Newborn Screening STFU: Collaborating with Families & Providers in Community Birth Settings

Courtney L. Everson, PhD

Midwives College of Utah, Midwives Alliance Division of Research

Sources

1

Extensive participant observation as a medical anthropologist

2

Immersed as a midwifery educator, researcher, and practitioner

3

Comprehensive Literature Review

Including previous MPH project by Gina Gerboth, CPM, RM, MPH, IBCLC

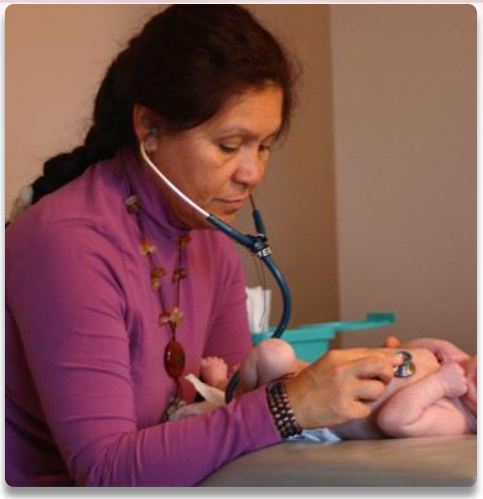
Welcome!

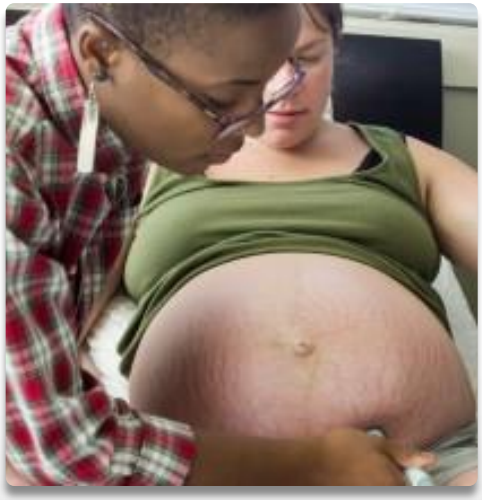
- **Purpose**: two-fold purpose today
  - to examine communication and outreach strategies for working with clients and midwives in community birth settings
  - to discuss challenges facing midwives and clients for NBS in community birth settings
- **Outline:**
  - Understanding midwives
  - What is community birth?
  - Understanding models of care
  - The midwife-client partnership
  - Why do parents reject NBS?
  - Barriers to STFU
  - Overcoming identified barriers
  - Communication strategies

Images Courtesy of: Google Images

Understanding Midwives

- Two main types of midwives in the US
  - **Direct-entry midwives (DEMs)**
  - Certified nurse-midwives (CNMs)
- DEMs bypass nursing school and go directly into midwifery training
- National certifying credential: Certified Professional Midwife (CPM)
- DEMs primarily work in community birth settings
  - Homebirth
  - Freestanding Birth Centers





Images courtesy of: AME & MEAC

Understanding Midwives

JUST Added Alabama too!

Legislative work continues

Map courtesy of: the Big Push for Midwives

Understanding Midwives

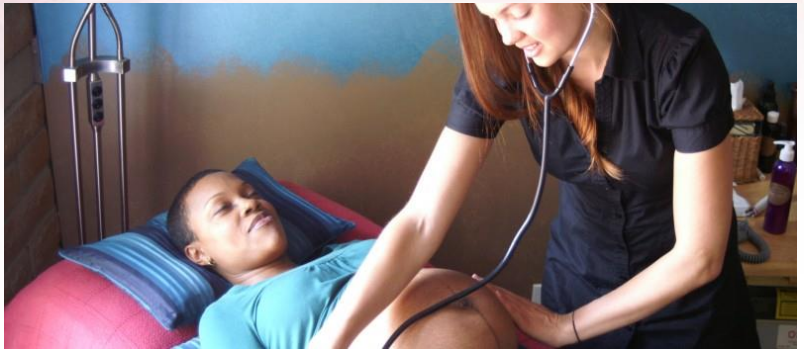
Outcomes are overwhelmingly positive

Quick Points

- This study reports maternal and neonatal outcomes for women planning to give birth at home under midwife-led care, as recorded in the Midwives Alliance of North America Statistics Project dataset (version 2.0, birth years 2004-2009).
- Among 16,924 women planning a home birth at the onset of labor, 94% had a vaginal birth, and fewer than 5% required oxytocin augmentation or epidural analgesia.
- Eleven percent of women who went into labor intending to give birth at home transferred to the hospital during labor; failure to progress was the primary reason for intrapartum transfer.
- Nearly 1100 women attempted a vaginal birth after cesarean (VBAC) in this sample, with a total VBAC success rate of 87%.
- Rates of cesarean, low 5-minute Apgar score (< 7), intact perineum, breastfeeding, and intrapartum and early neonatal mortality for this sample are all consistent with reported outcomes from the best available population-based, observational studies of planned home births.

