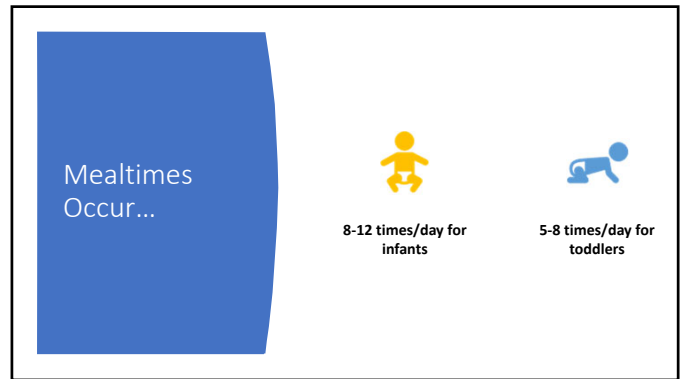




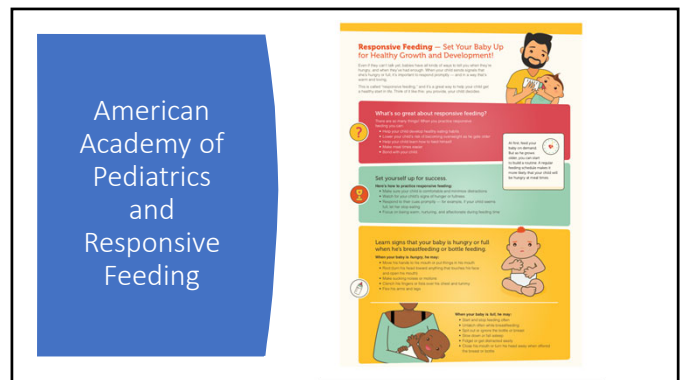
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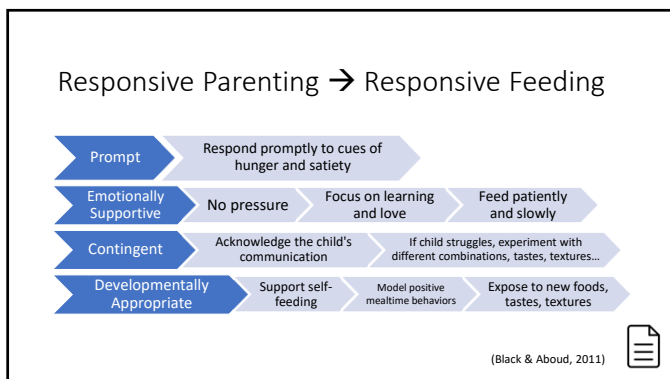
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10



11



12

Definition

Pediatric Feeding Disorder (PFD)

"Impaired oral intake that is **not age-appropriate**, and is associated with **medical, nutritional, feeding skill, and/or psychosocial dysfunction.**"

Goday et al., 2019

13

Pediatric Feeding Disorder (PFD)

- Prevalence between 33% to 80% in children who have developmental disorders, incidence increasing (Lefton-Greif, 2008)
- For these infants and children, every bite of food can be painful, scary, or impossible, potentially impeding nutrition, development, growth, and overall well-being (www.feedingmatters.org)

14

Pediatric Feeding Disorder (PFD) may occur with:

Prematurity

Poor growth

Chromosomal abnormalities

Syndromes

Disease/Disorders

Neurological problems

Dysphagia

Allergy or intolerance

15

Pediatric Feeding Disorder (PFD) may occur with:

Developmental experiences or lack thereof

Environmental challenges

Sensory processing difficulties

Mental Health

Poor Attachment

Trauma

16

Breastfeeding is Responsive Feeding

- Babies who are fed responsively are more likely to continue being breastfeed
- Breastfeeding was associated with lower levels of control compared to formula feeding (Brown & Lee, 2013)
- Parent-led routine for infant feeding may discourage breastfeeding; encouraging a baby to feed to a parent-led routine rather than its own natural patterns may promote obesity
- The association between maternal anxiety and formula use has been well established. (Brown & Arnott, 2014)
- Please seek out education, can and should happen through EI

17

Cue-Based Feeding in the NICU: Using the Infant's Communication as a Guide

When pre-term infants are fed using cue-based practices:

- Focus of feeding is on **experience** not on **"getting it all in"**
- Infants gain physiologic stability
- Infants gain enhanced self-regulation and coping skills

(Shaker, 2013)

18

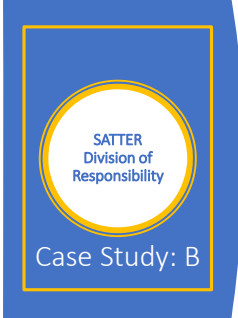
Reading the Feeding

Catherine Shaker

ASHA Leader, 2013

- The infant behaves certain ways during feeding for a reason.
- Volume-driven responses to physiologic instability may create a pattern of stress and feeding refusal behaviors.
- Focusing on emptying the bottle, or defining an empty bottle as success, may alter the preterm infant's feeding experience and adversely affect neuromaturation and feeding outcomes.
- If each feeding is as stress-free as possible, however, the infant learns to respond positively to feeding.

