

Tuesday, 2:30 – 4:00, C1

## **Tailor-made Nutrition for Developmental Disability**

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### Objective:

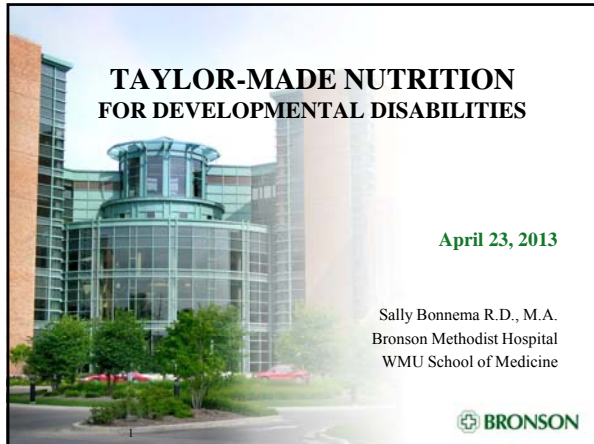

1. Identify effective methods for the practical application of concepts related to improving the delivery of services for persons with developmental disabilities
2. Identify advances in clinical assessment and management of selected healthcare issues related to persons with developmental disabilities
3. Identify nutrition risks and interventions for persons with developmental disabilities

### Notes:

**TAYLOR-MADE NUTRITION  
FOR DEVELOPMENTAL DISABILITIES**

April 23, 2013

Sally Bonnema R.D., M.A.  
Bronson Methodist Hospital  
WMU School of Medicine



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No disclosures



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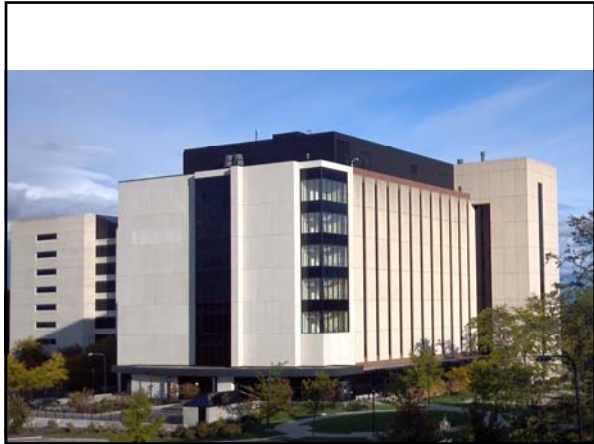
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**Nutrition Objectives**

- Identify feeding / nutrition related problems & interventions tailored to this population
- Review nutrition care for health & growth challenges
- Discuss parameters to meet nutritional needs & improve health
- Multidisciplinary Team management to address health & development concerns

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**Multidisciplinary Team**

Clinic Coordinator	Orthopedics	Pediatrician	Resident Physicians
Occupational Therapist	Physical Therapist	Certified Orthotist	Registered Dietitian
Speech Pathologist	Social Worker	School OT, PT, teachers	Family / pt. caregivers

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### Common Challenges may include

- Growth
- Feeding
- Dysphagia
- Body Composition
- Gastro-intestinal
- Pulmonary Status
- Muscle Tone
- Orthopaedic
- Mobility
- Medications
- Alternative or Complementary meds



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### DD population – Nutrition Risk Factors

- Altered growth, short stature, genetic
- Altered energy & nutrient needs
- Feeding problems
- Gastrointestinal issues
- Medication, med-nutrient interactions
- Physical, mental / behavioral concerns

Nutrition Focus Jan/Feb 2011

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### Effects on Developmental Disabled Person

- Slowed growth, low wt/lg, FTT
- Under or Overly nourished; ↓ or ↑ fat
- Lengthy feeding times, ↓ volume / fluid
- Dehydration, constipation
- Vitamin/mineral deficiencies

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## What to consider?

