

Supporting Parents with Disabilities: Inclusive, Multidisciplinary Care for Lactation and Beyond

Alesha Thomas, BS, IBCLC, Founder & Executive Director Adaptive Parent Project

A little about me...

Education and motivation

- I graduated from University of California, San Diego (UCSD) in 2013 with a bachelor's in Human Biology and a minor in Healthcare-Social Issues.
- After having my son Nolan in 2019, I became aware of a significant lack of resources and programs for parents with disabilities.
- After breastfeeding my child for 4.5 years and considering my background in human biology and my desire to go work in healthcare from the time, I was three, I was motivated to be able to provide lactation care to other parents with disabilities.
- I completed my IBCLC program in 2024, through the UCSD extended studies lactation program; this certification allows me to extend my knowledge and disability expertise to parents all over the world.

How Adaptive Parent Project Started

- In 2020, during COVID, I started sharing adaptive parenting techniques on YouTube in hopes of getting other parents to contribute content and making a safe space for parents with disabilities.
- In 2021, I applied to a contest from Aerie about how I was making change in the community and how I helped a quadriplegic mother put her twins to bed for the first time. Out of 600 applicants, our idea was selected as the top 20 people to get funded. This allowed us to expand and become the 501(c)(3) non-profit, Adaptive Parent Project (APP).
- In 2022-2023 APP applied for a healthcare and safety grant from the California State Council of Developmental Disabilities. With this grant, we focused on plain language material on different healthcare topics for people with disabilities, as well as improving communication between healthcare providers and their patients.



San Diego Regional Center Features APP

When Alesha became a mother, she quickly discovered a gap that many never see: the almost complete lack of programs and resources designed to support parents with disabilities. As a mom with cerebral palsy, she wanted what every parent wants: to safely care for, play with, and nurture her child.

Through experience and determination, she mastered adaptive techniques to care for her child and wanted to teach other parents with disabilities how to as well.

With the help of the @aerie Changemakers program, Alesha's visions were brought to life: @adaptiveparentproject

An organization that's mission is to empower other parents with disabilities to support their children independently. Through her journey of motherhood and nonprofit ownership so far, Alesha has created dozens of tutorial videos: breast-feeding tips, how to pick up and transfer a child from a wheelchair, techniques for changing diapers, and more.

Since the launch of Adaptive Parent Project in 2021, Alesha has supported parents far and wide in caring for their children. We can't wait to see Adaptive Parent Project continue to grow and to cheer Alesha on as she shapes a more inclusive future for parents and families.

Learn more about Adaptive Parent Project at adaptiveparentproject.org



Population Overview

- There are 65.9 million parents in the US and 4.4 million have disabilities (Sonik et al., 2018).
- Nearly 3.3 million Americans in the United States are currently wheelchair users, primarily due to mobility7 impairment (Nie et al., 2024).
- The disability community is the one community that anyone can join at any time, regardless of age, gender, ethnicity, financial status, etc.



