

# **Developing a program for substance-exposed newborns and their families: Lessons from Project NESST**

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# Voices of Mothers

- *“...it’s a real struggle being a mom with an addiction...I can’t say I wasn’t a good mom...I just wasn’t what I should have been and could have been...”*
- *“I just started crying and I’m like...here’s the dream I always wanted in a really shitty situation... I was mostly crying about the fact that I had just binged completely on dope and the fact that I was now pregnant.”*
- *“...a lot of the nurses they were awesome...but I don’t think they really understand how it is to have a baby that’s born, you know, addicted.”*

# Talk Outline

- Our understanding of the context
- Foundation & building of our intervention program, Project NESST
- Lessons *learning*
- Ideas for impacting policy & practice

*Throughout: the voices of mothers*

# Core Beliefs

- “There’s no such thing as a baby.” -- D. Winnicott, 1940
- Addiction is a chronic disease which affects brain functioning
- Addiction is often successfully managed with treatment
- Our words matter

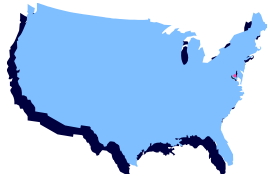
# Core Beliefs

- Relationship-based: all levels of relationship matter and affect each other
- Informed by attachment theory and understanding of trauma
- Change happens in the context of trust and shared exploration
- Cultivate curiosity and reflection in staff and clients

# What do we mean by substance-exposed newborn (SEN)?

- Infants can be exposed knowingly or unknowingly to a wide range of substances in utero
- Tobacco, alcohol, misused medications, illegal drugs, methadone/suboxone and other prescribed opiates
- In Mass., estimates of 1/3 of infants have some degree of substance exposure
- 10-12% may be affected
- Opiate exposure includes:
  - Street opiates such as heroin
  - Painkillers: e.g. oxycontin, by prescription or misused
  - Medication-assisted therapy: methadone or suboxone

# How is This Problem Addressed?



States: Policies and public awareness campaigns (Young et al., 2009)



Hospitals: Screening and treatment of NAS (Jones et al., 2010)



Researchers: Consequences of prenatal substance use on child growth and development (Bandstra et al., 2010; Coles and Black, 2006)



Media: Alarm of painkiller abuse among pregnant women



# New York Times

## Surge in Narcotic Prescriptions for Pregnant Women

By CATHERINE SAINT LOUIS  
APRIL 13, 2014



George Bates

JF&CS



By Jenifer McKim and Michael Bottari NEW ENGLAND CENTER FOR INVESTIGATIVE REPORTING

# Cases soar of newborns with opiate addiction



## Withdrawal agony for hundreds

MARSHFIELD— Mya Barry was born in April 2011 with opiates already coursing through her tiny veins. But it was not the heroin passed to her in utero by her drug-addicted mother that killed the infant, prosecutors say.

JOHN TLUMACKI/GLOBE STAFF



# What's Missing?



States: Policies and public awareness campaigns (Young et al., 2009)



Hospitals: Screening and treatment of NAS (Jones et al., 2010)

