Children's Hospital LOS ANGELES | USC University of Southern California

Engaging Families to Support Pediatric Feeding Interventions

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Introductions

- Who are you?
  - Practice experience?
  - Current practice setting?
  - Working with feeding clients?
  - Including families in care?
- Who are we?
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Agenda

- Background on Pediatric Feeding Disorders
  - Complexity of the problem
  - Impact of PFD on families
- The WHAT/What is the barrier?
  - Gap in addressing complexity of feeding challenges
  - Systems of Care- OT Scope of Practice
  - Culture of Occupational Therapy Service Delivery
- The HOW/How can we work through these barriers?
  - Skill-building
  - Ideas for changing culture of care

Objectives

- Objective 1: Participants will be able to describe the importance of incorporating caregivers into feeding interventions.
- Objective 2: Participants will be able to identify practical strategies for caregiver involvement that can be applied to feeding interventions across ages and settings.
- Objective 3: Participants will be able to problem solve barriers to incorporating caregivers into feeding interventions.

What is the problem?

OVERVIEW OF FEEDING NEEDS

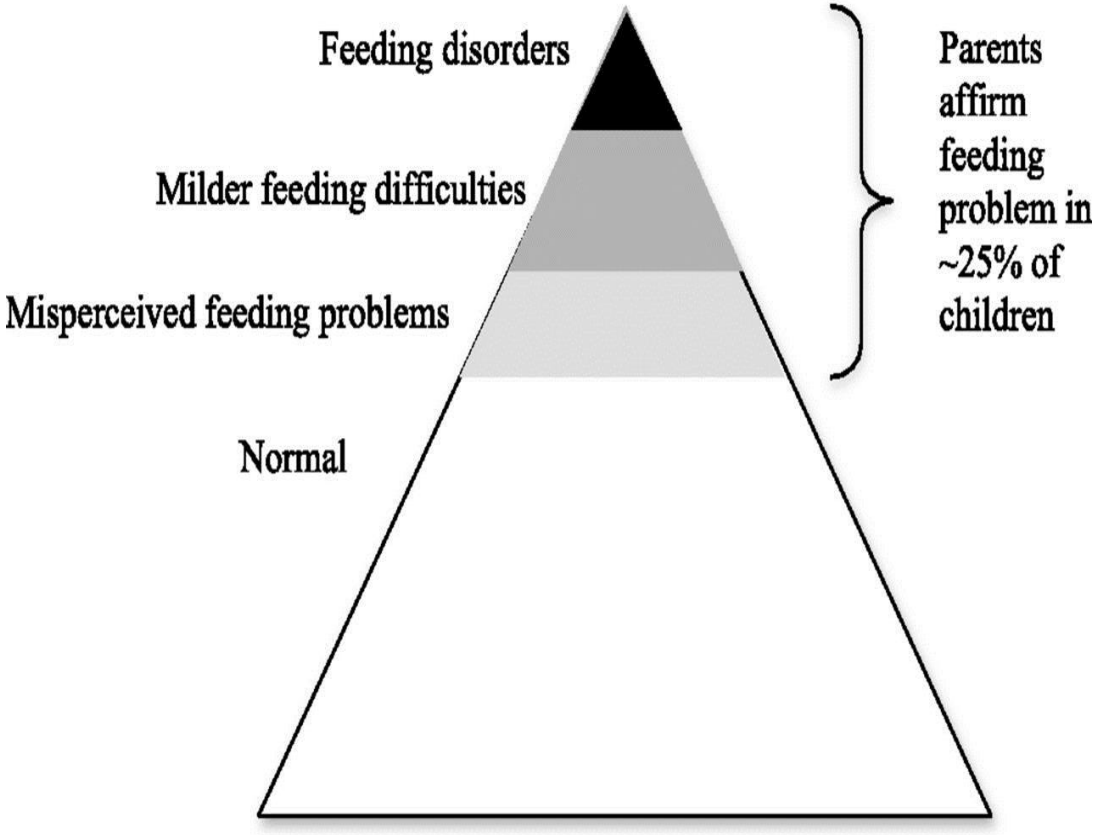
Common Reasons for Referral

- Failure to thrive
- Difficulty chewing
- Concerns/history of choking
- Trouble with specific textures (transition to solids, only accepts purees, refuses meats)
- Picky eating
- Difficulty with self-feeding
- Stressful mealtimes
- Refusing to eat
- Mealtime behaviors
- Gagging/vomiting with foods
- Difficulty staying at table
- Etc.

Overview of Feeding Needs

Prevalence

- Feeding challenges affect up to 25 % of typically developing children (Aviram et al., 2016)
- Up to 83% of children with ASD (Postorino et al., 2015)
- Pediatric Feeding Disorder (PFD) national prevalence study: 1 in 23 have PFD; 1 in 37 under age 5 (Kovacic et al., 2020)



(Kerzner et al., 2015)

Pediatric Feeding Disorder: Consensus Framework

- Feeding is a complex, multi-factorial process
  - Medical Factor
  - Nutritional Factor
  - Feeding Skill Factors (OT/ST)
  - Psychosocial Factors
- Impairment in one area can lead to dysfunction in other areas
- Many providers involved
  - Need for consistent terminology—pediatric feeding disorder