@rkbarkley

Parenting is an Occupation

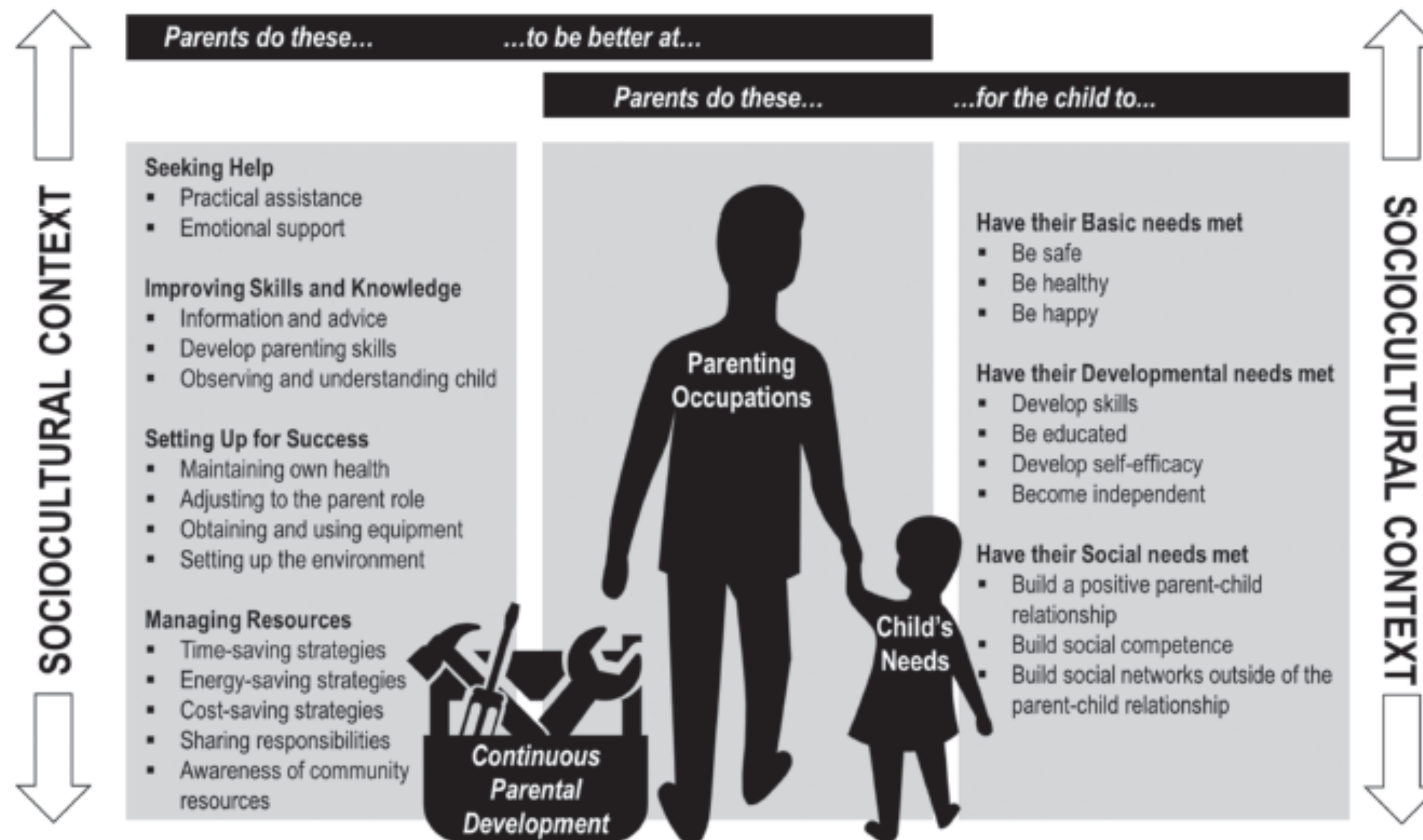
Parenting Occupations and Purposes (POP) Framework

(a) The Occupations frame:



Parenting Occupations and Purposes (POP) Framework

(b) The Purposes frame:



ADLs and IADLs

Comparing the two...

- Activities of Daily Living (ADLs) are fundamental tasks for self-care and survival, including bathing, dressing, eating toileting, and transferring (i.e. wheelchair to bed).
- Instrumental Activities of Daily Living (IADLs) are more complex skills that are needed to live independently such as cleaning, cooking, medication management , money management, and transportation.

Occupations of Parenting

ADL with Child
Dressing upper body
Dressing lower body
Feeding
Grooming & Hygiene
Bathing/Showering
Bathing Transfers
Diaper change/Toileting
Transfers to changing table
Transfers to toilet

Functional Mobility with Child
Baby wearing: Home environment
Community environment
Transfers baby/child:
• Bassinet/ Crib
• Baby bouncer/ Swing
• Crib
• Highchair
• Floor
• Car

Occupations of Parenting

IADL with Child
Meal preparation
Home Management
Laundry
Food Preparation
Shopping
Telephone
Finances
Medication
Transportation

IADL with Child
Baby/ Child Proofing
Health Management
Leisure/ Play
• Home-based
• Indoor community participation
• Outdoor community participation
• Education

Common Barriers for Parents with Physical Disabilities

Barriers Can Include but Are Not Limited to....

