Breastfeeding assistance for all abilities

Julie Matheney, MS,CCC-SLP, IBCLC

Hello!

Julie Matheney, MS, CCC-SLP, IBCLC

The LA Lactation Lady

@lalactation

Lalactation@gmail.com

Objectives

(1) To understand the different types of differences and disabilities that impact breastfeeding

(2) To describe the challenges that lactating people with various differences and disabilities face during their breastfeeding process

(3) To learn about adaptations to the environment to assist the lactating person

(4) To discuss support systems for lactation success

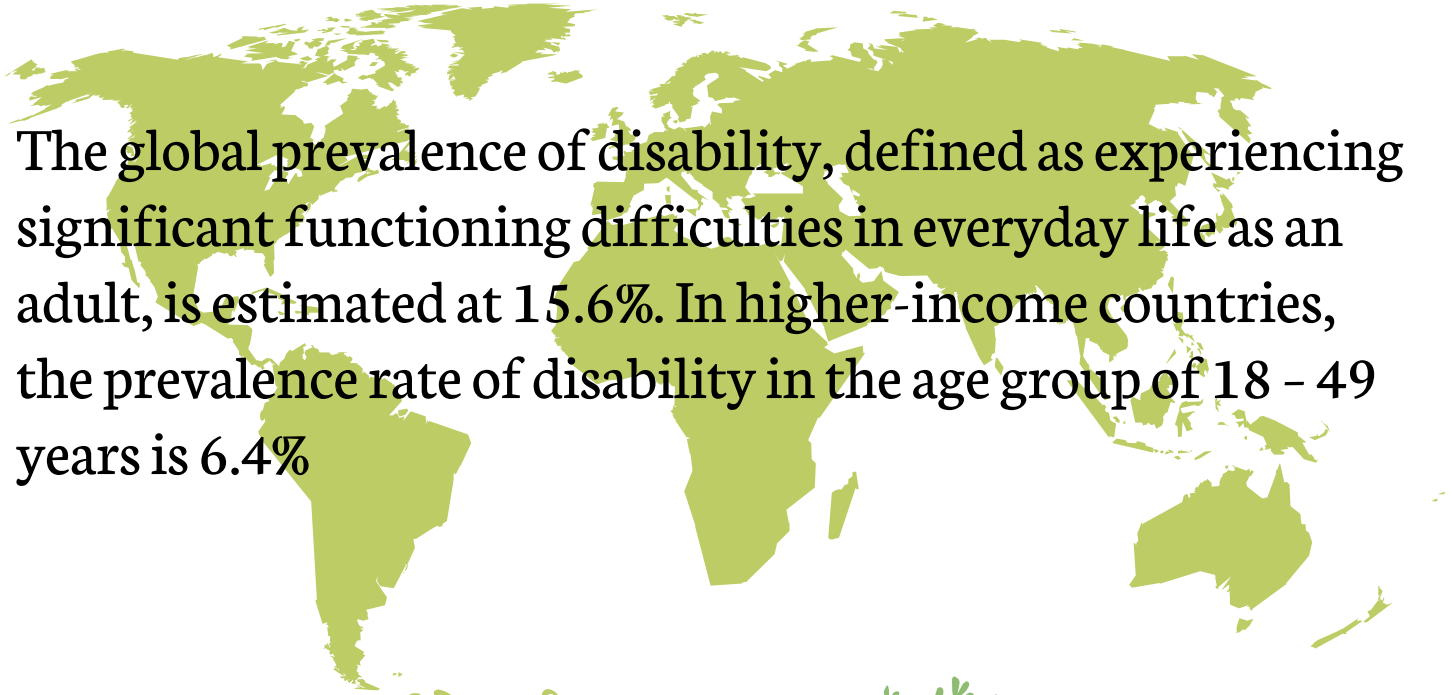
Disclosure

I have nothing to disclose

What is a disability?

Disability is defined as a consequence of impairments, activity limitations, participation restrictions, and environmental factors (World Health Organization, 2001).

