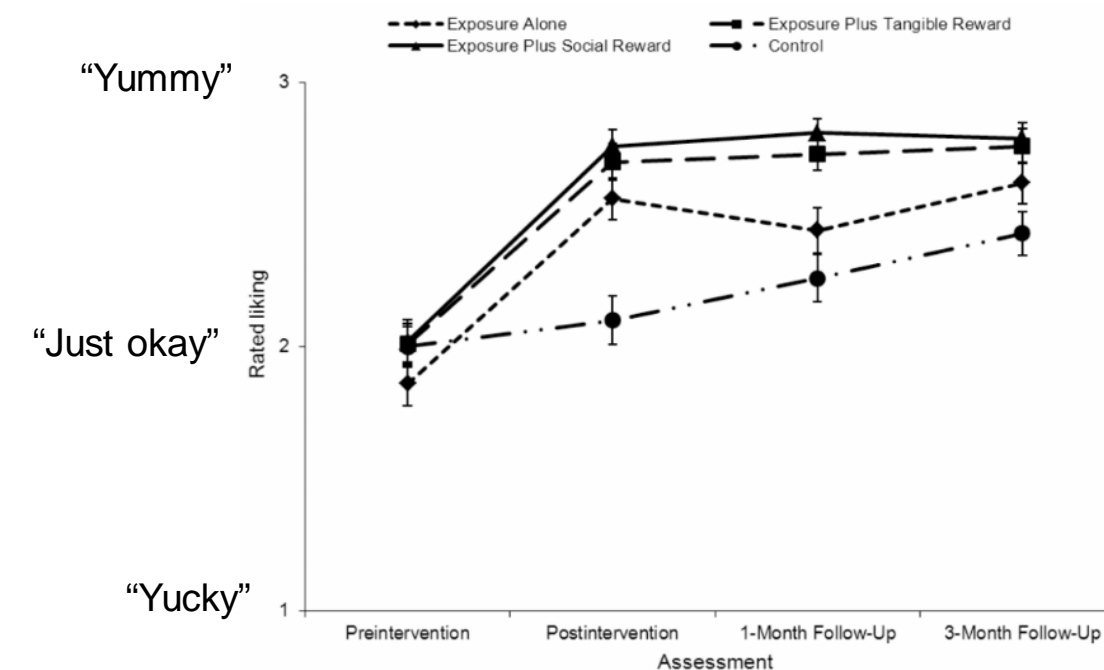
# Expanding Food Selection

**“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)
- Role modeling (Food Dudes vs. Junk Punks, Eur J Clin Nut 2004)
- Make meals social and positive, ↓ distractions
- Food Chaining = new foods similar to a preferred food (shape, color, taste, texture, etc.)





**Fats, Oils & Sweets**  
**USE SPARINGLY**

**KEY**

● Fat (naturally occurring and added)

■ Sugars (added)

These symbols show fats and added sugars in foods.

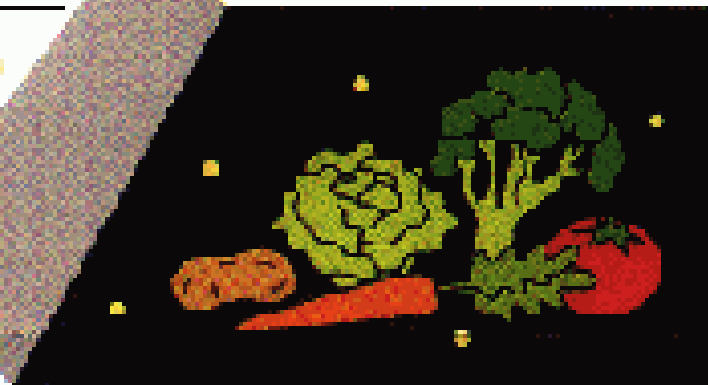
**Milk, Yogurt & Cheese Group**  
**2-3 SERVINGS**



