# Background

Breastfeeding has been established as the optimal food for infants: moreover there are health risks involved in feeding infants formula. Nevertheless the majority of hearing women in the US face significant structural barriers to breastfeeding, constraining individual choice. How Deaf women access information about infant feeding, how they negotiate these barriers, and ultimately, how they feed their infants, is unknown. This qualitative study cannot establish the frequency of breastfeeding among Deaf mothers, but explores data on the range and types of information sources, as well as barriers and facilitators they face in trying to breastfeed.

This work brings together two community-based participatory research projects in the Department of Community & Preventive Medicine at the University of Rochester. The PRC-funded National Center for Deaf Health Research (NCDHR) and an NIH-funded community breastfeeding support and promotion project, NDCHR has as its mission to identify and eliminate health disparities in deaf populations.

NCDHR uses a cultural model of deafness which views deaf people who use American Sign Language (ASL) to communicate as a cultural-linguistic minority group, not a disability group. As such we use a capital 'D' to designate Deaf, indexing the cultural group as opposed to indexing audiological status.

This project was undertaken in direct response to a request from the Deaf Health Community Committee to learn more about how Deaf mothers find and use information related to infant care.

#### Objective

To understand infant feeding practices among a group of Deaf mothers in Rochester, NY.

# Methods

Using a social ecological model to understand individual behaviors within a broad context, we conducted 4 focus groups (FGs) with 15 Deaf women who had a child under 6 years of age. Given the auditory and "over-heard" aspects of much health information our hypothesis was that Deaf mothers would have a lower fund of information than hearing mothers. This notion was reinforced by FGs done recently at NCDHR among Deaf adults on cardiovascular health (CVH) risks. Finding from those FGs indicated a great deal of misinformation about CVH was circulating in the Deaf community.

Participants were recruited through e-mailed fliers to local Deaf organizations including Deaf Mothers of Rochester, and through an ad in the electronic newsletter the Deaf Times. A \$25 gift card incentive was offered.

Given historical relationships of paternalism and exploitation between hearing and deaf people, the research team decided that only ASL-using Deaf members of the team would moderate and assist at the focus groups. We have successfully used this approach previously in focus groups with Deaf adults. We used two video comeros to conture the discussion. An experienced bilingual Deaf research assistant translated and transcribed the video tapes into English for analysis.

#### Participants

"Name"	# children	Youngest (Index Child)		
		age	BF	Duration
Colleen	2	14 m	yes	9 m
Amelia	3	15 m	yes	7 m
Claire	2	13 m	yes	3 wk
Jane	1	9 m	yes	still
Jayce	1	5	yes	6 m
Mary Ann	2	3 wk	yes	still
Margie	2	2 wk	yes	still
Lissa	2	19 m	yes	still
Claudia	2	3	yes	4 wk
Josie	2	2	yes	still
Marion	3	17 m	yes	3 m
Susie	2	1	yes	still
Vickie	2	4 m	yes	still
Cynthia	2	14 m	yes	1 wk
Annie	1	19 m	yes	12 m

# Deaf Mothers and Breastfeeding: Assessing their Knowledge and Practices through Focus Group Discussions

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"Breastfeeding was a struggle. My mother-in-law didn't give me any encouragement at all. The baby's crying...bothered her. I tried for three weeks before I gave up and quit. My husband was devastated but I told him that nobody was giving me enough support." ~ FG 1 Claire Lissa: "...Luckily, I had no problems [breastfeeding]" Katia: "Obviously your breast milk is delicious." Community Institutional "The doctor warned me about the problems with breastfeeding...not to give up even after 2 or 3 weeks of struggle. Fine, I took Interpersonal her word for it and I'm glad I didn't give up. I was ready to give up. My mom supported me. My friends supported me. I'm Individual appreciative of that." ~ FG 4 Annie

"I remember going to a birthday party when I was pregnant. A mother came up to me and told me to be patient about breastfeeding because it's not easy. She reiterated the importance of this patience ...and I took her words seriously." ~ FG 2 Lissa