- Dx, Medical History
- Growth History
- Medications
- Lab values
- Tanner stage
- Bone age
- Anthropometrics
- Skin fold measures
- Feeding Assessment
- Dietary Intake
- Fluid Intake
- Physical abilities

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Reference: Fotosarch u1409768.jpg

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Reference: Fotosarch

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## Measurements

- Height, lg, segmental, sitting ht., crown-rump
- Arm span, upper arm lg, lower leg lg, knee ht
- Weights, head circumference
- Consistent techniques
- Incremental weight and linear changes
- Skin fold thickness
- Arm circumference

AND: Pocket Guide to Children with Special Health Care Needs

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## Growth Charts

- WHO chart 0-2 yrs. wt/lg, HC, ref. population
- CDC chart 2-20 yrs. wt/ht, BMI,ref.population
- kids-special health care needs-not included
- Challenge of accurate measures
- Special equipment may be needed
- Maternal & Child Health bureau has an
  - Online training module  
(<http://depts.washington.edu/growth/eshcn/text/intro.htm>)

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## Nutrition indicators (interpretation CDC growth charts)

Index	Percentile cut off	Interpret special child
BMI/age or Wt/lg - /Ht	>95 <sup>th</sup> percentile	Obesity Ex. Down's, spina bifida
BMI/age	>85 <sup>th</sup> yet <95 <sup>th</sup>	Overwt. Ex. Limited ambulation
BMI/age or Wt/lg	<5 <sup>th</sup> %ile	Underweight Ex. Spastic Quad CP, feeding, metabolism, GI
Stature – Lg/age	>95 <sup>th</sup> %ile	Tall for age Rare genetic disorders
Head Circumference/age	>95 <sup>th</sup> %ile <5 <sup>th</sup> %ile	Macrocephaly Microcephaly Developmental problems

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## Specialty Growth Charts

- Achondroplasia
  - Cornelia de Lange
  - Down Syndrome
  - Myelomeningocele
  - Noonan Syndrome
  - Prader-Willi Syndrome
  - Skeletal Dysplasias
  - Trisomy 13 & 18
  - Turner Syndrome
  - Williams Syndrome
  - Growth Collections
- <http://www.ggc.org/education/resources/ggc-publications/publications.html>  
<http://depts.washington.edu/nutrpeds/fug/growth/specialty.htm>

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## Specialty Growth Charts

- Cerebral Palsy-Kennedy Krieger Quad CP Krick et. al., JADA 1996;96:680-685.
  - Life Expectancy Project. Steven Day Charts – functional disability levels  
<http://www.lifeexpectancy.org/articles/GrowthCharts.shtml>
- \*CDC and US Maternal Child Health Bureau – ‘Use of special charts developed to assess growth of children who have conditions with no genetic or chromosomal basis for an altered growth pattern, such as CP is not recommended’

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## Growth patterns GMFCS

- Growth charts stratified 5 severity groups  
Day sm, et al. Dev med Child Neurol 2007 Mar;49(3):167-71
- Gross motor function classification system  
Pulsano R, et al. Dev Med Child Neurol 1997;30:214-223
- 1-walks well alone > 20 ft. & balances well
- 2- supported walk or unsteady alone 10 ft, does not walk well or balance well >20 ft.
- 3-crawls, creeps, scoots, no walk
- 4-no crawl, creep, walk, does not self feed, no G-tube
- 5-no crawl, creep, walk, no self feeds, +G-tube

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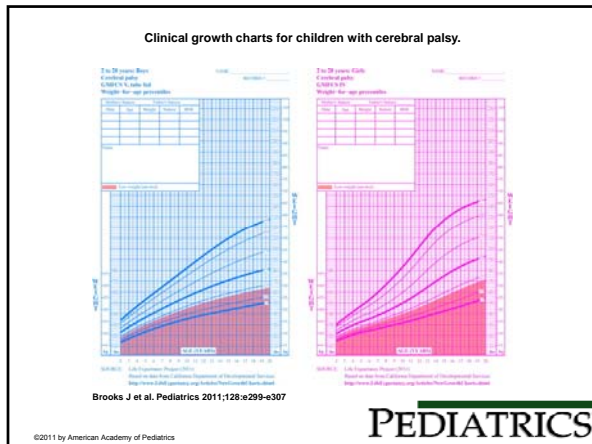
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### Body Composition

- Atypical, lower muscle & bone mass
- Bandini– ↑fat levels with low/avg. wt.
- Sullivan-CP ↑fat, ↓muscle than ref. children
- Skinfold calipers – Lange, Holtain
- Body fatness, TSF, SS, serial measures
- Ref. curves 18 mo.-19 yrs. Addo & Himes Am J Clin Nutr. 2010;91:635-642
- Limitations – technique, obesity, 1 site, repeat

Ican Infant, Child, & Adolescent Nutrition Vol 3, No. 3, June 2011, 158-170

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### What Weight is Healthy?

