

## 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. NCDHR 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 cameras to capture the discussion. An experienced bilingual Deaf research assistant translated and transcribed the video tapes into English for analysis.

## Participants

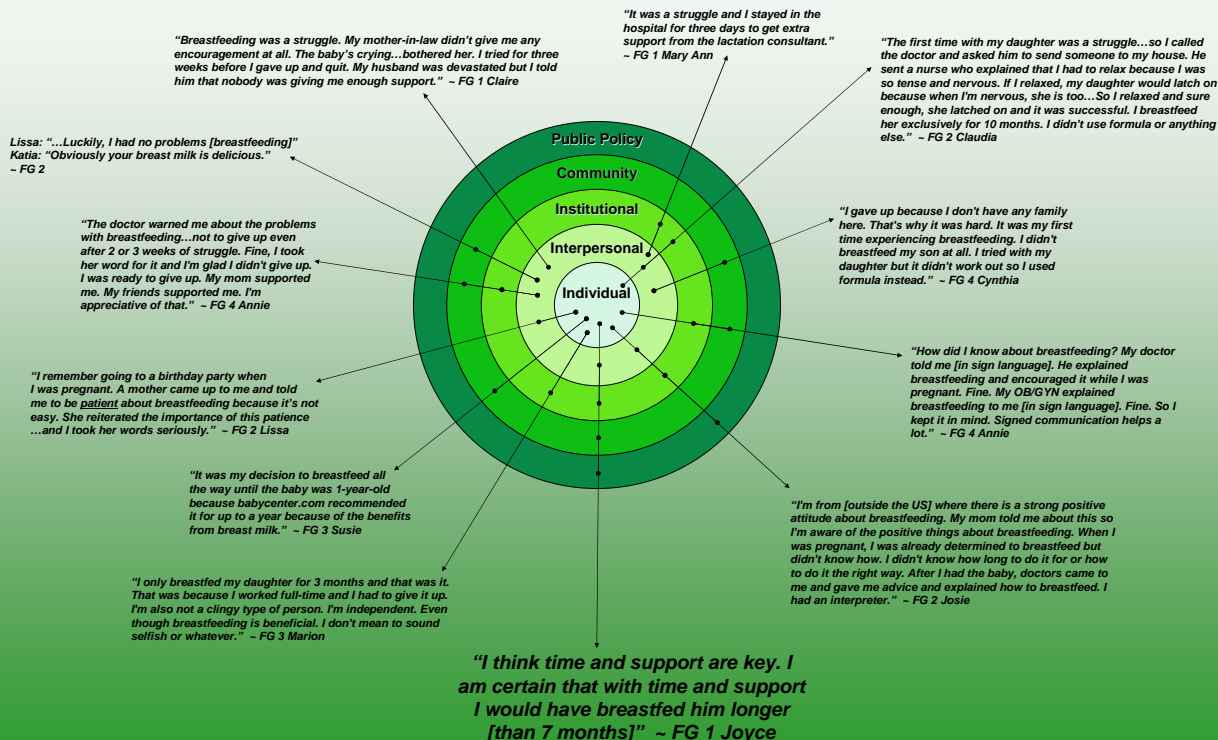
Name <sup>1</sup>	# children	Youngest (Index Child)			
		age	BF	Duration	
Colleen	2	14 m	yes	9 m	
Amelia	3	15 m	yes	7 m	
Claire	2	15 m	yes	3 wk	
Jane	1	8 m	yes	still	
Joyce	1	5	yes	6 m	
Mary Ann	2	3 wk	yes	still	
Marge	2	2 wk	yes	still	
Lissa	2	19 m	yes	still	
Claudia	2	3	yes	4 wk	
Josie	2	2	yes	still	
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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## 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 conceptualize 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, long 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 seeking help from health professionals, even seeking out doulas who could use sign language. Their resources for information are shown below.

- Facebook
- Youtube
- Books
- Deaf Mother's Club
- Web sites
- Vlogs
- Magazines
- La Leche League for Deaf Mothers
- Captioned videos

## 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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