

Nutrition for Children and Adults With Special Needs

Monica Andis, MS, RD, LD

May , 2014

Contact Info

Monica Andis, MS, RD, LD

WVU-CED Nutrition Services

959 Hartman Run Road

Morgantown, WV 26505

Phone: (304) 293-4692 ext 1148

Fax: (304) 293-7294

E-mail: mandis@hsc.wvu.edu

WVU Center for Excellence in Disabilities (CED)

- www.cedwvu.org
- CED Mission: provide resources and training in best practices for people with disabilities and chronic disease throughout the lifespan.
- Fill in the gaps in services and supports for people with disabilities.

CED Nutrition Services Program

- Clinical nutrition services in community and outpatient settings.
- Training, education and resources.
- Community and state level consultant services.

Special Needs

Group 1: Single gene mutations

- Single gene mutations that affect nutrition- PKU, tyrosinemia, glutaric academia, etc.
- Nutrition therapy is the lifesaving medical treatment here.
- State metabolic/genetics RD.
- Highly specialized formulas and diets.
- Ongoing one-on-one counseling with patients.

Special Needs

Group 2: Cystic Fibrosis

- A subgroup of Group 1.
- Requires its own unique medical and nutrition skill sets, management protocols and interdisciplinary team.
- CF clinics- Charleston and Morgantown.
- RDs that specialize in CF.

Special Needs Group 3: Everyone Else

- Other genetic syndromes, chromosomal abnormalities
- Brain damage, neurological problems
- Neurodevelopmental problems
- Neurodegenerative problems
- Cognitive impairment
- Autism, Down syndrome, cerebral palsy

Subset: Slow to Grow Population

- Population who are significantly smaller and/or thinner than the typical population.
- Adults in this population may weigh 65-90 lb.

Slow to Grow vs Failure to Thrive

- Slow to grow includes failure to thrive.
- Failure to thrive= poor growth or poor health due to nutrition problems that can be improved or overcome.
- Slow to grow= even with optimal nutrition, will still have a low weight or slow growth.
- What diagnoses cause slow to grow?

Diagnoses and Conditions

- Neurologic problems and brain damage.
- Genetic syndromes that cause neurological problems and /or metabolic or physiologic problems.
- Some chronic medical conditions (G-I problems, prematurity, organ problems, etc)

Neurological Problems/ Altered Brain Function

Affects weight and growth in different ways:

- Motor delays, non ambulatory, atrophied extremities.
- Extremities contribute 20% of adult body weight.
- So with wasting/non ambulatory, you may see a 10-15% reduction in weight and BMI due to reduction in muscle and bone mass.

Neurological Problems/ Altered Brain Function

- Hormonal changes → altered blueprint for growth and altered adult size.

Indicators of Neurological Problems/ Altered Brain Function

- Low muscle tone, “floppy” baby or child.
- Unable to hold head up at 3-4 months, unable to sit up at 6 months= gross motor delays.
- Low weight
- Low head circumference – not always present in neurological problems.

Evaluating Weight and Growth In the Slow to Grow Population

- Bottom line BMI= 12.0.
- For children 2 years and older and adults.
- For a sub set, BMI of 12.0- 12.9 is acceptable.
- For most children and adults, BMI of 13.0 or better.
- For 0-12 months, I aim for BMI of 15.0 or more- babies need more body fat.

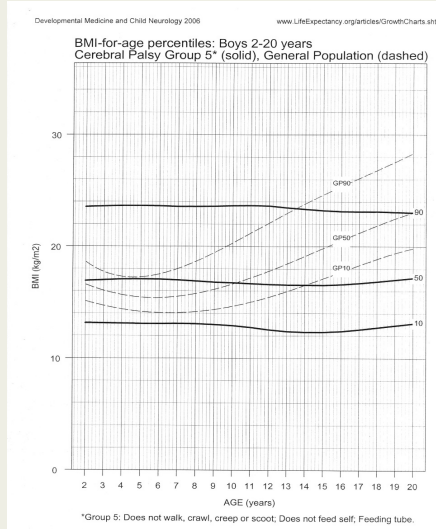
BMI ranges for the Slow to Grow Population

- Cerebral Palsy growth charts generated by Brooks, Day, Shavelle, and Strauss , 2006.
- Low weight, morbidity, and mortality in children with cerebral palsy: New clinical growth charts. Pediatrics, 128; e299.
- Total study group- 25,545 children from 2 to 20 years. Took 102, 163 measurements.

