I Can Do It Myself!

FACILITATION OF SELF-REGULATION AND PARENT EMPOWERMENT IN A HUNGER-BASED TUBE WEANING PROGRAM

HEIDI MORELAND, MS, CCC-SLP, BCS-S, CLC, BRIANNA BROWN, MS, CCC-SLP, JAMIE HINCHEY, MS-CCC-SLP

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Disclosure Slide

- This presentation is intended to discuss the evidence for a specific program's treatment philosophy and discuss treatment outcomes from that program.
- Heidi Moreland received no compensation for this presentation. She is employed by Spectrum Pediatrics and is a treating therapist and clinical coordinator for Thrive by Spectrum Pediatrics.
- Jamie Hinchey received no compensation for this presentation. She is employed by Spectrum Pediatrics and is a treating therapist for Thrive by Spectrum Pediatrics.
- Brianna Brown received no compensation for this presentation. She is employed by Spectrum Pediatrics and is a treating therapist for Thrive by Spectrum Pediatrics.

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Learner Outcomes

1. Learners will be able to explain the principles of self-regulation and its application in special populations

2. Learners will be able to explain the importance of family mealtimes and family-based interventions and identify mealtime stressors that can have a negative impact

3. Learners will describe the different mealtime roles using the division of responsibility for parents and develop a division of responsibility for their own practice

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Feeding Tube Weaning Program

- 6 month program, including a 10 day period of intensive treatment
- Utilizes natural hunger as a motivator to eat
- Intervention provided primarily through coaching
- Home-based
- Strength-based
- Primary Goal: SELF-REGULATION which will lead to independent eating and weight gain

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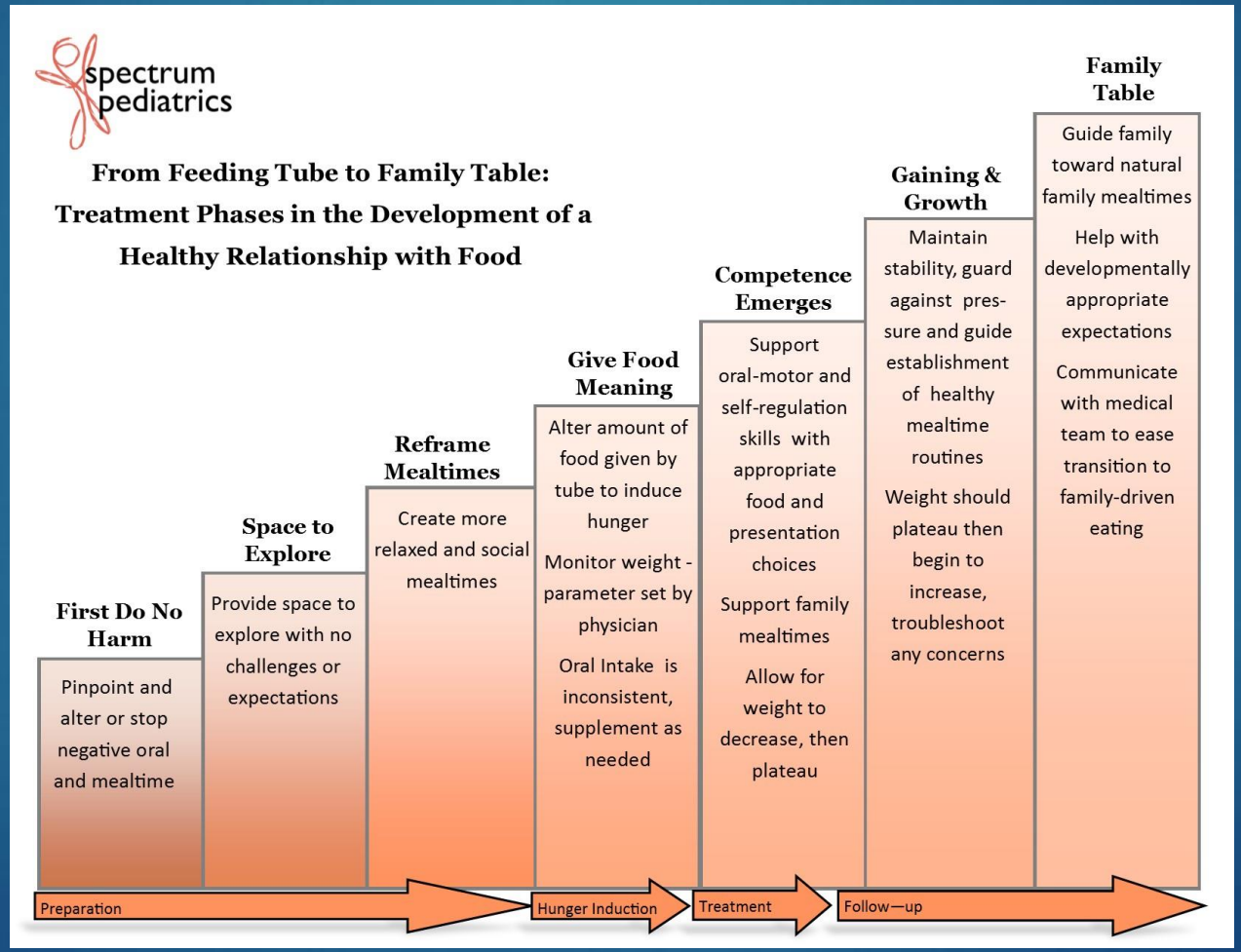
Spectrum Pediatrics Treatment Progression