Prevalence



The global prevalence of disability, defined as experiencing significant functioning difficulties in everyday life as an adult, is estimated at 15.6%. In higher-income countries, the prevalence rate of disability in the age group of 18 – 49 years is 6.4%

Prevalence of mothers with disabilities/differences

Prevalence of mothers with disabilities/differences:

- Depends on the country
- Depends on the definition of disability

Vocabulary

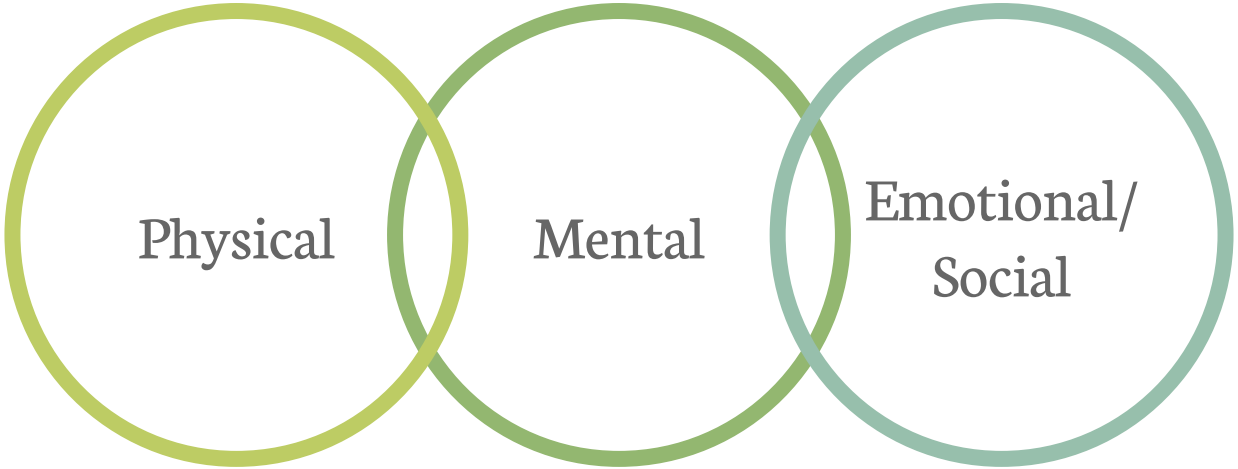
“The difference between the right word and the almost-right word is the difference between lightning and a lightning bug.”

— Mark Twain

Vocabulary

Disability	Out-Dated Language	Respectful Language
Blind or Visually Impairment	Dumb, Invalid	Blind/Visually Impaired, Person who is blind/visually impaired
Deaf or Hearing Impairment	Invalid, Deaf-and-Dumb, Deaf-Mute	Deaf or Hard-of-hearing, Person who is deaf or hard of hearing
Speech/Communication Disability	Dumb, “One who talks bad"	Person with a speech / communication disability
Learning Disability	Retarded, Slow, Brain-Damaged, “Special ed”	Learning disability, Cognitive disability, Person with a learning or cognitive disability
Mental Health Disability	Hyper-sensitive, Psycho, Crazy, Insane, Wacko, Nuts	Person with a psychiatric disability, Person with a mental health disability
Mobility/Physical Disability	Handicapped, Physically Challenged, “Special,” Deformed, Cripple, Gimp, Spastic, Spaz, Wheelchair-bound, Lame	Wheelchair user, Physically disabled, Person with a mobility or physical disability
Emotional Disability	Emotionally disturbed	Emotionally disabled, Person with an emotional disability
Cognitive Disability	Retard, Mentally retarded, “Special ed”	Cognitively/Developmentally disabled, Person with a cognitive/developmental disability
Short Stature, Little Person	Dwarf, Midget	Someone of short stature, Little Person
Health Conditions	Victim, Someone “stricken with” a disability (i.e. “someone stricken with cancer” or “an AIDS victim”)	Survivor, Someone “living with” a specific disability (i.e. “someone living with cancer or AIDS”)

Áreas of disability or difference



Needs of women with disabilities

Women with disabilities are more likely to:

- Use social health care programs
- Have emergency room visits
- Have hospital admissions during pregnancy
- Have cesarean deliveries, preterm deliveries and low-birth-weight infants

They are less likely to receive adequate prenatal care and breastfeeding assistance compared to women without disabilities

In the 2018 study, one thing mothers brought up time and time again was that health professionals didn't know what to say to people with disabilities opting to breastfeed. Many of the women interviewed felt they were given little information or conflicting information.

