





IN TIMES OF CRISIS

Thursday, Feb 27 noon - 1 p.m.



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Parenting After the NICU: Prioritizing Perinatal Mental Health and Family Well-Being

Parenting After the NICU: Prioritizing Perinatal Mental Health and Family Well-Being

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WithinReach Learning Series February 27, 2025

Today's goals

- Understand challenges families face when an infant requires care in the NICU and transitions home
- Identify strategies to strengthen the parent-child relationship to integrate into your interactions with families
- Describe the efforts of Hospital-to-Home Systems Change work

Terms

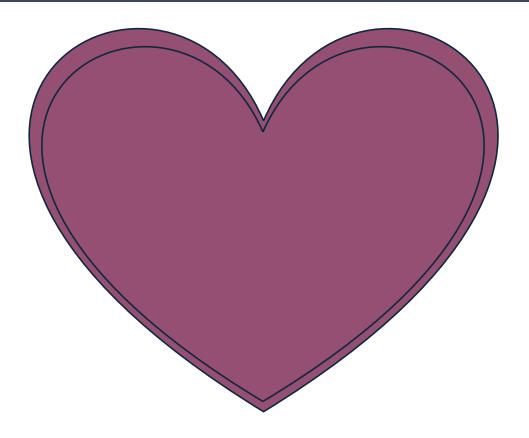
- NICU Neonatal Intensive Care Unit
- ESIT Early Support for Infants and Toddlers (Name for Part C of IDEA services in Washington State)
- Perinatal Refers to the time from conception to a year postpartum
- PMADs Perinatal Mood and Anxiety Disorders
- PFD Pediatric Feeding Disorder

Language

- Use "caregiver" and "parent" interchangeable to recognize:
 - Non-biological parenting roles
 - Acknowledge not all birthing individuals identify as women or mothers
- Hospital-to-Home (H2H) Care Model interdisciplinary
 approach to ESIT services for infants discharging from the
 NICU integrates support for the perinatal mental health of
 parents within therapeutic support for the infant's feeding,
 growth, and development



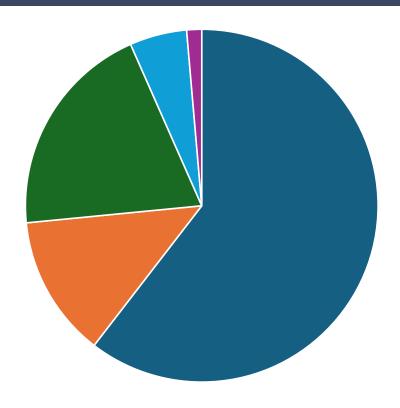
Trigger warning





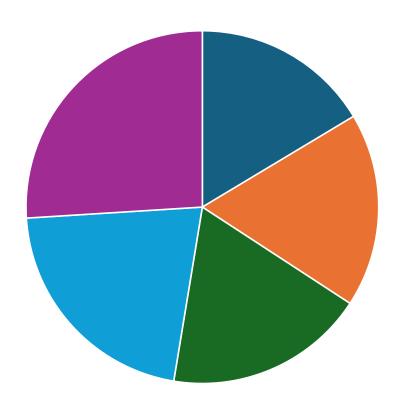
WA State Live Births: 2020-2022

- White
- Asian/Pacific Islander
- Hispanic
- Black
- American Indian/ Alaska Native



WA State Preterm Birth Health Disparities

- White
- Asian/Pacific Islander
- Hispanic
- Black
- American Indian/ Alaska Native



Neonatal Levels of Care Among Birthing Hospitals in Washington, 2022 Births PEACE HEALTH SAINT JOSEPH 1,876 MID-VALLEY 297 Pend Oreille **NEWPORT 25** JEFFERSON HEALTHCARE 95 FORKS COMMUNITY 38 LAKE CHELAN 89 MULTICARE PROVIDENCE SAC VIRGINIA MASON SAMARITAN 978 KITTITAS VALLEY 317 Whitman HARBOR REGIONAL HEALTH 293 OTHELLO COMMUNITY 410 REGIONAL 36 PROVIDENCE CENTRALIA 661 YAKIMA VALLEY MEMORIAL ASTRIA TOPPENISH HOSPITAL 241 IDENCE - KADLEC 2,640 PEACEHEALTH 767 Level 1 Klickstat LEGACY - SALMON CREEK 3, Level 4 No CON December 27, 2023

Psychosocial Challenges for NICU Parents

NICU babies are fragile and need their parents' engagement and encouragement to develop and thrive

Their parents need the same level of loving kindness and skill building help to grow and thrive as new parents

Obstacles to Successful Bonding/Attachment

Infants

- Medical intervention, not relationships
- Fragility of baby's appearance
- Medical touch, not loving touch
- Unable to generate "typical" attachment behaviors
- Cannot offer regulating function for parent

Caregivers

- Discrepancies expectations vs reality (grief, loss, shock)
- Attachment vulnerabilities magnified to high levels
- Lack of emotional engagement
- Inability to perform typical parenting behaviors that build relationship and role confidence