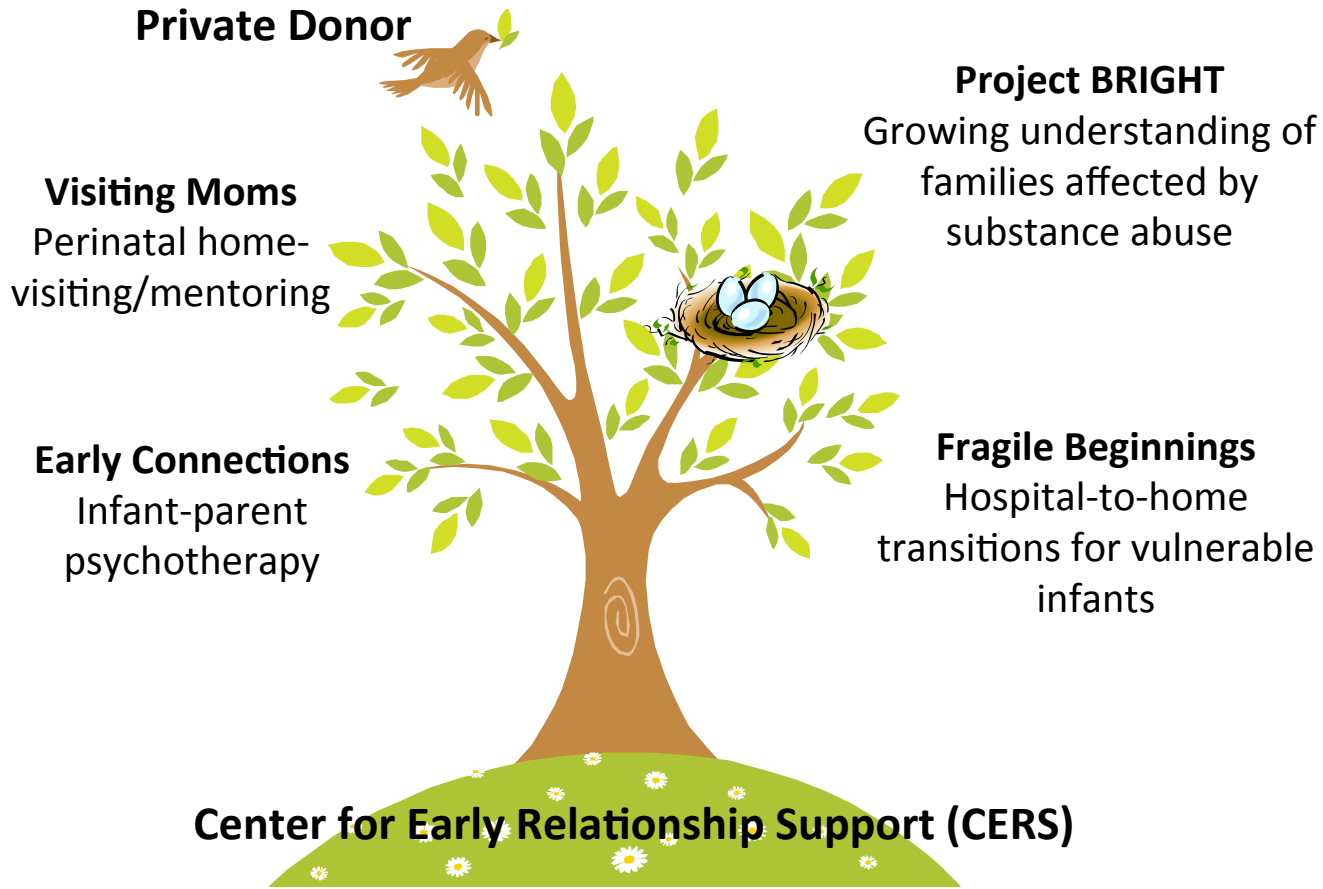


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# Building Our NESST (Newborns Exposed to Substances: Support and Therapy)



# Sources for Our Needs Assessment Year

- Interview study
- Key informant interviews: child welfare staff; developers of similar programs; providers in medication-assisted treatment and other outpatient programs
- Literature review: Suchman, Pajulo, Velez, Moran
- Webinars and conferences: SAMHSA; AIA; NCTSN
- Pilot cases

# Aims of the Needs Assessment

- Fill a gap in the understanding of the experience of women through pregnancy, birth and early parenting of a substance-exposed infant
- Use this data—from consumers, providers, the literature and pilot cases-- to inform the development of our services in Project NESST (Newborns Exposed to Substances: Support and Therapy)

# Interview Study

- Qualitative, semi-structured interview
- Eligibility: mother of a child under 4 who was using (crack/cocaine, opiates or opiate replacement) during pregnancy
- Focus on three general areas:
  - Emotional experience of pregnancy, birth, postpartum and early parenting
  - Experience of interface with systems of care: health care/hospital staff, child protection, social service
  - Reflections on their needs and what was helpful or might have been helpful

# Interview Participants

- 21 interviews across Massachusetts
- 18 Caucasian; 1 Latina; 2 African-American
- Ages: 21-44 (average age = 29)
- 13 had high school education or less
- Substance use: most polysubstance use during pregnancy; majority on MAT when interviewed