- Disability Diagnosis- Ex. cerebral palsy (CP), spinal cord injury (SCI)
- Disability Classification- Ex. hemiplegia versus diplegia, complete versus incomplete injury
- Accessibility of an individual's home environment
- Accessibility of an individual's community
- Access to disability informed healthcare providers/caregivers
- Access to mobility aids and tools for completing activities of daily living (ADLs)
- Access to disability inclusive baby products
- Bias and stigma



Parents with physical disabilities, may struggle with positioning at the breast/chest for various reasons:

- decreased core strength
- limited range of motion
- fine motor skill impairment

Using a Heel Protector as a Positioning Aid

Think outside the box

- This graphic shows standard instructions for using a heel protector.
- This device is commonly stocked in hospitals and available online. Due to the fact that it is highly adjustable it is a potential option if a parent is struggling to keep baby in a certain position during feeding at the breast or chest or when bottle feeding.
- This is a short term option for small infants.

HCS HEEL PROTECTOR INSTRUCTIONS



APPLY

Open the heel protector and position the patient's heel into the opening. Ensure the patient's heel is centered and offloaded. You should be able to see the patient's heel through the opening.



SECURE

Secure straps around the heel protector, ensuring they are tight across the patient's foot to prevent heel drop. DO NOT over tighten the straps. *Attach straps following steps 1-4 as indicated on boot.*



PLACE

Place the anti-rotation wedge tight against the side of the heel protector, positioning it either on the medial or lateral side to prevent internal or external rotation of the foot and knee.



CONFIRM

Position your hand under the heel protector to verify that the heel is offloaded from surface and that the straps are secure.

To Use with Sequential Compression Device: run the tubing through the side ports on either side of heel protector. Ensure tubing is connected outside the heel protector and the tubing does not run up through the heel protector.



OPEN

HCS Premium Heel Boot- Open Foot Gate Use the open foot gate for quick and easy skin assessments and to allow airflow without removing the heel protector.



REMOVE

For removal, gently release the straps from the heel protector and remove the wedge.

[Instruction PDF](#)

Using a Heel Protector Boot

Using hospital items for nontraditional purposes

- Using a heel protector boot can be a potential option to position a preterm, infant or full-term newborn for feeding.
- If a parent is having difficulty holding their child in a particular position, this might be a viable option to reduce strain and fatigue from trying to maintain a particular position.
- The boot has multiple Velcro straps and can be adjusted. In this photo, the boot is completely open and laying flat.



Using Pillows and Other Supports

A 6 minute video on breastfeeding/chestfeeding and bottle feeding with a disability

- This video demonstrates how Alesha uses different breast-feeding pillows and other supports such as a foam wedge and standard bed pillow to help decrease the physical demands of having to hold baby in position during feeding.
- Parent and baby are much more likely to have a positive experience feeding if the parent with a disability, not having to struggle to maintain proper position.
- A comfortable baby and a comfortable parent is more likely to lead to positive feeding outcomes.



Skin-to-Skin & Carrying Baby



Joey Band @brenwarnick



Hippie Joey @emblan

Let's Talk About Milk Supply

Lactation Care Immediately Postpartum

- Some of the most common challenges, immediately postpartum for individuals with physical disabilities include latch, positioning, and low milk supply.
- In a 2023 study, 31 people were interviewed regarding their pregnancy, birth and postpartum experience. All participants identified as having disabilities, 14 identified as having physical disabilities. The major identified themes were:
 - Lack of adequate care
 - Lack of provider awareness of disability and disability accommodations
 - Fear of judgement, discrimination, and intrusive surveillance (Tarasoff et al., 2023)

Managing Milk Supply with Fine Motor Skill Impairment

- Creative positioning
- Positioning aids
- *Remember baby grows quickly so challenges in the early days are short-



[Positioning
Wedges](#)



[Breastfeeding Pillow
with Strap](#)



[No external supports
needed](#)

Pumping with a Disability

- It is critical not to decrease pumping sessions too early, even when there is oversupply
- As long as the parent is not experiencing repeated clogged ducts, and mastitis, please let the milk flow.
- Depending on fine motor skill involvement, some parents will need help with setting up pump parts and pumping.
- Consider wearable pumps when appropriate as this may decrease need for assistance, but also increase mobility during pumping, especially for parents on wheels.
- Figuring out what works and what pump is the best fit is trial and error in many cases

Mental Health and Disability Postpartum

The Brain and the Body Are at Odds

- Immediately postpartum, parents with disabilities often struggle because their brain is saying figure it out now and their body is still trying to figure out how to adapt. This can be extremely stressful.
- Parents often feel that they have to do extremely well in order to prove that they are capable and many report intrusive surveillance in the hospital setting (Tarasoff et al, 2023).
- The biggest gap in services comes after hospital discharge and this is why having safe providers is so important.