Obstacles to Learning Infant's Cues

- Instead learning to read medical cues
 - "Read" staff for cues
 - "Med-speak", not baby talk
- Hyper-vigilance
- Machines—lifesaving AND interrupt the natural development relationship
- Going home—anxiety provoking, without hospital cues and timing

Perinatal Mood & Anxiety Disorders (PMADs)

- NICU parents at high risk
- Likelihood increased with delayed or frayed attachments
- Creates obstacles to successful bonding and attachment

PMADs Rates in NICU Parents

- Posttraumatic Stress Disorder (PTSD) NICU itself may be traumatic event separate from and in addition to other birth-related traumas.
 - PTSD rates in parents ranges 4.5% 30% (McKeown et al; 2022)
- Depression NICU mothers had 74% higher risk of developing PPD
 - general population PPD increased 3-fold during pandemic (Shuman et al; 2022), BIPOC and marginalized groups with marked increase
- Anxiety NICU mothers show anxiety range 18-43%
 - Recent study just under half of parents in NICU level 4 had clinically significant levels of anxiety or depression

Parent Role Development

- Proximity
- Frequent interactions
- Successful completion of behaviors consistent with (pre-existing) images of "good parenting"

Becoming a Parent in the NICU

Requires building parental identity on a very different basis

new and never imagined tasks must be mastered in the context of emotional distress, trauma, and grief.

Why does this Matter?

- On your doorstep, one or both parents:
 - 80% likely suffering from a PMAD
 - May be grieving loss of "normal..."
- Others may not have mentioned PMADs and/or provided resources
- Respectful acknowledgement, proper labeling helps parents enhance connection to baby

Challenges of Being Home Post-NICU

Social

- Discomfort in role
- Isolation and grief
- Future filled with unknowns

Economic

- Financial pressure
- Lack of childcare options

Physical

- Birth recovery
- Health exposure concerns

Logistical

- Home not set-up for medical equipment
- Difficulty navigating follow-up

Risk Factors

- Infants are at risk for feeding concerns and/or developmental delay
- Parents are at risk of experiencing PMADs

Addressing the Service Cliff: What can we do?

Critical to make timely referrals and provision of community therapy

- Reduces parental stress
- Improves parent-child attachment
- Supports better infant health outcomes
- May reduce overall medical expenditures

Early Support for Infants & Toddlers (ESIT)

- What is ESIT?
- Where do I learn more?
 - https://dcyf.wa.gov/services/

child-dev-support-

providers/esit

Early Support for Infants and Toddlers

Early intervention services during the first three years can make a big difference in a child's life. The Early Support for Infants and Toddlers (ESIT) program provides services to children birth to age 3 who have disabilities or developmental delays.

Part C of the Individuals with Disabilities Education Act is a federal grant program that assists states in operating a comprehensive statewide program of early intervention services for infants and toddlers with disabilities, ages birth through age 2 years, and their families.

Congress established this program in 1986 in recognition of "an urgent" and substantial need" to:

- enhance the development of infants and toddlers with disabilities
- · reduce educational costs by minimizing the need for special

Contact Resources I need services or support in my local area **ESIT Statewide Directory** Information for Healthcare Providers Early Intervention Referral Form for Healthcare Providers **ESIT Program Staff ESIT Staff Directory** ☑ ESIT@dcyf.wa.gov **** 360-725-3500 For Families Needing Help with a Referral WithinReach Help Me Grow Washington Hotline 155 N.E. 100th St., Suite 500,

Seattle, WA 98125 Toll Free: (800) 322-2588

withinreachwa.org

Email: childdevelopment@

H2H Care Model

Care
Continuum
Handout for
Providers



Community-based infant feeding and developmental therapy can support caregivers' emotional well-being by

Providing therapy in natural environment (e.g., home)

Offering family-centered care

Connecting families to community resources



H2H Care Model

Specially trained team

Rapid follow-up post discharge

Interdisciplinary team

Understanding & supporting perinatal mental health

Clear communication with families and medical providers

Feeding & Attachment Considerations

- Parents equate their parenting success to ability to feed their baby (Thoyre, 2001)
- Infant stable and still learning
- Evolution of feeding goals
- Support caregiver with intentional engagement

Feeding & Emotional Wellbeing are Connected

- Perinatal mental health impacts attachment, development, ability to implement feeding strategies (Park et al., 2016; Parker et al., 2016).
 - Learning, understanding and using feeding skills
 - Interactions and ability to read, respond and respect infant's cues

