



Under the Magnifying Glass: Meeting the Needs of Mothers with Physical Disabilities

- Created by Jennifer Sexton
- In partnership with the West Virginia University Center for Excellence in Disabilities
- A workshop for Nursing Professionals



“Just as a ramp to the court house enables me to exercise my civil rights today, I need a ramp to parenting—a ramp to enable me to exercise my human rights and to fulfill the responsibilities that go along with parenting.”

--Leigh Campbell-Earl
(Prilleitensky 2003)



Mothers with Disabilities

- Traditional discouragement
- Denial of opportunity
- Perceptions of women with disabilities
- Myths
- Prejudiced assumptions regarding care



Medical Model of Disabilities

- “Sue has a problem”
- Focuses on the impairment, rather than the person
- Focuses on disabilities, rather than disabilities
- Emphasis on dependence
- Stereotypes of pity and fear
- Providers feel a fear of doing or saying something wrong
- Cycle of dependency and exclusion



Medical Model of Mothers with Disabilities

- Removal of infant from room
- Feeding of infant by nurse or aide
- Quizzing the mother, “How are you prepared to handle...?”
- Developing of a birth plan based on what is typical of the mother’s disability
- Ignoring the desires of the mother
- “Every shift there was a new nurse and I was grilled as to how I was going to take care of her. Every shift a new nurse would ask me how I was going to manage...they grilled me, “how are you going to bathe her, have you thought about that?”—Mother with multiple sclerosis (Prilleltensky 2003)



Support Model of Disabilities

- Identify barriers and develop solutions
- Resources and external supports are discussed and/or brought in
- Focus on the goals of the mother, rather than the goals of the staff
- Empowerment of the mother



Support Model of Mothers with Disabilities

- Allowing Mom to change, feed and dress infant
- Encouraging the infant to stay in Mom's room
- Asking the mother "How do you expect to handle...?"
- Developing a birth plan based on the desires and needs of the mother
- Engaging the mother in the decision making process
- "She was working alone that night, although it may have been two of them on the ward...she took the time, she got all the pillows propped up and she set the baby down where I could nurse her and she said, 'You tell me when you're ready for the other side'...she was just wonderful."—Mother with paraplegia (Prilleltensky 2003)



Blindness and the Birthing Experience

- “The birth of my twins should have been special, but the experience of giving birth to them had been taken away. I had been made to feel vulnerable, powerless and unable to take control of what was happening to me.”— Mother with blindness (AIMS 2002)
- Provide materials in an accessible format
- Explain who is in the room, as well as their role there
- Explain test results, ultrasound images and monitors
- Ask mothers with visual impairments how they are best able to see objects and pictures
- Do not assume what the mother can and cannot see



Blindness and the Maternal Experience

- Allow the mother to make suggestions
- Describe where the infant is and what is being done
- Encourage one-to-one instruction
- Bend the rules to meet her needs
- Side wards, if available, should be utilized to provide safe space
- “Perhaps the greatest modification to care was the way in which parenting education was provided. Tactile and experiential learning strategies were used as alternatives to visual approaches and demonstrations.”— Alison McFadden, midwife (McFadden and Herbert 2001)



The Right to Motherhood

- Provider obstacles
- National Center for Rehabilitative Medical Research
- Natural right
- Component of a woman's identity
- “And as I get to know more and more of my self worth, it sort of helps me to identify myself, thinking that I am a woman created by God and I am so precious and so loved and I have so much beauty inside of me. I should not hide it.”—36 year old mother with polio (Nosek, Howland, Rintala, Young and Chanpong 2001)



Person First Language

■ Say:

Mother with a disability

Uses a wheelchair

Has a physical disability

Congenital disability

With paralysis, with para/quadruplegia

Typical, without disability

■ Instead of:

Disabled/handicapped

Wheelchair bound

Is physically disabled

Birth defect

Paralytic, invalid

Normal, healthy



The Roles and Importance of Nurturing Assistants

- Physical assistance to parents in order to undertake the traditional parenting tasks
- Assistants are not babysitters or nannies
- Paid employees or volunteers who work under the presence and direction of the parent
- There are no programs for assistants in the United States.



Roles within the Family: Informal Support Systems

- Extended family
- Mother may act as primary caregiver
- Father may take on maternal role-
Mother may work outside the home
- Employment of Nurturing Assistant
- Mother may focus on domestic tasks,
father cares for children
- “The disability in some ways has
allowed for more equality to take place
in our relationship.”—Mother with
paraplegia (McKay-Moffat 2003)



Adaptation of Baby

- “When I would pick them up I would use my right side a lot and they’d lean on my right side. And then as babies they almost automatically knew to reach for my right side, they would lean in the direction.”—Mother with paraplegia (Prilleltensky 2003)
- Encourage Mom to interact independently with baby
- Assist in only *establishing* techniques—rather than carrying them out
- Encourage the relationship building process between Mom and baby—as you would any other mommy



Bring Baby Home

- Acknowledge the scrutiny that the mother feels
- Determine the support that Mom needs-instrumental and/or social-emotional support
- Discuss support systems that are available at home
- “My biggest fear is CPS. They can come at any time, and if my neighbor sees something out of the normal, if it doesn’t look right how I carry her...This could happen just because I have a disability.”—Mother with cerebral palsy (Prilleltensky 2003)



Violence Against Women with Disabilities

- Women with disabilities experience the highest rate of violence in the United States
- Recognition of important issues
- Signs of physical and sexual abuse
- Atypical abuse



Three Questions to Ask During Pregnancy

- Within the last year, have you been hit, slapped, kicked, or otherwise physically hurt by someone?
- Since you have been pregnant, have you been hit, slapped, kicked, or otherwise physically hurt by someone?
- Within the last year, have you experienced any forced sexual activities?



Guidelines for Effective Nursing

1. Relax. Do not feel threatened.
2. Decide to become inclusive.
3. Consider the impact of your care and patience.
4. The patient is the expert in regard to her own body.
5. Learn from the mistakes that you make.
6. Assume the solutions exist.
7. Remember your power. You have the ability to wield both good and bad.
8. Take responsibility. Patient advocacy now has a more holistic meaning.
9. Question your own ideas.
10. Be constructive-not prescriptive.

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- “As you continue your work in maternity services and in the lives of the individuals who use them, you too choose what route to take. You can opt for a route that causes vulnerability, dependency and trauma, that turns every pregnant woman with a disability into a problem or a phenomenon. But, equally, you can choose to work in a way that supports those same women simply to be pregnant.—Lize Crowe, Writer, filmmaker, disability equality consultant and mother with a disability (Crowe 2003)

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