# Interview experience

## (participant & Interviewer)

- Initial question: tell me your story of becoming a mother to \_\_\_\_\_, beginning in pregnancy, in as much detail as you'd like.
- Most women seemed very candid and invested in sharing their story; some seemed more hesitant
- Participants expressed:
  - *“it’s good to have someone care to listen to my story”*
  - *“it’s helpful to remember where I’ve come from”*
- Interviewers expressed:
  - Concerns re: single session of sharing such potentially triggering material
  - Sense of privilege, and occasional overwhelm, in hearing painful stories
  - Moments of doubt re: what a single program can offer to such big problems



# Select Interview Findings

- **Pregnancy as motivation:** Concern for infants and desire to be good mothers served as motivator for treatment and sobriety
- **Obstacles to help:** most mothers faced uncertainties, not knowing what to do or where to get help
- **Mixed experiences with providers:** interface with health and social services felt as both helpful and stigmatizing
- **Shame, guilt and fear:** these pervasive feelings led to secrecy, denial and avoidance
- **Ideas about help:** women themselves had clear suggestions about what could be helpful to others

# Pregnancy as Motivation

*“There’s a certain safety for the most part of being pregnant...it’s almost like that extra push to not pick up anything because even when you can’t do it for yourself, you’re supposed to instinctively be able to do it for the baby and that’s not always true but for me at that time, it was...”*

*“So I talked to this guy ... I told him ... I felt like a monster, and all these crazy things .... He’s like, ‘Did you want this, do you want this pregnancy?’ I said, ‘I absolutely... I want this pregnancy but I want it to go good for him. I’ve been pushed in this direction for months now, I’ve been trying to do it on my own, clearly that’s not working so I need some kind of help.’ ”*

# Obstacles to Help

*“it was hard because I didn’t have stable living...I was worried about rent 24/7 and it just sucked...and I went to a program and he (partner) couldn’t come with me and that was the worst part because I would have to leave my partner homeless on the street...”*

*“I thought I would lose my kids...they(DCF) need to be more understanding you know, we’re not bad people because we’re having, we’re having a problem. We don’t deserve to have our kids ripped out because we have a problem.”*

*“I totally wished that when I found out and they took my blood, that they would have been like, ‘there’s opiates in your system, we need to put you in some kind of help, or get you to some kind of program like methadone’. I didn’t even know that was an option at the time ... I thought that was worse for you when you’re pregnant...”*

# Mixed Experiences with Health Providers

## Negative experiences:

*“when I was in (the hospital), one of the midwives said, in front of all my company, and this is the stuff that I believe shouldn’t happen, she said, right in front of everybody that was there, ‘did the social worker come and see you yet?’... why would you say that in front of everybody, you know? I know it was all family and stuff, but still that’s my personal...business.”*

*“I just had nurses constantly judging me, I had one come in (and say to the baby) ‘oh you poor baby, that’s awful that you have to detox like this’ in front of me, just to make me feel like crap...”*

# Mixed Experiences with Health Providers

## Positive experiences:

*“...the nurses in the NICU were really helpful and so were the neonatologist that took care of her. Cause everyday they’d come and they’d check her out, her breathing and they would explain everything you know, ‘this is why she is doing this, and you might see her do a little bit of tremor. And then you know when she gets home you know (you) have to give her her medicine and to watch for any side effects’ and so they were really nice and helpful and supportive”.*

*“I set up an appointment to go to (the hospital) with the doctor of the NICU...she explained everything. She showed me the level 2 room. She showed me the parenting room...she told me about the morphine and the phenobarb how she might need the morphine, she might not. She might need the phenobarb, she might not or both together...she explained it.”*

# Mixed Experiences with Child Welfare

- Negative experience:

*“I was there one day alone and I was kind of depressed because DCF had come in... the lady was horrible, she was so rude, she’s like “you obviously had no respect for your kid, you almost killed him” and all these things, like she was just totally putting me down...”*

- Positive experience:

*“DCF offers a lot of services; you know what I’m saying? I’m saying they’re really not there to do harm, you know they’re just doing their job and like I think, like they really do want to make sure that the kids is safe.”*