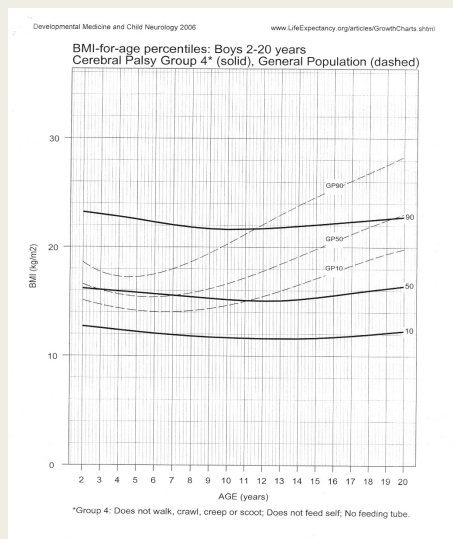
CP Growth Charts Comparisons

Group	Age	No CP		CP			Height age 20	No CP	CP
		Wt 50 th %	BMI 50 th %	Wt 50 th %	BMI- 50 th %	BMI 10 th %			
1 ambulatory	3 yrs	32 lb	16	30 lb	16.9	14			
2 can walk or stand with assistance				28 lb	16.4	13.5			
3 can creep or crawl				26.4 lb	16.0	12.5			
4 can't creep or crawl, oral eater				26.6 lb	17.0	13.2			
5 can't creep or crawl, G tube				26.4 lb	17.0	13.2			
1 ambulatory	8 yrs	57 lb	15.8	51 lb	16.9	13.8			
2 can walk or stand with assistance				48 lb	16.5	12.9			
3 can creep or crawl				42 lb	15.5	12.0			
4 can't creep or crawl, oral eater				38 lb	15.5	11.8			
5 can't creep or crawl, G tube				46 lb	16.8	13.0			
1 ambulatory	20 yrs	156 lb	23	136 lb	21.9	17.2	69"	69"	
2 can walk or stand with assistance				119 lb	20.0	15.0		66 1/2"	
3 can creep or crawl				102 lb	17.0	14.3		61"	
4 can't creep or crawl, oral eater				79.4 lb	15.3	12.2		59"	
5 can't creep or crawl, G tube				84 lb	17.1	13.3		59"	

Group 5 BMI for Age Non ambulatory, G tube



Group 4 BMI for age Non ambulatory, Oral eaters



Clinical Applications Growing More Slowly

- When BMI flat lines, children may stay at same weight for months or several years.
- Growth spurts do happen but are fewer and may be less pronounced than for typical kids.

Clinical Applications Growing More Slowly

- During periods when children don't grow in height, we never know when they do or don't need more calories.
- So we do try periodic calorie increases, but we back off when they do not work.

Clinical Applications When Push Calories?

- When child has grown 1-2" and not gained any weight.
- We allow 6 months after a gain in height to allow for a gain in weight. If not seen, we increase calories.

Signs That Calorie Increases Are Not Working

- Individual gets fat, not taller.
- Reflux appears or worsens.
- Residuals come back out of feeding tube.
- Swallowing problems (dysphagia) appear or worsen.
- Bowel problems appear or worsen.

Signs That Calorie Increases Are Not Working

- Distress, agitation, apparent signs of discomfort appear or worsen.
- Food aversions or behavioral feeding problems appear or worsen.
- Use COMMON SENSE when dealing with calories and weight goals for special needs.

Clinical Applications Things to Remember with BMI

- This population can be extremely difficult to weigh and measure.
- Before you push calories, do your best to make sure changes in weight or height are accurate and real.
- Also note that using length instead of stature decreases BMI.

Clinical Applications Don't Fix It If It Ain't Broke!

- Remember not everyone in the slow to grow population has failure to thrive.
- It is possible to have good body fat stores and still have a weight and BMI below normal range, in other words- an ideal body weight below normal ranges.
- These individuals do not need extra calories!!





Estimated Needs for Adults with Special Needs

- I prefer the WHO calculations for calories because they calculate BEE.
- Many adults need no more than this, or need 40-75% of “normal” adult needs.
- To determine actual needs: trial and error.
- I use regular calculations for protein and fluid. For fluid, more flexible- trial and error.

Estimated Needs for Children with Special Needs

- EER formulas (some children need as little as 25-30% of calories for age)
- WHO formulas
- Current intake + trial and error
- Protein calculations: standard pediatric calculations
- Fluid: standard pediatric calculations + trial and error.

Commercial Nutrition Formula Cons

- Monotonous and artificial diet. After a while, absorption problems can occur.
- Constipation and reflux are common side effects.
- Common formulas high in fat and sugar.
- Expense.

Commercial Nutrition Formula Cons

- Nutrients in fixed proportions: If need multiple cans of formula for calories, easy to overdose on some nutrients.

Commercial Nutrition Formula Pros

- Convenient.
- Sterile.
- Easy to quantify what is in diet.
- More micronutrients than over the counter MVIs.
- High nutrient density in reasonable volume.

Blenderized Diets

- A really good blenderized diet takes more effort.
- Sterility/food safety.
- Vitamin supplementation could still be needed and tricky to provide. MVIs do not have all trace nutrients.
- May be harder to quantify.

Blenderized Diets

- Nutrient density not as good as formula:
- So may not work well for very low calorie diets, where a low volume of food may not provide enough other nutrients.
- Or higher calorie diets- which could require more volume than child or adult can tolerate.

Feeding Problems



RDs and Feeding Problems

- Because we are the food and nutrition experts, the general public assumes we are also the feeding experts. Not so!!
- Clinicians who actually “fix” feeding problems are: speech pathologist (speech therapist), occupational therapist, behavioral psychologist and sometimes- physical therapist.

What Are Feeding problems?