What is a "Safe Provider"?

Inhibitors

Providers

- Stigma from healthcare providers
- Lack of knowledge of disability
- Intrusive surveillance
- Lack of change

Parents

- Fear

Facilitators

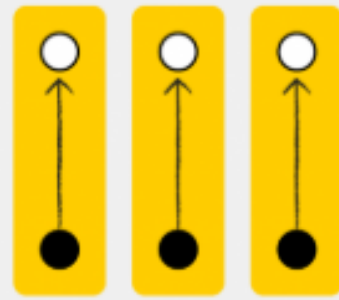
- Provide supports and resources to parents to help parents be successful
- Provider continuing education
- Assess your biases toward disability
- Not making assumptions of what the person is capable of for parenting
- Talking to the parent to find out their strengths
- Support needs to go beyond the

Transdisciplinary Care and Advocacy

What Does Recent Research Show?

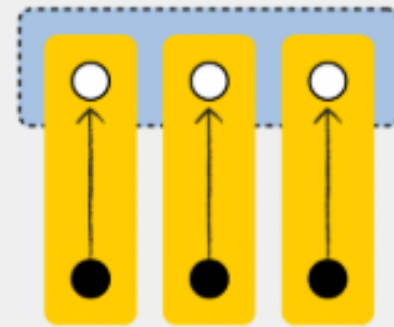
- In 2021 the journal *Midwifery* published a systematic review article discussing the maternity care experiences of women with physical disabilities. This was a mixed methods study. After an extensive database search of over 4000 articles, 10 articles were found to meet the study criteria.
- The key themes and conclusions of each article were listed and put into a table. Some of the studies that were reviewed included interviews in person or by phone.
- This review concluded that women with physical disabilities still encounter multiple barriers when accessing maternity care related to the accessibility of the care settings, as well as the negative attitudes and the lack of knowledge that healthcare providers have about the needs of disabled individuals surrounding pregnancy and birth. Training must be developed and evaluated to better education healthcare providers on the specific needs of people with disabilities receiving maternity care (Heideveld-Gerritsen et al.,2021)

- Goal, shared knowledge
- Discipline
- ⦿ Stakeholder participants
- Academic knowlegde
- Conventional knowlegde
- ⋯ Thematic umbrella



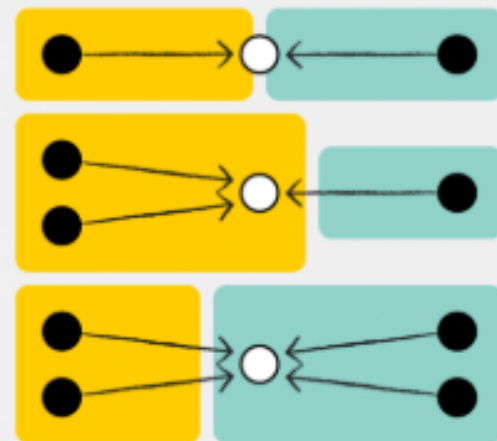
DISCIPLINARY

- Within one academic discipline
- Disciplinary goal setting
- Develops new disciplinary knowledge



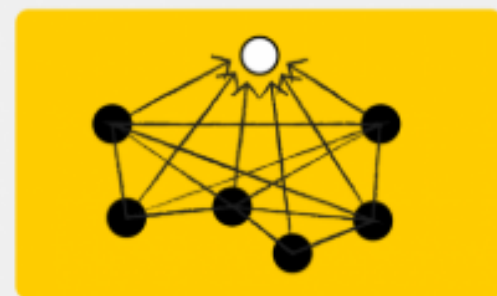
MULTIDISCIPLINARY

- Multiple disciplines
- Multiple disciplinary goals set under one thematic umbrella