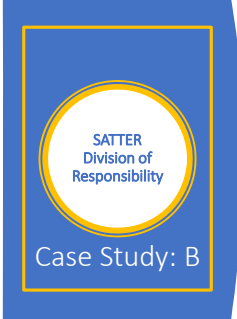
19



Case Study: B

- Medical/feeding hx:
 - Milk and soy protein intolerances in infancy
 - Gagged and coughed with early introduction of solids
 - Diet slowly expanded with therapist and sitter
- Mealtime Dynamics:
 - B still would not eat well with her parents
 - Parents would offer separate meal for B
 - Parents would prepare additional foods as B requested at meals
 - Parents prompted and tried to convince B to try new foods


20



Case Study: B

- Recommendations:
 - Parents coached to serve food family style, including 1 of B's favorites at each meal
 - Encouraged B to serve others
 - Parents modeled positive mealtime behavior
 - Parents stopped prompting
- Outcomes:
 - Family meals more pleasant
 - Parents felt less stress
 - B seemed more relaxed at mealtimes and tried new foods

21



Controlling Feeding

"Controlling feeding may arise when children experience problems in feeding or growth, such as recovery feeding after illness.

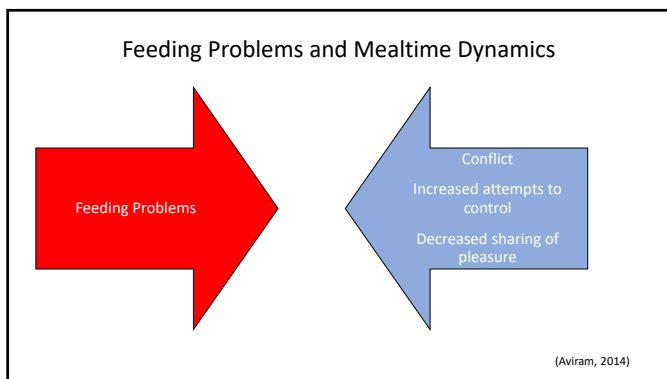
Under these circumstances, recommendations tend to be guided by a children's nutritional needs, focusing on the quantity and quality of food and the frequency of feeding.

As a result, health and nutrition counselors may not focus on parent responsivity and parents may interpret the recommendations as a mandate to use controlling strategies to "get their child to eat."

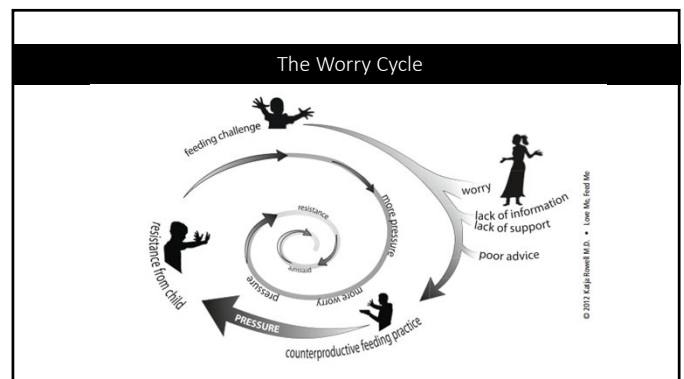
This strategy has the potential to **undermine the child's trust** in an otherwise responsive parent."

(Black & Aboud, 2011)

22



23



24

Impact of feeding problems on relationships

Maternal stress related to mothers' own sense of competence

Paternal stress is more related to child temperament and individual characteristics

(Aviram et al., 2014)



25

Discussion



26

Impact of feeding problems on relationships

- Feeding relationship and bonding (Satter, 1995)
- "The lack of a feeding relationship disturbs the development of maternal identity, and the loss of oral feedings can be assumed to have a **traumatic impact**." (Wilken, 2012)

27

Trauma

Individual trauma results from an event, series of events, or set of circumstances experienced by an individual as physically or emotionally harmful or life-threatening with lasting adverse effects on the individual's functioning and mental, physical, social, emotional, or spiritual well-being.

<http://www.integration.samhsa.gov/clinical-practice/trauma>



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Trauma

Acute OR Chronic



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Trauma

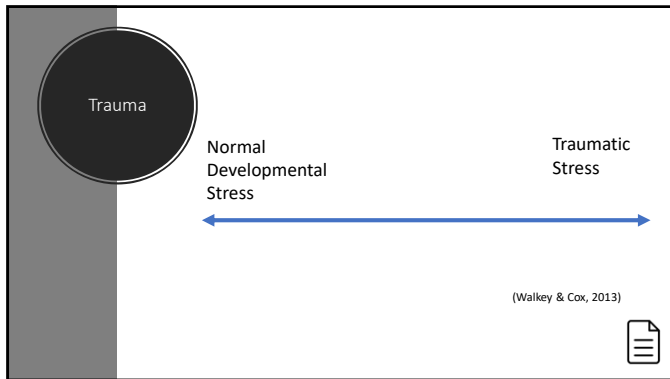
ACES STUDY

ACES:

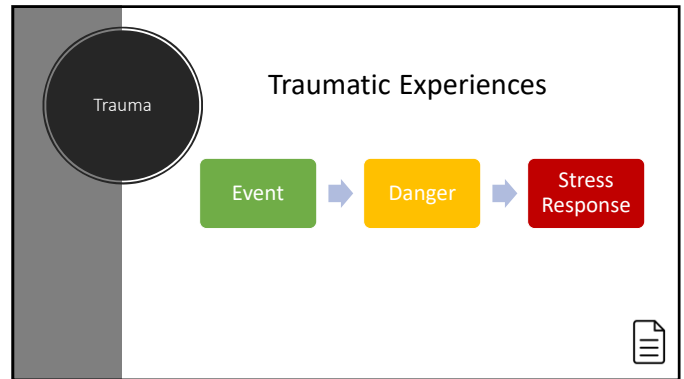
- Physical Emotional or Sexual abuse
- Physical or Emotional neglect
- Parental mental illness
- Substance dependence
- Incarceration
- Parental separation
- Domestic violence



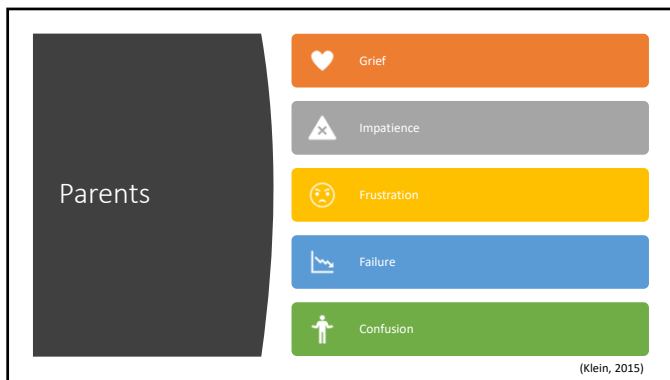
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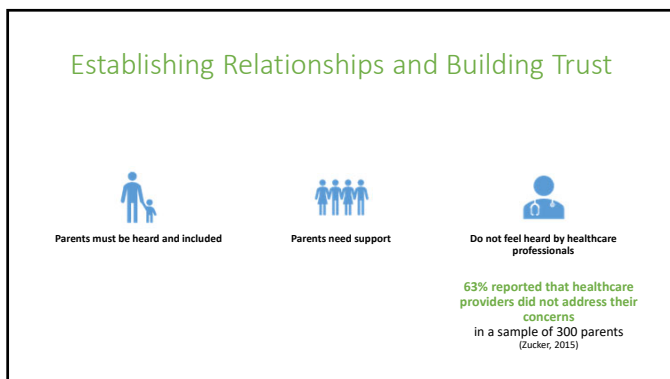
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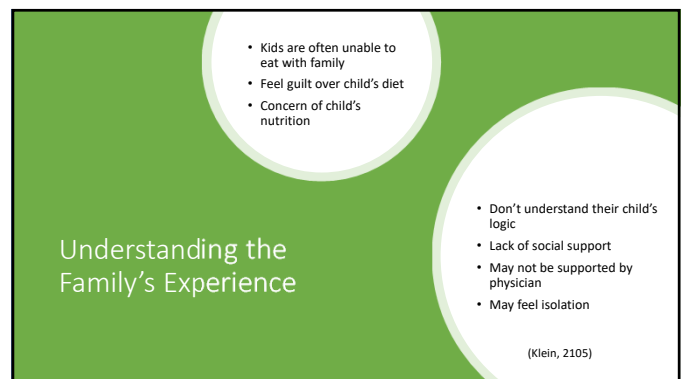
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34



35



36

Parent Solutions: What's working for NOW

Parents may have tried a variety of different things to help:

- Offer same foods in the same way
- Feed child separately
- No eating out
- Use of screens or other distractions

(Klein, 2015)

37

Judgement and Bias

How do we assess and describe...

- Children?
- A child's eating patterns?
- Foods?
- Parents/Caregivers?

38

Noun

1. an act or instance of judging.
2. the ability to judge, make a decision, or form an opinion objectively, authoritatively, and wisely, especially in matters affecting action; good sense; discretion: *a man of sound judgment.*
3. the demonstration or exercise of such ability or capacity: *The major was decorated for the judgment he showed under fire.*
4. the forming of opinion, estimate, notion, or conclusion, as from circumstances presented to the mind: *Our judgment as to the cause of his failure must rest on the evidence.*
5. the opinion formed: *He regretted his hasty judgment.*

Judgment

39

What Do We Judge?