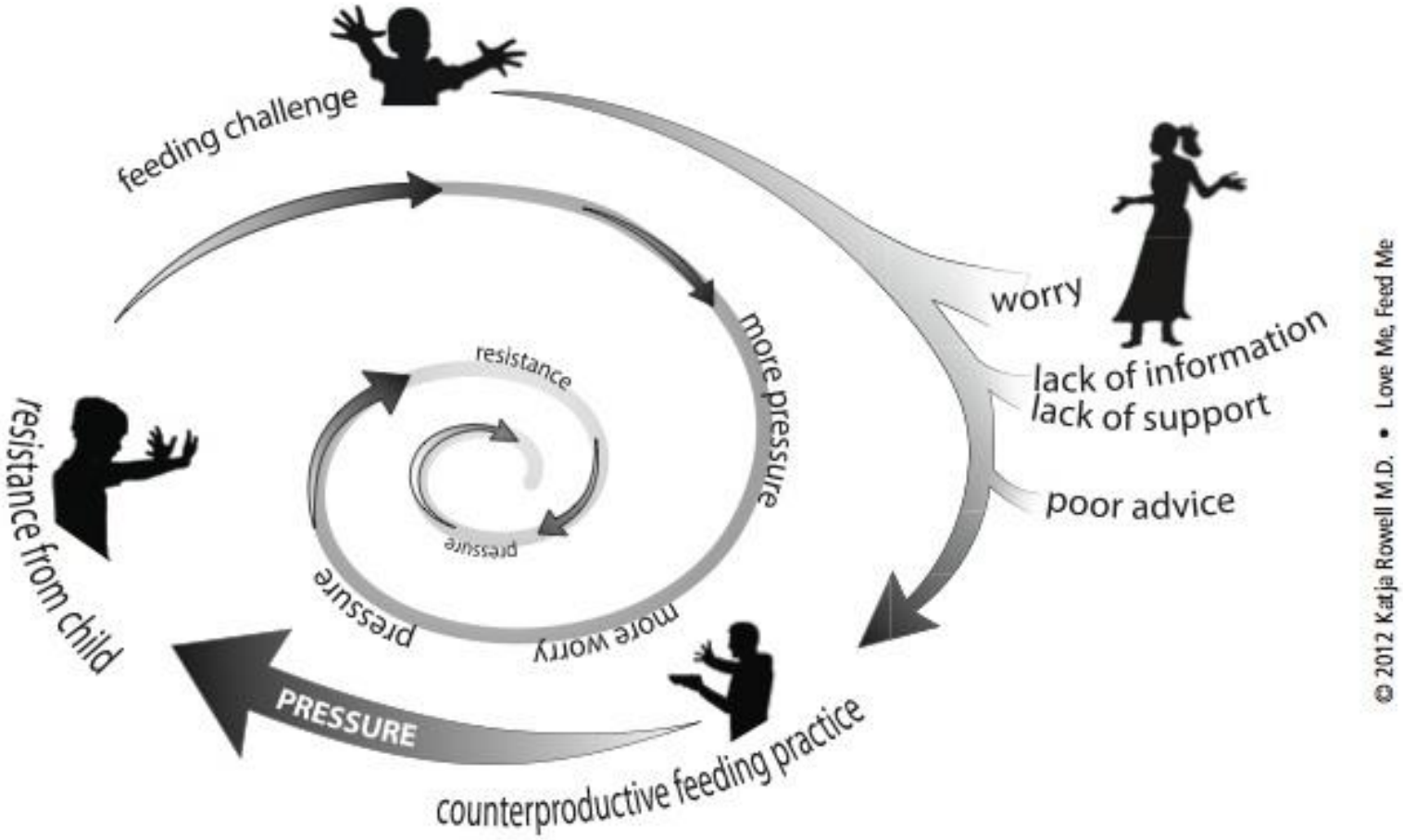
(Goday et al., 2019)

Parental Stress and Anxiety

- Higher level of behavioral feeding problems across diagnoses:
  - Autism - Cerebral Palsy
  - Eosinophilic Esophagitis (EoE) - Type 1 Diabetes
  - Food Allergies - Gastronomy Tubes
- Parents Report Stress related to:
  - Not being able to share burden of feeding with other caregivers
  - Impacting sleep, food preparation
  - Fear of not having what they need/something is unsafe
- Measures Incude:
  - Parent Stress Inventory (PSI)
  - Life Participation of Parents (LPP)
  - Quality of Life Measures (QoL)
  - Qualitative Research

Aviram et al. (2014), Brotherton, Abbott, & Aggett, (2007), Curtin et al. (2014), Fingerhut (2013), Kajornrattana et al. (2017) & Wu et al. (2012)

Parental Stress and Anxiety



(Rowell & McGlothlin, 2015)

Parent Confusion??

- So complex
- Many providers
- Many opinions
- Conflicting information
- Limited communication/coordination of care

What is the barrier?

THE WHAT

Small Group Activity

Move to the area you most identify with:

1. I don't include families in sessions, I provide them feedback after I work with the child

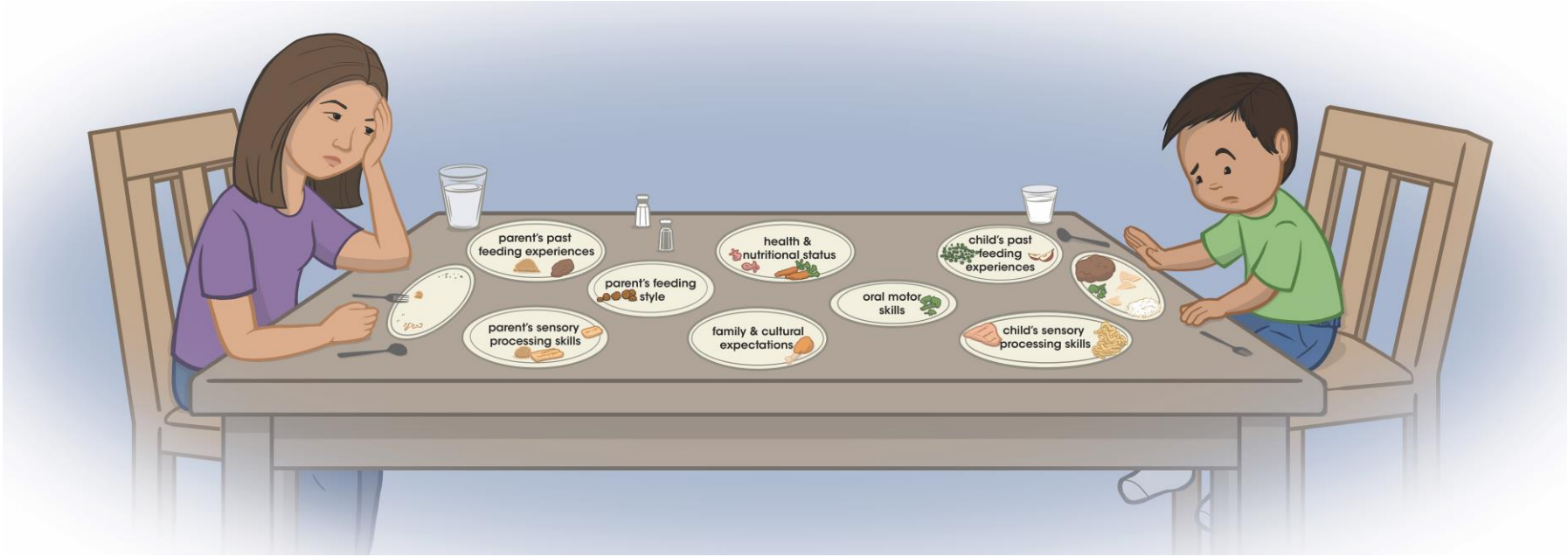
2. I try to show parents strategies but sometimes they don't seem to understand, or seem to but when I return the next session, the have not done any of the home program I recommended

3. I work with families and bring them into sessions and have good ideas in how to get them to implement what I am recommending

Barriers Discussion

- Why do you include families at the level you include them?
- What would help you include them more?