**Meat, Poultry, Fish, Dry Beans, Eggs & Nuts Group**  
**2-3 SERVINGS**



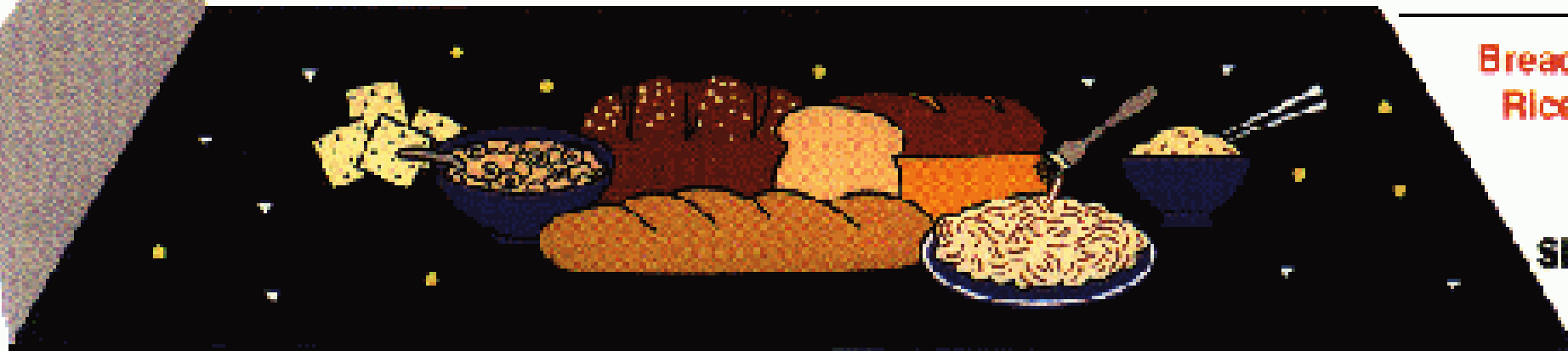
**Vegetable Group**  
**3-5 SERVINGS**



**Fruit Group**  
**2-4 SERVINGS**



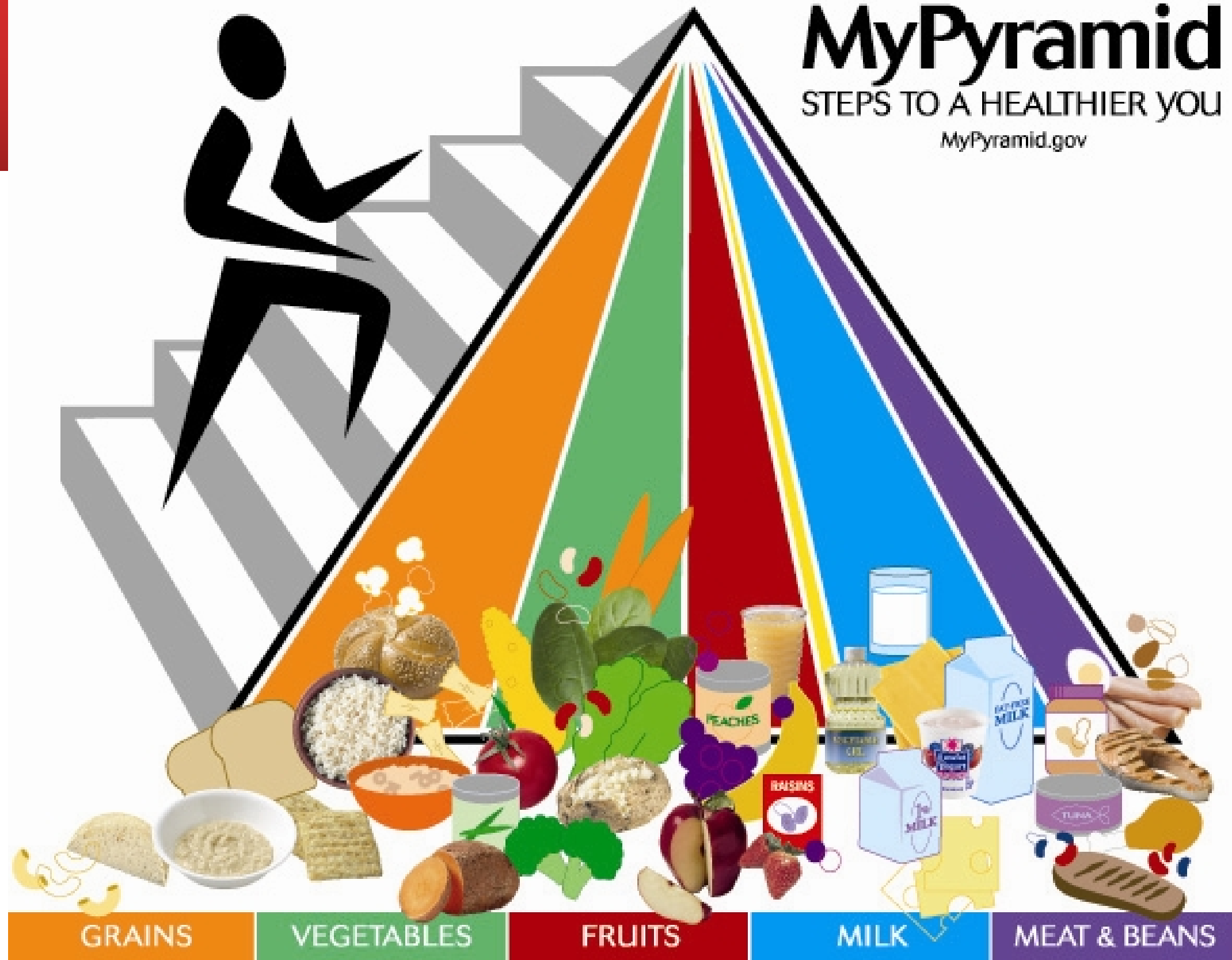
**Bread, Cereal, Rice & Pasta Group**  
**6-11 SERVINGS**