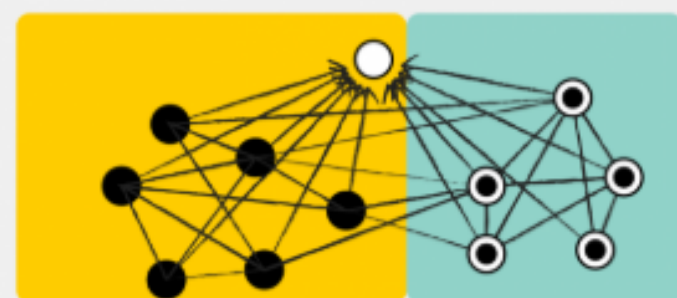
PARTICIPATORY

- Academic and non academic participants
- Knowledge exchange without integration



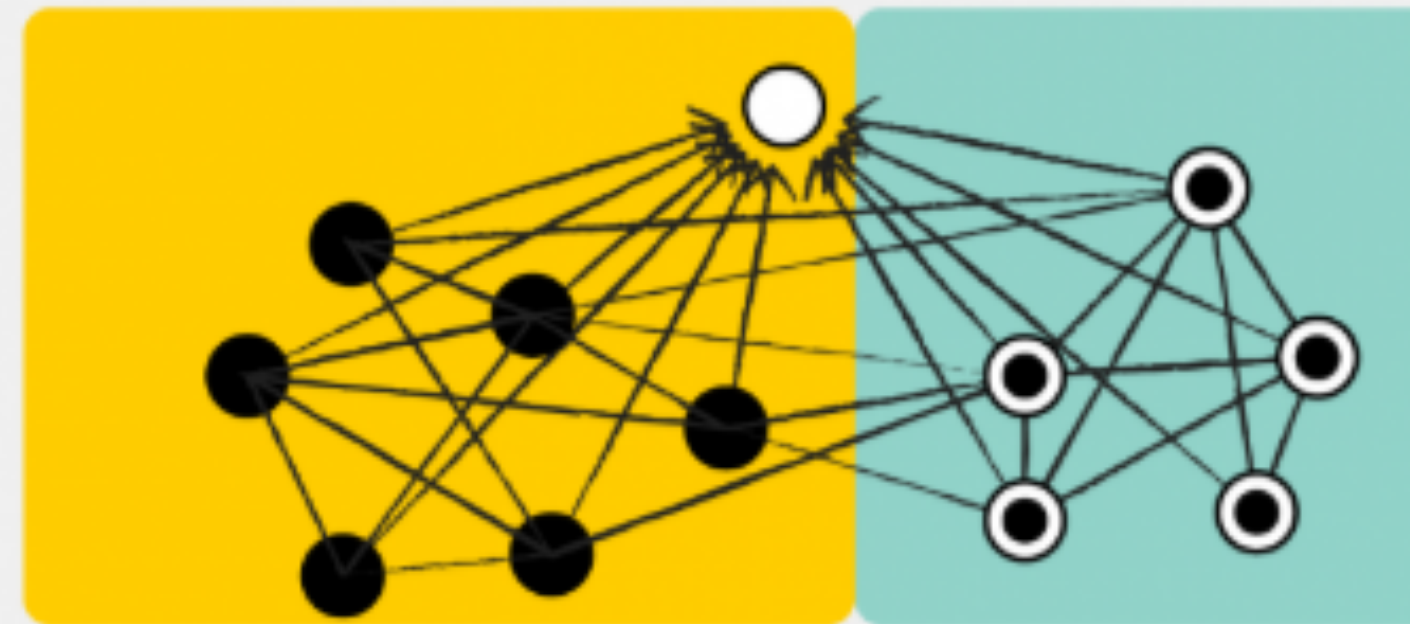
INTERDISCIPLINARY

- Crosses disciplinary boundaries
- Develops integrated knowledge
- Draws from and contributes to 'inderdisciplines'



TRANSDISCIPLINARY

- Crosses disciplinary and sectorial boundaries
- Common goal setting
- Develops integrated knowlegde for science and society
- Draws from and contributes to 'inderdisciplines'



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It Takes a Team

- When working with families with disabilities, it is important to work together as a team. The IBCLC, parent and baby are all working together to optimize feeding. Disabled people know and understand their bodies very well and can help provide strategies to problem solve.
- A transdisciplinary care approach is crucial when working with families with disabilities. Often in our society, receiving care and support is hierarchical in nature. For example, the IBCLC is supposed to tell the parent what to do because they are the expert when in reality, lactation is a team sport where everyone is equal.
- Whenever possible, consult with an occupational therapist in your area as they can provide a wealth of knowledge and other possible solutions to solving challenges.

