How Lactation Professionals Can Support Client Informed Decision-Making and Advocacy

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My Background

- Birth and Postpartum Doula
- Childbirth & Newborn Care Educator
- IBCLC
- Parent Coach

Agenda

- Introduction
- Principles of Informed Decision-Making and Advocacy
- Value of Self-Advocacy
- Concerns/Challenges Families May Face
- Offering Support, Encouragement, and Guidance
- Scenario Discussions

Definitions

- *Informed Decision:* decision based on facts or information
- *Informed Consent:* permission granted in the knowledge of the possible consequences, typically that which is given by a patient to a doctor for treatment with full knowledge of the possible risks and benefits.
- *Informed Refusal:* refusal of a recommended medical treatment based upon an understanding of the facts and implications of not following the treatment. Informed refusal is linked to the informed consent process, as a patient has a right to consent, but also may choose to refuse.

AMA Definition

Process of informed consent occurs when **communication** between a patient and physician results in the patient's **authorization or agreement to undergo a specific medical intervention**. In seeking a patient's informed consent (or the consent of the patient's surrogate if the patient lacks decision-making capacity or declines to participate in making decisions), physicians should:

a) Assess the **patient's ability to understand** relevant medical information and the implications of treatment alternatives and to make an independent, voluntary decision.

b) **Present relevant information accurately and sensitively**, in keeping with the patient's preferences for receiving medical information. The physician should include information about:
- The diagnosis (when known)
- The nature and purpose of recommended interventions
- The burdens, risks, and expected benefits of all options, including forgoing treatment

c) **Document the informed consent conversation and the patient's (or surrogate's) decision** in the medical record in some manner. When the patient/surrogate has provided specific written consent, the consent form should be included in the record.

- American Medical Association

Shared Decision Making

Washington State Health Care Authority
https://www.youtube.com/watch?v=HWlpMBQu8Uc&feature=youtu.be

PDAs

- Patient decision aids (PDAs)
  - Tools that can help people engage in shared health decisions with their health care provider
  - Different from educational materials
  - Lead to increased knowledge, more accurate risk perception, and fewer patients remaining passive or undecided about their care
  - Currently no certified PDAs for feeding or lactation specific topics

Definitions

- *Advocacy:* the act or process of supporting a cause or proposal, often used on the context of rights
- *Health advocacy*: supports and promotes patients' health care rights as well as enhance community health and policy initiatives that focus on the availability, safety and quality of care.
- *Advocate:* someone who provides advocacy support to people who need it
- *Self-advocacy:* the action of representing oneself or one's views or interests
- *Empowerment* - authority or power given to someone to do something; the process of becoming stronger and more confident, especially in controlling one's life and claiming one's rights

Reflections

- Why is having informed decision-making important for the families we support?
- Why is it important that we as lactation professionals play a role in supporting informed decision-making?

Informed Decision-Making

Parent(s) must understand:
- The facts/situation as it is,
- What is being recommended, and why,
- Implications – both positive and negative - of actions that may come from a change in course or doing nothing,
- and possible future consequences

Decision-Making Process

- Obtain information/recommendations
- Ask questions / Do research
- Risk-Benefit Analysis
- Discuss with support persons
- Review goals
- Create and implement plan
- Obtain necessary support
- Follow-up steps, as appropriate

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Offering Support

- If in a clinical role, obtain background health history information
- Start with goals
- Offer assurance of personalized support
- Reflective listening
- Compassion & empathy

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Offering Support

- Answer questions and provide resources
- Provide accessible evidence-based information
- Establish rapport
- Discuss values and preferences
- Balance clinical and holistic priorities

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Complex Emotions

- Confident
- Anxious
- Vulnerable
- Overwhelmed
- Conflicted
- Guilty
- Angry

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Supporting Client Decision-Making

- Ask if they know if these are patient specific recommendations
- Team approach / brainstorming
- Offer assistance with listing and analyzing pros and cons
- Discuss and model informed decision-making
- Offer to create a script
- Offer to role play

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Considerations

- Level of support needed
- Whether that support is available
- Difficulty of reversing a given decision
- Conflict between parents and/or other family members
- Possible consequences of informed refusal
  - Clinically, but also:
  - Perceptive or labeled as adversarial or acting AMA
  - Child Protective Services involvement

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Key Questions

Penny Simkin's Key Questions

Available at:
https://www.pennysimkin.com/shop/key-questions-cards-file-download-2/

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Scripts

- I don't understand.
- Please explain this to me.
- What could happen to me or my baby if I do that? What if I don't?
- What are my other options? What if I take no action ("watchful waiting")?
- Please show me the research to support what you're recommending.