Parent and Child Mealtime Factors



Psychosocial Factors

Psychosocial Restriction (Health Conditions and Problems*)	Impact on Feeding Behaviors

Developmental (child and/or caregiver)
• Delay
• Disorder
Mental/Behavioral Health (child and/or caregiver)
• Diagnosed disorder
• Undiagnosed signs/symptoms of disorder
• Deregulated temperament/personality characteristics
Social
• Caregiver-child interaction problems
• Cultural expectations are not commensurate with AAP nutrition guidelines
Environmental
• Disorganized/distracting feeding environment
• Disorganized or poorly timed schedule of feedings
• Access to food or other necessary resources
• Inadvertent reinforcement of food refusal behavior
	• **Learned aversion (child and/or caregiver)**
	• **Stress/distress (child and/or caregiver)**
	  • Caregiver disengagement
	  • Caregiver over-engagement
	• **Disruptive behavior**
	  • Food refusal (passive & active resistance)
	  • Gagging/vomiting
	  • Elopement/attempts to disengage or flee from meal
	• **Food over-selectivity**
	• **Failure to advance to age-appropriate diet or feeding habit despite adequate skill**
	  • Reliance on formula beyond expected chronological age
	  • Failure to consume age-typical texture
	  • Not feeding self at age-typical level
	• **Grazing behavior**
	• **Caregiver use of compensatory strategies to feed child**

Legend: * International Classification of Functioning, Disability, and Health (ICF) terminology; AAP: American Academy of Pediatrics

(Goday et al., 2019)

Barriers to Including Families

- Parents' own picky eating and difficulty modeling new foods
- Parents' tolerance for messy play (or messes)
- Parents' difficulties picking up on playfulness with foods
- Parents offering rewards or consequences without consulting therapist (doesn't jive with feeding approach)
- Parents are often distracting or anxious during mealtimes, put pressure on children that therapist would not
- Parent/child dynamic around food is so stressed, helpful to work on food first, relationship later
- Parents' anxiety around getting child to eat; difficult to manage simultaneously with child's anxiety/behaviors/skills
- INCLUDING PARENTS IS HARD!! MAKES THE WORK HARDER!!

Additional Potential Barriers

- Is it in my scope?
- Is it in my skillset?
- Can I manage all of the pieces?
- Will my employer/colleagues allow or accept this?
- Will insurance reimburse this?

Is this in my scope?

"**Caregiving** is a **co-occupation** that requires active participation by both the caregiver and the recipient of care. For the occupations required during parenting, the socially interactive routines of eating, feeding, and comfort may involve the parent, a partner, the child, and significant others." (Olson, 2004 as cited in OTPF-4, 2020, p. 9)

Family participation: Engaging in activities that result in "interactions specifically required and/or desired familial roles" (Mosey, 1996, as cited in OTPF-4, 2020, p. 34)

Intervention type: Education

"Imparting of knowledge and information about occupation, health, well-being, and participation to enable the client to acquire helpful behaviors, habits and routines" (OTPF-4, 2020, p.61)

OT Skills & Strengths

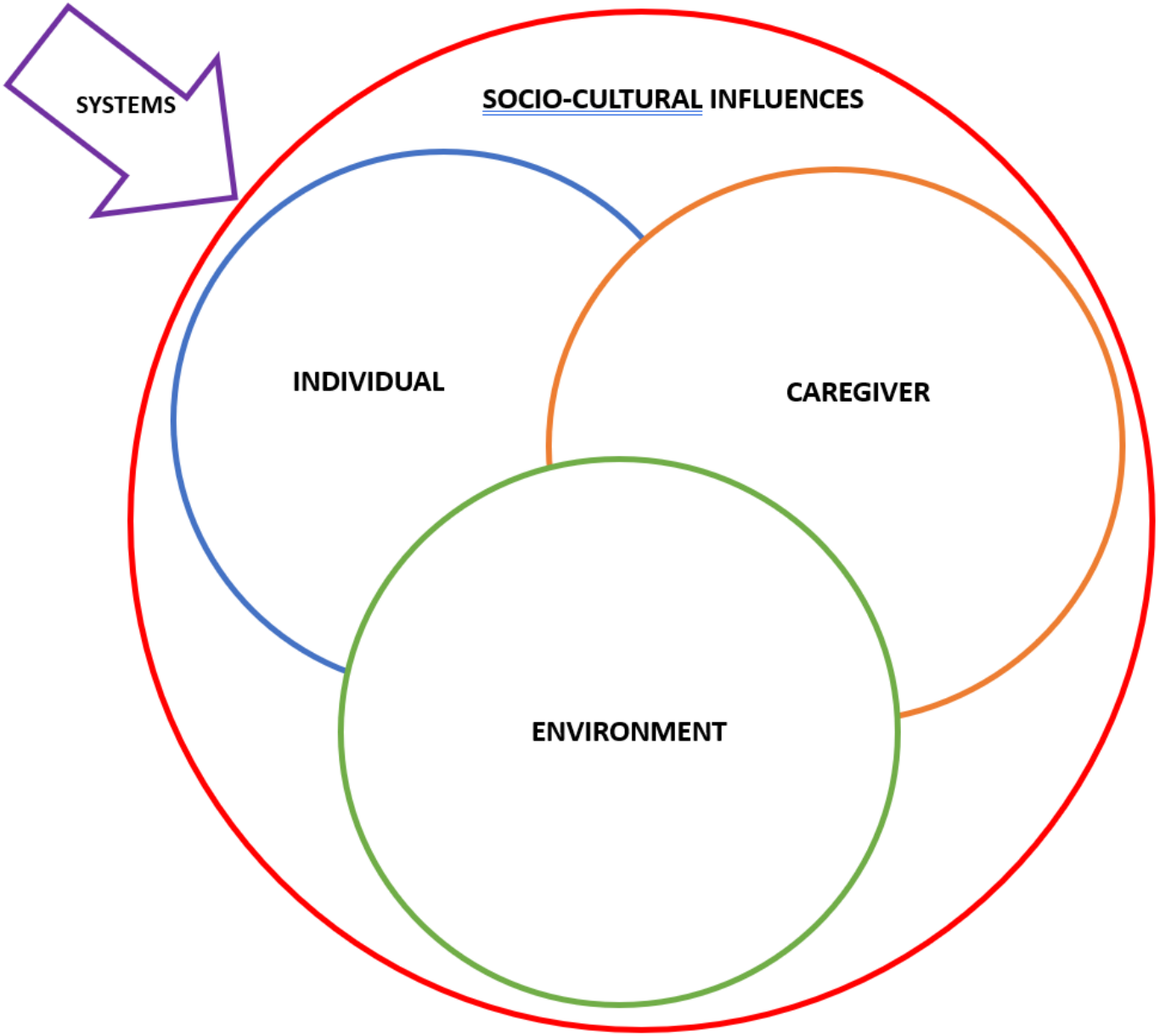
- Holistic perspective
- Understanding of all domains
- Strengths-based
- Communication skills

OT Culture

- Traditional models of seeing clients alone
- Leverage home programs
- Educate on areas of need
- Time limited sessions/insurance limits
- Goals are client-focused

Popular Traditional Feeding Approaches

- Sequential Oral Sensory (SOS) Approach to Feeding (Kay Toomey, PhD)
- Beckman Oral Motor Assessment & Intervention (Debra Beckman, MS, CCC-SLP)
- Get Permission Approach to Pediatric Feeding Challenges (Marsha Dunn Klein, MEd, OTR/L, FAOTA)
- Behavior Modification Approaches
- Food Chaining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IMPORTANCE OF INCLUDING FAMILIES

Family-Centered Care

Basic Tenets of Family-Centered Care:

- Adopting a social systems perspective
- Placing the family as a unit of intervention
- Empowering families
- Promoting growth-producing behavior rather than treatment of problems
- Focusing on family-identified needs
- Building upon family's capabilities
- Strengthening the family's social network
- Expanding professional roles and the way the roles are performed

(Dunst, Trivette & Deal, 1994)

Family-Centered Care

*"….**taking time to just be together is a critical and meaningful aspect of family occupation**. Therefore, a family unit is more than a unit engaged in doing. As practitioners, we need to understand **who the families want to be** and **how they can engage** in meaningful experiences together. I believe this is the core of family-centered care and meaningful occupation-based practice."*

- DeGrace (2003) p.348

How can we better embed caregivers in our intervention?

