Raising Children with Special Needs to be Competent Eaters

Session 2 Applying the feeding dynamics model with a child with Down Syndrome

What happened in session 1

Joseph age 11 months, multiple health problems, gastrostomy tube, successfully learned to eat tube, successfully learned to eat

• Doing the feeding dynamics based assessment
• Doing the feeding dynamics based intervention

TRUST MODEL:
The parent does the intervention, supported by the therapist
The child’s desire to grow up motivates him/her to learn how to eat

fdSatter is Competency-based
Internal processes push children to learn how to eat
• Hunger: the drive to survive
• Appetite: need for pleasure
• Social reward: sharing food
• Biology: the body’s tendency to maintain preferred and stable weight

fdSATTER BASED ASSESSMENT SUPPORTS CHILD’S AUTONOMY
• It is normal for children to eat and grow normally
• From birth, to retain their capability with eating and growth, children need appropriate grownup support
• When a child does not eat and grow normally, something is the matter
• The organizing question is, “what is interfering with this child’s eating & growth capability?”

CHILD AT RISK OF IMPAIRED EATING COMPETENCE
• “At risk” or “at nutritional risk”
• Small child; one who eats little
• Ill, especially critically
• Temperamentally negative; slow to warm up
• Prematurely born
• Neuromuscular and/or cognitive limitations
ASSIGNING RISK UNDERMINES THE CHILD’S AUTONOMY

- Carries assumption of child’s incapability
- Creates agendas for feeding or growth
- Comes with ill-conceived feeding guidance: Pressure or lack of support

TALKING WITH PARENTS: PLANNING TREATMENT

- Remind parents: this is a parent-centered approach
- Reconstruct the child’s history: Share results of assessment
- What is causing the presenting complaint?
- Outline treatment, including recommendation (if any) for nutritional support
- Make recommendations for followup

Let the parent decide to go ahead with treatment—or not

TRUST MODEL FOR TREATMENT

1. Establish and maintain the division of responsibility in feeding
2. Do developmentally appropriate feeding
3. Provide realistic mastery opportunities
4. Make mealtimes pleasant & rewarding
5. Manage food to support eating competence
6. Follow and support parents as they institute the treatment plan

Satter, E. Your Child’s Weight, Appendix F, Treatment of Feeding/Growth Problems
TRUST MODEL FOR TREATMENT OF POOR EATING, GROWTH

The child’s desire to grow up motivates him/her to learn how to eat

1. Establish and maintain the division of responsibility in feeding
   - Use SDOR that reflects what the child can do, now how old s/he is
   - Follow the child’s cues
   - Let the child feed herself to the best of her ability
   - Always get child’s permission before giving nipple or spoon, serving

2. Do developmentally appropriate feeding:
   - Feed based on what the child can do, not how old s/he is
   - For (developmental) almost-toddler on up, sit-down family meals & structured snacks are the bottom line

3. Provide realistic mastery opportunities
   - Assume child will learn to manage own anxiety, evolve developmentally appropriate eating
   - Teach appropriate mealtime behavior
   - Explain the changes to child ahead of time
   - Challenge, but don’t overwhelm: Make unfamiliar food available; reassure child s/he doesn’t have to eat

4. Make mealtimes pleasant & rewarding
   - Eat with the child, don’t just feed
   - Reassure him: You don’t have to eat
   - Include the child in conversation but don’t make him the center of attention
   - Excuse the child if he behaves badly

MANAGE FOOD TO SUPPORT EATING COMPETENCE

Be considerate without catering
- Offer a variety of good-tasting food
- Let the child (same as everyone else) pick and choose from what’s at the meal
- Pair foods
  - Familiar foods with unfamiliar
  - Favorite with not-so-favorite
- Include, but don’t emphasize, high-caloric-density foods
- Don’t make children (or other people) eat
- Don’t limit the menu to foods children (and grownups) readily accept

Getting the meal habit
EMPHASIZE GOOD-TASTING FOOD

- If the joy goes out of eating, nutrition suffers
- Children only eat food that tastes good
- Too low-fat food doesn’t taste good
  - Have high and low-fat food at meals
  - Let children pick and choose

FOLLOW & SUPPORT PARENTS

- Weekly sessions (as parents can manage)
  - Optimize feeding: focus on quality, not quantity
  - Give mastery opportunities
  - Expect child’s capability to evolve
- Do problem-solving with the division of responsibility
- Detect parents’ tendencies to over-encourage
- Encourage parents to reassure child s/he doesn’t have to eat if s/he doesn’t want to
- Help parents detect child’s evidence of eating competence

REFERRAL :: COMPLAINT

To: NUTRITION
From: NEONATOLOGY CLINIC

‘Child with Down Syndrome. Not eating well or refusing to eat; not gaining weight.’

ORGANIZING LOGIC FOR ASSESSMENT

Satter Feeding Dynamics Model

- It is normal for children to eat and grow normally
- From birth, to retain their capability with eating and growth, children need appropriate grow-up support
- When a child does not eat and grow normally, something is the matter
- The organizing question is, “what is interfering with this child’s eating & growth capability?”

MEDICAL & PHYSICAL

Clues to reason child is seen as being incompetent with eating and growth
Identify whether adjunct treatment is needed

- Review & summarize clinical record
- Replot growth
- Past: Was child ill? Are issues resolved?
- What were significant events?
- Present: Oral-motor problems? Illness? Other?
MEDICAL & PHYSICAL

• Born 39 0/7 wks with trisomy 21, Ventricular Septal Defect, Atrial Septal Defect, Patent Ductus Arteriosus, small for dates
• Age 8 months: 6 d. hospitalization for bronchiolitis and respiratory distress
• Age 9 months: 1 mo. Hospitalization for heart surgery: VSD repair, PDA ligation.