- Oral-Motor problems –physical problems eating.
- Self- feeding problems.
- Behavioral feeding problems- includes sensory problems with food textures. And “bad” behaviors- spitting food out, refusing, not sitting for meals, etc.

What Causes Feeding problems?

- Brain damage, brain differences
- Genetic syndromes
- Developmental delays
- Vision impairment
- Never been fed by mouth
- Fed by NG tube for too long

Feeding Basics

- Window of opportunity:
- 10 months of age.
- Must have had some oral stimulation of some kind by 10 months of age.
- If not- good luck trying to introduce oral eating later on.

Feeding Basics

- The window of opportunity refers to oral stimulation of ANY kind.
- Children who drink from a bottle are getting oral stimulation.
- Children who cannot eat or drink can have oral stimulation sessions with spoons, soft toys, soft toothbrushes and other similar things.

Feeding Basics

- Oral-motor skills develop in a sequence.
- *You can't skip steps.*
- Example: if you have not yet learned to suck food from a spoon, you cannot skip to biting and chewing.
- And the **ONLY** way to develop oral-motor skills is to practice them in the context of eating.

Feeding Basics

Normal Development of Oral Skills

- Suckling 0-6 months (liquid diet)
- Sucking 6-8 months (soft solids)
- Cup drinking 6-8 months
- Munching 6-10 months (more texture)
- Chewing 7-12 months (more texture)
- Mature chewing 15-24 months (regular diet)

Feeding Basics

Transition to Solid Foods

- Need proper oral anatomy:
- At birth, oral cavity is small compared to tongue. Ideal for suckling. Not good for solids.
- By 6 months, oral cavity has grown sufficiently to allow for sucking food from a spoon.

Feeding Basics

Transition to Solid Foods

- Need proper gross motor skills: *Humans evolved to eat solid foods in an upright position.*
- Oral-motor skills are tied to gross motor skills.
- MUST be able to sit independently to be able to physically eat a solid foods diet.

Feeding Basics

Gross motor skills

- So an infant must have the proper oral anatomy AND the proper gross motor skills to support introduction of solid foods.
- And this occurs around 6 months of age.

Feeding Basics

Transition to Solid Foods

- What if you can't sit up at 6 months?
- Solid foods will be delayed.
- Work with a physical therapist to catch up when this is possible.
- If not possible → will be on a liquid diet permanently.

Feeding Basics

Transition to Solid Foods

- Speech pathologist or occupational therapist key clinicians to improve feeding skills to whatever extent possible.
- Any improvement in oral skills is important, because even small amounts of solid food can improve diet variety and quality.

Feeding Basics

Transition to Solid Foods

- What about kids who delay solids for other reasons- food allergies, reflux?
- In our experience, delaying solids is not usually a problem, if child has other forms of oral eating or oral stimulation in meantime.

So What's the RD's Role in Feeding?

- We help determine when children and adults can and cannot meet their nutrient needs by mouth.
- We teach individuals and families how to follow special diets (ex. puree diet, thickeners).
- We manage feeding tube diets and help people transition off tubes when possible.

What's the RD's Role in Feeding?

- For behavioral feeding problems, we set nutrition goals and help select specific foods to introduce.
- We develop the dietary strategies to introduce new foods into the diet.

Feeding Tubes

- It is completely possible to continue eating by mouth when you have a feeding tube.
- G and J tubes interfere with feeding far LESS than do NG tubes.
- NG tubes should be used for no more than 6-8 weeks.

Behavioral Feeding Problems

- Problems that are not caused by physical or muscular limitations.
- Children with behavioral feeding problems have the physical ability to eat appropriate foods and self feed.

Food Selectivity

- Food selectivity is the consumption of an abnormally limited variety of food.
- We usually reserve this term for individuals who avoid one or more entire food groups or eat no more than 3-5 different foods.
- Common in autism.
- “Picky” eaters are defined as individuals who eat at least one food from each food group.

The Food Groups

- Protein foods (meats, eggs, milk, cheese, legumes)
- Starchy foods (cereals, grains, and starchy vegetables)
- Fruits and non starchy vegetables
- Dairy products (or substitutes).

Causes of Behavioral Feeding Problems

- Developmental delays, cognitive impairment
- Sensory problems, food aversions, food selectivity.
- Difficult medical history- eating causes discomfort, or never been fed by mouth.

Treating Behavioral Feeding Problems

- Break goal into very small steps.
- Immediate praise, and extra reward if needed.
- Set up environment to make child succeed at each step. Then praise and reward-reinforcement.
- Repeat consistently- days-weeks-months.

Nutrition for Behavioral Feeding Problems

- What's reasonable number of foods to introduce? What's a reasonable variety of foods from the nutrition and developmental standpoint?
- Answer: The rule of 3.

The Rule of 3

- (By age 3): Be able to eat:
- 3 different protein foods
- 3 different starchy foods
- 3 different fruits
- 3 different vegetables

The Rule of 3

- Be able to eat:
- 3 different breakfasts
- 3 different lunches
- 3 different dinners
- Handouts. www.cedwvu.org

The End!



Any questions?