Family member attitudes toward mothers with differences

- Initial negative reactions
- Concern about mother's well-being
- Questioning of parenting capability
- Negative perceptions of disability
- Genetic concerns
- Excited and supportive

Social pressure

There is a societal misconception that women with disabilities cannot give birth to children or would not properly care for them.

Concerns of mothers with disabilities

- Violations of personal borders
- Feeling of being watched and controlled.
- Communication with health care professionals was often characterized by mutual aspects of fear, uncertainty and awkwardness.

Areas of concern for women with disabilities

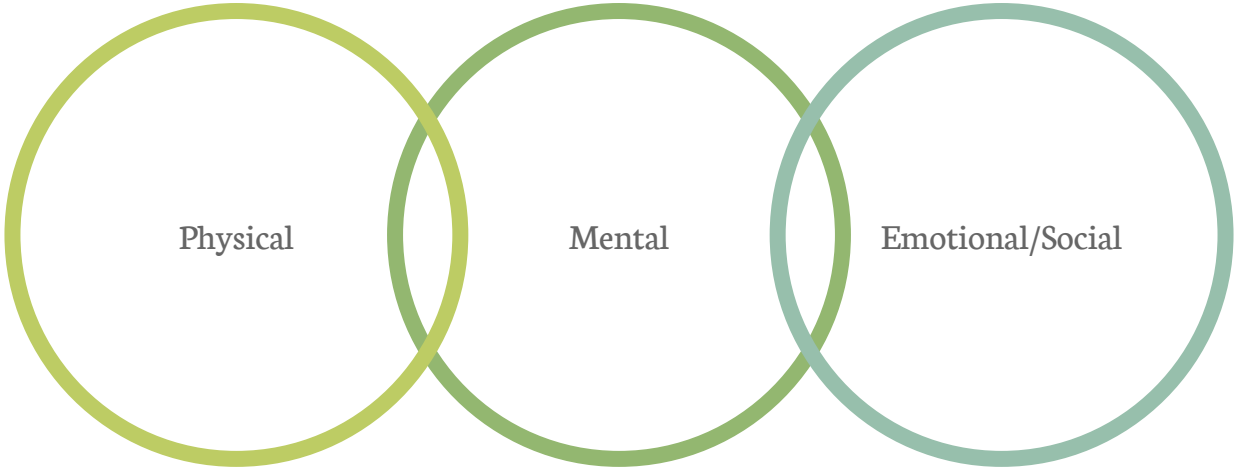
A small 2018 study of women with disabilities who breastfed showed five main areas of concern for these women:

- Lack of support for breastfeeding
- Disability-related health concerns
- Limited information
- Difficulties with milk production
- Difficulties latching

Quotes

From mothers with various disabilities

Areas of disability or difference



Physical differences

Physical differences

Carpal tunnel

Missing limbs

Paralysis

Stroke from childbirth

Cerebral Palsy

Pain

Deaf

Facilitating breastfeeding: Physical differences

Key concepts:

- Know the right questions to ask
- Adaptations and equipment
- Use of breast pump
- Physical assistance from others
- Peer support

Limb differences

Carpal Tunnel

Paralysis

Missing Limb

Alpremio Baby Care Seat

Limb differences: Possible questions

- Congenital or acquired?
- Is the difficulty caused by the repetitive act of breastfeeding?
- Flairs with breastfeeding?
- Do they need help with self care or are they independent?
- Are there other caregivers or help available?
- What supports do they need?