# MyPyramid

STEPS TO A HEALTHIER YOU

[MyPyramid.gov](http://MyPyramid.gov)



# My Pizza Plate



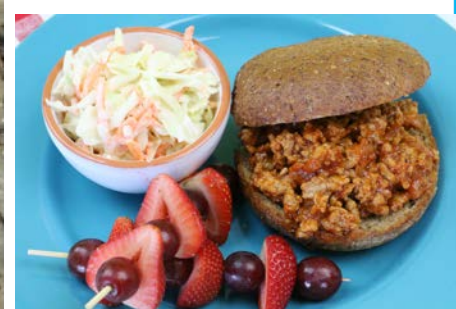
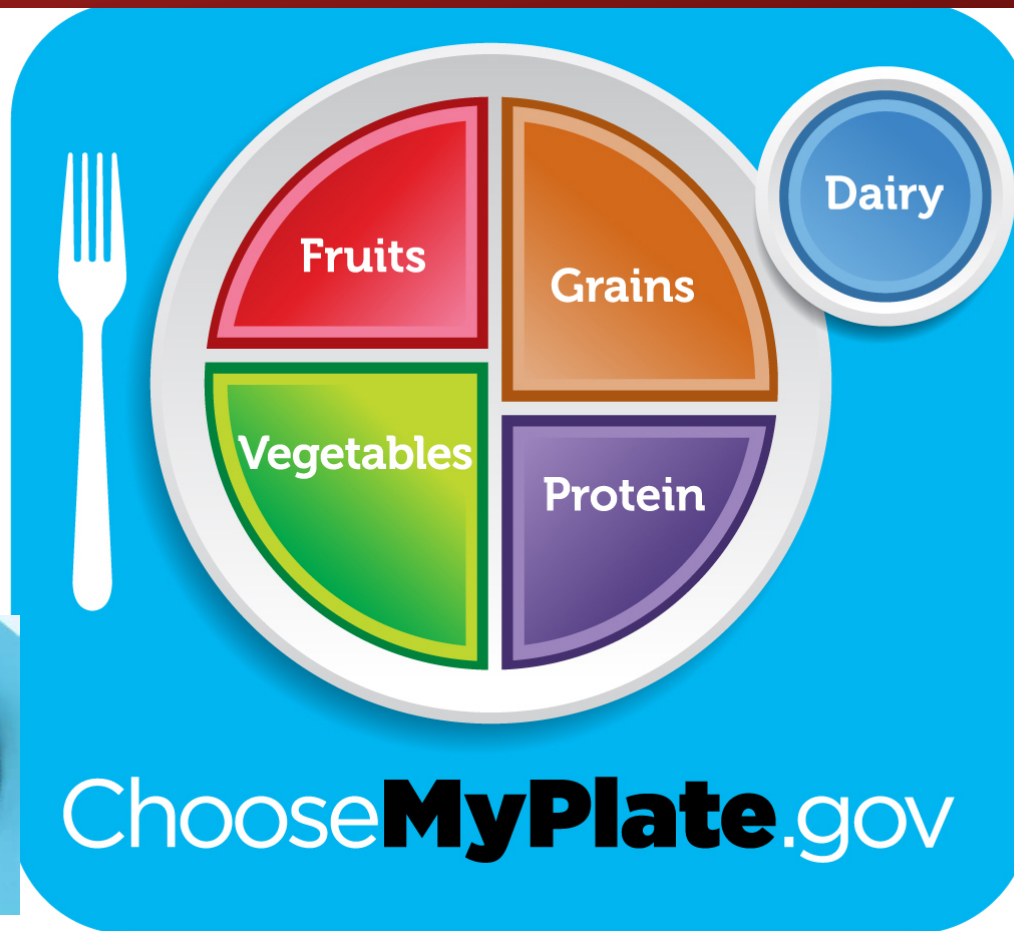