- Childbirth Connection

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Scripts

- I have some information I'd like to share with you.
- I'm uncomfortable with what you are recommending.
- I'm not ready to make a decision yet.
- I'm thinking about getting a second opinion.

- Childbirth Connection

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Supporting Client Self-Advocacy

- Encourage asking questions and obtaining patient specific recommendations from their HCPs
- "What questions do you need answered?"
- "What concerns do you have?"
- "What support to you have? What support do you need?"
- "What is your intuition telling you?"
- "Would a second opinion be helpful?"

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Communications Concerns

- If clients confide that they are having challenges communicating with their HCPs:
  - Ask if they feel they have been able to ask questions and/or express concerns
  - Ask what is the greatest communication barrier
  - Brainstorm strategies for the next communication
    - Asking for more time, detail, written information?
    - Requesting a medical translator?
    - Brining in or sending questions/thoughts in writing?
  - Suggest bringing a support person

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If You're A Provider

- Ask yourself if you are:
  - Aware of this family's goals?
  - As aware as possible of their personal context?
  - Presenting evidence-based information in a fair and balanced manner?
  - Presenting all options?
  - Presenting with (obvious) bias? Or disclosing bias?
  - Trying to sway the parent toward a certain decision?

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Specific Scenarios

- Jaundice
- Offering Supplementation
- Weaning
- Dental Care of the Nursing Child

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Decision-Making: Jaundice Treatment

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Jaundice Basics

- Hyperbilirubinemia - common in newborns
- More than 80% of newborns appear jaundiced in first week of life
- Bilirubin is an antioxidant and may have protective qualities
- Most often "physiologic" or unknown etiology
- "Breastfeeding jaundice" = Suboptimal Intake Jaundice
- "Breast milk jaundice" persists past the onset of robust weight gain
- Differences between breastfeeding/chestfeeding babies and formula-fed babies based on volume fed

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Jaundice Risks

- Acute bilirubin encephalopathy
  - Hearing loss
  - Brain damage
  - Death
- Kernicterus
  - Athetoid cerebral palsy - involuntary and uncontrolled movements
  - Permanent upward gaze
  - Hearing loss
  - Improper development of tooth enamel

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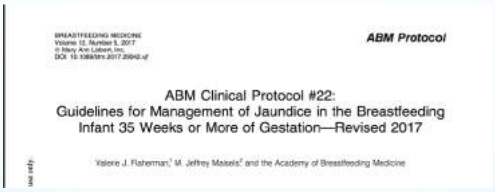
Lactation Management



ABM Protocol

ABM Clinical Protocol #22:
Guidelines for Management of Jaundice in the Breastfeeding Infant 35 Weeks or More of Gestation—Revised 2017

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Lactation Management

1. Initiate early breastfeeding.
2. Encourage frequent exclusive breastfeeding.
3. Optimize early breastfeeding management.
4. Provide education on early feeding cues.
5. Identify mothers and infants at risk for hyperbilirubinemia.
6. Do not supplement infants with anything other than mother's own expressed milk in the absence of a specific clinical indication.

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Lactation Management

7. ...Infants discharged before 72 hours of age should be seen by a healthcare provider within 2 days of discharge from birth hospitalization. This is especially important for exclusively breastfed infants.

All good management practices regardless of risk factors or signs of jaundice.

