Nutrition Concerns and Models of Nutrition Services with Early Intervention Teams

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Introduction of Speakers
Conflicts of Interest
Objectives

• Specific Nutrition Issues Common Among Children Receiving Early Intervention
• Parent Perspective on Nutrition Services
• Models of Nutrition Services
• Resources
Prevalence for CSHCN

• United States – 15.1% of children 0-17 years are CSHNC

• Washington State – 15% (235,920 children SHCN)

• Age prevalence (%) Nationally | WA State
  
  0-5 years of age: 9.3% | 8.1%
  6-11 years of age: 17.7% | 17.6%
  12-17 years of age: 18.4% | 19.5%

2009/2010 National Survey of Children with Special Health Care Needs
http://www.childhealthdata.org/learn/NS-CSHCN
Nutrition Risks

- 79-90% of children under age 3 yrs in early intervention (EI) programs had 1 or more nutrition risk factors
- Chronic condition = chronic nutrition problems
- Access to nutrition services specific to children with special health care needs may be limited
Why are these children at higher risk for nutrition concerns?

- Altered growth – short stature, growth retardation
- Increased or decreased energy needs due to medical condition, limited mobility over/under weight and/or failure to grow
- Inadequate nutrient intake – may be related to feeding difficulties including oral motor difficulties; self-feeding delays; behavioral issues; disrupted parent-child feeding interactions; anorexia; needs

Continued on next slide
Why are these children at higher risk for nutrition concerns?

- Bowel management issues
- Medication-nutrient interactions
- Special diets, e.g. renal, diabetic, PKU
- Dental issues impacting feeding/diet
- Use of complementary and alternative medicine (CAM) including supplements alternative diets/megavitamins

Specific Nutrition Issues

- Cerebral palsy: Sara
- Trisomy 21: Justin
- Autism: Yaroslav
- Unspecified developmental delay: Michael
Cerebral Palsy (CP)

• Motor nerve disorder caused by injury to CNS

• Varied clinical manifestations:
  – Mild to severe neurological problems, hyper-/ hypo- tonicity
  – +/- ambulatory
  – +/- mental retardation

• Nomenclature
  – Spastic, hypertonic vs. Ataxic, hypotonic
  – Dyskinetic, athetoid
  – Hemiplegia, Diplegia, Paraplegia, Quadriplegia
CP: Common nutrition issues

- Growth impairments
  - inadequate intake
  - neurological problems
  - often prematurity

- Medical
  - Seizures
  - multiple medications
  - constipation

- Diet/feeding
  - oral-motor problems, other feeding problems
  - increase/decreased energy needs
Sara: a child with CP

Nutrition summary

• **Growth**
• Intake
• On-going issues
  – Ensure adequate intake
  – Increase oral feeding?
Sara: Growth

- Weight-for-age
- Length*-for-age
- BMI*-for-age
Sara: a child with CP

Nutrition summary

• Growth
• Intake
• On-going issues
  – Adequate intake
  – Increase oral feeding?
Sara: a child with CP

Nutrition summary

• Growth
• Intake
• On-going issues
  – Adequate intake
  – Increase oral feeding?
Trisomy 21 (Down syndrome)

- “Extra” 21st chromosome
- Distinct facial appearance
- Mental retardation
- Cardiac defects
- Hypotonia
- GI malformations (e.g., duodenal atresia)
Trisomy 21: Common nutrition issues

• Growth
  – Short stature; less dramatic pubertal growth spurt
  – Problems with underweight, then overweight

• Medical
  – multiple medications, ?fluid restriction
  – constipation

• Diet/feeding
  – oral-motor problems, other feeding problems
  – Malabsorption
  – Mealtime endurance (related to cardiac problems)
  – decreased energy needs
  – nutritional supplements, other CAM
Justin: A child with trisomy 21

Nutrition summary

- Growth
- Intake
- On-going issues
  - Adequate intake, appropriate growth
  - Feeding skills
  - Prevent overweight
Justin: Growth
Justin: Growth
Justin: A child with trisomy 21