# My Ice Cream Bowl





# Choose My Plate





# Food Preparation

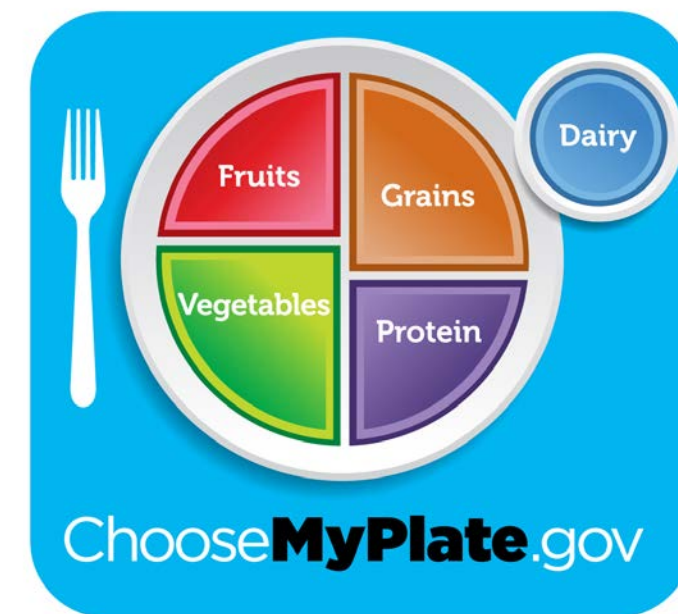
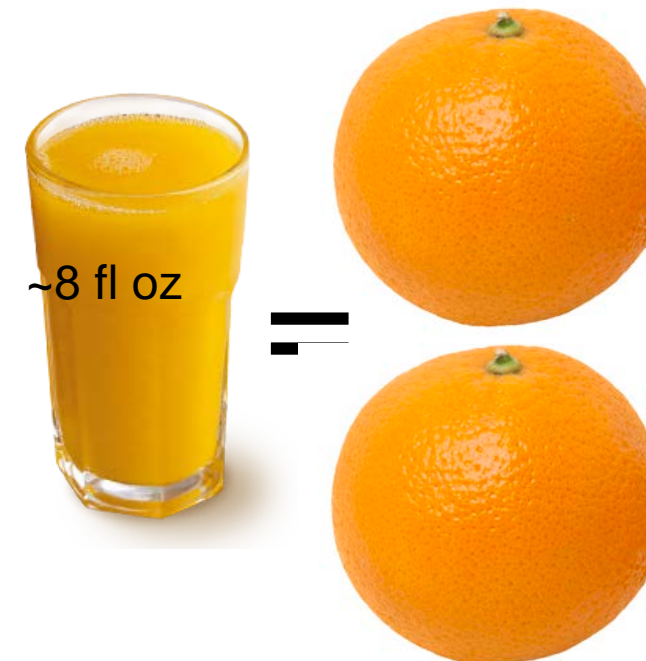
- Cut up fruits and vegetables when you get home from the store
- Make extra; freeze some for another time / freezer meals
- My favorite way of cooking vegetables = roasting
- Fresh, frozen, canned – I'm fine with it all
  - Canned Fruit – 100% juice, drain the juice
  - Canned vegetables – drain and 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, its 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 Kids' 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