THE HOW

Key Principles

- Intentional Communication
- Hold the complexity of the problem and the solution
- Support Regulation & Co-Regulation
- Support Reflection
- Scaffold & support skill building for both caregivers and clients

Intentional Communication

Model empathy and compassion

- Get caregiver's perspective and interpretation of child's behavior or skills
- Strive to understand the caregiver's experience of the child's feeding
- Keep a strengths-based approach
- Ask caregivers what they are hoping for
- Parallel process
  - Model this for family—narrating
  - Apply this to family—have empathy
- Strive to understand the child's experience of feeding and help caregivers understand this
  - Child's sensory processing will change
  - Kids are allowed to have hard days!

Partner with Families

- Set the expectations for family participation from the start
  - This is the family's time (not just the child)
  - Recognize that you are treating the family occupation of mealtimes… and allow your sessions to reflect that
  - Have a clear plan for food responsibilities

- Explicitly discuss your roles before you get started
  - Where will you sit? Where will the caregiver sit? Who will feed the child? What will you do? What will the caregiver do?
  - How can you structure the session to increase the caregiver's feeling of confidence and sense of competence with feeding their child?

Explain What and Why, and Repeat Often

- Frontload intervention with parent-focused sessions to ensure adequate explanation and understanding—this can take time!
  - explain approach/model and its relevance
  - Give realistic expectations for progress
  - Stages of Progress:
  1. Less Stress
  2. Increasing Comfort
  3. Greater Confidence

  (Rowell & McGlothin, 2015)
- Help make connections in session
  - Explain scaffolding and rationale for strategies used—it's not common sense!
  - One day it will click!
- Include education across feeders
  - In-person or using visuals or handouts
  - Consider each learning style, literacy level

Hold the complexity of the problem and solution

Activity

Model Vulnerability

- Get comfortable with not being the "fixer"
  - Traditional question from parents:
    - "Why do you think he doesn't want to eat?"
    - Expect therapist to have all the answers
  - If you answer too confidently or concisely, it can minimize the complexity of the challenges

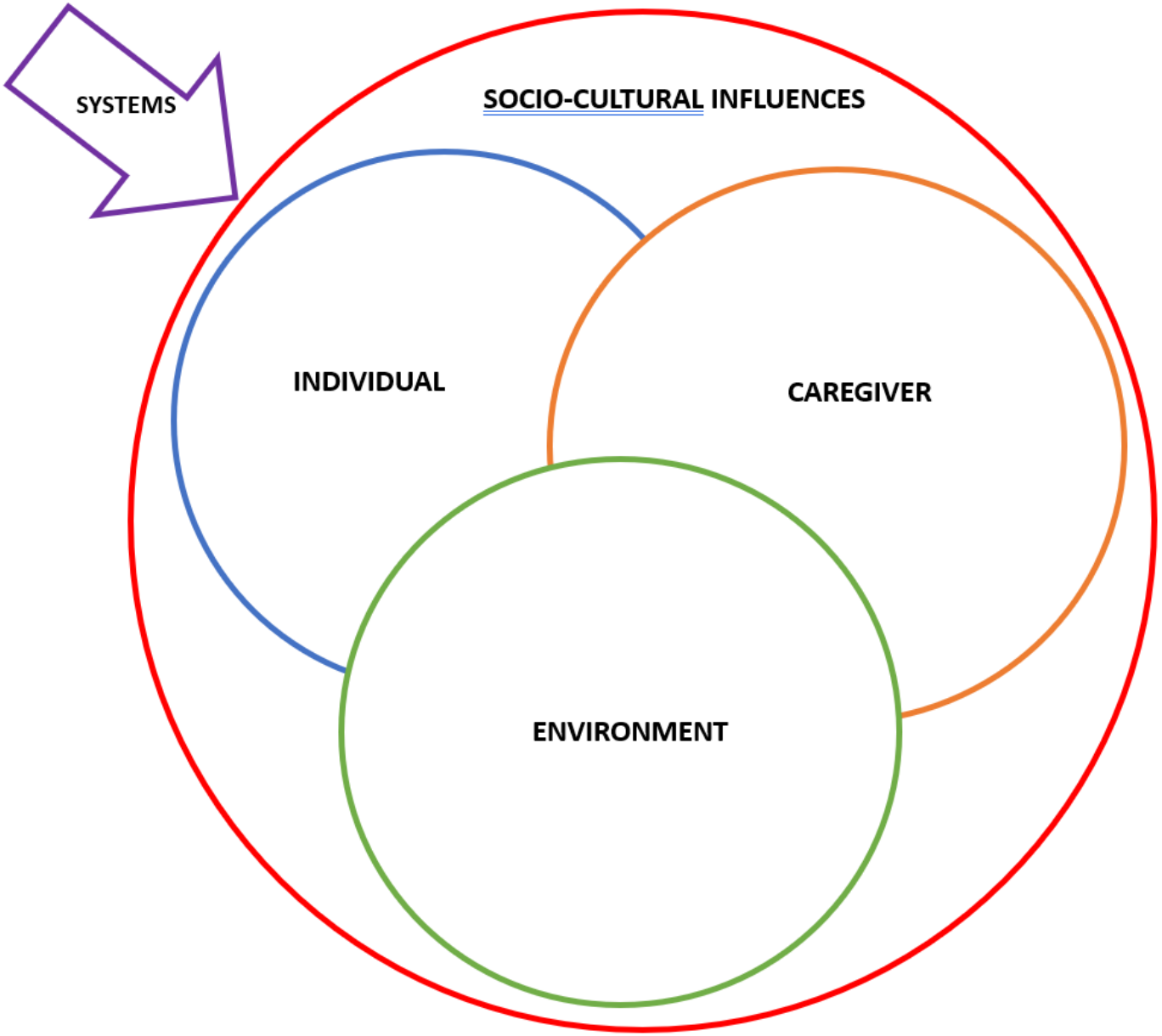
    "It's sensory...."