Nutrition summary

• Growth
• Intake
• On-going issues
  – Adequate intake, appropriate growth
  – Feeding skills
  – Prevent overweight
Justin: A child with trisomy 21

Nutrition summary

• Growth
• Intake
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  – Adequate intake, appropriate growth
  – Feeding skills
  – Prevent overweight
Autism Spectrum Disorders (ASD)

• Diagnostic criteria
  – Problems with verbal and non verbal communication
  – Ritualistic behaviors
  – Inappropriate social development
  – +/- cognitive deficits

• Common nutrition issues
  – Typically, no problems with growth
  – Risk of inadequate intake because of behavior-related eating problems
    • Selectivity, food refusal, “pickiness”
    • Sensory-motor problems
  – Use of supplements, therapeutic diets
Yaroslav: a child with ASD

Nutrition summary

• Growth
• Intake
• On-going issues
  – Adequate intake, appropriate growth
  – Mealtime behavior
Yaroslav: Growth
Yaroslav: a child with ASD

Nutrition summary

- Growth
- **Intake**
- On-going issues
  - Adequate intake, appropriate growth
  - Mealtime behavior
Yaroslav: a child with ASD

Nutrition summary
• Growth
• Intake
• On-going issues
  – Adequate intake, appropriate growth
  – Mealtime behavior
Michael: A child with unspecified developmental delay

- ↓ communication skills, some sign language
- Behavior problems
- No identified organic cause
Michael: A child with DD

Nutrition summary

• Growth
• Intake
• On-going issues
  – Adequate intake
  – Feeding skills
  – Mealtime behaviors
Michael: Growth
Michael: A child with DD

Nutrition summary

• Growth
• Intake
• On-going issues
  – Adequate intake
  – Feeding skills
  – Mealtime behaviors
Michael: A child with DD

Nutrition summary

- Growth
- Intake
- On-going issues
  - Adequate intake
  - Feeding skills
  - Mealtime behaviors
Family-centered Care

“Family-centered care is an approach to the planning, delivery, and evaluation of health care that is governed by mutually beneficial partnerships between health care providers, patients, and families.”

http://www.familycenteredcare.org
Why Family-centered?
Sara...an example

• Sara has a g-tube
• Sara’s family began making blenderized formula (formula, whole milk, vegetables, egg) because they wanted to provide “real food.”
• RD told family:
  Sara’s nutrient needs are being met by her formula, and she doesn’t need the extra food. You should just use the prescribed formula.
• Sara’s family felt that the RD didn’t consider their wishes and used the blenderized formula anyway; it was not nutritionally complete
RD realized the need for collaboration, and explained concerns

- raw egg is unsafe
- nutrient composition may not meet needs
- can have problems with contamination

RD worked with family to make it possible:

- Raw egg is unsafe; they agree to stop using it
- Recipe is adjusted to meet Sara’s nutrient needs
- Family will watch for clogging problems and communicate them to RD
Sara: An example of teamwork

The people involved in Sara’s care were frustrated

- Dad: “Juggling too many recommendations, hard to fit everything in and keep it straight.”
- RD: “Only one or two recommendations actually makes it into Sara’s food pattern.”
- OT: “I am trying to help Sara eat different foods, but I don’t know which foods to offer.”
- Teacher: “I’d like to continue the OT’s interventions in the classroom, but I’m not sure what to do…they don’t match the information sheet that the RD gave me.”
Sara: An example of teamwork

Food- and eating-related issues are addressed efficiently, and efforts are streamlined:

– Dad: “Now, I know that we are following the recommendations at school and at home.”
– RD: “We’ve developed more effective interventions, and I am confident that all recommendations are considered.”
– OT: “I know that the foods and skills I am working with are also improving Sara’s nutritional status.”
– Teacher: “I can continue to help Sara learn to eat now that the therapies are manageable”
Educational System

• IFSP (Individualized Family Service Plan)
  – for 0-3 year olds in early intervention programs
• interdisciplinary agreements between family, teachers, and therapists
• revised at least once per year
• specify how each goal to be accomplished
Early Intervention IFSP

• Given a cup filled $\frac{1}{4}$ to $\frac{1}{2}$ full, Michael will take in the proper amount of liquid and return the cup without spilling in 4 out of 5 opportunities by September 15.