## 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



## 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



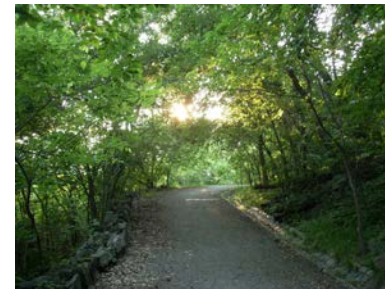


# Physical Activity

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

- Benefits for Exercise

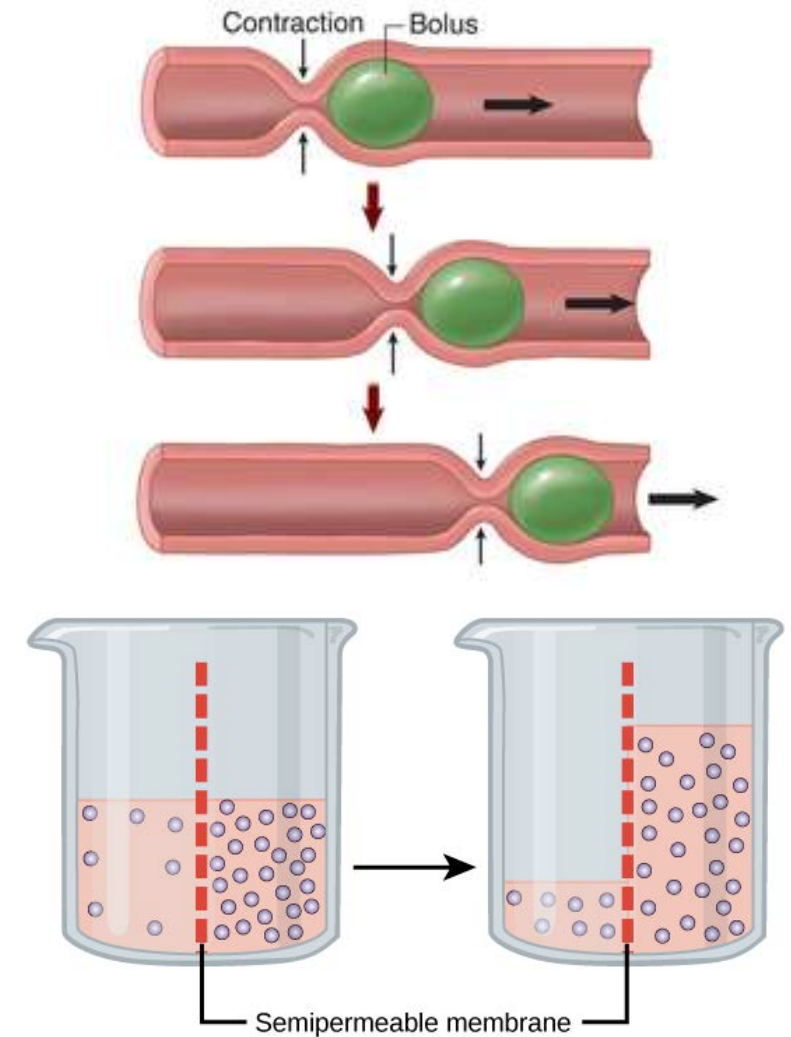
- Burn calories, helps maintain a healthy weight
- Increase mitochondrial function
- Helps build and maintain bone and muscle
- Reduce risk for heart disease, insulin resistance/diabetes, cancer, and other conditions
- Help with mood, self-esteem, stress
- Improve cognitive performance in DS?





# 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  $\neq$  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](http://www.Choosemyplate.gov/kids)