    "He just needs to learn how to chew"

Model Vulnerability

- The power in learning together
  - Be ok with not having all the answers
  - "I don't know, let's find out together"
    - Allows parents to be expert on child
    - Reinforces caregivers as essential players
    - Embraces the complexity of the challenge and the solutions

Are you seeing the photo album?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Support regulation and co-regulation

Support Sensory Regulation

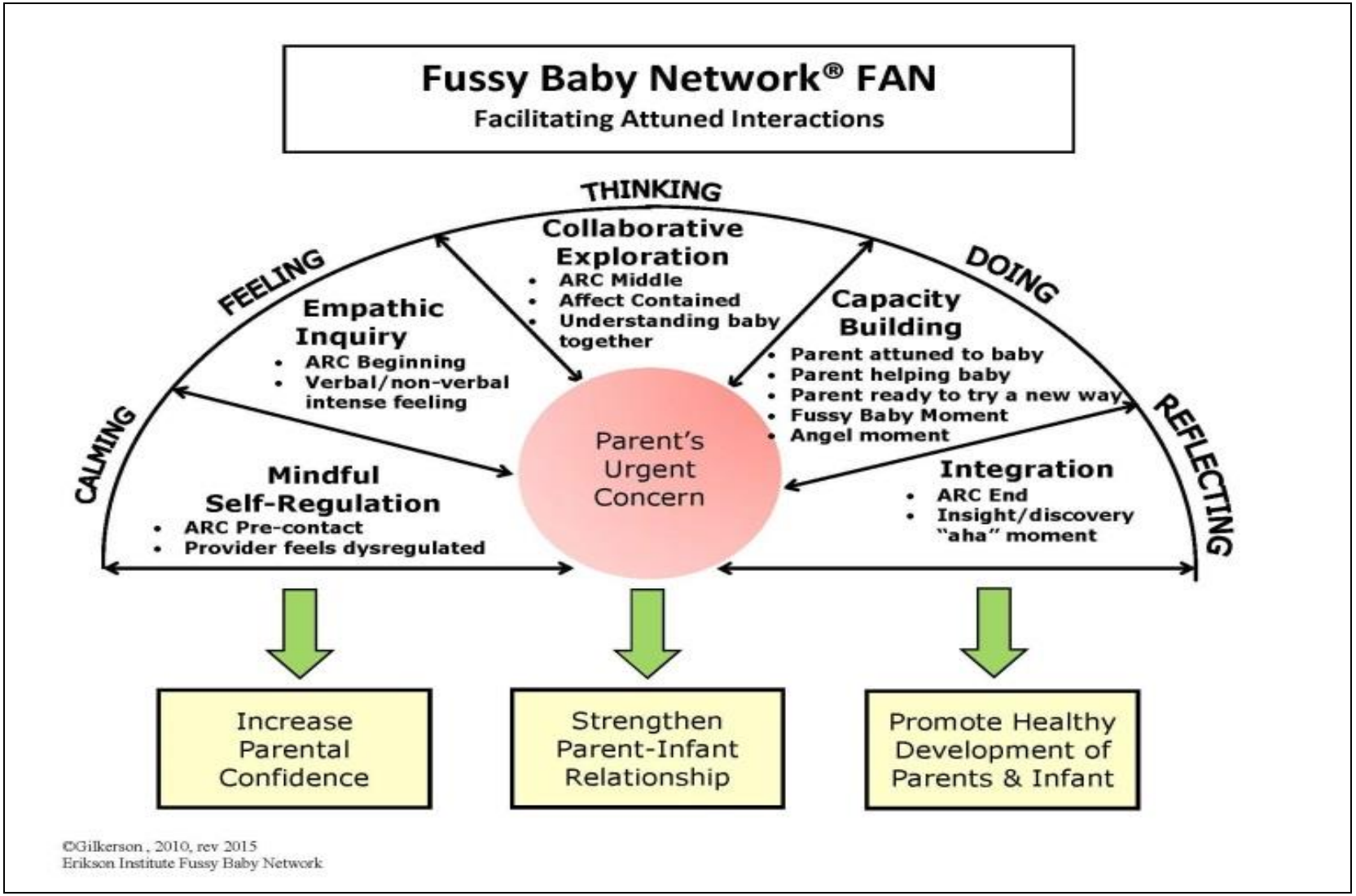
Support Regulation and Co-Regulation

- Model regulation—coming calm and prepared
  - Be present—center yourself before the session to be present to engage the family
- Continue to practice and model calming strategies
  - Deep breaths
  - Taking a break
  - Cognitive strategies
  - Sensory strategies
  - Environmental adaptations
- As OTs, give yourself permission to spend as much time on regulation in the sessions as needed (for parent and/or child) before moving on – this is the therapy
- Strive for everyone to be calm for end of session to have positive associations with feeding therapy → better carry-over

Support the Parent's Regulation

- Notice
  - Closely observe the parent's responses
- Empathize
  - To create safety
- Narrate
  - To increase awareness
- Reflect
  - To identify triggers and learn from responses in past experiences
- Praise
  - Efforts and attempts to cope with big feelings

Support the Parent's Regulation



Support Co-Regulation Between the Parent and Child

- Notice
- Empathize
- Narrate
  - Help the parent notice and understand the "why" behind the behavior to allow the caregiver to be present to co-regulate
    - Use narration to model and scaffold reading cues
    - Support with interpretation and attributions to behavior
    - Be the voice for the actions and the "why"
  - Model being the child's voice… then allow the parent to take on that role
- Reflect
  - Reflect on sessions, child's responses, caregiver's experience
  - "I wonder…" "How was that for you?" "What was it like for you when ____" "What do you think it was like for him when ____"
- Praise
  - Efforts to stay calm and to co-regulate
  - Increase caregiver's sense of confidence to co-regulate their child

Support Reflection

Ask Intentional Questions

- Bring reflection into the OT sessions
  - Explore parents' childhood feeding stories & note experiences that created joy or displeasure
  - Ask parents about their early feeding experiences with their child
  - Ask parents what they learned from their parents about feeding
    - What were the rules?
    - What did they bring into their parenting?
    - What do they want to do similarly or differently?

Reflective Activity

Ask Intentional Questions

Sample reflective questions:

- <u>Assessment:</u>
  - Why do you think she is _____?
  - What do you think it is like for them when _____?
  - What is your experience during mealtimes?
  - What is it like for you when ____?
  - How would you like mealtimes to look?

Ask Intentional Questions

Sample reflective questions (cont.):

- Treatment:
  - What did you notice about her response when you _____?
  - Why do you think he smiled right then?
  - What do you think it is like for them to _____?
  - I noticed you paused when feeding him. What did you see him do that made you think to stop?
  - How does she tell you that she is all done?
  - What do you think would happen if _____?
  - What helps him calm down?
  - In what way does it bother you when _____?

Self-Reflection

- Reflect on your own experiences with food and feeding.
- Reflect on your experiences as a therapist, your training, your successes and failures and how they may impact how you support families.
- Reflect on any biases.