• Given a developmentally-appropriate meal/snack, Michael will remain seated during the meal/snack time (or until excused) in 4 out of 5 opportunities by September 15.
Parent Sharing
Twenty Cs of Teamwork

- Concern
- Caring
- Compromise
- Commitment
- Cohesiveness
- Communication
- Common goals
- Collaboration
- Cooperation
- Consideration

- Confronting problems
- Consensus decisions
- Consistency
- Confidence
- Confidentiality
- Constructive feedback
- Conflict resolution
- Creativity
- Concentrated effort
- Coordination
Models of Service
Nutrition Service Models: Real World Examples

- Holly Ridge, Bremerton
- Kindering, Bellevue
- MOSAIC, Bellevue and Seattle
- Dynamic Partners, Kent
  - South King Early Intervention Program (SKIP)
  - Children’s Therapy Center (CTC)

Thank you to Sharon Feucht, Mari Obara and Beverly Pressey for sharing their work!
Who Might be Seen by the RD?  
Children with.....

• Developmental and neurologic disorders
  – Autism
  – Down syndrome
• Medical conditions that affect nutrition and/or eating
• Overweight
• Failure to thrive/Failure to grow
• Prenatal drug exposure
• Difficulty progressing to new textures
• Feeding tubes
  – transitioning to home made blended foods
  – and need follow-up that is close to home
• Sensory aversions
• Food allergies
• Parents who are concerned about adequacy of child’s intake
Sidebar: What is an RD??

• RD = registered dietitian or RDN = RD/nutritionist
• CD = certified dietitian (WA state credential)
• “Nutritionist” doesn’t necessarily = RD

• Bachelor’s degree with approved coursework (including food & nutrition sciences, biochemistry, physiology) – most pediatric RDs have additional training and advanced degrees
• Supervised practice program
• National exam
• Ongoing continuing education
## Nutrition services – different models

<table>
<thead>
<tr>
<th>Center</th>
<th>Arrangement</th>
<th>Funding for Position</th>
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| 1      | Contract with RD at UW  
10% FTE (16 hours per month)  
2-3 six-hour days per month | • Early intervention funds  
• Insurance, Medicaid reimbursement for individual evaluations |
| 2      | RD is employee of the center  
Approximately 8-10 hours per month (1 day per month) | • Insurance, Medicaid reimbursement for individual evaluations  
• Fundraising  
• Other sources |
| 3      | RD is employee of the center  
Variable | • Insurance, Medicaid reimbursement for individual evaluations  
• Fundraising  
• Other sources, including EI |
| 4      | RD receives reimbursement (insurance/Medicaid) for services | • Insurance, Medicaid reimbursement for individual evaluations |
What does the RD do?

• Direct services
  – Individual evaluations/assessments
  – Ongoing intervention and follow-up
• Consultation
• Family education
  – In existing programs
  – Special events
  – Newsletter, blog
• Staff education
Direct Services: Nutrition evaluations

- Center-based or in-home
  - Family/child needs
  - EI requirements
  - Provider/center preference
- 45-60 minutes
- Capacity varies – 2-10 evaluations per month, depending on need, center, contract
- Some are team evals (with ARNP or referring team member)

- Screening
- Evaluation Process
- Follow-up
Nutrition evaluations for individual children

- Screening and referral
  - Identified at program intake
  - Provider/therapist identifies risk
    - Discuss with RD
    - PEACH Survey
  - Need identified by RD in feeding group
- Family self-refers – requests appointment through FRC
- PCP referral
Nutrition evaluations for individual children