- Age, Lg/age, Ht/age, HC, if < or >3 yrs.
- Wt/Lg, Wt/Ht & BMI, %iles, trends,
- Growth-actual vs expected (pop. specific)
- Lean body mass & fat stores
- General health, physical, feeding
- Use clinical judgment

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### Nutrients Needs

- Assess current or “home diet”
- Adequate protein, fluids
- Vitamins/minerals DRI/age
- Tailor calories - LBM, growth, mobility, muscle tone, med’s
  - EER equations – use clinical judgment
  - RDA cal’s/kg + adjustment (ht/age)
  - Cal’s per cm (ht) population specific

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### Estimate energy by dx & cm

Diagnosis	Age	Calories
Down’s syndrome	Girls: 5 – 11 years	14.3 kcal/cm
	Boys: 5 – 11 years	16.1 kcal/cm
Prader-Willi	Children & adolescents	Maintain: 10-11kcal/cm Slow loss: 8.5 kcal/cm
Spina Bifida	Children >8 yr min. active or 50% < ref. for age	Maintain: 9-11 kcal/cm Wt. loss: 7 kcal/cm
CP – Ambulatory	Children: 5-12 years	13.9 kcal/cm
Non-ambulatory Athetoid	Adolescence* <small>* Manual of Pediatric Nutrition 4<sup>th</sup> ed: Henricko/Daggan 2005</small>	11.1 kcal/cm Up to 6000 cal’s/day
Severe restricted active		10 kcal/cm
Mild-moderate activity	<small>HOM DRI: The Essential Guide to Nutrient Requirements: Washington, DC: National Academies Press; 2006.</small>	15 kcal/cm

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### Nutrition Goals



- Adequate nutrition in a safe, tolerated way
- Macronutrients: Protein, Carb’s, Fat
- Micronutrients: Vitamins, Minerals
- Fluids, Fiber
- To maintain acceptable body stores
- To meet energy demands for growth
- Achieve and maintain “Ideal Body Wt.”

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### Low Weight - Under nutrition

- FTT – wt. <3<sup>rd</sup> percentile; wt. <80% of IBW
- Weight decelerations  $\geq 2$  major percentiles
- Medical history, growth history
- Organic – inability to take, retain, utilize or increased caloric needs, altered growth
- Nonorganic – inability to provide adequate food, psychosocial or environmental issues, lack of info or “mis” info regarding feeding practices

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### Nutrition Therapy

- Est. catch up calorie needs – ht/age
- Modify diet plan, set realistic goals
- Communicate plan with medical team
- Anticipate wt. gain per week or month
- Address contributing factors
- Involve others in care, school, in home support services, relatives, etc.

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### How To Grow – feed / eat

- Feeding disorder – 25% general pop., 80% in DD children  
Manikam R, et al. J Clin Gastroenterol. 2000; 30(1): 34-46
- 75% ASD children atypical feed patterns, limited food preferences  
Mayes SD, et al. Infants & Young Children 1999; 12: 90-97
- Oral/motor coordination-enjoy food, want to eat
- Sensory issue-able yet avoid, don't want to eat
- Early identification, therapy, family based care
- Early intervention, Outpt., school, program
- Therapy (OT/PT/SLP's), feeding team

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## Feeding Issues

Screen: eat/drink, gag/choke/cough, URI  
If aspiration risk, VFSS/swallow study SLP

- Common - bite reflex, tongue thrust, lip retract, sensory, nasal regurgitation
- Appropriate food/fluids, utensils, position, equipment, technique/support (therapist)
- Modify food textures, fluids, thickeners,

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## Nutrition Perspective

- Feeding safety, nutritional adequacy, sufficient fluids
- Thickeners – puree, baby cereal, yogurt, bread crumbs, potato flakes, smoothie, naturally thick food, commercial products
- Need for add'l calories &/or protein
- Most practical, affordable, beneficial