Four Domains

feeding matters

Pediatric Feeding Disorder: The Four Domains at Work

MEDICAL

Screens for and manages medical conditions which may be contributing to feeding difficulty, assesses for safety to initiate the intervention, and addresses new medical needs which arise via medical testing, medication management, referrals, and coordination of care.

FEEDING SKILL

Focuses on building feeding, eating, and swallowing skills needed for functional mealtime participation, including mechanical and nutritive oral-motor coordination for mastication and control of solid and liquid boluses. Also assesses swallow safety, works toward normalization of intra and peri-oral sensitivity (e.g., reduced gagging), advances diet texture in meals, modifies seating and positioning for safe feeding practice, and promotes self-feeding skills.

PSYCHOSOCIAL

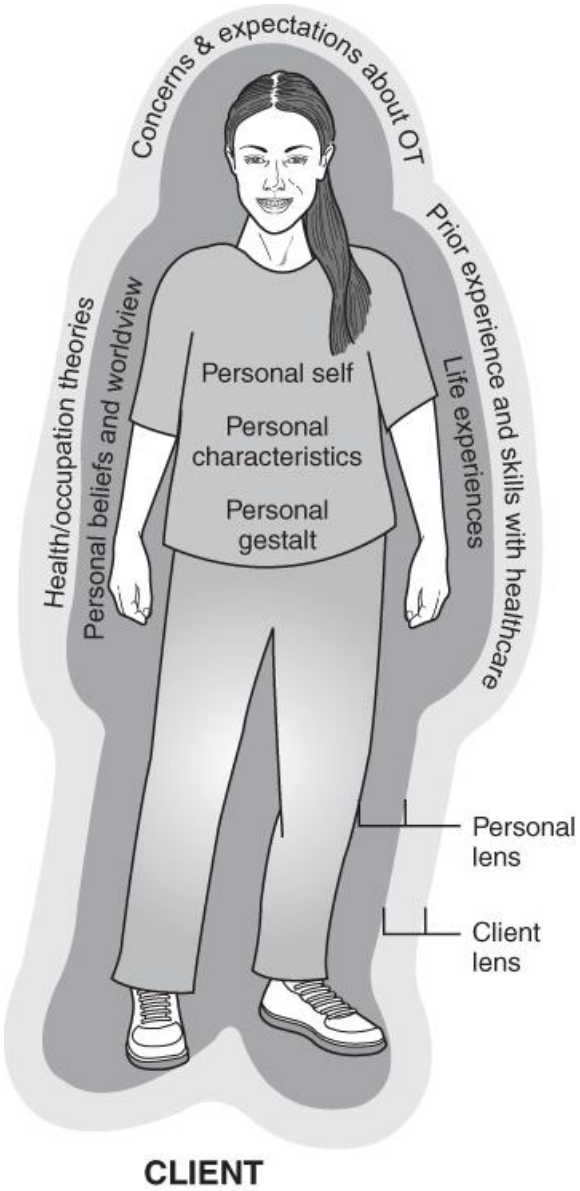
Focuses on improving child mealtime behaviors, modifying parent-child interactions during meals, and enhancing caregiver management approaches with the goal of the child developing a positive relationship with food. Systematically introduces exposure to new foods and conducts caregiver training to support generalization of skill into the home setting.

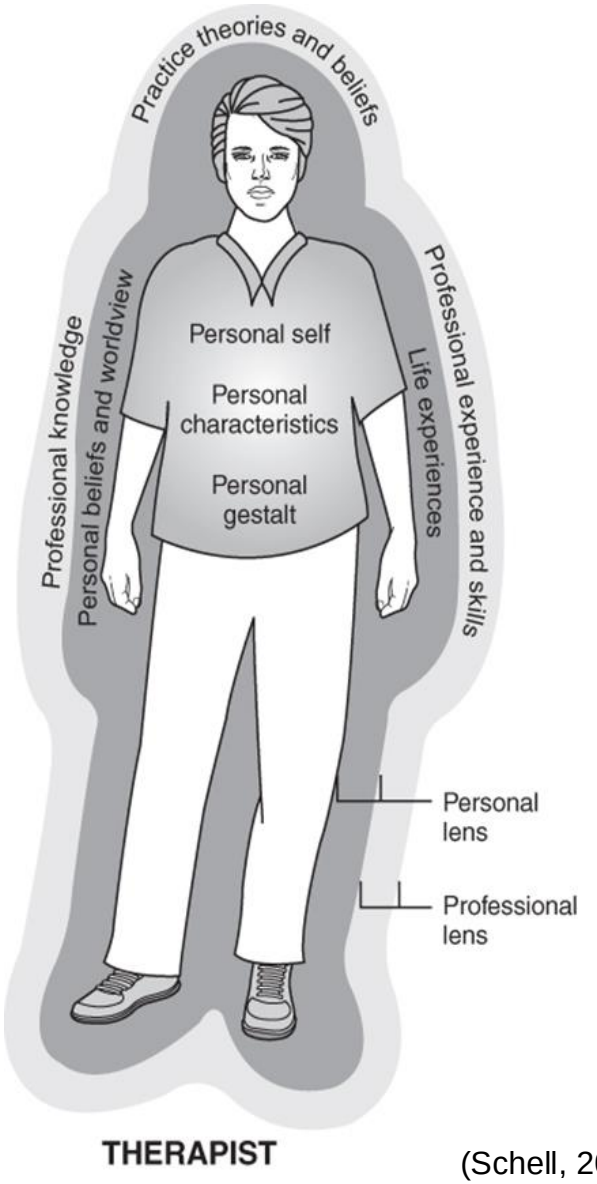
NUTRITION

Determines meal and nutrition plans, monitors growth and nutritional intake and provide oversight to ensure children are provided with balanced nutrition, grow appropriately, and tolerate new foods. Adjusts feeding schedules to best facilitate oral intake and oversees supplementation transitions.