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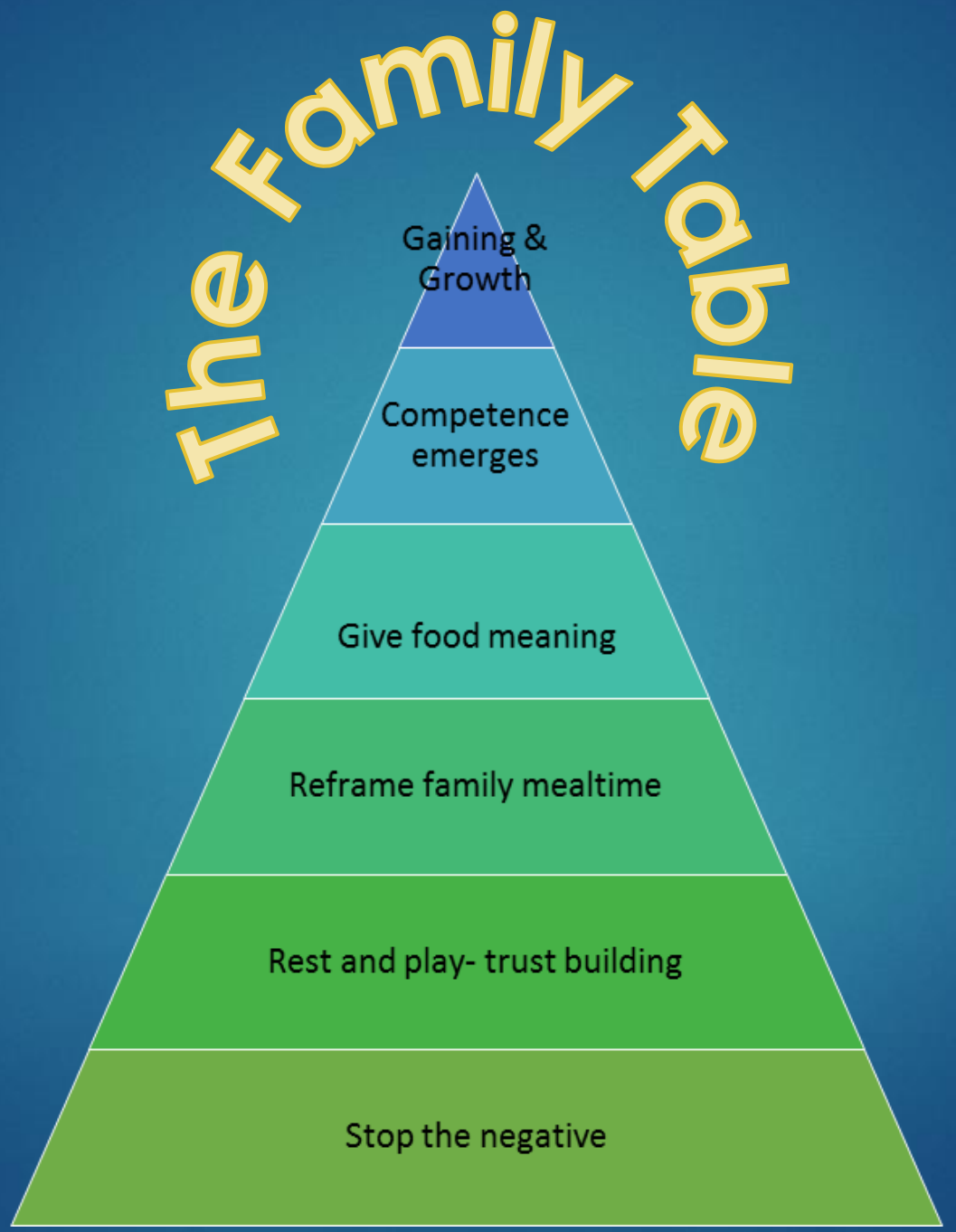
Another View: A healthy relationship with food is the FOUNDATION needed for self-regulation of eating



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What is self-regulation?

AND HOW DO YOU GET IT?

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Self-regulation

- "A child's ability to gain control of bodily functions, manage powerful emotions, and maintain focus and attention."
  - Shonkoff & Phillips

- We are born with the ability to self-regulate (use feedback to refine skills and mature) but need support in order to develop that ability.
- Most clear in infancy (and adolescence) but continues through life.
- Experiences with manageable challenges that are built on strengths will promote healthy regulation.

- In other words, becoming increasingly independent with taking control of self to meet needs and function with others.

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Self-regulation of eating

- Eating is extremely basic and a priority of the body to survive (just behind breathing and safety)
- Programmed in with infantile reflexes – because of it's importance. It's isn't taught, it is *learned* from those basic experiences
- All infants have this ability, unless it is disrupted by medical complications
  - Brief (fear, reflux, aspiration, breathing problems, cardiac deficits…….)
  - Chronic (metabolic disorders, growth disorders)
- Energy compensation - over rolling 24 hour period
- Infants and young toddlers are the best
- Older toddlers and pre-schoolers are beginning to be susceptible to outside influences

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How does eating develop from reflexive to self-regulated?