Limb differences

- If known ahead of time, OT/PT
- Bodywork
- Environmental adjustments
- Positioning and positioning aids will be very important

Stroke

- Incidence ranges from 9-34 per 100,000 deliveries
- Highest risk during the third trimester and the first 12 weeks after giving birth.
- Two types: Ischemic and hemorrhagic
- Factors that increase risk of stroke:
  - Preeclampsia and eclampsia
  - Amniotic fluid embolism
  - Postpartum angiopathy
  - Postpartum cardiomyopathy

Risk factors for stroke

- Over 35
- African-American/Black
- Preeclampsia/eclampsia/ gestational hypertension
- Thrombophilias
- Migraine headaches
- Diabetes
- Pre-pregnancy hypertension
- Hyperemesis gravidarum
- Anemia
- Thrombocytopenia
- Postpartum hemorrhage
- Transfusion,
- Fluid, electrolyte and acid-base disorders
- Infection

Symptoms of stroke

- Chest pain or pressure
- Difficulty breathing
- Pain or swelling in one leg
- Sudden and severe headache
- Sudden change in consciousness, speech, balance, strength or sensation on one side of the body.

Stroke

Stroke crosses the physical/mental difference/disability line. It depends on the nature and severity of the stroke as some strokes can impact both arenas.

Stroke: Questions to ask

- Type and nature of the stroke?
- Can she complete self care independently?
- Is she able to complete cares for the infant?
- Is there support available?
- What disabilities have been caused? Mental and/or physical?
- Is OT/PT available?
- What adaptive equipment and positioning tools are needed and available?

Cerebral Palsy (CP)

- About 764,000 children and adults currently have CP (500,000 are under age of 18)
- About 2-3 children out of every 1,000 have CP
- About 10,000 babies born each year will develop CP
- Spastic CP is most common, making up approximately 70% of all Cerebral Palsy case
- There is no current research on the number of mothers with CP.

Cerebral palsy

Varies in severity and symptoms:

- Variations in muscle tone (stiff or floppy)
- Stiff muscles and exaggerated reflexes (spasticity)
- Stiff muscles with normal reflexes (rigidity)
- Lack of balance and muscle coordination (ataxia)
- Seizures
- Learning difficulties
- Tremors or involuntary movements
- Favoring one side of the body, such as reaching with one hand or dragging a leg
- Difficulty walking
- Difficulty speaking
- Difficulty with fine motor skills, such as buttoning clothes or picking up utensils

Cerebral palsy: Questions to ask

- What type of CP does she have and how is it affecting her?
- Is she able to complete self care independently?
- Is she able to complete cares for the baby?
- What type of limb involvement is there?
- Is there spasticity or tremors in the limbs increasing the risk of dropping the baby or making positioning difficult? Medications for spasticity?
- What kind of positioning aids and adaptive equipment will be needed?

Breastfeeding with CP: The Adaptive Parenting Project

Pain

- Physical
  - Pregnancy or Birth trauma (sciatica, tearing, c-sec)
  - Carpal tunnel
  - Prior injury
- Emotional
  - Unmet expectations of the birth experience
  - PTSD
- Psychological
  - Manifesting as real pain

Pain

- Where is the pain located?
- Does medication help?
- Are other therapies necessary? Bodywork? Massage? Art? Music? Psychology? Support? Exercise?
- What is the root of the pain and can that be fixed?
- Do certain positions exacerbate the pain?

Barriers to breastfeeding with physical differences

- Lack of supports
- Disability-related health considerations
- Limited information
- Difficulties with milk production
- Difficulties latching

Medications

Most medications are compatible with breastfeeding

Educate on possible side effects

- Milk supply
- GI/stooling
- Infant sedation/drowsiness

Know the right questions to ask

- Do not assume. Ever.
- Open ended statements often work best
- Tell me about your previous experience with handling babies
- What questions or concerns do you have with feeding?
- How can we support your breastfeeding goals?
- Who is your support system?
- Do you have help at home? What kind of help? How often and who?
- Are adaptations needed?