FEEDINGMATTERS.ORG

Ecological Model of Professional Reasoning





(Schell, 2018)

Scaffold and support skill building for caregiver and client

Give Manageable Tasks to Empower Families

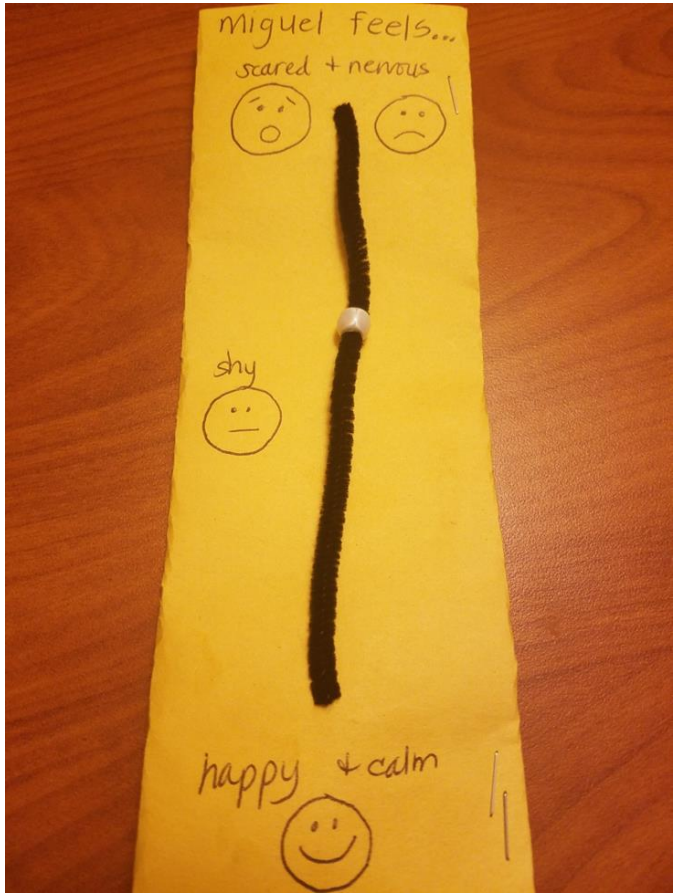
- Support success!
  - Give no more than 1 or 2 things to work on at a time
    - Improves their learning and focus
    - Avoids overwhelming the family
  - Coach caregivers on how to read child's cues
- Create Confidence
  - Praise every effort
  - Reflect on successes (big and small)

Give Manageable Tasks to Empower Families

- Build home programs into daily routines—be relevant
  - Be clear on plan and expectation
  - Provide visuals for successful carry-over
  - Ensure understanding and feasibility
    - What feels manageable to do at home?
    - What questions do they have?
- Confirm Comfort & Learning
  - Review and agree on plan
  - Have family tell or teach you what they learned
    - How would you explain this to other family members?

Teach Parents to Ask Intentional Questions

- Questions parents can ask:
  - How are you doing? How did you sleep?
  - Offer choices vs yes/no questions
  - What did you like the best?
  - What was the hardest part?
  - How do you feel when you touch that food?
  - What does your stomach feel like when you are hungry?

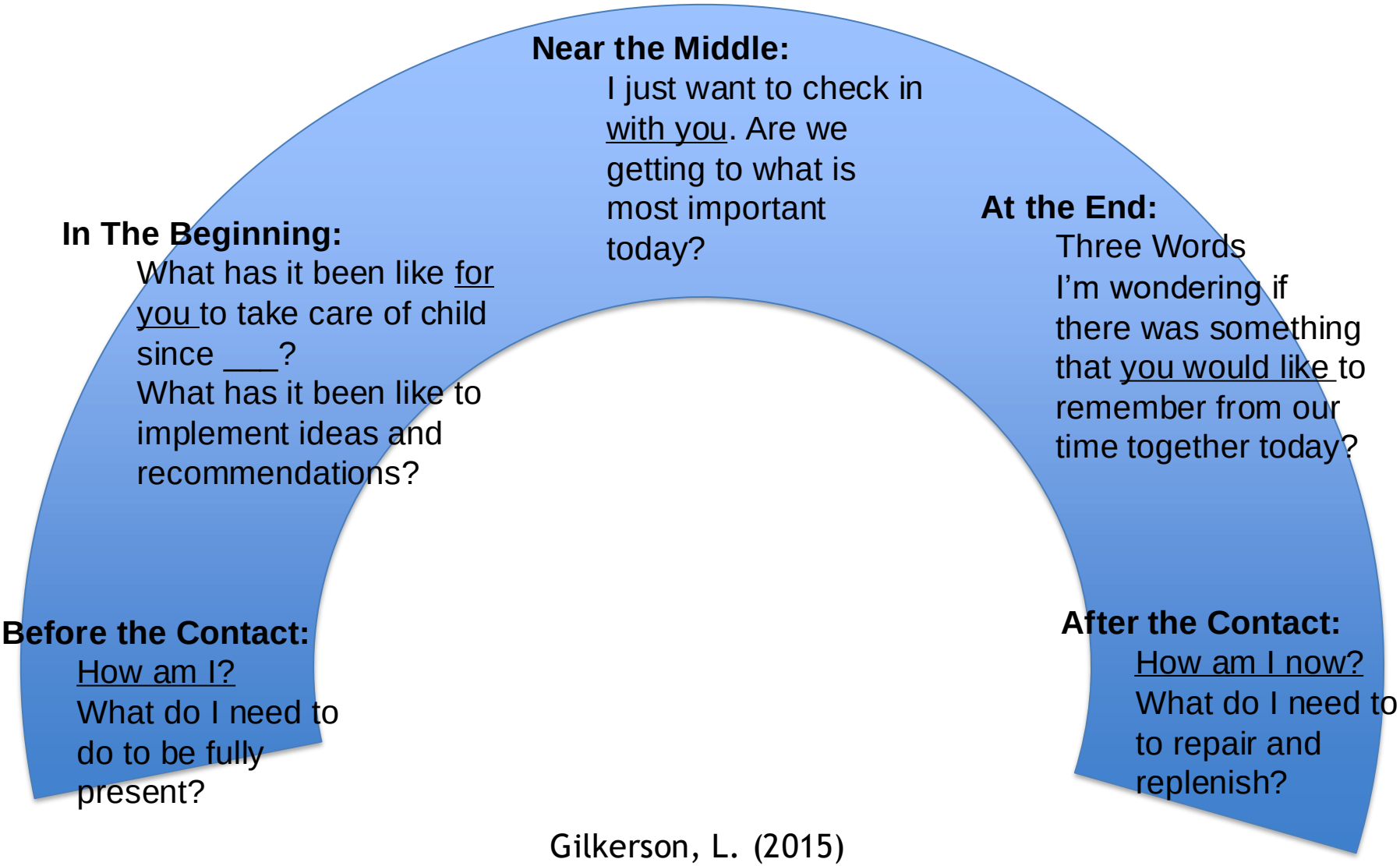


Check for Understanding & Integration

- Don't make assumptions—some things are masked/hidden
  - Power differential & cultural humility (Hammell, 2014)
- Ask with Curiosity
  - Ensure no judgment, no shame
- Give the parents the time they need
  - What they need may change week to week
  - Meet with caregivers individually
    - Provide the child with a play activity while you have a discussion with the parent that contributes to the family's therapeutic process
  - Follow-up phone calls