- Child experiences hunger
- Child signals distress
- Adult responds with food, bottle, nursing, etc.
- Child controls feelings of distress related to hunger enough to eat
- Child begins to suckle with reflexive movements
- Child maintains attention to the feeding long enough to finish
- Child eats until full
- Child signals satiation
- Child learns from the process and repeats

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Impact of feeding tube on development of self-regulation

Typical

- Child experiences hunger
- Child signals distress
- Adult responds with food, bottle, nursing, etc.
- Child begins to suckle with reflexive movements
- Child controls feelings of distress related to hunger enough to eat
- Child maintains attention to the feeding long enough to finish
- Child eats until full
- Child signals satiation
- Child learns from process and repeats

Feeding Tube Dependent, no disabilities

- Adult determines timing, hunger not considered
- Adult anticipates needs
- Adult initiates, child may respond or be unaware
- Adult does the activities of feeding
- Emotions are not related to hunger or satiation
- Child distracted (≠ to attention)
- Adult determines full
- Adult feeds pre-determined amount, often continuously or until vomiting ≠ satiation
- What have they learned?

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Impact on children with disabilities

- Greater motor deficits
- Greater sensory deficits
- Cognitive deficits or delays

Slower to learn and respond

- More medical procedures
- More hospitalization/static periods development

More fearful experiences

- More challenges
- More interventions
- More dependent
- More adults directing, anticipating

Fewer chances to develop independence

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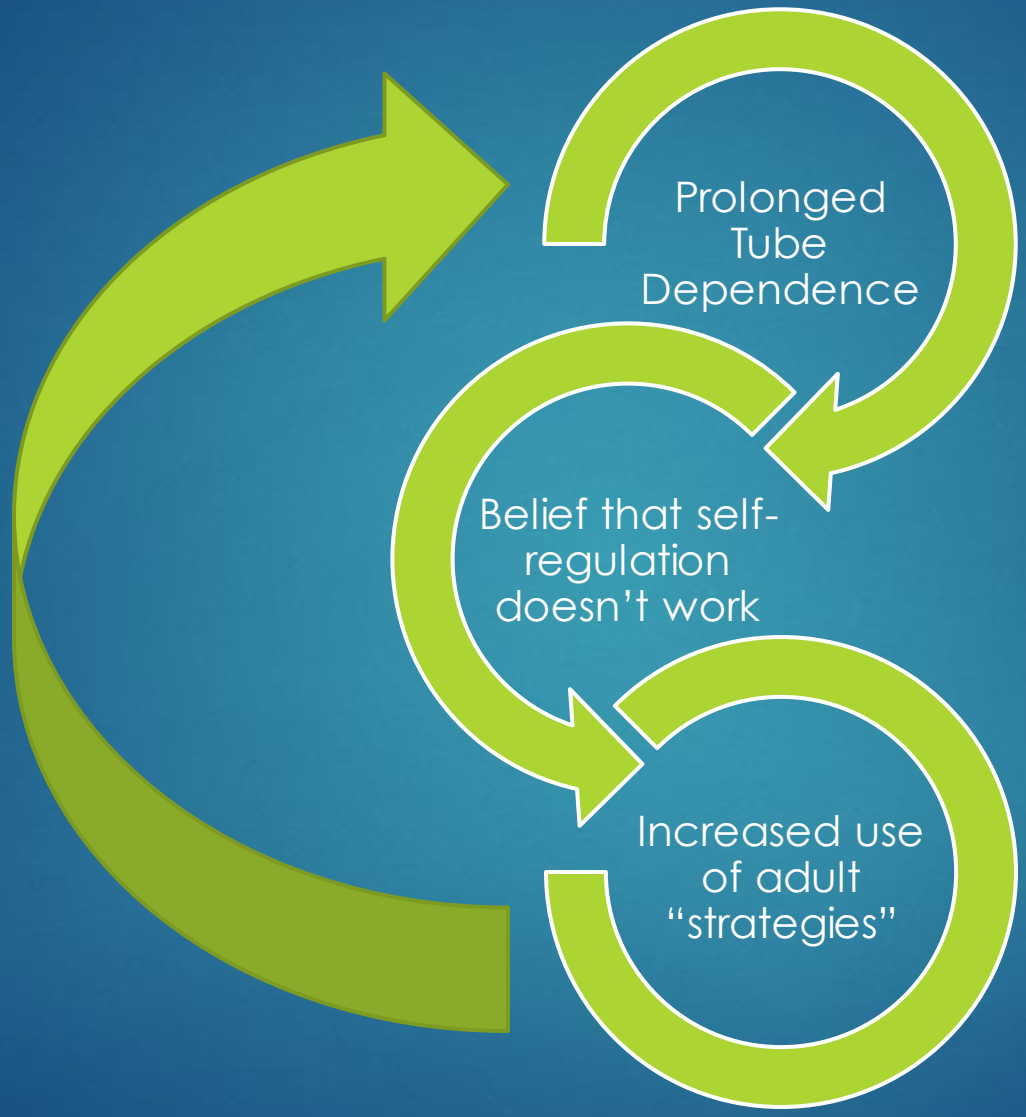

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Strategies

- Force
- Adult control of meals
- Eating only for social or emotional reasons
- Rewarding for food

Extensive research - These strategies are HARMFUL to the development of a healthy relationship with food. Those strategies are also weakness-focused and don't build on strengths.

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Our most *fragile* eaters

Are subjected to the most harmful strategies when learning to eat.