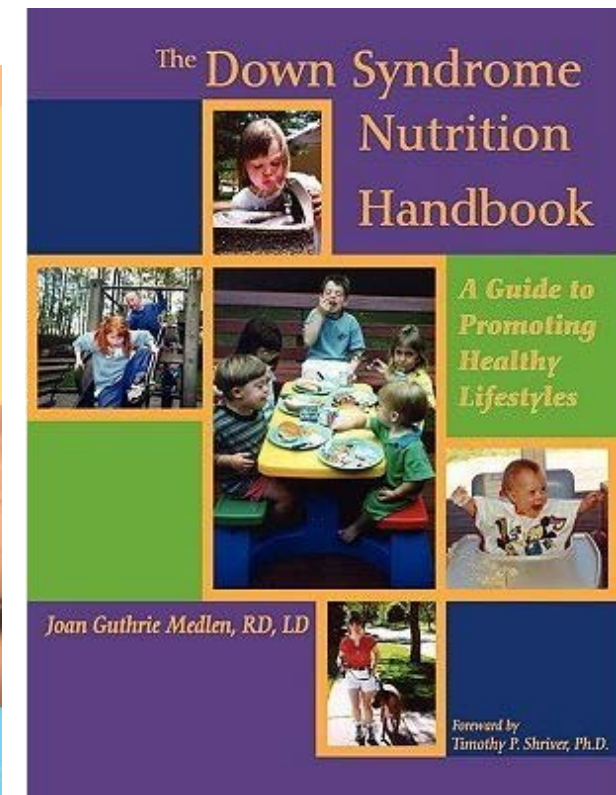
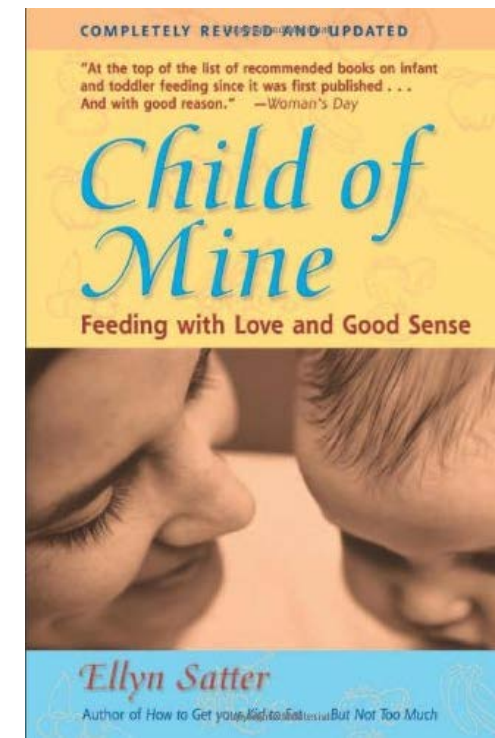
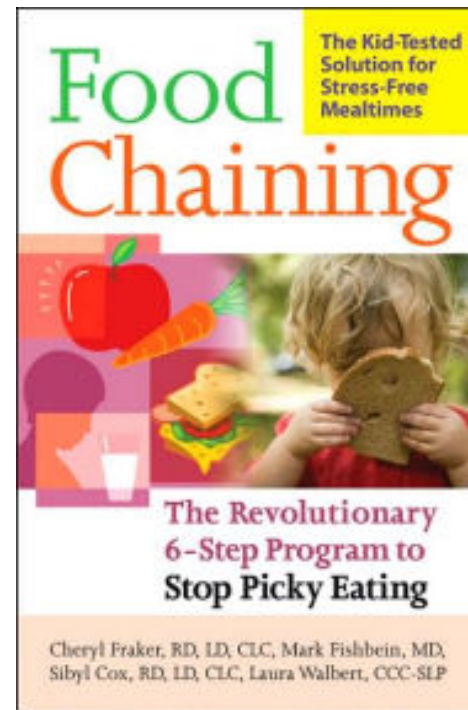
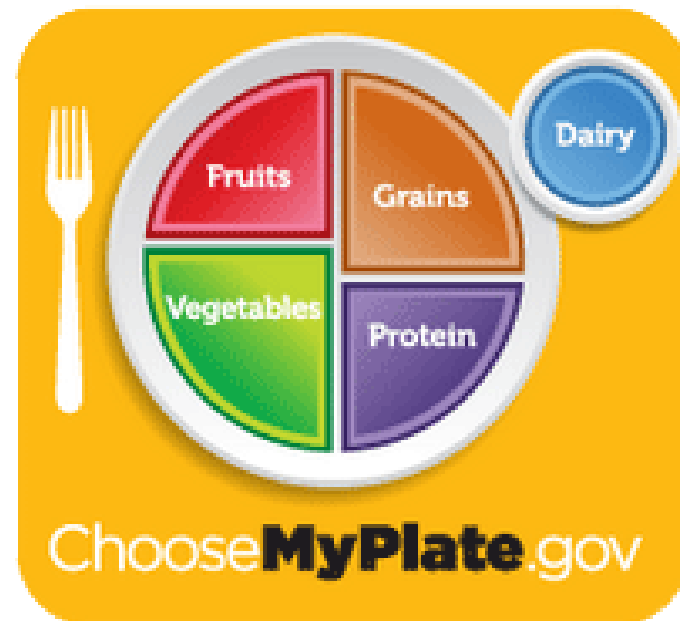
# Take Home Points

- 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](http://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