> "It was my decision to breastfeed all the way until the baby was 1-year-old because babycenter.com recommended it for up to a year because of the benefits from breast milk." ~ FG 3 Susie

"I only breastfed my daughter for 3 months and that was it. That was because I worked full-time and I had to give it up. I'm also not a clingy type of person. I'm independent. Even though breastfeeding is beneficial. I don't mean to sound selfish or whatever." ~ FG 3 Marion

> "I think time and support are key. I am certain that with time and support I would have breastfed him longer [than 7 months]" ~ FG 1 Jovce

hospital for three days to get extra support from the lactation consultant." ~ FG 1 Marv Ann

"It was a struggle and I stayed in the

"I gave up because I don't have any family here. That's why it was hard. It was my first time experiencing breastfeeding. I didn't breastfeed my son at all. I tried with my daughter but it didn't work out so I used

> told me fin sign languagel. He explained breastfeeding and encouraged it while I was pregnant. Fine. My OB/GYN explained kept it in mind. Signed communication helps a lot." ~ FG 4 Annie

"I'm from foutside the USI where there is a strong positive attitude about breastfeeding. My mom told me about this so I'm aware of the positive things about breastfeeding. When I was pregnant, I was already determined to breastfeed but didn't know how. I didn't know how long to do it for or how to do it the right way. After I had the baby, doctors came to me and gave me advice and explained how to breastfeed. I had an interpreter." ~ FG 2 Josie

"The first time with my daughter was a struggle ... so I called the doctor and asked him to send someone to my house. He sent a nurse who explained that I had to relax because I was so tense and nervous. If I relaxed, my daughter would latch on because when I'm nervous, she is too...So I relaxed and sure enough, she latched on and it was successful. I breastfeed her exclusively for 10 months. I didn't use formula or anything else," ~ FG 2 Claudia

formula instead." ~ FG 4 Cynthia "How did I know about breastfeeding? My doctor

breastfeeding to me [in sign language]. Fine. So I





# Results

Some of the results are shown graphically to the left. Other significant themes that emerged from the data include:

#### Breastfeeding Depicted as 'Struggle'

Almost all of the mothers used the sign for 'struggle' in describing their first attempts at breastfeeding, a word we have not seen used among hearing women of Rochester. According to ASL scholar Ted Supalla, "One of its meanings is 'to figure out how to do something independently.' An analogous concept in English might be phrased: 'It took me a while to figure it out, but I did " Deaf mothers seem to concentualize breastfeeding as a process embedded in the developing relationship between mother and child, making them persistent in establishing breastfeeding.

#### Support within the Deaf Community

Deaf communities in Rochester, NY are tight knit and members give one another social, informational, and emotional support. The group interactions in FG 4 were especially poignant and illustrative of this theme. Cynthia was new to the Rochester area. She had little financial or social support. She felt isolated and unprepared for some of the challenges of parenting. Annie and Vickie Jong time members of the Rochester community told stories that explained the challenges they faced and how they activated social networks, accessed information, and established key alliances with hearing people to overcome parenting difficulties.

#### Knowledge, Resources, and Agency

This group of Deaf mothers was well educated. They were proactive in asking for help from health professionals, even seeking out doulas who could use sign language. Their resources for information are shown below. -Facebook -Voutube -Books -Magazines -Deaf Mother's Club -La Leche League for Deaf Mothers -Web sites -Captioned videos -Vlogs

# Strengths

This is the only study that has asked Deaf women about their breastfeeding experiences. Our qualitative approach captured women's experiences in their own voices

# Limitations

We had a small sample with limited social class diversity. Some women may have provided what they perceived to be socially-desirable answers as opposed to what they really felt or thought. There could also be some issues with accurate recall of past events and feelings.

### Conclusions

This group of Deaf mothers are for the most part educated, highly resourceful. and active agents in seeking support for breastfeeding. They had good support from health professionals including doctors who used sign language. Findings indicate that the 'struggle' to breastfeed requires persistence, patience and support at all levels of the social-ecological spectrum. These data do not support our hypothesis that Deaf mothers in this group have a low fund of knowledge.

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~ FG 2

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