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

- Doing the feeding dynamics based assessment
- Doing the feeding dynamics based intervention

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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

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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

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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?"

Satter, E. *Your Child's Weight*, Appendix E, Assessment of Feeding/Growth Problems

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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

Satter *Journal of Pediatric Health Care*

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Children at risk of feeding problems

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

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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

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1) Parent positive Love your child Have gone to trouble to find help Other...	**3) Parent negative** Ineffective feeding practices (Not following division of responsibility) Other...
4) Child positive Loves the parent & wants to please Appealing and attractive (be truthful) Can do certain things Will respond to treatment Other...	**2) Child negative** Shows problem parent identifies Has limitations in these areas (e.g. medical, oral-motor, temperamental) : Other...

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

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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

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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

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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
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

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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
2. Do developmentally-appropriate feeding
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

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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
2. Do developmentally-appropriate feeding
3. Provide realistic mastery opportunities
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

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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
2. Do developmentally-appropriate feeding
3. Provide realistic mastery expectation
4. Make mealtimes pleasant & rewarding
5. Manage food to support eating competence

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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

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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

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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

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Luis

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REFERRAL : : COMPLAINT

To: NUTRITION

From: NEONATOLOGY CLINIC

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

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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 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?"

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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?

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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

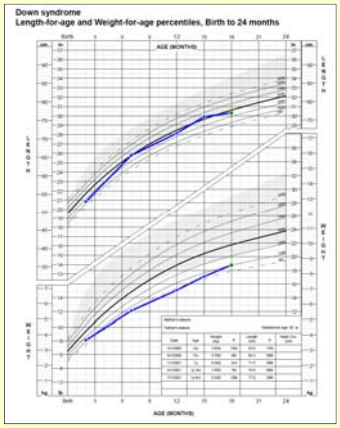
- Overall low tone; concerns related to feeding 'nippling problems'
- 7 months – delayed in gross motor - communication, fine motor, and problem solving at 40-45 of ASQ-3 (Ages and Stages Questionnaire – 3rd version)
- 3 - 11 months – 'floppy baby'

MEDICAL & PHYSICAL

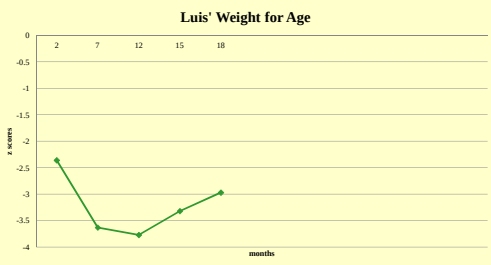
- 12 months – delayed in gross motor – not sleeping or eating well – no change in communication, fine motor or problem solving since 7 months
- 14 months 26 days
  - Not walking or crawling
  - Sits up with support
  - Hold head
  - Cognition, communication, soc/emotional delayed

Length/age

Weight/age



MEDICAL : : GROWTH



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

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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?

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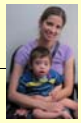
PSYCHOSOCIAL: PARENTS



- 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 need
- Deciding where to live – El Paso or Juarez

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PSYCHOSOCIAL CHILD

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

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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

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NUTRITION & FOOD SELECTION

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

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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

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NUTRITION & FOOD SELECTION
Assessment 14 m 26 d

- Feeding capabilities (spoon & nipple)
  - Cannot sit without support – floppy child
  - Holds head with a bit of help
  - Not interested in solid foods
  - Drinks Pediasure from the bottle

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NUTRITION & FOOD SELECTION
Assessment 14 m 26 d

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

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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

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FEEDING DYNAMICS
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

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FEEDING DYNAMICS
Assessment 14 m 26 d

- Spoon Feeding – (After ~8 oz bottle Pediasure)
  - 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

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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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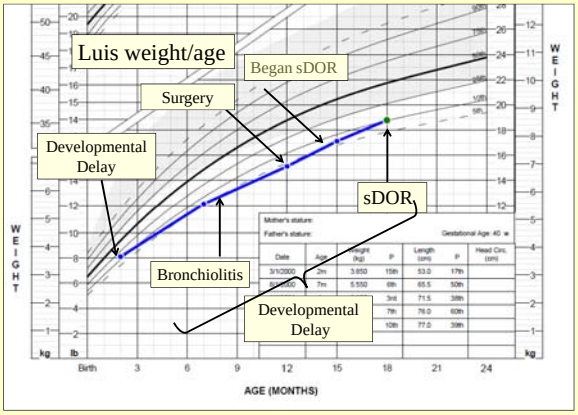

IMPRESSIONS
Assessment 14 m 26 d

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

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Feed the way your child can eat

How do you know when to start solid foods?
How do you know when to feed your baby table food?
How do you know when to wean her from the breast or bottle?