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## Oral Nutrition Supplements

- To complement oral diet
- Availability, cost, ease of providing
- Consider allergy, type of protein, with or without fiber, dysmotility factors
- Favor nutrient dense, pro, vit & minerals
- Age appropriate, tol. Consistency
- Home available, caregiver purchases
- Commercial supplements, requiring PA

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## GI Issues

- Dysphagia—screen @ visits, tone meds can affect, can worsen or change
- Dysmotility –
  - GERD- frequent in ND pop.
  - Delayed gastric emptying
  - Dumping syndrome
- Constipation- in children with ND 50%

Sullivan, et al. Current Pediatrics 2005;15:347-353

Veugelers, R. et al Dev Med Child Neurol.2010;52:e216-e221

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## Nutrition Interventions

- Upright positioning
- Modify feed – ↓fat, ↑MCT, hydrolyzed pro, AA formula, continuous feed, GJT
- Smaller volume given frequently
- Thickened liquids
- Medication / Surgical (fundoplication)

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## Nutrition Perspective

- Delayed gastric empty-leads to early satiety, nausea, vomiting, retching
- Impaired motility, constipation, diarrhea
- Lengthen feed time, reduce volume
- Impact adequacy of intake
- Cal's, pro, vitamins, minerals, fluids

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## Constipation

- Immobility, hypotonia, bowel dysmotility

Veuggelers R. et al. Dev Med Child Neurol. 2010;52:e216-e221

Potential causes, hx & assess by team

- ↑ fluid loss, ↓ fluid intake, poss. ↓ fiber
- Med side effect or could be w/holding
- Treatment – fluids, juice (sorbitol), if mild grad. insoluble fiber, OTC, Rx med's, bowel training, plan of care to prevent

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## Drug Nutrient Interactions



- Vitamin D, folate availability
- Calcium, bone status
- Gum hyperplasia, ↓ or ↑ appetite
- GI effects, constipation, diarrhea
- Bone Health – calcium / Vit D DRI/age,
- √ Vit D 25 OH, supplement if  $\square$  20 ng/mL per IOM or  $\square$  30 ng/mL Shinchuk L. et al. Nutr Clin Pract 2007;22:297-304
- Re √ serum level in 3 months

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## S & S consider non-oral feed

- Unable to take 80% cal's, 90% fluids over an extended time, fatigue
- Malnutrition, low-albumin, TSF, decubiti
- Anthropometrics, poor growth
- Wt. loss-illness, surgery, not recovering
- Repeated URI or pneumonia
- GER, failed medical treatment

Charney P. et al. ADA Pocket Guide to Enteral Nutrition Chicago, IL: ADA; 2006  
Yan V, Lucas B, Feucht S. Chap. 10. Nutrition Interventions for Children with Special Health Care Needs. 3rd ed. Olympia, WA: Washington State Dept. of Health; 2010:121-8.  
Poht, JR. et al. Pract Gastroenterol. 2005(May);14:22.



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## Tube Feedings

- Supplemental or total feeds
- Combine oral & tube, adjust max. oral
- Daytime or nocturnal feeds
- Bolus-intermittent or continuous pump
- GT, gastrostomy button, PEG, JT,
- Monitor regimen, growth, fluids
- Assure adequacy & adjust periodically

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## Enteral Formulas

- Standard, lactose-free 1 kcal/mL, 1-13 yr
- Milk-based, 50% whey, soy, blended
- +/-Fiber, DHA Omega-3, pre/probiotics
- Calorically dense – 1.2, 1.5, 2.0 kcal/mL
- High protein formulas
- Elemental formulas, allergy, MCT
- Recent 0.6 cal/mL, ↑ pro, vit's & minerals
- Home blenderized regimens



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## Nutrition Perspective

- Can formula meet nutr'l needs?
- Tolerance, pro, fat issues, volume
- Adequacy of vitamins & minerals
- Benefits of prebiotics
- Affordable, age appropriate,
- Home available, caregiver purchases
- Commercial supplements, requiring PA



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## Health Risk Obesity-Ped's

- Orthopedic – slipped capital femoral epiphysis, Blount's
- Cardiovascular – HTN, dyslipidemia
- GI – NAFL, gallstones, GER
- Endocrine – Type 2 DB, Insulin resist,
- Pulmonary – sleep apnea, asthma
- Psychosocial – ↓self-esteem, depression

Barlow SE, Expert Committee. Pediatrics. 2007;120(Suppl 4):S164-S192.