Support Beyond Lactation

Create individualized plans with community partners to help parents adapt to childcare tasks throughout early development

- Whenever possible, consult with an occupational therapist and other professionals in your area as they can provide a wealth of knowledge and other possible solutions to solving challenges.
- Access to mental health services and support groups for parents with disabilities is crucial. Being a parent with a disability can be extremely isolating due to the fact that there is not usually a large group of parents with disabilities in any given city, and we are spread out all over the United States and internationally. Connecting with other disabled parents is so important.
- Safe providers in all specialties are essential to ensure that trust is built between the provider and the client. It is important to understand that just because a parent is doing something differently, it does not mean that they are not capable or need to be reported. Even if a parent is physically unable to do something, what matters is that they have supports in place.

Advocacy for Supporting Parents with Disabilities

Practical strategies, healthcare providers can use to better support parents with disabilities and how to start making changes in your local community

- Start local with your local health department
- Collaborate with your local maternal child health program
- Collaborate with WIC
- Find providers in your area that are disability informed
- Find maternal health occupational therapists
- Advocate for community inclusive spaces for children and parents with disabilities so that everyone can play together

VOLUME 1

OCTOBER 1, 2025

Navigating Parenthood with a Disability:

Practical Tips and Support



Photo credit: @Jessicaslice Image description: a toddler uses a wheelchair foot rest to climb up on his mothers lap.

Parenting with a Disability

Parenting with a disability can present unique challenges, from navigating physical tasks to balancing extra responsibilities. However, with the right tools, resources, and support parents can adapt and create a strong foundation for their families.

1

COMMUNITY

Connect with other parents with disabilities

2

CONNECTION

Connect with professions that are disability informed

3

RESOURCES

Tools to help you and your family thrive



Adaptive Parent Project
Empowering
Parents with
Disabilities



Wheel Good Motherhood
Free monthly peer
support group for
moms on wheels



Free virtual OT clinic
for parents with
disabilities

Empowering Families

Strategies for boosting confidence

- Working with parents with disabilities is crucial
- Stigma
- Transdisciplinary approach
- Limited knowledge of disability rights
- Safe healthcare providers
- Opportunities for collaboration
- Education for healthcare providers

Resources



[HTTPS://WWW.ADAPTIVEPARENTPROJECT.ORG/](https://www.adaptiveparentproject.org/)

Breastfeeding/Chestfeeding Positions for Parents with Disabilities

	Laid back/Reclined Position In this position, you are reclined and the baby is belly to belly with you. The baby's head is supported in the crook of your arm. This position is ideal in a bed or recliner. It can be particularly helpful for mothers that have a fast letdown or to help baby get an optimal deep latch.
	Side-Laying Position You and baby lying facing each other, belly to belly with baby's nose to nipple. This position can be particularly comfortable for nighttime feedings or anytime the parent needs to rest, relieve pressure from sitting or change positions throughout the day. Pillows can be used for support.
	Koala Hold This position involves the baby straddling the parent's thigh or hip, sitting upright while breastfeeding. It can be especially helpful as baby grows older and can sit up with minimal assistance. This position is particularly useful for parents who use wheelchairs or for babies with reflux or ear infections, as it keeps them in an upright posture.
	Cradle Hold In this position, bring the baby across your belly and support their head with your arm. If you are feeding your baby in a seated position and the chair you are using does not have armrests, a nursing pillow can provide additional support.

Please note: In each position baby's ears, shoulders and hips should be in line.



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coming soon

More Information



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(760) 410-5312



AdaptiveParentProject@gmail.com

Brandeis University and the Lurie Institute for Disability Policy

- [Pregnancy, Disability and Lactation Resource Page](#)

Support For Mothers Who Are Wheelchair Users



[Zoom Registration](#)



@johnjreynolds

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