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Results for tube-dependent children

Therapy meals, not hunger dependent

Appropriate refusal when full (indicator of self-regulation) is often ignored

No voice

Passive participant

Stressful oral attempts without understanding reason for eating

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Results for children with disabilities

First tastes may happen in an office, making carryover even more difficult

Even fewer opportunities to initiate due to safety or medical complications

Delayed ability or misunderstood attempts to say no

Decreased opportunities to develop this skill leads to greater deficits

They may be more passive

Motor delays make progress slower

Weight may already be a concern due to disability

Don't build on their biggest strength, which can often be self-protection

More adult control over the child's body, cues and learning

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Impact of stress on interactions

According to the National Child Traumatic Stress Network

- "Between 20 - 30 % of parents and 15 - 25% of children and siblings experience persistent traumatic stress reactions that impair daily functioning and affect treatment adherence and recovery." When they persist, traumatic stress reactions can:
  - Impair day-to-day functioning
  - Affect adherence to medical treatment
  - Impede optimal recovery

- Stress makes it easy to justify strategies that wouldn't be used on other children

https://www.nctsn.org/what-is-child-trauma/trauma-types/medical-trauma/effects

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Teaching children to respect and protect their bodies is everyone's job.

NO MATTER THEIR SIZE OR ABILITY

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Division of Responsibility

WHAT IS IT AND HOW DOES IT LEAD TO A HEALTHY RELATIONSHIP WITH FOOD?

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What is the DOR?

- The parent and child have different jobs: The parent's job is to determine what, when, and where and the child determines how much and whether or not to eat (Ellyn Satter Institute)
- Learning to trust that your child can self-regulate and will eat how much their body needs at that time
- Identifying the jobs of the parent and the child is a crucial step to working towards healthy mealtimes
- CAN work for all kids, even those with disabilities

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Why is DoR important?

THE DIVISION OF RESPONSIBILITY HELPS TO DEFINE ROLES AND ESTABLISH TRUST

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DoR in the tube-fed population

Children who have been tube-fed may have not had the opportunity to learn what their "job" is

Tube feedings are adult-directed and do not allow for a child to decide "how much" and "if they are going to eat "

For children that are tube-dependent:

- Family Mealtimes are crucial
- How can you practice "jobs" when your child is not able to self-regulate?

For children that are "new" oral eaters:

- The jobs may be hard to identify
- Responsive, child-directed mealtimes will naturally show child and parent their jobs

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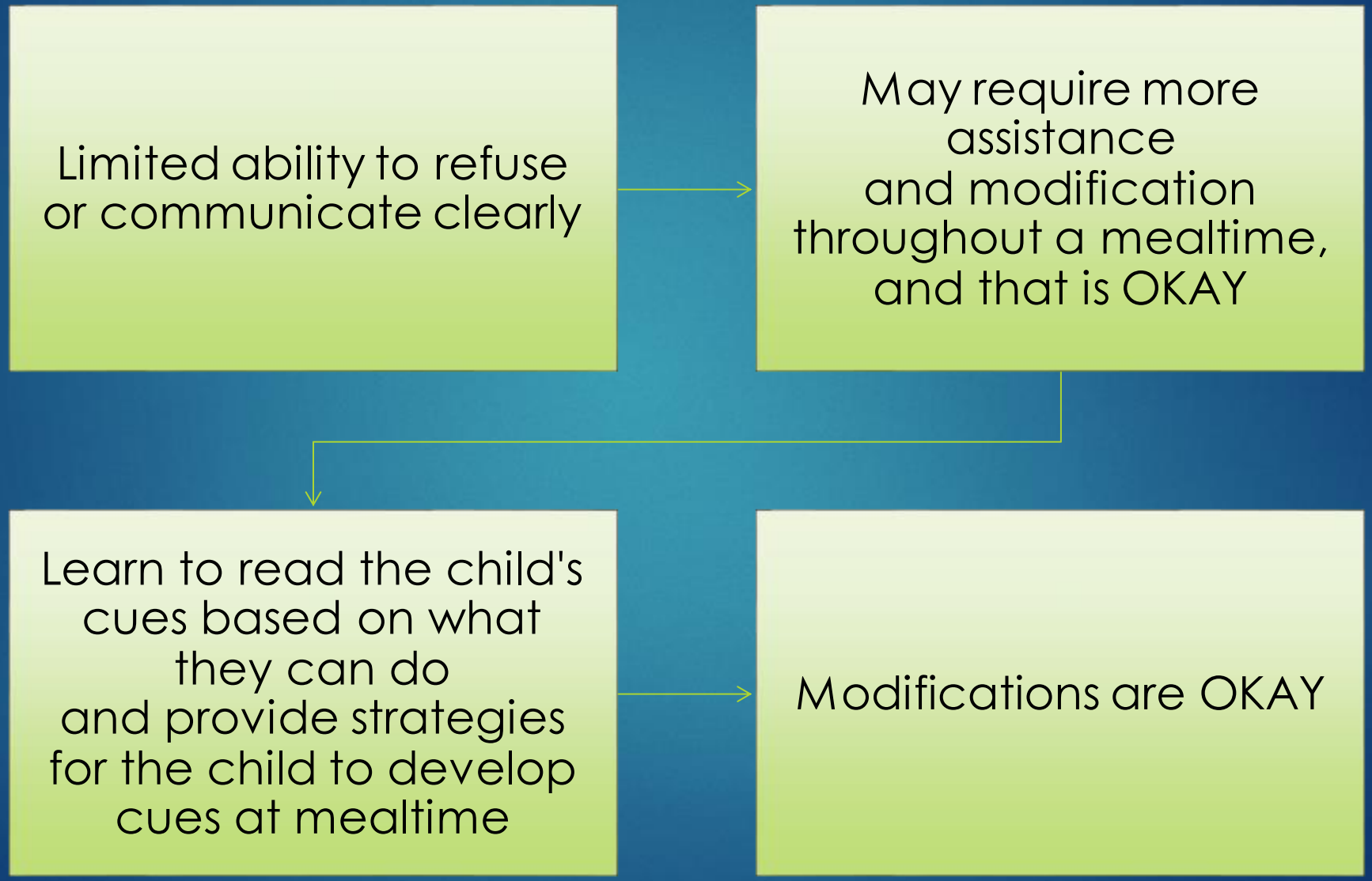
DoR in Children with Disabilities



Family Mealtimes

WHY ARE THEY SO IMPORTANT?