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## Common General Causes

- Portions - > needs
- Sugared beverages
- Low veg, fruit, fiber
- Fast Foods, ↑ fat
- Freq. snacks & type
- Convenience foods
- Meals lack balance
- Lack of consistency
- Physical Inactivity
- Screen time
- Sedentary
- Technology

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## Obesity, treat, prevent

- NHANES 07-08 prevalence
- 2-5y 10.4% 6-11y 19.6% 12-19y 18.1%
- Assess – growth/chg, hx, screen, labs, diet, activity, sleep, attitude, readiness
- Staged approach to treat
- Prevention Plus, Structured Wt. Mgmt.
- Comp. multi-team, Tertiary care

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## Overwt. & Disabilities

- Higher incidence in DD pop., myelo, Prader-Willi and Down's syndrome
- Low muscle mass, difference muscle tone
- Calorie effect may be magnified
- Varying lower physical activity
- ↑ wt magnifies movement difficulties
- Close supervision – outdoor activities
- More likely indoor, sedentary activities

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## Obesity for DD

- Cognitively delayed ↑er than physical
- Obesity similarly worsens with age
- Likely risk + 2ndary re: to disability
- Activity- more sedentary + barriers
- Nutrition – feeding, limited selection
- Foods used to reinforce good behavior

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## Interventions

- Brenner FIT Program Skelton, JA et al. Child Obesity, 2011; 7: 185-196.
- Multidisciplinary team – Dr, RD, SW, PT, exercise physiologist, counselors (5%DD)
- Motivational interview & constant collaboration
- Family guides pace & chg, Key to behavior chg
- Ed, support, child involved, individual goals
- Collaborate with teachers,
- Interdisciplinary approach for complex issues

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### Team nutrition

- Current diet – oral, tube, eat, drink
- Pertinent medical, growth changes
- Assess readiness & areas for change
- Caregivers and family support
- Team rec's for physical activity, group activities, organizations, behavior chg
- Nutrition plan portions, meals, snacks
- Involve caregivers, school, therapists, team

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### Nutrition Perspective

- Start early, involve others support
- Make a change as a family
- Be consistent, make a plan
- Monitor progress, adjust as needed
- Team intervention more successful
- Utilize technology to ↑ activity

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### Conclusion

- DD population has a variety of challenges
- Reversing these challenges will require multiple interactions from family, team community and caregivers
- Continued collaboration and team work can be the consistent steps move all of us forward to healthier outcomes!

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## References

- Cloud H, Ekvall S, Hicks L. Feeding problems of child with special healthcare needs. In: Ekvall SW, Ekvall VK, eds. *Pediatric Nutrition in Chronic Disease and Developmental Disorders*, 2nd ed. New York: Oxford University Press; 2005.
- *Pediatric Overweight and Obesity: trends and health consequences*. In: Muller, MD, Shiel, J, eds. ADA pocket guide to pediatric weight management, American Academy Association; 2010.
- Krack J, Miller P, Enagonio L, Growth Weston S, Murray P. Diet and nutrition. Owens A. Feeding and eating. Baer M, Krentzer C, Wills L, Leatham M. Non-oral enteral feeding. In: DeVore J, Shenton A, eds. *Academy of Nutrition and dietetics pocket guide to Children with Special Healthcare and Nutritional Needs*, Academy of Nutrition and Dietetics; 2012.
- Irby M, Kolbash S, Garner-Edwards D, Skellon J. Pediatric obesity treatment in children with neurodevelopmental disabilities. *ICAN: Infant, Child & Adolescent Nutrition*. Aug 2012;4(4):215-221.
- Yan L, McLennan M, Bellou T. Overweight in children with intellectual disabilities no simple matter. *ICAN: Infant, Child & Adolescent Nutrition*. Apr 2013;5(2):92-96.
- Wolff J, Sinesi M. Enteral management of children with neurologic disability. *Support Line*. Oct 2011;33(5): 3-10.
- Position of the American Dietetic Association: Providing nutrition services for people with developmental disabilities and special health care needs. *J American Dietetic Association*. Feb 2010;110(2):296-307.
- *Nutrition Interventions for children with special health care needs* 3rd ed. Washington State Department of Health 2010.
- Brooks J, Day S, Shavelle R, Strauss D. Low weight, morbidity and mortality in children with cerebral palsy: new clinical growth charts. *Pediatrics* 2011;128:e299-3307.
- Pinder G. How sensory issues impact feeding in children. *Nutrition Focus Mar/Apr 2008;23(2):1-10*.
- Feuchl S, Torkelson R, Fabury A. The why and how of thickening foods with a review of videofluoroscopic swallowing studies. *Nutrition Focus Sep/Oct 2008;23(5):1-6*.