# Shame, Guilt and Fear

*“I always felt like if I was to tell a doctor or to tell somebody that I’d be so judged and looked at like a piece of crap, for having a new born and having a drug addiction.”*

*“I never realized how bad it was until I was actually pregnant and doing all of these things, I mean, I was disgusted in myself...”*

*“I got pregnant with my second son when I was in the grips of my disease and I couldn’t stop, and I thought I was the only person, yeah, I thought I was the only woman on the face of this earth scum bag enough to use while pregnant, so I didn’t know who to tell, I thought that if I told somebody I’d be walking around with like the letter “A” on my chest.”*

# What Would Help

*“...somebody that will go along with a mom to these places, like a Suboxone clinic, it’s scary, it sucks admitting it to all these people... somebody to help talk to these doctors, you know, an average drug addict to the doctor are from two different worlds, really, it’s hard to talk to them... you don’t want to feel judged, you need somebody there that isn’t judging you, and understands...”*

*“I think it would have been good to have like a case worker that’s not, like not a counselor, not like a DCF worker, like a case worker... kind of like a sponsor but for parenting, that I could have talked to, and um, that I wouldn’t have to worry about being punished for my thoughts, or, you know, just somebody that would listen to me.”*



# Building a NESST

- Given what we heard from our needs assessment, what did we take into consideration regarding:
  - Shape of our **program design**
  - Outcomes and process in **program evaluation**
  - **Consultation and training** to other providers

# Considerations for Program Design

- Model is **flexible and individualized** as the needs of the women are varied and shift depending on their stability in recovery and living situation as well as other demands
- Meeting of **basic needs**--housing, health care, clothing, food—can be facilitated either directly by staff or through referral
- Staff need **reflective supervision** where they can be open about the complex feelings evoked in work with vulnerable mothers and babies
- Affecting the lives of these families means engaging with the **systems of care** that surround them

# Considerations for Program Design

- Clinical opportunities for mothers to work through unresolved histories of trauma and loss, ongoing mental health needs, and complexity in the development of a maternal identity
- Peer recovery support from someone who's "been there" and can offer encouragement, coaching, modeling, and connections to other moms who have "been there" too.
- Home, hospital and community availability to meet moms where they are; typically weekly but can adjust depending on needs
- Engagement opportunities during pregnancy; barriers related as much to guilt & shame as to practical realities

# Considerations for Evaluation

- Close collaboration with our research partner in developing evaluation: what do we want to know; what do we want to measure
- Baseline: demographics; substance use; trauma hx
- Pre and post-measures:
  - Experience of motherhood
  - Psychological distress
  - Child development
- Value of qualitative research and continuing to listen to and learn from program participants

# Considerations for Training

- Interviews highlighted the importance of working with health, social service and child welfare providers re: issues of language, stance and communication
- Moms with lived experience have a special role to play in this
- Interactions with providers can be very powerful, for good or ill

# Learning As We Grow

- Since beginning service delivery in 2013, NESST has served 85 families
- Over 90% involved in child welfare
- Almost 1600 providers received training in MA in FY16.
  - Focus on “high touch” providers including Healthy Families, Early Intervention
  - Hopes for FY17: Child Welfare

# Engagement: the long and winding road

- Flexibility: time, place, frequency, dosage
- “Persistence through discomfort”: attend to internal and external obstacles
- Expect ambivalence and “layers of truth”
- Understand that moms have often kept their parenting and their substance misuse separated and we represent both
- Hold in mind the links between difficult behaviors (cancellations; inconsistent communication) and underlying feelings

# Clinical Needs

- Many mothers present with an overlay of serious mental health issues
- Mentoring Moms may not be equipped to respond fully to these vulnerabilities
- Common challenges: perinatal mood difficulties; partner violence; grief & loss; PTSD; isolation
- Meeting the need:
  - Ensure that each family has involvement/oversight from a clinician; offers better safety net for the family and for the MM
  - Close collaboration with DV and perinatal psychiatry



# Case Management Needs

- Identify concrete service needs at intake and continually reassess
- Addressing these can make space to focus on emotional needs of self and baby
- Working on issues like housing and food insecurity buffers stress, a significant protective intervention
- Potential significant clinical value:
  - Opportunity for experience of a collaborative relationship; thinking together about ways to problem solve
  - Building trust: you are important; I will follow through
  - Bridge to broader world of services and support