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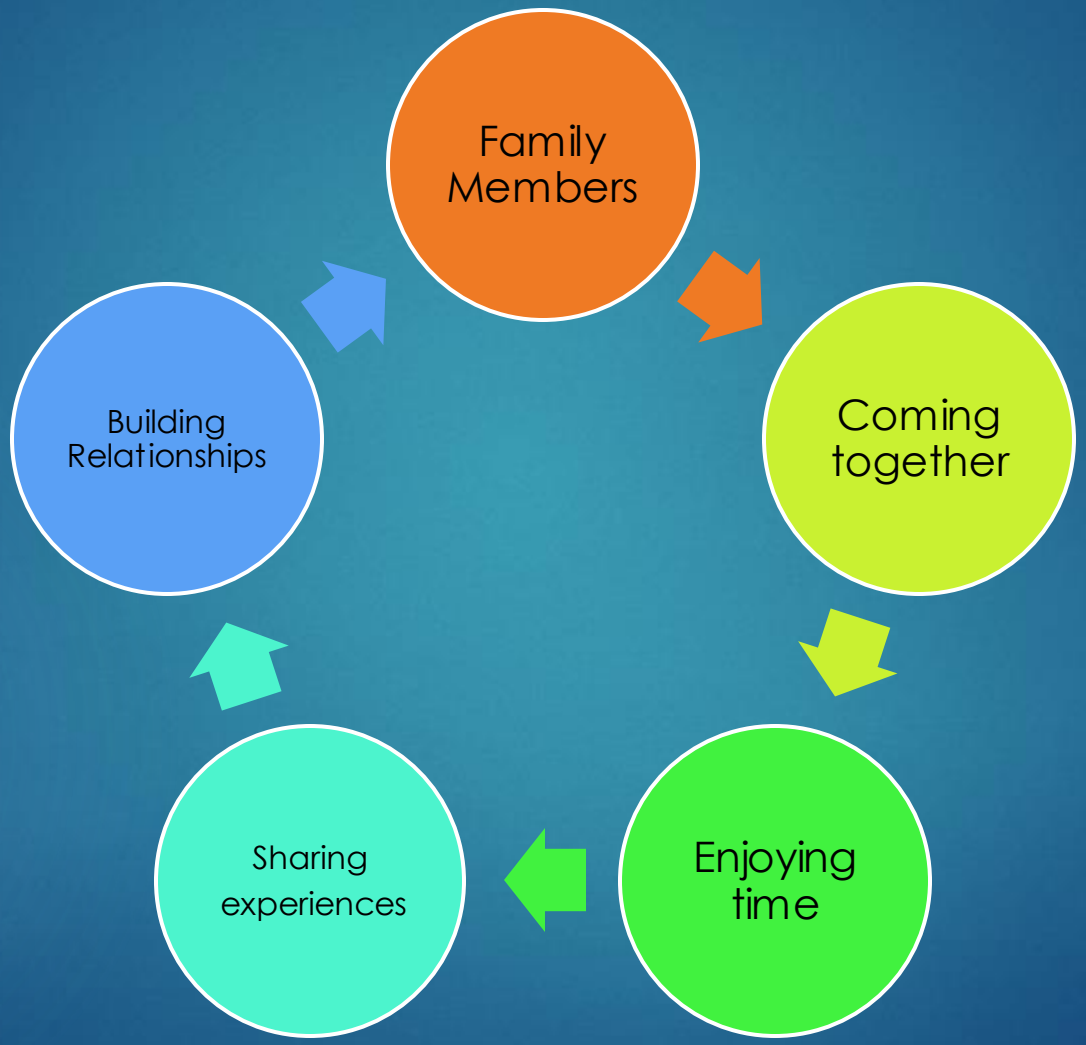
What is a family mealtime?



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Benefits of eating together

- Children who participate in family mealtimes have lower rates of substance abuse and depression, higher self-esteem, higher grade-point averages, and lower rates of obesity and eating disorders
- Watching parents and siblings eat, which research has shown to be the most powerful tool in the development of healthy eating habits.
- Children that feel safe and relaxed at the table are more likely to develop healthy eating skills and try again at future settings.
- Eating as a family reduces the pressure on the child who is working on any feeding difficulties.

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What does family mealtime look like for tube-fed children?

Tube-fed kids are usually included in the wrong part of meals or excluded all together

Adults want them to eat but their bodies are telling them otherwise

Negative effects of *pressure* leads to further damage to comfort and interest in food

- What *can* we do?
  - Give Space to explore
    - Reduce pressure
    - Respect refusal

IN TRYING TO BE HELPFUL, ADULTS TAKE ON MEALTIME PERSONALITIES THAT CAN HAVE UNINTENDED NEGATIVE EFFECTS…

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Sneaky stressors…..

The Mafia – Force feeding with a smile

The Rodeo Clown – Offering a distraction for every bite so they don't notice what you are really doing

Snake Charmer – Singing through the meal as if to hypnotize them into eating

Pushy Waiter - Hovering over the meal

The Voice-Over Narrator - Self-talking every bite in hopes of drawing attention to eating

Papparazzi – Cheering and taking pictures with every bite

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Home shopping Network Salesperson – Always displaying and showing food, utensils and plates, hoping that your child will suddenly want one.