- Breastfeeding vs. bottlefeeding
- Cultural feeding practices
- Homemade vs. storebought baby food
- Organic vs. non-organic
- Homemade blend vs. formula (tube-fed kids)
- Mealtime expectations for toddlers
 - Mess at mealtimes
 - Manners

40

ALTERNATIVE Language we use to describe children:

AVERSION

FOOD REFUSAL

DELAYED

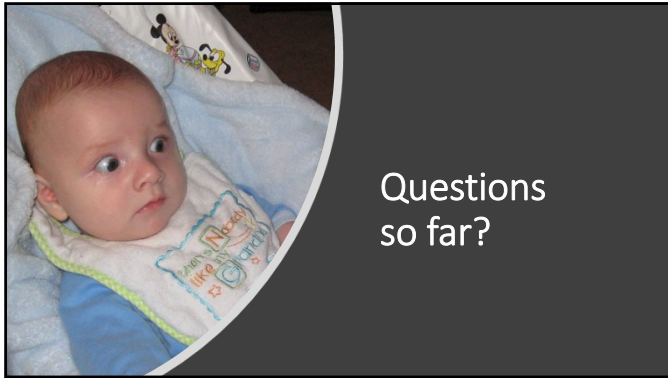
HYPERSENSITIVE

"BEHAVIORAL"

41

Conversations with Parents

42



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Early Intervention Guidelines

Have you seen this document?

Raise your hand if yes.

<https://blogs.illinois.edu/files/6039/114615/4529.pdf>

44

Early Intervention Guidelines

"SLPs in EI may provide services for children with feeding/swallowing deficits related to sensory integration, medically stable oropharyngeal disorders and behavioral issues only."

All other feeding/swallowing deficits are medically related and should be referred to the child's primary medical physician or medical home for medical intervention."

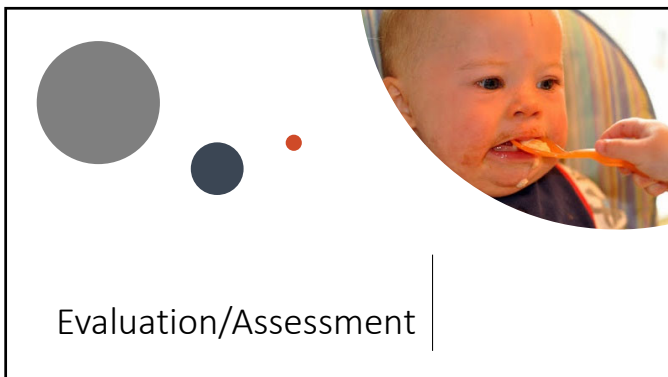
<https://blogs.illinois.edu/files/6039/114615/4529.pdf>

45

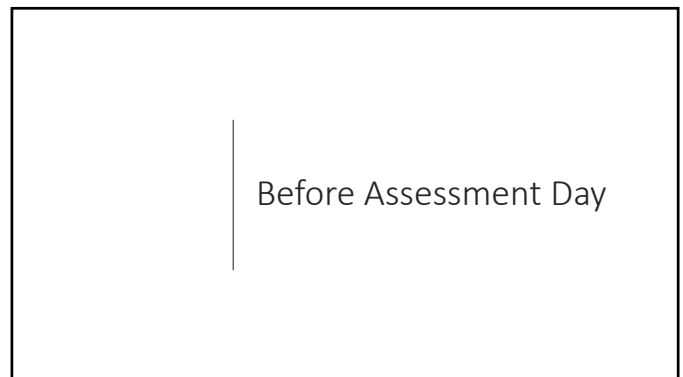
Mission and Key Principles

Part C early intervention builds upon and provides supports and resources to assist family members and caregivers to enhance children's learning and development through everyday learning opportunities.

46



47




48

Review Paperwork

Medical history

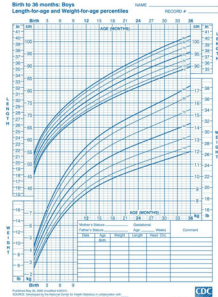
- Birth history
- Diagnoses
- History of medical procedures
- Hospitalizations, significant illnesses
- Past and present assessments and/or therapies
- Medications
- Psychosocial history



49

Review Paperwork

Review Growth



50

Who's on the Team?

- FAMILY
- Extended family members
- Pediatrician
- Service coordinator
- Social worker
- Registered dietician
- Speech-Language pathologist
- Occupational therapist
- Child care educator
- Gastroenterologist
- Allergist
- ENT
- Pulmonologist
- IBCLC
- Nurse
- Psychologist

51

Who Should be Present at Initial Eval/Assess?

- Avoid "this is how we always do it"
- What is best for this family?
- The family should know their options
- Evaluators should have specialized expertise
- Best practice is a multidisciplinary perspective

52

Prepare the Parent

Build Rapport BEFORE the visit

Listen to parent concerns

Explain what will happen

Conversation
Feeding
Feedback

Ask parent to bring familiar foods, utensils, etc.