Cheyney, M., Bovbjerg, M., Everson, C., Gordon, W., Hannibal, D., & Vedam, S. (2014). Outcomes of Care for 16,924 Planned Home Births in the United States: The Midwives Alliance of North America Statistics Project, 2004 to 2009**.** *Journal of Midwifery & Women's Health, 59*(1): 17-27. DOI: 10.1111/jmwh.12172

What is Community Birth?



Images Courtesy of: Morag Hastings, Apple Blossom Families Photography; Thinkstock; Birth Outside the Box; Puget Sound Midwives & Birth Center; Midwives College of Utah

NBS Blood Spot Screen & Community Birth

Weighing baby and performing screen in home setting

Images Courtesy of: Baidi & Gentle Delivery Midwifery Services

However…

- A small percentage of the time (~6%), another provider performs the screen on the midwife's behalf (e.g., a pediatrician) (Gerborth, 2015)
- This poses an additional layer of difficulty
- Focus today remains on clients receiving NBS through midwives in community birth settings

Understanding Models of Care

- Clients commonly choose midwives and community birth settings in order to receive the Midwives Model of Care™ (Citizens for Midwifery)
- Based on the fact that pregnancy & birth are normal life processes
- The MMOC includes:
  - Monitoring the physical, psychological, and social well-being of the mother throughout the childbearing cycle
  - Providing the mother with individualized education, counseling, and prenatal care, continuous hands-on assistance during labor and delivery, and postpartum support
  - Minimizing technological interventions
  - Identifying and referring individuals who require obstetrical attention
  - The application of this client-centered model of care has been proven to reduce the incidence of birth injury, trauma, and cesarean section.

Understanding Models of Care

Medical/Technocratic Model	Midwifery/Holistic Model
Provider-centered, male centered	Person-centered
Patient	Client
Top down decision-making	Shared decision-making
Social support unimportant or secondary	Family as significant social unit
Passive subject	Active agent
Hospital as “factory”; baby as “product”	Home as nurturing; Mother-baby dyad
Technical, scientific knowledge as only knowledge of value	Bodily, experiential, emotional knowledge valued
Childbirth as dysfunctional, pathological	Childbirth as normal, physiologic process
Controlled by interventions	Supported by low-tech, high-touch techniques
Obstetrician as “manager/skilled technician”	Midwife as “skillful guide”

(Adapted from: Davis-Floyd 1992; Katz Rothman 1982)

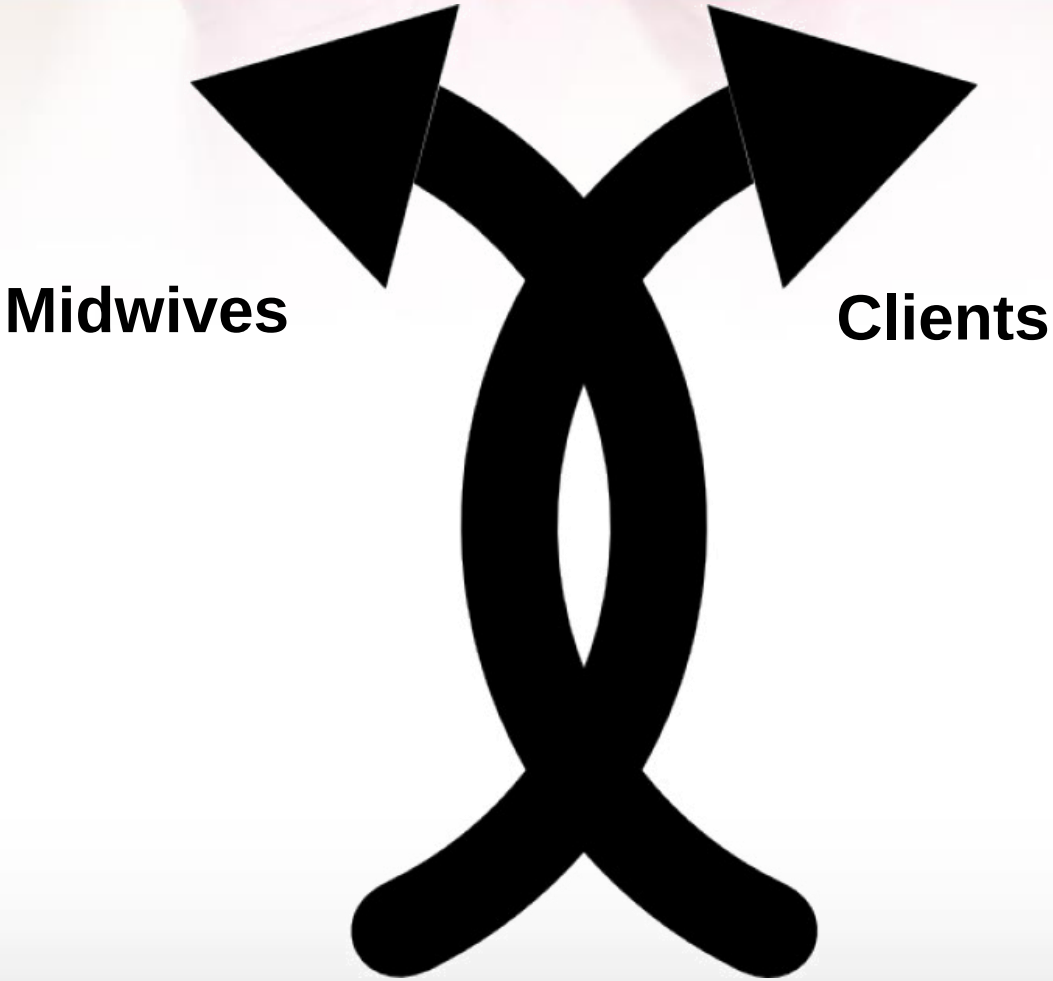
MMoC Principles Summarized: What this looks like in practice