Check-In Often

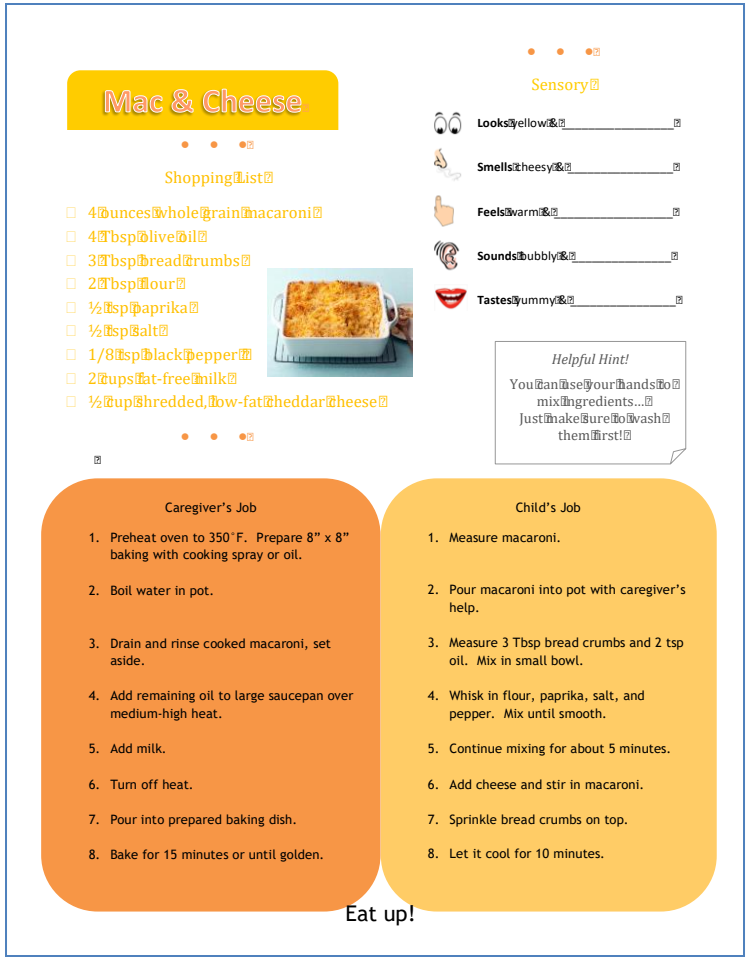
ARC OF ENGAGEMENT



Gilkerson, L. (2015)

Work Yourself Out of the Equation

- Steps to Scaffold:
  - Modeling
  - Take Turns
  - Coaching
  - Move distally
    - Parent lead with immediate feedback
    - Parent lead with video feedback
    - Reduced frequency of visits to generalize to home



Work Yourself Out of the Equation

Child + Parent + **Therapist** + Food + Relationship = Successful Mealtime

Becomes

Child + **Parent** + Food + Relationship = Successful Mealtime

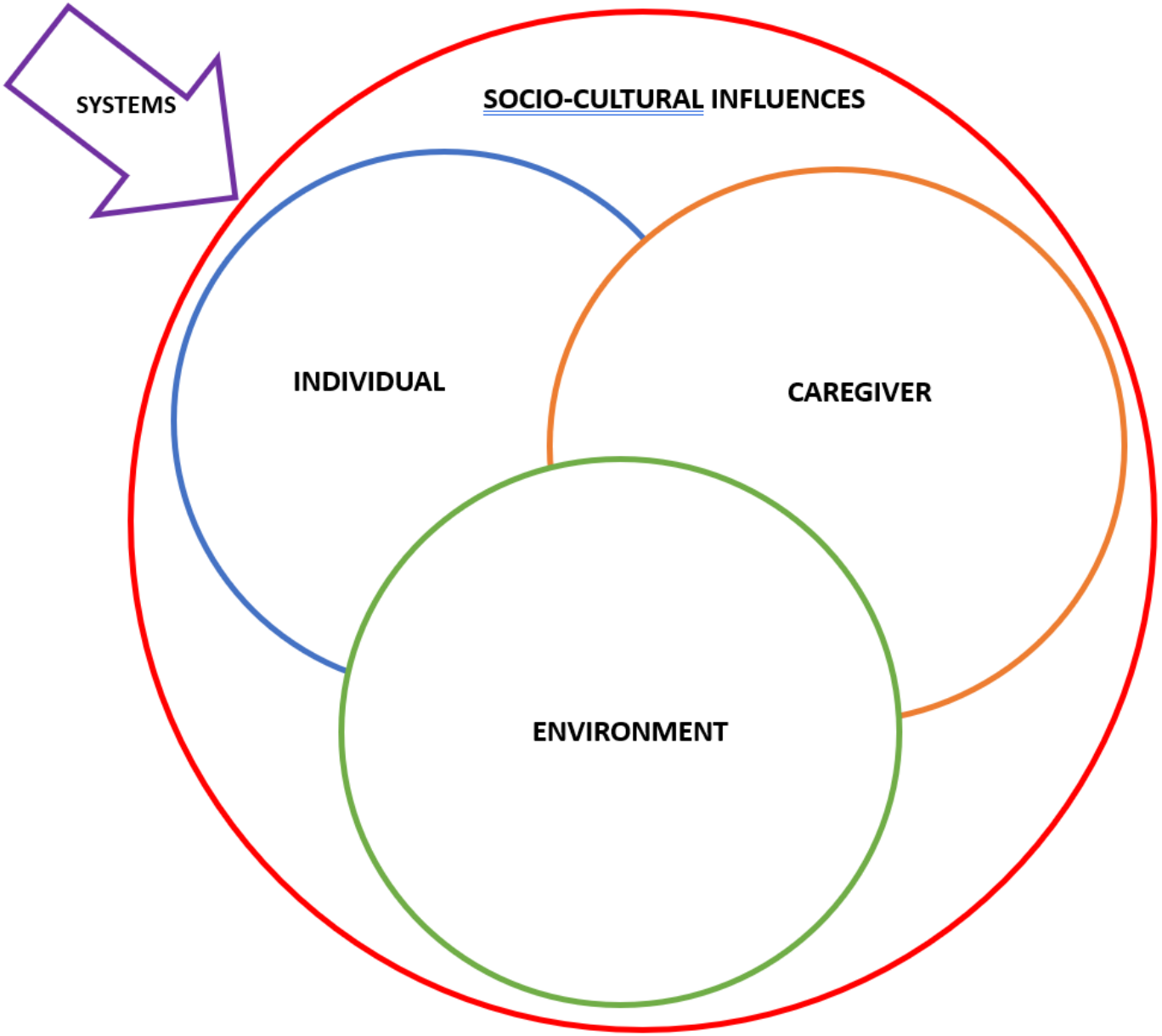
Giving Away the "Magic Moments"


MOST
ELIGIBLE
Vegetables
choc

Ideas for changing OT culture

HOW: Advocate!

- Challenge traditional models of practice:
  - Include caregivers in the session
  - Explore caregiver CPT codes for training sessions
  - Advocate for shifts in clinic culture
- Use the depth and breadth of your scope of practice to support more than oral motor and sensory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Talk it Out!

- Discuss with your neighbor, what are a few things that feel manageable to take with you and implement in your sessions in the next few weeks?
- What barriers do you continue to anticipate? What further questions do you have?

Questions

DOING TO versus BEING WITH

"How you are is as important as what you do"

- Jeree Pawl

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