53

Assessment

54

Parent Interview

55

Medical History

- Review information from paperwork
- Gauge parent(s)'s understanding of child's diagnoses, medical procedures, test results
- Family history of feeding problems, allergies, other illnesses

56

Feeding History

- Describe early feeding experiences:
 - Bottle fed or breast fed?
 - Formula? What kind?
 - Breast milk, via breast or bottle?
 - NG or G tube?
 - When were solids introduced?
 - Were there any difficulties with transition to solids?
- How did early feeding experiences *feel* for the parent? Child?
- How did any complications influence the child's ability to eat?



57

Current Status

- Current diet/food repertoire
- Report of mealtime structure and routine
- Any special preparation or modification of food that is required
- Utensils and vessels used
- Typical quantity of intake
- Coughing, gagging, protective responses
- Behavioral responses during mealtimes
- Family and mealtime dynamics

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Pre-Feeding Skills Checklist

Morris & Klein, 2000

Reproducible Forms

Developmental Pre-Feeding Checklist: A Global Approach

Name: _____ C.A. _____ Assessment date: _____

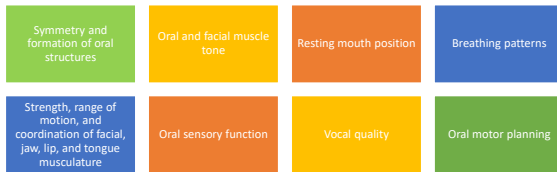
	1 Month	Progress— Spontaneous	Progress— With Facilitation	Not Present
Feeding position	Aligns with the breast slightly elevated, or prone or reclining at an angle of less than 45 degrees, or reclining			
Food types	In fed only liquids from the bottle or breast			
Food quantity	Takes 2 to 4 ounces of liquid per feeding at or more feedings per day			
Sucking liquids	Uses a suckling or sucking pattern with the bottle or breast. Loves some liquid during suckling			
Swallowing liquids	Swallows thin liquids with a suckle-swallow pattern. Tongue may protrude slightly through the lips with an excessive retraction movement			
Coordination of sucking, swallowing, and breathing	Sequence two or more sucks from the breast or bottle before pausing to breathe or swallow			
Control of drooling	Rarely drools because of minimal saliva production			
Feeding position	Is fed in a supported semi-sitting position reclining at an angle of 45 to 90 degrees			

59

Feeding Observation

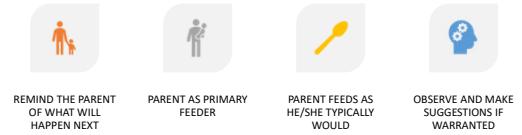
60

Oral-Motor Exam



61

Feeding Observation



62

Feeding Observation

Observe:

- How is the child positioned?
- What is the environment?
- What foods are offered?
- What is the child's reaction to the food?
- What is working best?
- What are the challenges?

*Ask if this meal resembles typical mealtimes.

63

Feeding Observation: Mealtime Dynamics

- Is the parent reading the child's nonverbal cues?
- How does parent respond to successes/difficulties?
- Is distraction used?
- Is the child engaged?
- Does the child help with the feeding?
- Does the child seem happy?
- Is the pacing appropriate?

(Klein, 2015)

64

Feeding Observation: Assess Foods Offered

- Taste
- Texture
- Variation



65

Feeding Observation: Assess Skills



- Breastfeeding
- Bottle drinking
- Cup drinking
- Straw use
- Utensil use
- Oral preparation/swallowing


66

Feeding Observation: Understanding the Dyad

Avoid making assumptions


Ask parents questions:

- I'm noticing that...What do you think this means?
- What has worked in the past?



67

What is working?



- Where is the child receiving their primary source of nutrition?
- What seems to be the "easiest"/most natural for the child?
- When does the child lean in?


(Morris & Klein, 2000)

68

Areas of Need

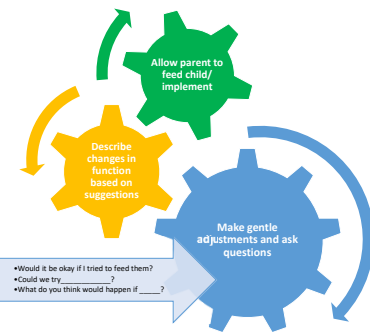
Describe what may be contributing to feeding difficulty

- Narrate what is happening
- It looks like _____.



69

Problem-Solving Together



• Would it be okay if I tried to feed them?
 • Could we try _____?
 • What do you think would happen if _____?

70

Communication

"I'm noticing that _____."

"What would happen if _____?"


"Could we try _____?"

"What would you think about _____?"

"Would it be okay if _____?"

71

Making a Plan



Check-in: parent's emotional state




Make sure the parent knows what to do, and have them try strategies/practice what you've demonstrated

Find out what is important to them: Out if everything we've tried today, what was the most useful to you?



Create outcomes together



Are there other professionals or resources that would be helpful?

72

Making a Plan



Ensure that parent understands recommendations in the context of development



Written recommendations



Make sure parent understands what will happen next

73

Report Writing



- Use parent-friendly language
- If necessary, have report translated
- Avoid jargon
 - Use professional language
 - Define professional language
- Describe **what happened** (don't use value-based terminology)
 - Jack refused his mother's presentation of the spoon.
 - Jack turned his head away when his mother presented the spoon.

