Disparities in perinatal care and outcomes among women with disabilities: A call to action

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What Is Disability? Who are People with Disabilities?

It depends. The definition is complicated and contested.
How is Disability Defined in the United States?

- Americans with Disability Act (ADA) of 1990
- Surveys including the US Census include a 6 question definition of disability
- Program eligibility (e.g. state agencies) – type of disability, employment, and income
- Benefit eligibility (SSI, SSDI, Medicaid) – level of impairment, work history, income and asset limits
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A call to action
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Outline

• Maternal characteristics and pregnancy outcomes among women with disabilities

• Unmet needs and barriers to perinatal care among women with physical disabilities

• Barriers to providing perinatal care to women with physical disabilities
Why?

- American Eugenics movement
- Institutionalization of people with disabilities
- Stigma and discrimination towards people with disabilities
Parents and prospective parents with disabilities still face stigma regarding their decision to have children.

Many states have laws that allow state child welfare agencies to remove dependent children from disabled parents’ homes solely because of their disability.

Moving toward a social model of disability and affirming disabled parents’ strengths can help dismantle stigma and systemic bias.
“If research pursuits reflect social values, it makes sense that a society that has long ignored or disdained the gender role of women with disabilities has invested little effort in understanding their potential for love, partnership and motherhood” (Gill, 1996, p. 183)
Three separate studies on the perinatal health and outcomes among

• Women with physical disabilities
• Women with intellectual and developmental disabilities
• Deaf and hard of hearing women
Similar proportions of women with and without disabilities experienced sexual intercourse between ages 12 and 24. (Namkung et al, 2019)

Among women without children, women with and without disabilities report similar pregnancy intentions and desire for children.

Women with disabilities at reproductive age are more vulnerable to multiple risk factors associated with adverse pregnancy outcomes compared to their counterparts without disabilities (Mitra et al 2016)
Similar proportions of women with physical disabilities (10.4%) and women without disabilities (12.6%) are pregnant (Horner Johnson et al 2016).

Adjusting for age, women with chronic physical disabilities and non-disabled women are equally likely to be pregnant (Iezzoni et al 2015).
Maternal Characteristics

Compared to non-disabled women, women with disabilities who recently gave birth were:

• Younger
• Less educated
• Public insurance
• Unmarried
• Household poverty status <=100% FPL

Smoking, Violence, and Access to Prenatal Care

Compared to non-disabled women, women with disabilities who recently gave birth were:

- Smoking
- Physical abuse
- Start prenatal care after the first trimester

Compared to non-disabled women, women at risk for disabilities who recently gave birth were:

- More likely to have a preterm birth infant
- Cesarean section

Unmet Needs and Barriers to Care: Perspectives of Women with Physical Disabilities
Interviews with Women with Physical Disabilities

- Interviews with 25 women from across the United States with physical disability who had a baby within the last 10 years (ages 21-55 years)

- Recruitment through social media, independent living centers, local and national disability organizations
Clinician Knowledge and Attitudes

Some clinicians were very supportive and respectful

“...she knew how badly we wanted to have a baby and was supportive... I feel like she treats me like a regular patient and like I don’t have a disability.”

Some women described being viewed by their clinicians as asexual

“I think probably the weirdest [comment] was ... from my doctor.... He asked us how we got pregnant, and if we had used a turkey baster.”
Clinician Knowledge and Attitudes

Lack of knowledge about effect of disability on pregnancy

“would automatically deliver at 26 weeks and my child, if it lives, would be mentally and physically disabled...Strictly because I was in a wheelchair and I needed care myself.”

Some clinicians had never had patient with a disability before

“(I)t just kind of felt like they didn’t know -- I was teaching them a lot of things, which is not totally uncommon.”
Accessibility of health care facilities and equipment

Women weighed through unconventional methods, or not at all

“(a)nd after he realized that I only put on like not even six pounds through about half of the pregnancy, [he said], ‘I’m not worried . . . I can tell by looking at you that you’re at a healthy weight, you’re OK.’”
Need for Information

Interaction of disability and pregnancy

“I really didn’t have anybody to turn to, so there -was - not much information that I knew about pregnancy and having a disability . . . There’s nobody I knew -- who was disabled and having kids.”

Appropriate prenatal care clinicians

 “[Finding a provider] was actually much harder than I thought it was going to be. The first couple preconception appointments I had, the OBs were very negative. They of course did not really understand SMA, so they were coming in just seeing the disability, with some preconceived notions.”
Barriers to providing perinatal care to women with physical disabilities: perspective from health care practitioners
Provider Interviews

- 14 obstetrician-gynecologists and certified nurse midwives with experience providing maternity care to women with physical disabilities
- Identified through the American Congress of Obstetrics and Gynecology, the American College of Nurse-Midwives, affiliations with disability-related organizations, publications in the area of pregnancy and disability, indications of work with women with physical disabilities
- Varying volume of care for women with physical disabilities, ranging from a few per year to 5+/month
- Variety of settings of practice, including hospitals, university practices, solo practices, specialty clinics for women with disabilities
Barriers to Providing Perinatal Care

Practitioner Level Barriers

Lack of training/education related to maternity care and specific clinical needs

Unwillingness in providing maternity care to women with physical disabilities

Inadequate coordination of care between practitioners
Practitioner Level Barriers: Lack of Training

One participant noted that formal education and training early on could possibly prevent practitioner bias toward pregnant women with physical disabilities.

“...physicians feel uncomfortable, untrained, unprepared, and their offices are also equally untrained and unprepared...So unfortunately, they [patients with disabilities] end up in a perinatology office just because they have a physical disability, not because they truly have an unusual obstetrical clinical problem.”
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Clinical Practice Level Barriers: Inaccessible Equipment

Accessible exam tables and scales

• “They sometimes get weighed at their other [doctors] that are taking care of them…we kind of rely on them, if they can’t get out of their wheelchair.”

• “I generally just eyeball. We spend a lot of time talking about it.”
System-Level Barriers: Scheduling and Reimbursements

Pressure to keep appointment times within prescribed time slots (often 10 or 15 minutes)

“We are so locked into these 15- and 30-minute slots now, in medical practice, that it’s very hard...for any one doc[tor] to *isolate an hour or an hour and a half for a patient visiting*. And many of these patients will take an hour.”

“You don’t get paid any extra. *You do this because it’s the right thing to do and you want to do it and you love to do it and the patients appreciate it*. And that’s why you do it. You don’t do it for money. It’s a money loser. No insurance company, whether it’s commercial, state, or federal is going to pay me more.”
Need for Guidelines and Evidence-Based Clinical Data

Extrapolating data about non-pregnant women and even men with disabilities to pregnant women

On-the-job learning and training

“…in my general practice almost any decision I make…I can [go] to UpToDate or some sort of reference, ACOG recommendation, and they’ll tell me exactly what to do, but in the disability clinic, that’s not the case.”
How do we move forward?
National Research Center for Parents with Disabilities

Parents Empowering Parents
Padres Empoderando a Padres

The National Research Center for Parents with Disabilities conducts research and provides training and technical assistance to improve the lives of parents with disabilities.

We offer resources to support parents with disabilities, and information about working with parents with disabilities for social workers, researchers, and legal professionals.

The Center for Parents recognizes that parents with disabilities know what they need. We are guided by the principle "nothing about us without us."
“I loved every part of it. I felt very healthy. I loved when I could feel her moving. … especially the experience of growing up with a disability and … having so many messages around you about what your body can't do and … we need to fix this and this isn't right. … it was like a sense of pride … in how well my body did it.”