- **Client autonomy**
  - Recognizes the autonomous rights of parents to choose or decline newborn screens
- **Shared decision-making**
  - Supports the collective decision-making strategy of provider and client around NBS
- **Wellness**
  - Explicitly promotes wellness in communicating NBS
- **Prevention**
  - Acknowledges newborn screening as a strategy for preventative care
- **Comprehensive education**
  - Benefits, risks, options, and next steps of NBS thoroughly explained with evidence

Balancing the art and science of midwifery

- **Negative attributes**
  - Intervention (identifies newborn screening as a medical intervention)
  - Fear-based (utilizes fear-based messages to promote newborn screening)
  - Total mandate (explains newborn screening as a state legal mandate)

Inherently Intertwined



Let's start at the top

- Why do some parents reject newborn screens?
  - Let's brainstorm together!
- Documented reasons include:
  - Ineffective NBS education approaches
    - Don't understand benefits and risks
    - Don't understand need for early intervention
    - False positives
  - Fear or distrust of how DBS will be used
  - Interrupts bonding time and baby may feel pain
  - Cost (and lack of insurance coverage)
- & which of these apply to providers as well?

Let's start at the top

- In addition, there are provider-level structural barriers:
  - Timely transport barriers
  - Training
  - Confidence
  - Reality of one-stop-shop midwifery pressures
  - Marginalization of midwives (and their clients)
  - Access to materials needed to do the screen
  - Legal status of direct-entry midwifery by state
  - Lack of midwife-friendly educational materials
    - Appropriateness to community birth settings
- Dynamic interplay between client and provider barriers

What about STFU?

- What are the barriers to STFU, specifically?
  - Let's brainstorm together!
- Documented barriers include:
  - Inadequate information provided on card
  - Ineffective NBS education
    - Don't understand need for early intervention
    - Don't know how to access services
  - Worried about cost of follow-up services
  - Don't want to be "shamed" for choice in birth
- & which of these apply to providers as well?

So how do we address these barriers?

- What are some ways to address these barriers?
  - Let's brainstorm together!

C. Background/Data Supporting Position

Newborn Screening (NBS) is an accepted, important and data driven public health initiative (1). Short term follow-up is an essential component of the NBS process that ensures confirmation of diagnosis or rules out conditions on the screening panel and then ensures all newborns with a confirmed diagnosis are in the care of the appropriate specialist and receiving the necessary treatment required for a better quality of life. Successful NBS requires timely collection of specimens by birthing facilities, dependable transport of specimens to the screening laboratory, prompt processing and analysis of specimens, and timely reporting of results to the follow-up team, primary care provider, subspecialty providers and families.

Addressing Barriers: Documented Ideas Include…

Parents (Clients)

- Prenatal as well as postpartum education
- Comprehensive education (true informed consent)
  - DBS focus
  - Emphasize next steps upfront
- Breastfeed while screen is being performed
- Find ways to support affordable access to NBS
- Dispel myths

Providers (Midwives)

- Use gentle lancets like Tenderfoot
- Find ways to support affordable access to NBS
- Ongoing provider education
- Interprofessional collaboration
- Courier services
- Dispel myths
- Provide midwife-friendly educational materials

Communication Strategies

Midwifery 38 (2016) 21–28

Contents lists available at ScienceDirect

Midwifery

journal homepage: www.elsevier.com/midw

Risk talk: Using evidence without increasing fear

Vicki Van Wagner, RM, PhD (Associate Professor, Midwifery)

Ryerson University, 350 Victoria St., Toronto, ON, Canada

Words Instead of Numbers

Risk	Word
1 in 1	Certain
1 in 2	Likely
1 in 10	Common
1 in 100	Uncommon
1 in 1,000	Rare
1 in 10,000	Very rare
1 in 100,000	Negligible
1 in one million	Theoretical

Fig. 3. Using words instead of numbers.