Handout, pg. 24



74

Outcomes and Strategies

75

Developing Outcomes

Key Principle #4 (NE)

Key Principle #4 (NE):

The early intervention process, from initial contacts through transition, must be **dynamic** and **individualized** to reflect the child's and family members' preferences, learning styles and cultural beliefs.

http://www.nectar.org/~pdfs/topics/families/Principles_LookstLike_DoesntLookLike3_11_08.pdf



76

Developing Outcomes

Key Principle #5 (NE)

Key Principle #5 (NE):

IFSP outcomes must be **functional** and based on children's and families' **needs and priorities**.

http://www.nectar.org/~pdfs/topics/families/Principles_LookstLike_DoesntLookLike3_11_08.pdf



77

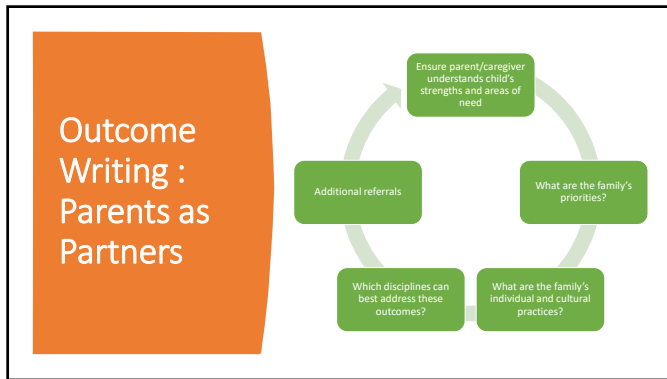
Outcome Writing: Parents as Partners

Parents are:

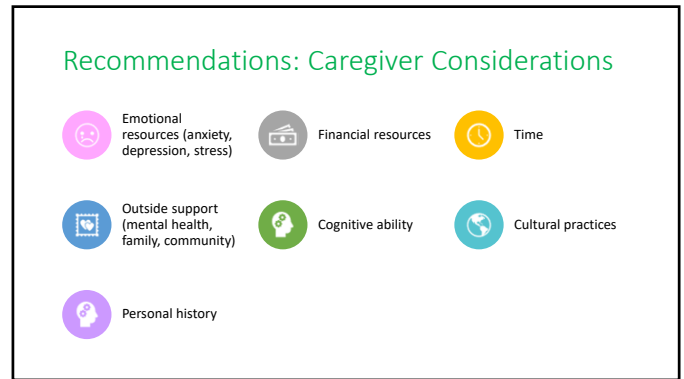
- more invested in reaching goals
- more satisfied with services
- more hopeful about managing life

(SAMHSA: Concept of Trauma and Guidance for a Trauma-Informed Approach, NCTSN)

78



79



80

Sample Outcomes

High quality IFSP functional outcomes:

- ✓ are necessary and functional for the child's and family's life
- ✓ reflect real-life contexts/settings (**mealtime routines**)
- ✓ integrate developmental domains and are discipline-free
- ✓ are jargon-free, clear, and simple
- ✓ emphasize the positive, not the negative
- ✓ use active rather than passive words

From IL EI Provider handbook

81

Sample Outcomes

- _____ so he can participate in mealtime routines with his family.
- Jose will be able to drink comfortably and efficiently from the bottle so he can grow well.
- Kate will eat a variety of table foods and be able to drink liquids from a cup so that she can participate in family mealtimes.

82

What EI or other supports are available?

Consider more than one discipline

- Speech
- Occupational therapy
- Physical therapy
- Social work
- Nutrition
- Include physicians and specialists outside of EI
- Assistive technology

83



84

Key Principle #2 (EI)

The focus of EI is to encourage the **active participation of families** in the therapeutic process by embedding intervention strategies into family routines.

It is the **parents who provide the real early intervention** by creatively adapting their child care methods to facilitate the development of their child, while balancing the needs of the rest of their family.

85

Treatment

Feeding issues are complicated.

Children need to **FEEL GOOD** before they can eat.

(Edwards et. al., 2015)

86

Use Development As a Guide

- Gross motor
- Fine motor
- Cognitive
- Communication
- Feeding skills

87

Start with What is Working

FAMILIAR

(Morris & Klein, 2000)

88



Parent Coaching

89

Help Caregivers Learn a Child's Cues

- Educate all caregivers
- Online observations
- Ask parent to interpret behavior
- Video review



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AL 1219

Communication

- "I'm noticing that _____."
- "What would happen if _____."
- "Could we try _____?"
- "What would you think about _____?"
- "Would it be okay if _____?"