Learn more about pediatric feeding disorder at www.feedingmatters.org/

Caregiver Support: Create Space

Photos

NICU Admission photo

Parent holding infant on CPAP and OG

Two pumped bottles of milk with pump parts attached

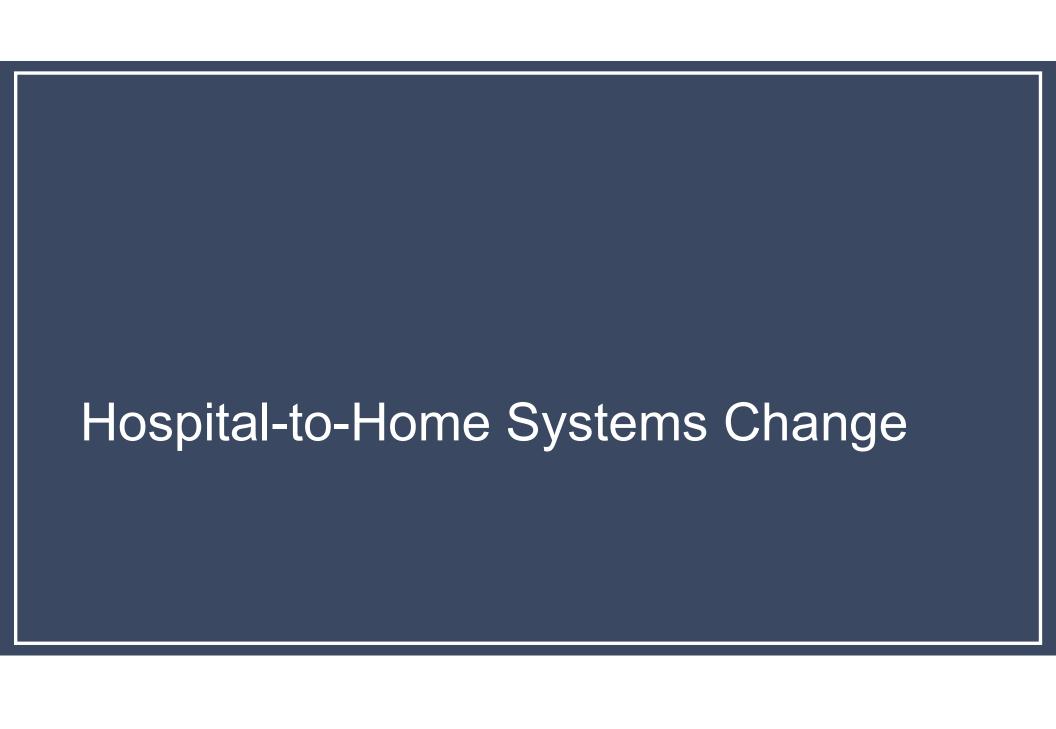
Parent bottle feeding infant

Caregiver Support: Parallel Process

Photo: Infant looking lovingly at parent

Caregiver Support: Emotion Cues

- NURSE: Responding to Emotions
- Naming
- Understanding
- Respecting
- Supporting
- Exploring



Mission / Goals

- Address the barriers, gaps in care, and inequities that exist for infants and caregivers transitioning from the hospital into ESIT and community therapy services throughout the state.
- Build workforce capacity to support the H2H population.

Tenets of H2H Systems Change Work

Hospital

Understand landscape

Connect with Referral sources to

- Educate about ESIT
- Support continuity

Home

- Build workforce capacity
- Develop community of practice
- Consultations

Advocacy

- Present / Share out H2H
- Convene PMH task force
- Supporting statewide change

Perinatal Mental Health

Training Efforts to Build Workforce Capacity

- Interdisciplinary innovative 3-day training
 - Day 1: PMH (foundational)
 - Day 2: PFD in infants
 - Day 3: Special topics & Parent voice
- Project ECHO series:
 - "all teach, all learn" model

"Our ESIT therapists have been an incredible source of support in helping us recover from the feeding challenges and from the anxiety and trauma that came with them. We had been in a never-ending grind of counting ounces taken in, weighing baby weekly (only to find he had barely gained weight), and feeding around the clock. We were so drained, and our lives were deeply impacted by the struggle. We couldn't go for walks, outings, or trips like other families because feedings were so fragile and tenuous. We hated to think how our anxiety about feeds and his lacking nourishment might impact our baby's development and attachment. But our ESIT therapist helped us regain trust in baby's perfectly healthy instincts and his clear communication skills. He knew and had always known what worked for him and what didn't and he'd always let us know. Our ESIT therapist helped us see this and... we learned to trust and listen to him in a way that healed all of us from the rough start we'd had."



~Hospital-to-Home Parent

In summary, ways to prioritize perinatal mental health and family well-being...

- Be Present sit with
- Listen to caregivers
- Collaborate seek opportunities to connect and partner
- Reflect on ways to integrate support for the emotional well-being of parents into the work already being done
- Advocate for systemic changes that best support the needs of infants and caregivers
- Make small changes, they can lead to bigger changes

How to Connect with Us

- Sara Circelli, MA, IMH-E, PMH-C <u>scircelli@nwcenter.org</u>
- Tiffany Elliott, SLP, CNT, IBCLC, NTMTC <u>telliott@nwcenter.org</u>
 or <u>feedingconnections@gmail.com</u>
- Leslie Butterfield, Ph.D. <u>dr.lesliebutterfield@gmail.com</u>
- www.hospitaltohomesystemschange.org

Next Steps

- Q&A Time
- Handout
 - contact info
 - resources