Bilirubin Testing

- Assessment of bilirubin level by transcutaneous bilirubinometry or serum bilirubin (mg/dL or µmol/L)
- Serum bilirubin level >13 mg/dl require work up
- Visible jaundice on the first day of life
- Total serum bilirubin level increasing by more than 5 mg/dl per day
- Direct serum bilirubin level exceeding 1.5 mg/dl
- Clinical jaundice persisting for more than 1 week in term babies

Jaundice Treatment

- Conflicting information about when and how to treat
- Treatment may lead to risk to the breastfeeding/chestfeeding relationship


Bilirubin Levels in Full Term, Healthy Newborns that may Require treatment

Serum bilirubin Levels	Age of baby
Above 10 mg	Less than 24 hours old
Above 15 mg	24-48 hours old
Above 18 mg	49-72 hours old
Above 20 mg	Older than 72 hours

Credit: American Pregnancy

Phototherapy

Credit: davidlevilindsay

- Bed
- Blanket
- Hospital
- Home

Supplementation

- Temporary supplementation with expressed milk, donor human milk or infant formula
- Temporary interruption of breast/chestfeeding and supplementation with infant formula
- "Most newborns with jaundice can continue breastfeeding. Decisions about supplementation of a jaundiced newborn should be made on a case-by-case basis." - CDC

Severe Cases


Management of Hyperbilirubinemia in the Healthy Term Newborn TSB* Level, mg/dL (µmol/L)

Age, hours	Phototherapy	Exchange Transfusion if Intensive Phototherapy Fails †	Exchange Transfusion and Intensive Phototherapy
≤ 24 ‡	-	-	-
25-48	≥ 15 (260)	≥ 20 (340)	≥ 25 (430)
49-72	≥ 18 (310)	≥25 (430)	≥ 30 (510)
>72	≥ 20 (340)	≥ 25 (430)	≥ 30 (510)

Credit: Iowa Neonatology Handbook

- Hospital admission
- Blood transfusion

Jaundice Scenario

Client reports that baby's doctor diagnosed jaundice in the "middle zone" at 3-day postpartum appointment.

Recommendation was to offer 1-2oz of expressed milk or formula after each feeding for 24-hours and return for a follow-up check.

Client reported pumping once today = 15ml.

They expressed concern that their baby would have to go back to the hospital or get very sick, but they are unsure about using formula.

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Jaundice Scenario

- What more, if anything, do you need to know?
- What is the first think you would say to this family?
- How would you offer support?

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Decision-Making: Offering Supplementation

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Supplementation Terminology

- Exclusive: Feeding only human milk (at the breast/chest or own parents' expressed milk), no food or water except vitamins, minerals, and medications.
- Supplementary feedings: Additional fluids provided to a breastfed/chestfed infant before 6 months (recommended duration of exclusive breast/chestfeeding). These fluids may include donor human milk, infant formula, or other human milk substitutes (e.g., glucose water).
- Complementary feedings: Solid or semisolid foods provided to an infant in addition to breast/chestfeeding when human milk alone is no longer sufficient to meet nutritional needs.

  ABM Protocol #3 (with some edits to increase gender-inclusivity)
- "Supplementation can include pasteurized donor human milk, infant formula, or other breast milk substitutes (e.g., glucose water)." – CDC

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Supplementation

- Need for supplementation
  - What are the criteria?
  - Is it urgent?
- Options for supplementation
- Methods of supplementation

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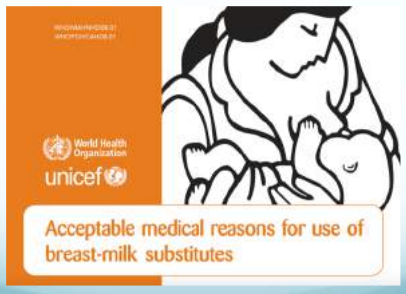
WHO & UNICEF



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WHO & UNICEF

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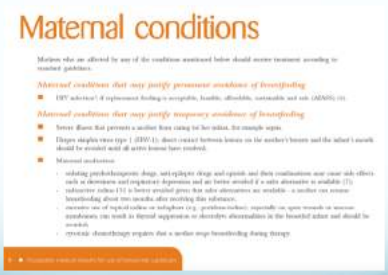

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WHO & UNICEF

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Lactation Management

Step 1. Prevent the need for supplementation

Step 2. Address early indicators of the possible need for supplementation

Step 3. Determine whether supplementation is required and supplement with care

ABM Clinical Protocol #3

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Choice of Supplement

- Parent's expressed milk
- Donor human milk
- Protein hydrolysate formulas may be preferable to standard infant formula
- Glucose water is not appropriate
- "The potential risks and benefits of other supplemental fluids, such as cow's milk formulas, soy formulas, or protein hydrolysate formulas, must be considered along with the available resources of the family, the infant's age, the amounts needed, and the potential impact on the establishment of breastfeeding."