Other considerations

Many long term conditions have other problems associated to consider:

- Hormone problems impacting milk supply
- Digestive problems
- Caloric needs
- Connective tissue disorders affecting joints and skin

Adaptations and Equipment

- Pillows
- Slings
- Baby wearing devices
- Foot stools
- Chairs, beds, couches

My Breast Friend

Borje Breastfeeding Pillow

ISPINNER Nursing Pillow with adjustable belt

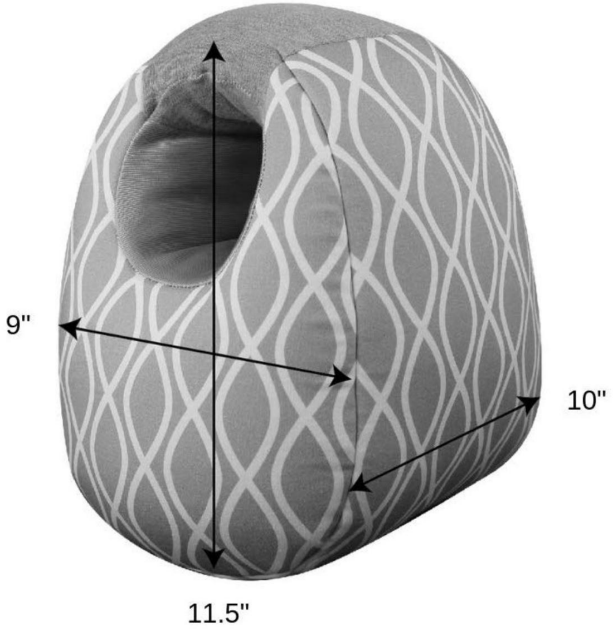
Leachco Natural Boost Adjustable Nursing Pillow

Infantino Elevate

Feeding
Friend

Nurse-Sling

Ergobaby



Itzy Ritzy

Great for C-Section Moms

Bring baby up to the breast instead of putting pressure on the stomach or leaning over.

Helps with comfortable positioning, latching and feeding

CRADLE HOLD

FOOTBALL HOLD

Little Beam

Boppy Travel Pillow

AS Awesling 60in
Full Body Nursing
and Maternity Pillow

Breast support

- Towel rolls
- Pillows
- Nursing bras
- Pumping bras

Breast Pumps

Educating on pump settings

Fitting for proper flange size

Hands-free pump bras

Haakaa

Milk savers/Lacticups

Belkin WeMo Smart Power Outlet

Physical assistance from others

- Do they have a support person available during the day?
  - Family or friend
- Do they qualify for paid assistance
  - Nurse, respite care
- What do they perceive as strengths and weaknesses?
- Can they model safe infant handling with you present?

Physical assistance for positioning

Assisting moms into various positions:

Laid Back

Football

Cross Cradle

Koala

Side Lying

Baby wearing

Koala Hold

If bottle feeding is necessary, consider alternate positions for increased infant support.

Safe bedsharing

- No drugs, alcohol, smoking or medications with sleeping/drowsy side effects
- Firm mattress (non couch, chair or waterbed)
- No bedding or pillows close to baby
- Avoid overheating
- Caregivers only (no siblings or non parents)
- Exclusive breastfeeding
- In the protective C sleep position
- Unswaddled baby

The Deaf

- Deaf mothers who use American Sign Language (ASL) consider themselves a linguistic minority group, with specific cultural practices. They do not see themselves as disabled
- Hard of hearing and deaf parents may or may not consider themselves to have a disability

The Deaf

- Deaf, deaf, and hard of hearing parents do not have the same access to breastfeeding resources as hearing parents
- Not every Deaf parent is fluent in English
- Their impairment with breastfeeding is not their difference, but a lack of access to resources.

Quotes

- Most Deaf mothers described problems with breastfeeding as a “struggle”
- English interpretations of a multidimensional language don’t capture the complexity of what that means.