- **Assessment/Evaluation**
  - **Prep:**
    - Authorization/referral (insurance/Medicaid)
    - Review of records, including growth charts
    - Collect 3-day food record
    - Discussion with other therapists
  - **Day of**
    - Weigh, measure length and head circumference
    - Interview
      - Growth, nutrition history
      - Current food pattern, feeding environment
      - Medical issues
      - Family’s concerns, goals
    - Diet analysis (3-day food record and/or diet history)
    - Initial recommendations and plans for follow-up
  - **Follow-up**
    - Communication with other providers (internal and external)
    - Continued monitoring, intervention as needed
    - Refer for additional services, if necessary
Consultation – Example from one center

- Feeding team includes
  - Motor therapists
  - Speech therapists
  - Family counselor
- Meets weekly

- Examples of support
  - In-depth discussion of ‘red flags’
  - Brief consultation about specific children
    - Is 40 ounces milk too much for a 2 year old?
    - What concerns if she eats no fruit?
    - Does this growth pattern seem concerning?
  - “Nutrition 201”
    - Feeding tubes
    - Specific formulas
    - Nutrition concerns re: specific conditions
Family Education

- “Guest speaker” in existing classrooms
  - Introducing solids
  - Family meals
  - Q&A
- Short article in family newsletter
- Nutrition blog
- Nutrition open house
- Develop education materials as needed
  - e.g., GFCF diet for autism – what to consider
Staff Education

• All-staff meetings
  – Feeding and Nutrition Red Flags

• Departmental meetings
  – General nutrition for young children
  – Nutrition red flags
  – How to refer for nutrition services

→ Collaboration
Coordination with Other HCP

- Dietitian/nutritionist
  - WIC
  - Tertiary care center (e.g., Seattle Children’s Hospital)
- Primary care provider
- Public health nurse
- Home infusion company
Considerations

• Funding
  – Salary
  – Employee vs. contract
  – Mileage, travel reimbursement
• Equipment
  – Access to records
  – Scale, length board, stadiometer
  – Space
• Needs
  – Of the center
  – Of the families
  – Of the community
• Communication, when RD is not on-site full-time
Models: Other examples of teams

- RD, OT, RN, family meet together at an Early Intervention Center
- PCP, public health RD, home SLP meet with family individually and then communicate by conference call
- RD, PHN, school SLP/OT/RN communicate about tube feeding and feeding therapy plan
Resources
Resources

• Nutrition Focus Newsletter – Nutrition concerns of children with ASD, includes resources at the end
Resources

Website – Nutrition – children with special health care needs Washington State

Gateway to many resources including WA State Community Feeding Teams; Nutrition Interventions for CSHCN and more

http://depts.washington.edu/cshcnnut/
Nutrition Interventions for Children with Special Health Care Needs

- Comprehensive tool for Registered Dietitians
- Sections:
  - Determination of Nutrition Status
  - Problem-based nutrition interventions
  - Condition-specific nutrition interventions
  - Extensive appendices
    (see R on page 379)

Available online:
WA State Nutrition Network

- CSHCN Nutrition Network (NN)
  - 164 members across WA
  - Network members from community (WIC, public health, schools, private practice, Head Start/ECEAP), hospital, home health care
  - Members offered support through continuing education and a evidenced based Listserve CSHCN NN and Pediatric Nutrition Consultation On-line
Resources

Nutrition Strategies for Children with Special Needs (2nd edition)

- 100 pages
- Client handouts in English and Spanish
- Tools for nutrition screening, growth assessment and general dietary assessment
- Chapters address:
  - underweight
  - tube feeding
  - oral/dental health

http://www.uscuceedd.org/index.php?option=com_content&view=article&id=166&Itemid=230
Resources

Bright Futures Series:

• Guidelines for Health Supervision in Practice
  • Nutrition
  • Mental Health
  • Oral Health
  • Physical Activity

http://www.brightfutures.org/
Resources

http://depts.washington.edu/nutrpeds

http://depts.washington.edu/growth

http://www.pnpg.org