MEDICAL & PHYSICAL

Birth
• Overall low tone; concerns related to feeding ‘nipping problems’
• 7 months – delayed in gross motor - communication, fine motor, and problem solving at 40-45 of ASQ-3 (Ages and Stages Questionnaire – 3rd version)
• 3 - 11 months – ‘floppy baby’

MEDICAL & PHYSICAL

• 12 months – delayed in gross motor – not sleeping or eating well – no change in communication, fine motor or problem solving since 7 months
• 14 months 26 days
  – Not walking or crawling
  – Sits up with support
  – Hold head
  – Cognition, communication, soc/emotional delayed

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DEVELOPMENTAL

To what extent has the child accomplished developmental tasks at every stage?
• Homeostasis
• Attachment
• Separation-individuation
• Initiative
DEVELOPMENTAL

- Homeostasis—still working on it
- Attachment—likely adequate
- Separation-individuation—Disrupted
  - Developmental delayed
  - Very dependent on parents

PSYCHOSOCIAL

Identify whether adjunct therapy is necessary

- Are parents able to institute a division of responsibility in feeding?
- Are parents able to apply the changes of treatment?
- Do parents/child require a referral to address associated/underlying issues?

PSYCHOSOCIAL: PARENTS

- Working at being a competent family
- Extended family available for help
- Mother struggles with attachment
- Parents appear not to grasp the extent and type of help Luis needs
- Deciding where to live – El Paso or Juarez

PSYCHOSOCIAL CHILD

- Developmental delay impacts social functioning
- Socially immature
- Baby-like behavior – acts like a 3-6 month old

NUTRITION & FOOD SELECTION

Nutrition and food selection related clues to child’s seeming incompetence with food acceptance or regulation

- Nutritional quality of child’s food intake
- Food selection and reliability of family meals
- Fat content of diet
- Developmental appropriateness of food

Determine whether feeding dynamics intervention requires adjunct nutritional support

- Assess the child’s nutritional status
- Does child have nutritional reserves to support treatment?
- Provide for nutritional support
NUTRITION & FOOD SELECTION

- Incomplete food intake record
- 619-928 calories 3-day average—+ or = 20% of calories estimated at 797 kcal/d
- Difficult for mother to produce accurate record
- Drinks Pediasure inconsistently because parents want child to eat

Assessment 14 m 26 d

- Nutritional support
  - Pediasure needs to be main source of nutrition
  - Tube feeding was discussed with mother (she refused)

FEEDING DYNAMICS

How does feeding distortion contribute to the child’s seeming incapability with eating/growth?

- Based on observation
- Mother’s report is not accurate
- Evidence of mother’s constantly offering food
- No schedule for meals and snacks

Assessment 14 m 26 d

- Bottle Feeding
  - Mom continually seeking feeding cues
  - Mom holds him with his back against her chest for support
  - Can’t see and misses many feeding cues
  - Her frequent checks interrupt feeding

Assessment 14 m 26 d

- Spoon Feeding
  - Child sits in car seat for support
  - Mom lets child pretend to feed himself, but when he is looking the other way she puts food in his mouth
  - Child is completely uninterested, when food is put in his mouth he begins to gesture as if he is choking
  - Eats “paper,” and unsalted saltines
  - Mom sings to child to distract him to make him open his mouth
IMPRESSIONS
Assessment 14 m 26 d

- Medical – Heart condition surgically cured
  - Weight gain – adequate
- Nutritional – Requires nutritional support
- Psychosocial - Coping and adjusting to parenting special needs child
- Developmental - Functioning as 3-6 mo. old
- Feeding Dynamics - Disconnect between mother’s expectation & child’s ability

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IMPRESSIONS
Assessment 14 m 26 d

- It is not about low weight
- It is not about getting food in the child
- It is about developmental delay

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To what extent can parents enact a division of responsibility in feeding?

- Primary: Can do it
- Secondary: Can do it with help
- Tertiary: Can’t do it until they resolve underlying or contextual issues

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TRUST MODEL FOR TREATMENT

1. Establish and maintain the division of responsibility
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4. Make mealtimes pleasant & rewarding
5. Manage food to support eating competence
6. Follow parents while they make changes in a stepwise fashion

Satter, E. Your Child’s Weight, Appendix F, Treatment of Feeding/Growth Problems

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**LUIS’S TREATMENT PLAN**

**Parents’ Jobs**

- Learn about Down Syndrome
- Initiate eating management
  - Establish and maintain sDOR
  - Feed in accordance with Luis’s rhythms
  - Identify, D/C pressure tactics – continually offering food
  - Feed developmentally appropriate and following schedule
  - Plan good-tasting, enjoyable menus – offer more than one food per meal and snack
  - Remind mother: There is no magical food
- Expect and enforce positive mealtime behavior

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**TREATMENT PLAN**

**Luis’s Jobs**

- Develop positive attitudes about eating
- Get hungry and show signs of it
- Eat until satisfied – with parents’ help
- Take interest in the parents’ food
- Learn to eat solid foods
- Sneak up on new food and learn to like it

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**FOLLOWUP SESSIONS WITH PARENTS**

- Weekly or every two weeks apps in 3 months and once a mo since then
- Optimize feeding
- Give mastery opportunities
- Trust that child’s capability will evolve
- Do problem-solving with the division of responsibility
- Interpret child’s reactions to food and detect mother’s tendencies

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**To prepare for next time**

- Print handouts
- Refresh your understanding of eating competence by reviewing Webinar 1, *Preventing Child Overweight and Obesity: Raising Children to be Competent Eaters*