The Deaf

- Typically get their information from:
  - web sites, books, parenting magazines, social media groups, and health care providers.
  - It tends to be more technologically driven
  - Give visual resources like YouTube or Global Health Media videos
- Their communication interactions tend to be blunt, non judgmental, problem solving and information driven
- They will prefer signed communication

Supporting the Deaf, deaf, and hard of hearing

- Make sure an interpreter is available for ASL users
- Written and visual information
- Videos with translation or subtitles
- Home support systems
- Clear communication with clearly written plan or care and recommendations

Questions to ask the Deaf, deaf, and hard of hearing

- Is there anyone hearing at home?
- How do you get notification of alarms, doorbells, etc?
- What was your plan for attending to baby when baby cries?
- Sleeping arrangements?

Supporting the Deaf, deaf, and hard of hearing

Sitter Baby Cry Signaler, Alarm Clock Receiver, Bed Vibrator Combo by Sonic

Mentally and intellectually diverse

Mental/Intellectual Differences

Down Syndrome

Mental/Intellectual differences: Cognitively impaired or severely learning disabled

- Unknown numbers due to wide variation
- At an increased risk of losing their children
- Higher risk of:
  - Living in poverty
  - Isolated and victimised
  - Have poor models of parenting
  - Have difficult relationship histories
  - Insufficient social support
  - Increased psychological distress

Mentally/Intellectually disabled

- What does their support system look like?
- Explore different learning styles
- Written and pictorial information
- Partner support

Support for the mentally/intellectually disabled

- Community resources
- Parenting groups
- Breastfeeding support group
- Repetition of education
- Return demonstration of education
- Written and pictorial handouts in simple language

Socially and emotionally diverse

Neurodiverse

Autism spectrum disorders

- Central Coherence
- Poor cognitive shifting
- Lack of a Theory of Mind

- Sensory disorders
- Anxiety
- Emotional disorders
- Obsessions

Aspergers: Cognitive shifting

Poor cognitive shifting

- Difficulties shifting and sifting attention
- Difficulties processing multiple stimuli
  - Sounds, cries, movements, smells
- When overwhelmed parent may have a variety of reactions
  - Leaving, melting down, self stimulating behaviors,

Aspergers Theory of Mind (ToM)

- An individual's thoughts, knowledge, beliefs and desires make up his or her own unique ToM.
- Lack of ToM, or mind blindness, proposes that a core feature of autism is the inability to know (deduce) what others know and what others do not know.

Face blindness and interpreting cues

Unable to understand what cries or facial expression mean

Unable to decide what to do when baby cries

Traits of Asperger parents

- Becomes withdrawn and seems to be uninterested in others, appearing aloof
- Intense and all-consuming special interest or hobby
- Difficulty interpreting body language and facial expressions
- Has difficulty understanding jokes, metaphor and sarcasm because he takes everything in a very literal way
- Has poor social awareness and finds it hard to imagine how his behavior impacts on other people
- Has sensory difficulties ...oversensitive to touch or smell or noise or to a particular taste ...has a very limited diet)
- Loves routines and gets very upset if these are broken
- Struggles to maintain friendships

Myths about autistic parents/parents with Asperaers

- People with autism don't feel normal emotions.
- People with autism can't love.
- People with autism can't empathize with others.
- People with autism can't communicate well.

Supporting the breastfeeding Asperger parent

- Education
- Awareness
- Support groups
- Peer support
- Written handouts
- Written feeding plans
- Written education that is clear and concise
- Resources in the community and the internet
- Sensory challenges
- Feeling touched out
- Perspective
- Coping with anxiety
- Asking for help
- Occupational or speech therapy
- https://researchautism.org/autistic-women-pregnancy-and-motherhood/

Questions to ask

- What are the patients coping mechanisms when overwhelmed?
- What support systems are in place?
- Level of education and occupation give insight into their ability to function on a higher level

Adaptive cues and strategies

Alarms

Lights

Reminders

Clocks

Bottles set out

Visual aids

Apps

Sensory processing disorders

Sensory information is processed differently in the brain. It can often be overwhelming

Often misdiagnosed as ADD/ADHD or behavioral issues

Often struggle in school

Have difficulties processing information in large chunks

Thanks!