# Managing Protective Risk

- Balancing the needs of mother and child can represent a significant challenge: mother may be preoccupied (recovery journey; partner issues) and unable to consistently attend to child
- Holding the responsibility for child safety while understanding the vulnerability to relapse can be a source of high stress for the clinician and potential rupture for the treatment relationship

# Our Approach to Managing Risk

- Focus on relapse prevention and safety planning from the start
- Highlight moments of infant's signals and shared pleasure to support maternal and dyadic competence
- Share observations of “levels of arousal” without attribution of cause
- Build strong therapeutic alliance that can hold difficult conversations
- Use mindful self-regulation and reflective supervision to manage own states

# Treatment Themes

- Building narrative coherence
  - When and how is it important to help a mom create a coherent story of her life: bridge the parts of her life she wants to leave behind with current hopes and plans
  - How do we support the integration of multiple “selves” into a whole
  - How do we help moms feel strong enough to tolerate our both knowing the dark places they’ve been—traumas they’ve suffered and potentially traumas they’ve caused

# Focus on the dyad

- Shared observation of the baby's capacities and communications
  - May offer respite from more difficult discussions
  - Present moment focus can be regulating
  - Mom can be the expert on her baby
- Building capacities for shared pleasure
  - Can parenting and relationship with baby be a source of pleasure to potentially build/repair the brain circuitry “hijacked” by addiction?
- Parenting this baby can be successful
  - May open possibilities for acknowledging losses and grief of older children not in custody

# Emotion Regulation

- Central to both parenting and recovery:
  - Substance use as a disorder of emotion regulation; compromised capacities for managing difficult feelings
  - SENs often challenged in regulating sleep and distress
  - Baby’s distress may trigger mom’s vulnerability
  - “The substance-exposed mother and child are difficult regulatory partners for each other.” (Pajulo, 2013)
- Building regulation skills:
  - Making space for knowing and tolerating distress—mom’s and baby’s
  - Mindfulness strategies:
  - Promoting self-compassion:
    - can heal feelings of shame and guilt

# Lessons for Consultation & Training

- Many women described difficulties in their relationships with health and social service providers: inconsistent information; blame, judgment
- Opportunities for program impact in training across many settings: children's protective services, obstetric care, birthing hospitals, addiction treatment programs, mental health settings, healthcare spending/insurance, Early Intervention...
- Found that providers are very interested in learning from "lived experience". Opportunities to bring the experiences of mothers to providers.

# Lessons for Policy-Makers

- Bringing the science of infant mental health to the care of SEN and their parents
  - Supporting dyadic care
  - Considering age & development in care guidelines
- Bringing the needs of parents in recovery to practice decisions and guidelines
  - Funding for prenatal, flexible, extended engagement
  - Funding mental health support for recovery program



# Learning When Things Go Well

- Some markers of positive change
  - Increased maternal capacities:
    - To hold the baby in mind
    - To regulate her own feeling states
  - Decreased depression/anxiety
  - Increased self-esteem
  - Stable recovery
  - Experience of support as helpful that can be accessed as needed in the future
- Therapeutic value of concrete services

# Learning When Things Do Not Go Well

- Tolerating our own feelings of disappointment, frustration, helplessness
- Seeing role for bearing witness to painful and troubling situations
- Using colleagues, supervisors for reflection and support
- Considering difficult issues: maternal ambivalence; social construction of motherhood; programmatic and personal limits

# Voices of Mothers: “Take-Home Points”

- Listening leads to a better provider-patient relationship, and a better relationship with a mother means better outcomes for both mother and baby.
- Pregnancy is a time of high motivation for recovery but the pathways to being open to help are strewn with many barriers, both internally and externally. Keep trying: ask, listen, care. Repeat.
- Mothers of substance-exposed newborns carry complex feelings about pregnancy, birth, and parenting. The behaviors we see on the outside – like secrecy, avoidance, and denial – often reflect shame, guilt and fear of judgment inside.
- Mothers want to participate and be valued both prenatally and during the NICU experience. Collaborate, educate, include... your stance will be welcomed.



# Thank You

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