

# What makes breastfeeding easier or harder for mothers with physical disabilities in the United States?

# Introduction

Research has shown that it is good to breastfeed babies. More and more mothers across the United States are choosing to breastfeed, at least in the short term. More women with physical disabilities are becoming mothers, but there is not much information about how these women breastfeed. Current research shows that mothers with disabilities sometimes have a hard time getting support after their child is born. Sometimes these mothers also visit doctors who don't understand disabilities very well. Some mothers have a difficult time finding tools and equipment that make taking care of a child easier. The children of mothers with disabilities should be able to get the same benefits from breastfeeding as the children of mothers without disabilities. In this study we wanted to find out what made it easier or harder for mothers with physical disabilities to breastfeed.

We held interviews with 25 mothers with physical disabilities between the ages of 18 and 55 from across the United States. The mothers we spoke to had to have a hard time walking or using their hands or arms while they were pregnant. They also needed to have given birth in the past ten years in the United States. We got in touch with these participants from social media, national groups, and email lists. Here is what we found out about the things that make breastfeeding easier or harder for mothers with physical disabilities.

#### Results

# **Participant characteristics**

- The average age of the participants at time of the youngest child's birth was 32.
- Fourteen of the mothers had one child at the time of interview and two were pregnant.
- Most of the participants were white and not Latina.
- Fifteen of the mothers had planned pregnancies and 10 had unplanned pregnancies.
- Participants had many different kinds of disabilities: multiple sclerosis, spina bifida, spinal cord injury, amputation, cerebral palsy, osteogenesis imperfecta, stroke, and muscular dystrophy.

## What made breastfeeding easier?

The interviews showed that there were four specific things that made breastfeeding easier for mothers with physical disabilities.

## 1. Helpful tools

Many mothers reported that they used different tools to help them breastfeed. Some mothers described the importance of finding the right position to breastfeed, which some said can take time and creativity. Some mothers also explained the need for breastfeeding pillows and other tools to make breastfeeding easier for them. Some of the mothers changed how they used breastfeeding pillows and other equipment to meet their specific needs, too. For example, some mothers reported lying down while others were able to sit while breastfeeding.

## 2. Use of breast pump

Some of the mothers we spoke to were not strong enough to hold their babies long enough to breastfeed. Others were unable to find a position that worked for them. It was still important for them to breastfeed their babies, so some mothers chose to use a breast pump, which they could do by themselves or with help. By using a breast pump, these mothers still were able to give their infants breast milk with a bottle.

# 3. Physical help from others

Breastfeeding was physically difficult for some of the mothers. Some participants were unable to hold their babies while breastfeeding. Others could not use a breast pump on their own. A few of the mothers said that other people, like the other parent or a family member, helped them physically breastfeed.

# 4. Peer support

Many of the mothers learned about breastfeeding from other women with disabilities, especially mothers with disabilities like theirs Some mothers connected with other mothers using social media and others attended disability conferences. Receiving advice and information from mothers who had similar experiences was very important for many of the mothers we spoke to.

# What made breastfeeding harder for mothers with physical disabilities?

The interviews showed five things that stopped mothers with physical disabilities from breastfeeding or made breastfeeding more difficult for them.

## 1. Not enough supports

Several of the mothers told us there are not enough supports for breastfeeding. Some of the mothers encountered lactation consultants (people who help women breastfeed) who did not have experience supporting mothers with physical disabilities. Some of the mothers also wished there were more in-home supports for breastfeeding mothers with physical disabilities.

## 2. Health issues

A few of the mothers explained that they chose not to breastfeed because of their disability. For example, some mothers were worried about their medications would affect their breastfeeding. Other mothers were concerned that breastfeeding may make some parts of their disability worse (for example, bone thickness). Finally, a few of the participants said they did not breastfeed because they could not physically do it.

#### 3. Not enough information

Many of the mothers expressed frustration with the lack of information about breastfeeding among mothers with physical disabilities. A few mothers told us that their doctor did not know if their disability would be impacted by breastfeeding. Other mothers explained that most of the information available to mothers about breastfeeding does not address the specific needs and experiences of those with physical disabilities.

# 4. Difficulties with milk supply

Several of the mothers said that they had a hard time making enough milk to feed their babies. Challenges with milk supply can be a problem for nondisabled mothers, too. But for many of the mothers in this study, the issue was often disability-related. For example, some of the mothers took longer to start breastfeeding because they had problems finding the right tools to help them. Sometimes mothers would "dry up" because they started breastfeeding too late.

# 5. Difficulties with latching

Some of the mothers experienced difficulties getting their babies to properly latch. Latching can be challenging for many mothers. But for the mothers in this study, it was usually made worse because of their disabilities. Many mothers had issues with positioning in particular. Starting breastfeeding late also led to difficulties with latching for some mothers.

# Limitations

As with all research, there are limitations to our study. The first limitation is selection bias. Selection bias means that the people who in your study may have been more likely to respond anyway. The mothers who we spoke with are connected to the disability community. Their stories may not be the same as mothers with disabilities who are not connected with the disability community.

Our study sample is small and does not show the experiences of every mother with a disability. This means that our study cannot be applied to every woman with a physical disability. Finally, because we interviewed some mothers who gave birth a long time ago, they may not remember everything well.

# Implications for policy and practice

This study shows that there are important things to consider for people who run programs. To help mothers with physical disabilities breastfeed, people should pay more attention to the things that make breastfeeding easier or harder. Below are specific changes we believe are needed.

- Health care providers need appropriate training and guidance on supporting mothers with physical disabilities. Lactation consultants should get this training, too.
- Personal supports, personal assistance, and adaptive parenting tools must be easily available for parents with disabilities.
- Information and other resources about breastfeeding by mothers with disabilities must be developed and shared with people with disabilities and health care providers.

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