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## References

- Gurka MJ, Kuperminc MN, Busby MG, et al. Assessment and correction of skinfold thickness equations in estimating body fat in children with cerebral palsy. *Dev Med Child Neurol*. 2010;52:e35-e41.
- Addo OY, Himes JH. Reference curves for triceps and subscapular skinfold thickness in US children and adolescents. *Am J Clin Nutr*. 2010;91:655-662.
- Stevenson RD. Use of segmental measures to estimate stature in cerebral palsy. *Arch Pediatr Adolesc Med*. 1995;149:658-662.
- Cloud HH. *Developmental Disabilities*. In: Queen Samour P, King K, eds. *Pediatric Nutrition*, 4th ed. Sudbury MA: Jones & Bartlett Learning; 2012.
- Cloud H, Ekvall S, Hicks L. Feeding problems of child with special healthcare needs. In: Ekvall SW, Ekvall VK, eds. *Pediatric Nutrition in Chronic Disease and Developmental Disorders*, 2nd ed. New York: Oxford University Press; 2005.
- Ekvall WE, Ekvall VK, Walberg-Wolfe J, Nehring W. Nutritional assessment-all levels and ages. In: Ekvall SW, Ekvall VK, eds. *Pediatric Nutrition in Chronic Disease and Developmental Disorders*, 2nd ed. New York: Oxford University Press; 2005: 47-48, 50-51, 47-481.
- American Academy of Pediatrics. Nutritional support for children with developmental disabilities. In: *Pediatric Nutrition Handbook*, 6th ed. Elk Grove Village, IL: American Academy of Pediatrics; 2009:821-842.
- Wittenbrock W, Rees Parrish, C. Nutritional assessment and intervention in cerebral palsy. In: Rees Parrish C, eds. *Nutrition issues gastroenterology*, series #92. *Practical Gastroenterology*. Feb 2011; 16-32.
- Pentlak S, O'Faberty T, Santoro K, Willging P, Kaul A. Pared by gastrostomy tube diet improves gagging and retching in children with fundoplication. *J Parenteral Enteral Nutrition* May 2011;35(3):375-379.
- Novak P, Wilson K, Ausleran K. The use of blenderized tube feedings. *ICAN: Infant, Child & Adolescent Nutrition*. Feb 2009;1(1):21-23.

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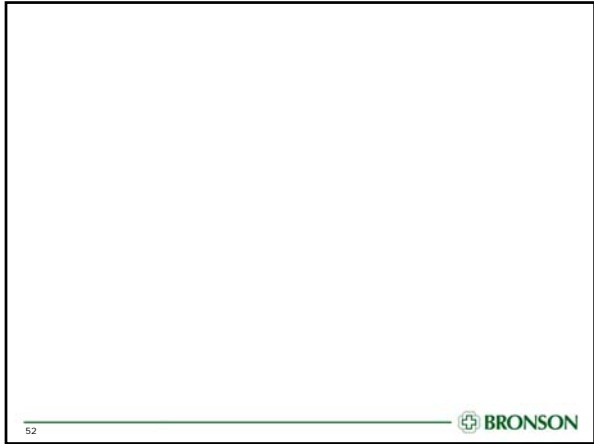
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