Communication Strategies

Keeping Risk in Perspective		
Numbers and More than Numbers	Avoiding Risk and Using Risk	"Risk Talk" as a Work in Progress
Comparing to everyday risks	Avoiding the word risk	Understanding power and limitations
Using words	Accounting for maternal altruism	Taking time to build confidence
Using visual aids	Including long term outcomes	"Both/and" permission giving
Using absolute risk	Listening versus listing	Sharing uncertainty
Using numbers needed to treat	Leaning toward normal	Awareness/humility
	Risks, benefits and alternatives	

Be Comprehensive & Align with MMoC

Benefits:

- Prevention
- Wellness (holistic)
- Support parent-infant bonding

Image courtesy of: van Wagner 2016

Communication Strategies

And recognize that even with all of this:

Every midwife is different
Every client is different

&

Clients have a right to autonomy in decision-making

Image Courtesy of:
moralsversusethics.weebly.com

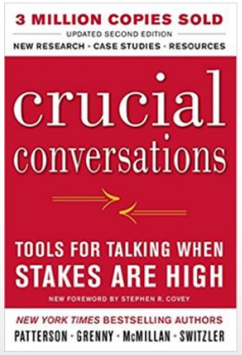
Communication Strategies

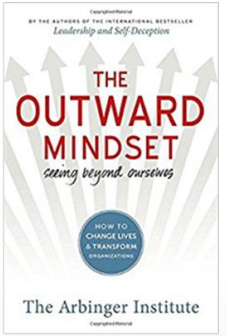
- Materials & Outreach Events:
  - Be creative!
  - Examples: myth busters approach; numbers with narratives; testimonials (from other homebirth clients & midwives); MW friendly resources; listening sessions
- Meet them where they are at
  - Parents: where do parents go?
    - Citizens for Midwifery (CFM): http://cfmidwifery.org/index.aspx
    - Local places: La Leche League, parent groups, prenatal yoga, WIC, library, etc.
  - Midwives:
    - Professional associations
    - Use local/state/national contacts
  - Respect is super important

This is reciprocal!

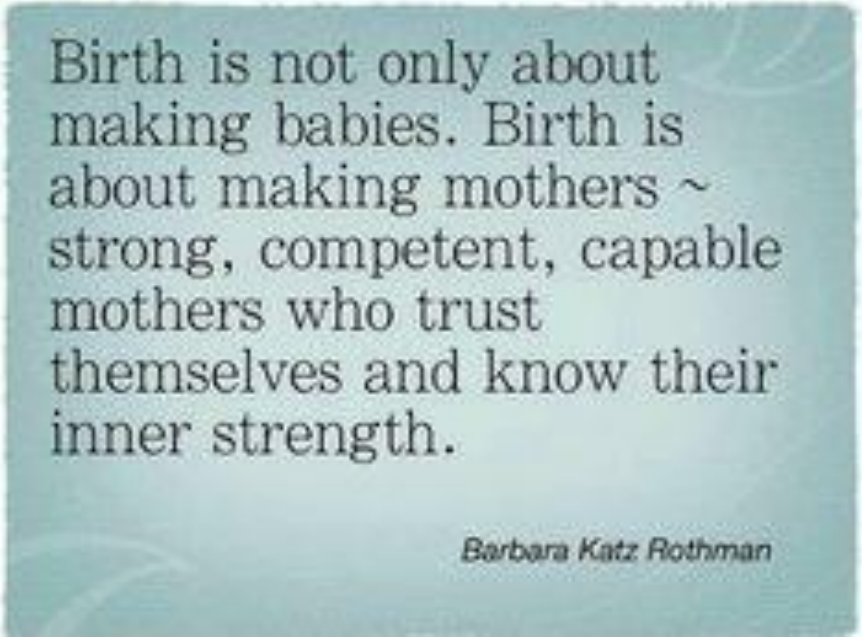
Communication Strategies:
Crucial Conversations for Crucial Times

- Most midwives, and most parents, are rational human beings that want what is best for their clients/children
- BUT, they are humans and subject to pitfalls
  - Buying into fallacies, anecdotal false decision making, (over)trusting nature, etc.
- Use this as a point of integration, not a point of a dissolution
  - AKA: check our biases
- Resources!
  - Critical Conversations: https://www.vitalsmarts.com/
  - Outward Mindset: http://arbingerinstitute.com/





Closing Words



Many thanks!

Courtney L. Everson, PhD
Courtney.Everson@midwifery.edu

References Available Upon Request