ABM Clinical Protocol #3

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Volume of Supplemental Feeding

- "…the amount of supplement given should reflect the normal amounts of colostrum available, the size of the infant's stomach (which changes over time), and the age and size of the infant." (ABM CP #3)

TABLE 2. AVERAGE REPORTED INTAKES OF COLOSTRUM BY HEALTHY, TERM BREASTFED INFANTS

Time (hours)	*Intake (mL/feed)*
First 24	2–10
24–48	5–15
48–72	15–30
72–96	30–60

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Volume of Supplemental Feeding

- After first 96 hours, what methods or resources do you use to calculate average intake amounts for supplementation directions?

Methods of Providing Supplemental Feedings

- Supplemental nursing device at the breast/chest
- Cup feeding
- Spoon or dropper feeding
- Finger-feeding
- Syringe feeding
- Bottle-feeding, ideally slow flow and paced fed

Methods of Providing Supplemental Feedings

"When selecting an alternative feeding method clinicians should consider several criteria:

a) cost and availability
b) ease of use and cleaning
c) stress to the infant
d) whether adequate milk volume can be fed in 20– 30 minutes
e) whether anticipated use is short- or long-term
f) [parental] preference
g) expertise of healthcare staff
h) whether the method enhances development of breastfeeding[/ chestfeeding] skills"

ABM Clinical Protocol #3

Supplementation Scenario

- Parents report that their 4-week-old baby nurses often. They want to know about giving baby some formula each day, ideally so they can get more rest.
- Baby recently had a one-month well-child exam.
- The mom has pumped a few times and has "a bit of milk stored," but they would like to save that for return to work in less than a month.

Supplementation Scenario

- What more, if anything, do you need to know?
- What is the first think you would say to this family?
- How would you offer support?

Decision-Making: Weaning

Influential Beliefs / Myths

- Milestones = weaning (age, teeth, etc.)
- Benefits of human milk stop at a certain point
- Weaning = more solids, increased weight gain
- Distractibility or "Nursing strike" = weaning
- Weaning = independent child (emotionally, in terms of sleep, etc.)
- Sooner is better than later / Now or never mentality

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Weaning

"Ideally, the time for weaning is a joint decision in which both the mother and the baby reach a state or readiness to begin weaning around the same time; however, this is not always the case. The child may be ready before his mother; more often, the mother is ready before her child."

– Riordan & Wambach

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Weaning

- Does the parent want to wean?
- What is the age of the child?
- What obstacles does the parent face in continuing lactation?
- What obstacles might the parent face during weaning?
- What support do they need?

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Considerations

- Stage of Lactation
- Infant Nutrition
- Physiology
- Psychobiology
- Abrupt vs. Gradual

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Abrupt Weaning

"Sometimes, the decision is made to wean quickly. Although the literature offers considerable advice about gradual weaning, there is little information for the anxious mother in a situation in which weaning must be rapid and will necessarily be traumatic. The following nondrug therapies may make deliberate weaning easier and at the same time avert plugged ducts and mastitis:

- Shower and allow the warm water to run over the breasts, or soak the breasts by lying down in the tub.
- Use a breast pump or manual expression to relieve breast fullness.
- Wear a supportive, comfortable bra.
- Observe for signs of plugged ducts or breast infection.
- Expect to feel very emotional during this time and seek support from people who will listen sympathetically.
- Give the baby extra cuddling and holding."

– Riordan & Wambach

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Gradual and Deliberate Weaning

- Over weeks or months
- Partial weaning until full weaning
- Reduced likelihood of painful engorgement and risk of mastitis
- Transition time for parent and child

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Discussion Points

- Knowledge of your population and common cultural norms
- Provide personalized education about appropriate alternatives to the parent's milk
- Education about alternatives
  - donor milk
  - formula
- Refer to pediatric health care provider for concerns
- Anticipatory guidance for next stages

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Weaning Scenario

A single mom of a 3-month-old reports that she has been thinking about weaning. She has been combination feeding since her return to work and feels it would be easier to exclusively formula feed. She enjoys breastfeeding her baby when they're together and likes the idea of her baby continuing to get some of her milk, especially through the winter cold season. Her parents and friends think she should "just do bottles."