Used Car Salesman - Talking only about food, the benefits of food, the tastiness of every bite.

Human Calculator (or actual calculator) – Keeping track of every single bite, gram and calorie.

PERFECTIONIST – failing to recognize and be satisfied with small attempts such as touching or tasting because they aren't as big or as varied or as frequent as hoped.

Bad First Date - Going straight to the mouth with the spoon without allowing an "introductory period"

Bad Date. Always. - Continuing to pressure after a child says (or communicates) "No."

Which one are you?

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For kids with disabilities…

THE SAME PERSONALITIES APPEAR, BUT IT FEELS *JUSTIFIED*

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What happens when we focus on family mealtimes?

Get back to the basics

- Shift focus away from oral motor challenges
- Functional skills vs. deficit

Why do we eat?

- Hungry
- Satisfied

What is a mealtime together?

- Conversation
- Enjoyment
- Learning
  - Cooking
  - Measuring
  - Cleaning
  - Organization and planning

Food

- Diet modification of real food a family eats,serves, and enjoys
- Model oral motor and feeding skills
- Natural motivators

We get happy, competent, healthy eaters!

The History of My Eating

by Evie Morse, age 11

Most kids can quickly be born and start eating grown up foods, but not me! My mom was very sick. The doctor demanded that she should have me now, and she'd survive. It was the only way. So I was born early, but it was worth it! I had trouble eating because of when I was born—on June 4, by the way. I had to eat by using a thing in my belly called a G-tube. (I don't know what the G is for, just so you know.)

When it was time to take the G-tube out, I did not want to. But somehow I was convinced to take it out anyway. But I still wanted something in that spot! Sure, it did not hurt to take the G-tube out but my parents suggested to put a bandaid in its place. We took the bandaid off more and more every day, so when it was time to take it off for good, I was less worried about it.

My parents took me to eating places all over the country that tried to teach me to eat. I started off with small food, but even that was hard for me. So one day, my parents took me on vacation to Virginia. In Virginia, there was a nice eating teacher named Brianna. Brianna suggested that it did not matter if I could learn to chew and swallow. All that mattered was if I liked the food. For the next ten days, we spent time in our apartment in Virginia, with Brianna coming for each meal.

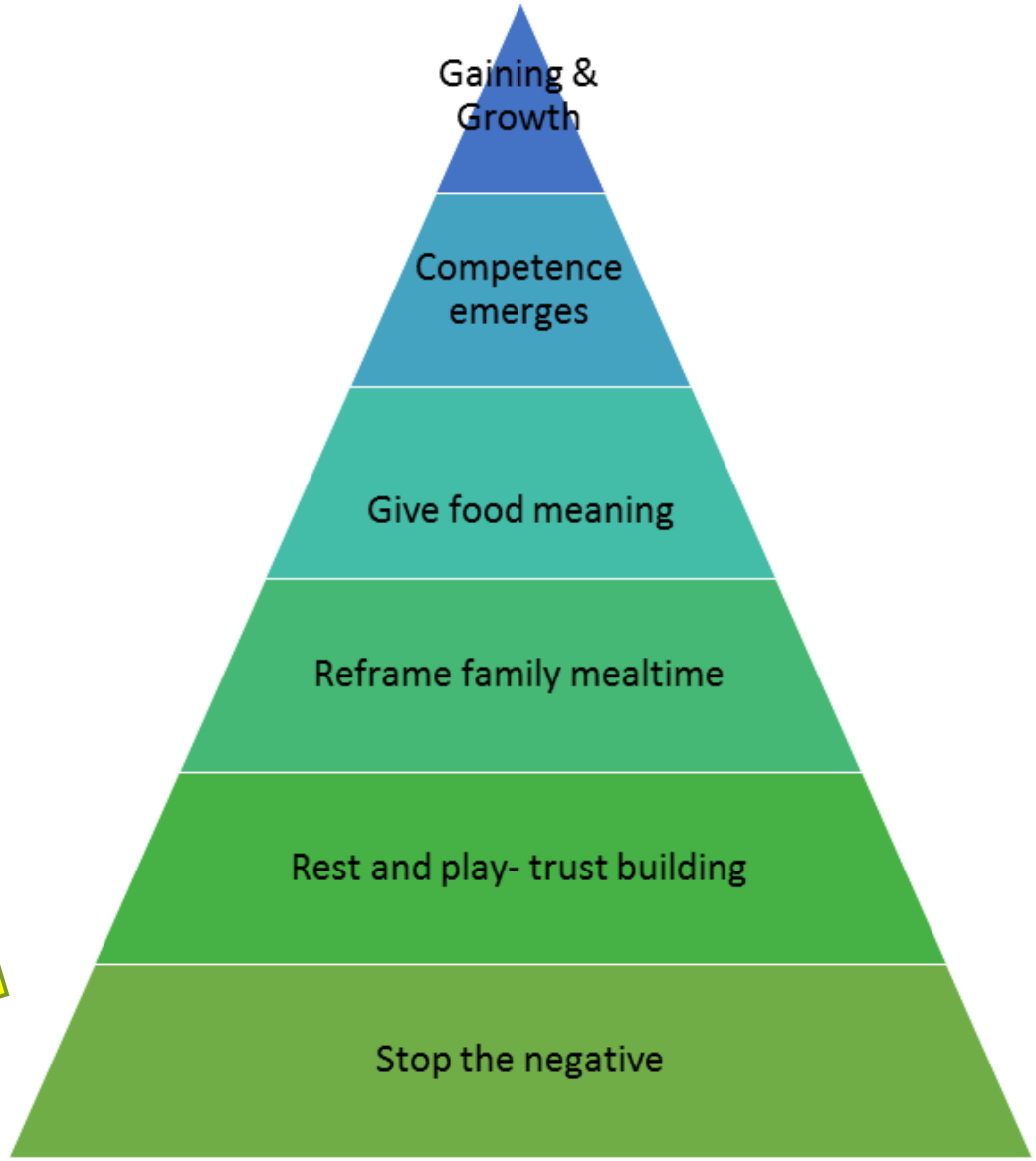
After ten days, I was better at eating. I got the hang of chewing and swallowing. I could eat solid food, but at school I had the same meal: blended up vegetables and yoghurt. So when I told my parents that I was ready to eat solid foods at school, too, they gave me notes that said what my new food was.

