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

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

No disclosures

Western Michigan University School of Medicine Clinics
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

Multidisciplinary Team

<table>
<thead>
<tr>
<th>Clinic Coordinator</th>
<th>Orthopedics</th>
<th>Pediatrician</th>
<th>Resident Physicians</th>
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<tbody>
<tr>
<td>Occupational Therapist</td>
<td>Physical Therapist</td>
<td>Certified Orthotist</td>
<td>Registered Dietitian</td>
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<tr>
<td>Speech Pathologist</td>
<td>Social Worker</td>
<td>School OT, PT, teachers</td>
<td>Family / pt. caregivers</td>
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</table>
Common Challenges may include

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

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

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
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
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

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/cshcn/text/intro.htm)

Nutrition indicators (interpretation CDC growth charts)

<table>
<thead>
<tr>
<th>Index</th>
<th>Percentile cut off</th>
<th>Interpret special child</th>
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</thead>
<tbody>
<tr>
<td>BMI/age or Wt/lg /ht</td>
<td>&gt;95th percentile</td>
<td>Obesity Ex. Down’s, spina bifida</td>
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<tr>
<td>BMI/age</td>
<td>&gt;85th yet &lt;95th</td>
<td>Overwt. Ex. Limited ambulation</td>
</tr>
<tr>
<td>BMI/age or Wt/lg</td>
<td>&lt;5th %ile</td>
<td>Underweight Ex. Spastic Quad CP, feeding, metabolism, GI</td>
</tr>
<tr>
<td>Stature – Lg/age</td>
<td>&gt;95th %ile</td>
<td>Tall for age Rare genetic disorders</td>
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<tr>
<td>Head Circumference/age</td>
<td>&gt;95th %ile</td>
<td>Macrocephaly Developmental problems</td>
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<tr>
<td></td>
<td>&lt;5th %ile</td>
<td>Microcephaly</td>
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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

[Links]
- http://depts.washington.edu/nutrpeds/fgrowth/specialty.htm

Growth patterns GMFCS

- Growth charts stratified 5 severity groups
- Gross motor function classification system

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
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.
- Limitations – technique, obesity, 1 site, repeat

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
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

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Age</th>
<th>Calories</th>
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</thead>
<tbody>
<tr>
<td>Down’s syndrome</td>
<td>Girls 5 – 11 years Boys 5 – 11 years</td>
<td>14.3 kcal/cm 16.1 kcal/cm</td>
</tr>
<tr>
<td>Prader-Willi</td>
<td>Children &amp; adolescents</td>
<td>Maintain: 10-11 kcal/cm</td>
</tr>
<tr>
<td>Spina Bifida</td>
<td>Children &gt;6 yr min. active or 50% &lt; ref. for age</td>
<td>Maintain: 9-11 kcal/cm Wt. loss: 7 kcal/cm</td>
</tr>
<tr>
<td>CP – Ambulatory</td>
<td>Children: 5-12 years</td>
<td>13.9 kcal/cm 11.1 kcal/cm</td>
</tr>
<tr>
<td>Severe restricted active Mild-moderate activity</td>
<td></td>
<td>10 kcal/cm 15 kcal/cm</td>
</tr>
</tbody>
</table>

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.”
Low Weight - Under nutrition

- FTT – wt. <3rd%ile; wt. <80% of IBW
- Weight decelerations ≥ 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

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.

How To Grow – feed / eat

- Feeding disorder – 25% general pop., 80% in DD children
- 75% ASD children atypical feed patterns, limited food preferences
- 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
**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,

**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

**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
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%

Nutrition Interventions

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

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
**Constipation**

- Immobility, hypotonia, bowel dysmotility
  
  Potential causes, hx & assess by team
  
  - ↑ fluid loss, ↓ fluid intake, poss. ↓ fiber
  
  - Med side effect or could be withholding
  
  - 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,
- 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

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**References**

### 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

### 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

### 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
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

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

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
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

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

Interventions

- 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
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

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

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!
Thank You!
bronsonhealth.com

References