91

Responsive Feeding Strategies: Supporting Development of Trust Between Child and Caregiver

- Modeling positive eating behavior at mealtimes (Harper, 1975)
- Encourage shared mealtimes
- No pressure (Galloway et al., 2006)
- Avoid using food as rewards for eating other foods (Finnanne et al, 2017)
- Respond promptly to child's cues of hunger and satiety (Black & Aboud 2011)

92

Making Changes

- What worked today?
- Offer a few options for integrating new strategies into routines
- Parent helps choose what to implement next
- Give the parent a "game plan" for every mealtime

93

Continuum of Options

Child Motivated ← → Adult Motivated

Self-feeding ← → Force feeding

(Klein, 2012)

94

Child-Led, Relationship-Based, Trust-Based Approaches

- Get Permission Approach (Klein)
- Sequential Oral Sensory Approach (Toomey)
- Mealtime Partners (Suzanne Evans Morris)
- SOFFI Method (Ross)
- Food Chaining (Fraker & Fishbein)
- STEPS Approach (McGlothlin & Rowell)

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Behavioral Modification Strategies

Goal	Treatment Strategy	Examples
Increase desirable feeding behaviors	Positive reinforcement	Praise for bite acceptance
	Negative reinforcement	Reward with access to preferred food or toys
	Structured feeding environment	Providing a break following bite acceptance
	Stimulus fading	Mealtime schedule
		Appropriate seating and utensils
		Start with small bite sizes and gradually increase the size as child is successful
Reduce unwanted feeding behaviors	Escape extinction	Maintaining bite presentation until child accepts bite
Strengthen primary feeder skills	Ignoring	Ignoring all inappropriate behavior to avoid reinforcing it
	Caregiver training	Gradually introduce the primary caregiver as the feeder while providing coaching on how to implement the individualized behavioral feeding treatment plan

Arvedson, Brodsky, Lefton-Greif, 2020

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Slide 91

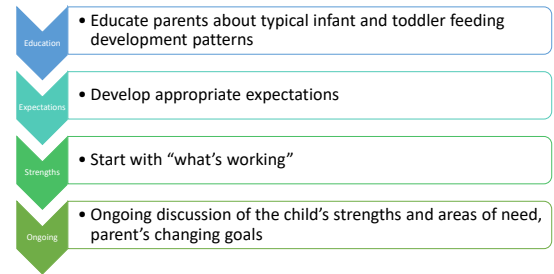
JAL [2]9 I left this "left block" black to match the earlier slide (101) and
reactivate prior knowledge

Jones, Alissa Leigh, 6/5/2019

Building Trust with Families

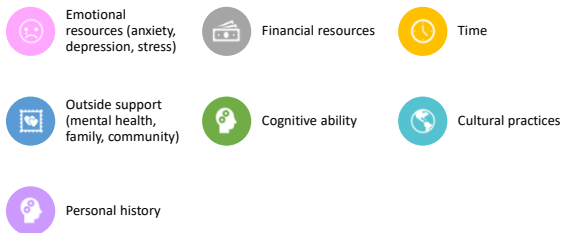
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Building Trust:



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Building Trust: Caregiver Considerations



99

Cultural Considerations

- Cultural responsiveness** is about reciprocity and mutuality. The process involves exploring differences, being open to valuing clients' knowledge and expertise, and recognizing the unique cultural identity of each individual client (Munoz, 2007).
- When cultural considerations are addressed, outcomes are better (Davis-McFarland, 2008)

100

Barriers to Communication with Parents

- Parent stress/mental health
- Misunderstanding of therapeutic relationship
- Misunderstandings regarding individual/personal factors
- Practitioner judgement/bias
- Practitioner difficulty grading communication

101

Avoid Judgment

- Make intentional language choices
- Consider questions we ask and how we ask them (e.g., "How did things go this week? What did you try?")
- Anna's mom- "I almost didn't want you to come today because I haven't done any feeding and I should be doing more. I need to do more."

102

How do we contribute to this?

How can we avoid contributing to this?

103



Questions
so far?

104

Teaming and Collaboration

105

Key Principle #3 (EI)

EI requires a **collaborative relationship** between families and providers, with equal participation by all those involved in the process.

An **on-going parent-professional dialogue** is needed to develop, implement, monitor, and modify therapeutic activities.

106

Team Collaboration & Communication



All team members are aware of the plan and parent is supported throughout the week



Use IFSP development time wisely (includes consultation with physicians identified on the IFSP)



Connect with team members outside of EI

107

Teaming and Collaboration



108

Teaming and Collaboration: Discussion

Can you think of a time when you collaborated with another member of the team in a way that benefitted the family?

109

ISSUES AND INNOVATIONS IN NURSING PRACTICE

The lived experience of families of children who are failing to thrive

Elizabeth H. Thomlinson PhD RN
Associate Professor, Faculty of Nursing, University of Calgary, University Drive, Calgary, Alberta, Canada

Submitted for publication 28 June 2001
Accepted for publication 30 May 2002

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2500 University Drive,
Calgary,
Alberta

THOMLINSON E.H. (2002) *Journal of Advanced Nursing* 39(6), 537-545

The lived experience of families of children who are failing to thrive

Objective. This study was conducted to explore the experience of families of children who were failing to thrive. The aim of the study was not to generalize the findings but to generate a rich description of the phenomenon of living with children who were not growing as expected.