My favorite saying is "What are we havin'?" (said in a southern accent) when I come down from my room for lunch or dinner. My breakfast routine is fun, too, on the weekend. On school days, I have to get up and hurry to the van to my school. I hate being rushed. I eat oatmeal for breakfast and rush on school days.

But on weekends, I'm much happier. The day starts off lazy, and so do my parents. I watch videos with the sound down while my lazy parents sleep. And then what do we have for breakfast when my parents wake up? Oatmeal. Because there's more time, I can chillax and drink my juice and milk upstairs on the bed. I drink out of a plastic bottle called a squeeze bottle. A squeeze bottle is a plastic bottle that is squeezable. You put a blue top with a hole in it on the opening in the bottle. Then put a straw in the hole. When I squeeze the bottle, the liquid in the bottle goes up the straw and into my mouth. That is, unless there's a hole in the straw! Can you guess what happens then? Yep. It spills everywhere.

I can eat bread, too. I can eat sandwiches, hamburgers, and hot dogs. I love spicy food too, like Thai food. So can you even believe that I used to have to eat with that G-tube? I'm so glad I can now experience the tastes of things. So, parents, if you have a kid struggling to eat, have them read this story. You could even go to Virginia to visit Brianna!

Treatment goals began with the basics



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Specific Goals in 3 Main Areas

- Hunger/Self Regulation:
  -
  -
- Division of Responsibility:
  -
- Family Mealtimes:
  -
  -

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History for A:

- Born at 36 weeks, Down Syndrome and complete AV canal defect diagnosed at birth
- NG Tube placed at birth, G tube at 5 weeks old
- Post heart surgery, diagnosed with laryngomalcia and reflux with vomiting 10x per day
- Hospitalized 2 more times due to other surgeries
- Continued with G-tube dependence due to poor weight gain and increased oral aversion

A Before Intensive Treatment

- Required max prompting and distractions to place anything towards her mouth
- 100% tube-dependent for nutrition/hydration/medication
- Had been sitting at mealtimes for 1-2 minutes (until therapy started) had begun throwing fits at table attempts
- Fearful of food coming towards her mouth
- No clear relationship or association with food and satiation (tube dependent since birth)
- Her biggest strengths were independence and self-protection

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A: Treatment Progression

Hunger/Self Regulation:

- Hunger initially helped with interest and initiation
- Needed to feel very hungry at first to see a change in volume/initiation

Division of Responsibility:

- Coached parents through identifying A's jobs as a toddler and their jobs as parents at mealtimes

Family Mealtimes:

- In a clinic, 1 on 1, A had no interest in eating or any food towards mouth
- At the family table, with her parents or siblings, A began to observe what they were doing.

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A in Action

- Since her intensive treatment….
- A has been off her g-tube supplementation for 4 months
- Eating various tastes and continuing to work on increasing textures and variety
- She loves peanut butter, banana, and whatever her siblings are eating!
- Working on mealtime communication
- Working on drinking to maintain hydration

History:

- Preterm infant 2,500 or more grams
- Omphalocele (Repaired)
- Chromosomal microdeletion syndrome
- Chronic respiratory disease
- Reflux
- Atrial Septal Defect (ASD) (Repaired)
- Patent Ductus Arteriosus (PDA)
- History of tracheostomy (Repaired)
- Autism
- NG and then G-Tube from birth

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Treatment for M

- Sat with her family at occasional mealtimes
- Refused by turning her head and closing her mouth if any food was offered by adults
- Tasted food out of novelty or exploration
- Mainly very small licks of purees
- Wipe all tastes from her mouth using her hands
- Drool to avoid food being swallowed
- Progressed to eating in the dark with music

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M Goals and Progress

Hunger/Self Regulation:

- Hunger helped with interest and initiation
- Bigger licks of purees, increased attention at meals
- Swallowing, starting with pacifier or spoon to initiate

Division of Responsibility:

- Adult focus: diet modification, schedule,and repetition of foods offered
- Help with spoon scooping but allowing full independence with spoon to mouth

Family Mealtimes:

- Desire for more independence led to fast transition to solid foods
- Increased attention span resulted in more time spent at the table with her family

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M in Action

- Since her intensive treatment....
- M has been off her g-tube supplementation for 2 months
- She loves and asks for Wegman's pizza, chocolate, and muffins
- Chews with greater control to eat fruit chews, pretzels, and raw fruit and vegetables
- Working on drinking to maintain hydration
- Working on mealtime attention
- Working on biting

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E

17 months

Chromosome Deletion only one other case known

NICU for 8 days after birth

Hypotonia

Drinking initially, FFT at 4 months with a decline in drinking

- Laryngomalacia diagnosed
- SSB discoordination, with no aspiration
- NG at 4 months, G tube at 6 months (poor tube tolerance)

Vomit after tube feedings, oral stopped. Blended diet ended vomiting, but oral did not increase.