Any questions?

You can find me at
IG: @lalactation
Facebook: The LA Lactation Lady
YouTube: The LA Lactation Lady
lalactation@gmail.com

Resources

Cetisli NE, et al. (2018). Experiences of Infant and Child Care of Mothers with Disabilities in Turkey: A Qualitative Study.Afr J Reprod Health.

Cetisli NE1, Isık G1, Akgul EA1, Topaloglu Oren ED1, Oztornacı BO1, Sarı HY1. Department of Nursing, Faculty of Health Science, Izmir Katip Celebi University, Izmir, Turkey. Afr J Reprod Health. 2018 Dec;22(4):81-91. doi: 10.29063/ajrh2018/v22i4.9.

Chin, N. P., Cuculick, J., Starr, M., Panko, T., Widanka, H., & Dozier, A. (2013). Deaf mothers and breastfeeding: do unique features of deaf culture and language support breastfeeding success?. Journal of human lactation : official journal of International Lactation Consultant Association, 29(4), 564–571.

Baum, S., Gray, G., & Stevens, S. (2011). Good Practice Guidance for Clinical Psychologists when Assessing Parents with Learning Disabilities. Leicester: The British Psychological Society.

Booth, T. & Booth, W. (1994). Parenting Under Pressure: Mothers and Fathers with Learning Difficulties. Buckingham: Open University Press.

Booth, T. & Booth, W. (1998). Growing up with Parents who have Learning Difficulties. London: Routledge.
Department of Health & Department for Education and Skills (2007). Good Practice Guidance on Working with Parents with a Learning Disability. London: HMSO.

McGaw, S. & Newman, T. (2005). What Works for Parents with Learning Disabilities? Essex: Barnado's.

Norah Fry Research Centre (2009). Supporting Parents with Learning Disabilities and Difficulties. Stories of Positive Practice. Bristol: Norah Fry Research Centre

Powell RM, et al. (2018). Breastfeeding Among Women With Physical Disabilities in the United States. J Hum Lact.

Powell RM1, Mitra M1, Smeltzer SC2, Long-Bellil LM3, Smith LD1, Rosenthal E1, Iezzoni LI4. J Hum Lact. 2018 May;34(2):253-261. doi: 10.1177/0890334417739836. Epub 2017 Nov 22.

Shpigelman CN. (2015). How to support the needs of mothers with physical disabilities? Disabil Rehabil.;37(11):928-35. doi: 10.3109/09638288.2014.948133. Epub 2014 Aug 7.

Tarleton, B., Ward, L. & Howarth, . (2006). Find the right support? A review of issues and positive practice in supporting parents with learning difficulties and their children. London: the Baring Foundation.

Tate, J., & Bushnell, C. (2011). Pregnancy and stroke risk in women. Women's health (London, England), 7(3), 363–374.

WHO . World report on disability. Geneva: WHO; 2011.

https://doi.org/10.2217/whe.11.19 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3137888/

https://www.mayoclinic.org/diseases-conditions/cerebral-palsy/symptoms-causes/syc-20353999

https://www.cerebralpalsy.org/about-cerebral-palsy/prevalence-and-incidence

https://doi.org/10.1177/0890334413476921

https://www.ncbi.nlm.nih.gov/m/pubmed/29166569/

https://www.ncbi.nlm.nih.gov/m/pubmed/30556199/?i=3&from=/29166569/related

https://www.ncbi.nlm.nih.gov/m/pubmed/28215842/?i=3&from=/30556199/related

https://www.ncbi.nlm.nih.gov/m/pubmed/25098594/?i=4&from=/30556199/related#fft

IG #disabledparents, #disabledparenting, #momwithcp, #autisticmom, #autismmom

Adaptive Parenting Project on YouTube