110

Teaming and Collaboration

- **12 Families with children with “FTT” diagnosis**
- **One third of families (4 families) felt as if they were part of the team**
- **Almost all families described:**
 - Feeling helpless
 - Not feeling heard
 - Feeling blamed for their child’s diagnosis
 - Feeling isolated

(Thomlinson, 2002)

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Teaming and Collaboration

Families felt part of the team when medical professionals:

- Accepted their assessment of the child’s condition
- Listened to them

(Thomlinson, 2002)

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Teaming and Collaboration

A multidisciplinary team can holistically address a child’s health and well-being:

- Medical management
- Sensorimotor skill building
- Behavioral support
- Hunger provocation
- Pain management
- Sensory integration difficulties

(Edwards et. al., 2015)

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- At four months Spencer’s parents noticed motor delay
 - Low tone
- Started working with Spencer at 18 months
 - Non verbal
 - Ataxic movement
 - Not growing well
- Feeding skills
 - No self feeding
 - Was refusing spoon feeding from parent
 - Was bottle drinking
 - Was not self-feeding

Case Study: Spencer

114

Key Principle #7
(NE):

Interventions with young children and family members must be based on **explicit principles, validated practices, best available research** and relevant laws and regulations.

115


Resources



116

Resources


- American Speech-Language Hearing Association: www.asha.org
- Catherine Shaker Swallowing and Feeding Seminars: www.shakerswallowingandfeeding.com
- Chicago Feeding Group: <http://www.chicagofeedinggroup.org/>
- Clarification of Existing Policy/Procedure Regarding Developmental Services Provided by Speech-Language Pathologists to Children Eligible for Early Intervention <http://www.wvu.edu/ProviderConnections/pdf/InfoNoticeclarifyingSLPPolicyProcedures1122.pdf>
- DEC Recommended Practices: <https://divisionearlychildhood.govt.com/4/cpe6GUV0V6>
- Dysphagia Resource Center: www.dysphagia.com
- Expert Feeding Help for Parents and Professionals (Melanie Potock): www.mymunchbug.com
- Feeding Flock assessment tools: <https://www.feedingflock.com/tools>
- Feeding Flock: <https://www.feedingflock.com/>
- Feeding Matters: www.feedingmatters.org



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Resources

- Frequently Asked Questions (FAQs) SLP Provider Information Notice (04/19/11): <http://www.wvu.edu/ProviderConnections/policy/ProviderUpdate.php?id=172>
- Helping Your Child with Extreme Picky Eating (Rowell & McGlothlin): www.extremepicky.com
- Mealtime Notions (Klein): www.mealtime notions.com
- New Visions (from Suzanne Evans Morris, Ph.D.): www.new-visions.com
- PAHO/WHO Guiding Principles for Complementary Feeding of the Breastfed Child: https://www.who.int/nutrition/publications/guiding_principles_compleeding_breastfed.pdf
- Pediatric Feeding News (Krisi Brackett): <http://pediatricfeedingnews.com/>
- Principles of Early Intervention: <https://etp.education.illinois.edu/principles.html>
- Seven Key Principles: Looks Like / Doesn't Look Like from Workgroup on Principles and Practices in Natural Environments: http://www.nectar.org/~pdf/topics/families/Principles_LooksLike_DoesntLookLike3_11_08.pdf
- The Feeding Relationship, by Eilyn Satter: <https://www.zerotothree.org/resources/1071-the-feeding-relationship>



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Resources:
Listsers, Newsletters, or Groups

Dysphagia listserv (www.dysphagia.com)

ASHA Division 13 (listserv and newsletter) (<https://www.asha.org/SIG/13/>)

Pediatric Feeding and Dysphagia Newsletter (Krisi Brackett, SLP) (<http://pediatricfeedingnews.com/>)

FeedR Pediatric Dysphagia Facebook group (<https://www.facebook.com/groups/88445812069/>)

The Chicago Feeding Group (www.chicagofeedinggroup.org)

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Recommended Reading

Pediatric Swallowing and Feeding: Assessment and Management by Joan Arvedson, Linda Brodsky

Pre-Feeding Skills: A Comprehensive Resource for Mealtime Development – 2nd edition by Suzanne Evans Morris, Ph.D., and Marsha Dunn Klein, M.Ed., OTR

How to Get Your Kid to Eat–But Not Too Much by Eilyn Satter RD, A.C.S.W.

Child of Mine: Feeding With Love and Good Sense by Eilyn Satter, RD, A.C.S.W.

Helping Your Child with Extreme Picky Eating by Katja Rowell, MD, Jenny McGlothlin, MS, CCC-SLP

Baby Self-Feeding, by Nancy Ripkin & Melanie Potock

Raising a Happy, Healthy Eater, by Melanie Potock

Check the EIC Lending Library for these <https://eicclearinghouse.org>

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JAL3 I noticed some resources or references were listed twice so I omitted them. I put titles in front of the links that were originally just links and alphabetized

Jones, Alissa Leigh, 5/22/2019

Feeding and Eating in Early Intervention: A Trust Based Approach

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