Not walking, not talking, no interest in oral feeding

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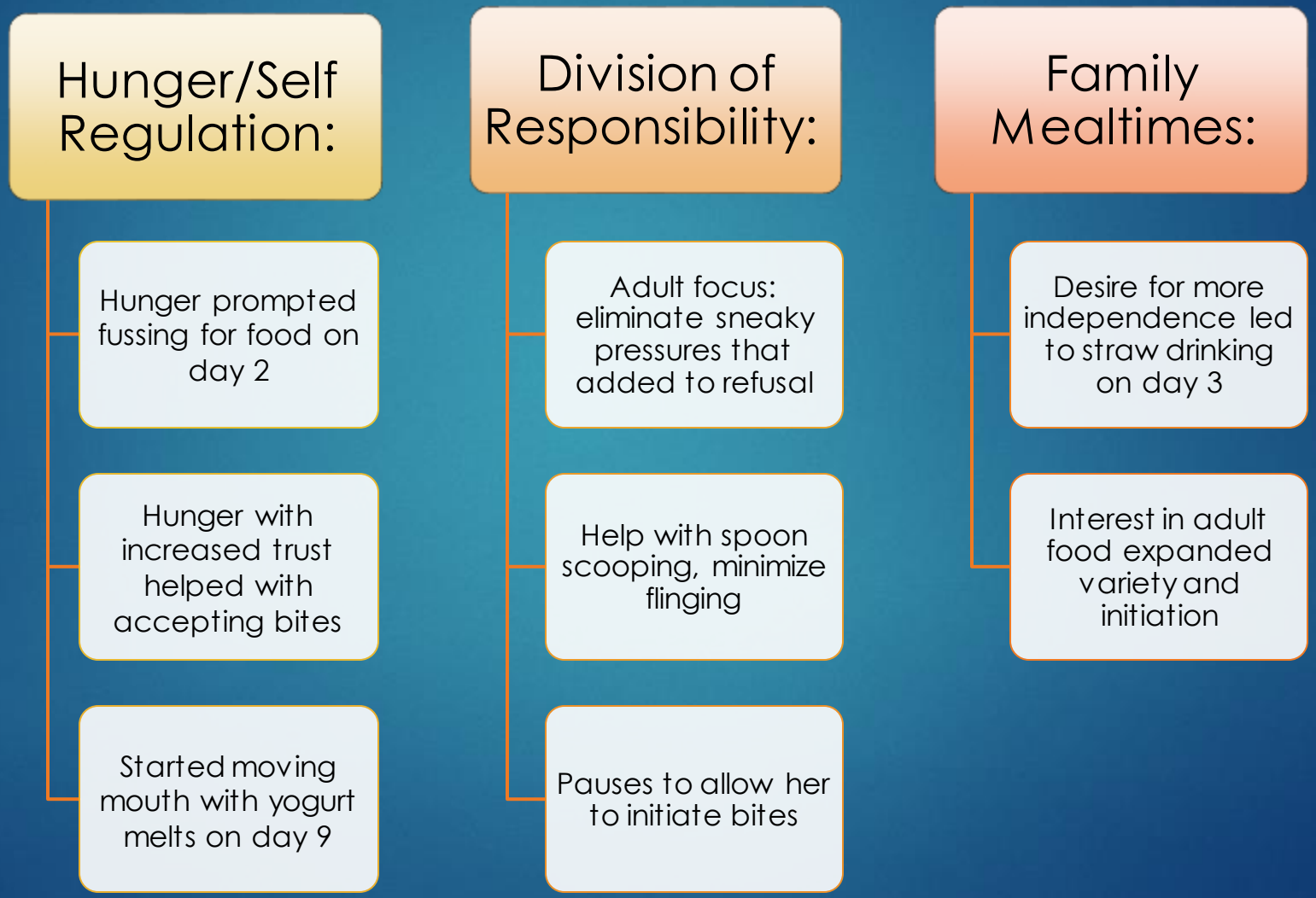
E during treatment



E in Action

- Since her intensive treatment....
- Has not used her tube for 2 months.
  - Used tube for 3 weeks after treatment due to concerns regarding extra work and low tone. Weight picked up after g-tube use was discontinued.
- Family has to keep their food out of her reach or she will try to eat it
- "Obsessed" with yogurt melts
- Working on chewing new foods one at a time, has added banana and working and orange slices
- Working on cruising

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Division of Responsibility for Therapists

- It is *NOT* my job to:
  - Make children eat
  - Create perfect mealtimes (vegetables always eaten, no whining)
  - Fix the past
  - Predict the future
  - Be a GI doctor, psychologist, teacher, social worker
  - Guarantee insurance coverage

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It *is* my job to:

- Develop a relationship with the child and family
- Practice and model empathy for the child's point of view
- Support the family as they develop their role as parents rather than responders or "forcers"
- Understand development and developmental progression
- Apply appropriate developmental strategies to the current situation
- Facilitate and support communication between child and family (including interpreting child's behavior for the parents)
- Provide a normalizing influence to meals
- Provide opportunities for parents and children to heal from the past so they can face the future
- Direct them towards providers/resources for problems that are not mine to fix
- Model appropriate boundaries – If we don't respect our own boundaries, how can they?

Your Division of Responsibility

- MY JOB
- NOT MY JOB

Photo Sources

- Tough girl http://soiguessiblog.blogspot.com/2010/12/one-tough-little-girl.html

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