Babies learn to eat step by step. Many babies are ready to start eating mushy foods from the spoon at age 3 to 6 months and are ready for table food by age 8 to 10 months. Others aren't ready to start solids until months later and only get to the table when they are 12 to 18 months old. Once you start, keep moving at your baby's rate. Don't get stuck on any one step. Remember that faster isn't better, slower isn't worse.

WHEN YOUR CHILD...	SHE IS READY FOR...
❑ Cuddles ❑ Roots for the nipple ❑ Sucks	Nipple-feeding from the breast or bottle
❑ Sits up alone or with support ❑ Opens his mouth for the spoon ❑ Closes his lips over the spoon ❑ Keeps most of the food in his mouth ❑ Swallows	Nipple-feeding from the breast or bottle Step 1 food: Mushy food that you feed from the spoon
❑ Picks up food but can't let go ❑ Keeps food in mouth instead of swallowing right away ❑ Moves the food to her jaws ❑ Munches the food	Breastmilk or formula from the nipple or cup Step 2 food: Thicker, lumpier food that you feed from the spoon
❑ Closes her lips around the rim of the cup ❑ Picks up food, puts it in her mouth ❑ Blows off food ❑ Chews ❑ Gags some but doesn't choke (if she's gagging she can breathe)	Breastmilk, formula or juice that you give her from the cup Step 3 food: Small pieces of soft finger food and foods she bites or breaks off with her gums
❑ Uses his fingers to pick up food ❑ Can chew and swallow ❑ Takes an interest in the family table	Whole pasteurized milk from the cup Step 4 food: Easy-to-chew and easy-to-swallow table food

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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 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
2. Do developmentally appropriate feeding
3. Provide realistic mastery opportunities
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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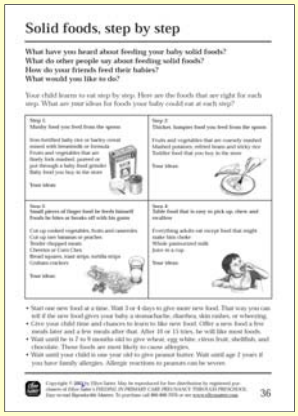

Solid foods, step by step

What have you heard about feeding your baby solid foods?
What do other people say about feeding solid foods?
How do your friends feed their babies?
What would you like to do?

Your child learns to eat step by step. Here are the foods that are right for each step. What are your ideas for foods your baby could eat at each step?

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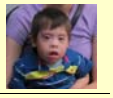
TREATMENT PLAN
Luis's Jobs



- 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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Eating after the baby

How do you go about feeding yourself? Is that the way you plan to feed your child when he is bigger? Do you want your child to eat the way you do?

Whether you breastfeed or formula-feed, you have to eat. Both mothers and fathers need to be strong and steady to be good parents. If you are hungry or try to go without food, you will be tired, cranky and discouraged.

Before the year is over, your baby will be ready to eat from the table. Start having family meals now, so you are ready when the time comes.

Here is what to do—and not do—to keep taking good care of yourself with your eating:

- Have meals with food you enjoy. Cook easy and tasty meals.
- Plan ahead. Know you will get the next meal—and the next!
- Eat both good and good-for-you food. Sneak up on new food and learn to like it!
- Pay attention and enjoy your food. Trust your body to tell you how much to eat.
- Eat until you feel satisfied. Stop. Do it again the next meal—and the next!
- Drink milk. Learn to like milk if you can.

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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*

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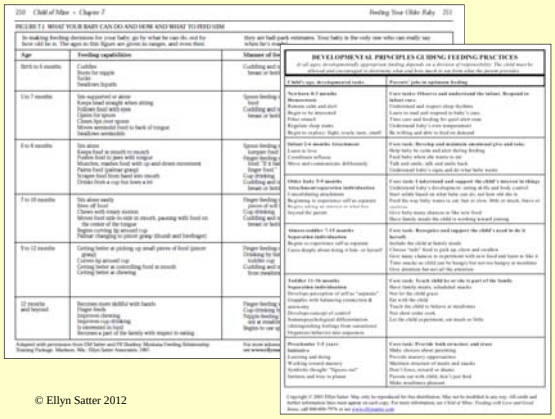

DEVELOPMENTAL PRINCIPLES GUIDING FEEDING PRACTICES

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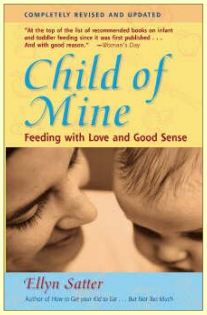
For more information



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