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Weaning Scenario

- What more, if anything, do you need to know?
- What is the first think you would say to this family?
- How would you offer support?

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Decision-Making: Dental Care of the Nursing Child

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Dental Care of the Nursing Child

- Primary concern is Early Childhood Caries (ECC)
- Formerly termed "nursing bottle caries," "baby bottle tooth decay," "bottle rot," or "nursing carries."
- Most common chronic infectious disease of early childhood
- Socioeconomic impacts
- Multifactorial etiology

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Causes of ECC

- Cariogenic bacteria (Streptococcus Mutans and Streptococcus Sobrinus)
- Oral health of the entire family
- Diet and nutritional status
- Low levels of saliva and saliva low in pH-level
- Fetal conditions
- Genetics
- Anatomy

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Lactation Understanding

The milk matters

The delivery matters

The anatomy matters

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Lactation Management

- Understand dental recommendations
- Lactation factors
  - Frequency of nursing
  - Duration of nursing sessions
  - Amount and frequency of solid Foods
  - Sleep Location
- Dental/oral hygiene factors
  - Frequency and quality of oral care
  - Challenges including anatomic, developmental, sensory, etc.

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Lactation Management

- Provide guidance on maintaining breastfeeding/chestfeeding based on clients' goals
- Support client decision-making and advocacy

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Understand Dental Recommendations

- Daily cleaning beginning early
- At least twice per day
- Between solid foods and nursing
- Water after food
- Wiping gums
- Brushing teeth

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Teeth Brushing

- Variety of methods and strategies
- Upright facing, lying on lap, etc.
- Games and distractions
- Amount of toothpaste

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Family & Caregiver Practices

- Limit transfer of oral bacteria
- Avoid sharing utensils, water bottles, etc.
- Set a good example
  - Good parental oral hygiene
  - Regular dentist visits
  - Talk about teeth and dental care
  - Read books about the topic

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Dental Visit

- Teeth Eruption
- Age
  - "Recommendation that first dental visit occur within six months after the presence of the first tooth or by a child's first birthday" ~ AADP
- Parental Concerns
  - "If a parent sees any signs of enamel decalcification, white spots, or discoloration developing, a visit to a dentist should occur followed by any needed corrective care." ~ Kotlow

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Quotes about Interactions with Dentists

"We get the most hassle from dentists. Both mine and pediatric. They didn't even bother to check what was safe/compatible with nursing. And if anything is wrong with teeth it's assumed to be nursing, but her non-nursing friends somehow have cavities as well."

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Quotes about Interactions with Dentists

- "We recently had a bad experience at a dentist and I think it was hearing stories for so long about how parents had advocated for their children that helped me trust myself and find my voice to advocate for my kid."
- "After visiting the dentist we had more questions than answers about how their recommendations would fit in with our nursing relationship. You [our lactation consultant] and the … group of other nursing families were so helpful in wading through my mixed emotions and deciding what was right for us."

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Dental Scenario

- Parents report that they recently took their 13-month-old breastfed child to the dentist for the first time. Dentist assumed they were weaning. When parents told dentist they were continuing, they were told to begin brushing or wiping off teeth after bedtime nursing sessions.
- Parents seem conflicted since their toddler falls asleep easily when nursing and nurses 1-2 times per night without issue.
- They would like to know if they need to wake and wipe/brush or night wean.

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Dental Scenario

- What more, if anything, do you need to know?
- What is the first think you would say to this family?
- How would you offer support?

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Lactation-Friendly Dental Professionals

- Pre-screen by phone or website
- Forms or questions that ask about "Nursing/Bottle Habits" indicate a conflation between the two
- Objective vs. Subjective Assessment
- Stories
- Personal experiences

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Lactation Professionals & Dental Professionals

- Network to determine lactation-friendliness
- Keep a list
- Provide referrals
- Work collaboratively as appropriate

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Summary

- We can help ensure that parents understand:
  - The facts/situation as it is,
  - What is being recommended, and why,
  - Implications – both positive and negative - of actions that may come from a change in course or doing nothing,
  - And possible future consequences
- Use active listening skills and a team approach
- Offer assistance with listing and analyzing pros and cons
- Discuss and model informed decision-making
- Provide on-going support

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Thank You!

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