Provider Attitudes towards People with Disabilities: Making the Case for Disability Cultural Competence in Health Care

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Outline

• **Background**: Health disparities, equity and disability

• **Case study**: Provider interactions with women with physical disabilities around the time of pregnancy

• **Next steps**: The need for disability cultural competence training
Background

1. Increasing numbers of people with disabilities in the United States
2. People with disabilities are living longer
3. People with disabilities use disproportionately more health care resources than non-disabled people
Health Disparities, Equity and Disability

- Significant **disparities in health** and quality of life between people with and without disabilities

- People with disabilities are less satisfied with the **quality of care**

- Greater difficulty in **accessing** health care services and programs

- **Structural barriers** (e.g. transportation, accessibility, communication barriers)

- **Financial** (under-insurance and out-of-pocket expenses)

- **Personal/cultural** (e.g. attitudes of health care professionals, lack of respect, stigma)

- **Social determinants of health**
Health Disparities, Equity and Disability

- Change in focus from disability prevention to the inclusion of persons with disabilities in public health programs and services

- Disability ≠ Poor health

- Intersectionality: disability, race, ethnicity, poverty, and gender
Case Study:

Unmet Needs and Barriers to Perinatal Care for Women with Physical Disabilities

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Perinatal Care for Women with Physical Disabilities: Provider Interactions and Attitudes

• Systematic, mixed method study to examine unmet needs and barriers to perinatal care for women with physical disabilities
• Interviews with 25 mothers with physical disabilities
• Interviews with 14 prenatal care providers

• Study funded by a National Institute of Child Health & Human Development grant (Award Number: R01HD074581).
Provider Interactions: Perspectives of Women with Physical Disabilities

1. Clinicians lack **knowledge of needs** of women with physical disabilities during pregnancy
2. Clinician failure to **consider knowledge and experience** of women with physical disabilities
3. **Negative attitudes** of health care providers
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

• “He literally told me that I needed to remain abstinent.”

• “[The physician said] ‘If I were your parents, I would do anything I could to convince you to adopt.’ ”

• “[The physician said] ‘Look how disabled you are and you really shouldn’t be -- you should not get pregnant.’ ”
Clinician Knowledge and Attitudes

• “The first couple preconception appointments I had, the OBs were very negative. …they were coming in just seeing the disability, with some preconceived notions. I had one tell me that I 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.”
Clinician Knowledge and Attitudes

• Mixed experiences with nursing staff
  – “[The nurse] refused to take the one [leg] and my husband had to actually come over and hold it because she didn’t want to touch my stump.”
Clinician Knowledge and Attitudes

“Treat them as women. They’re women who get pregnant just like everybody else and we’re able to be parents…just because you’re disabled, … you haven’t stopped being a woman, [and] you still want to be a mom.”
Clinician Failure to Listen to the Woman

• “And I said, ‘You know, I’m an expert on my body. I know what’s normal and what’s not normal.’ And the fact that he would refuse to take cues from me, he refused to take any suggestions I had. … I even said to him…‘I was a patient here before. Why don’t you pull up the info…from last time…just pull up the notes, the chart from last time.’ And he was like, ‘No, no. I’m fine. I’ve got this.’
Provider Interaction: Provider Perspectives

1. Misconceptions
2. Lack of training and education
3. Lack of familiarity with persons with disabilities
Misconceptions

• “My most rewarding experiences have been with patients who have disabilities who get pregnant and deliver. Part of that is because they were told -- well first of all the usual stereotypes, they don’t have sex, can’t have sex, they can’t get pregnant, and if they get pregnant they should abort. All of which is usually not true.”
Negative Attitudes

• “So we do have our own prejudices about disabilities. Whether it’s the baby or the patient. And I guess … some kind of open-mindedness about that early on would be helpful. I don’t know how you do that, except maybe going back to medical school, as before anybody even picks their field.”
Lack of Training

• “Because… you’re figuring it out as you go along. You’re trying to do your best, but if you haven’t been educated on specifically how to work with people that have contracted muscles, for example, it’s kind of hard to get them … in a position comfortably where you can, insert a speculum and do a GYN exam. It can be, as you can imagine, incredibly traumatic.”
# Recommendations to Providers

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<tr>
<th>From women with physical disabilities</th>
<th>From health care practitioners</th>
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<tbody>
<tr>
<td>Seek additional information</td>
<td>Seek information and think creatively</td>
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<tr>
<td>Coordinate with other providers</td>
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<tr>
<td>Listen to the woman and respect her as a person</td>
<td>Allow enough time</td>
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<td>Don’t make assumptions</td>
<td>Include women in her own care</td>
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How Do We Move Forward?

How do we go “beyond treating disease to addressing the needs of persons with disabilities?” (Iezzoni, 2006)


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Disability Cultural Competence in Health Care

• **Health care training and education**: “Promoting the inclusion of disability-related theory, research, and clinical learning experiences in health care training” ~Alliance for Disability in Health Care Education

• **CLAS standards** – Culturally and Linguistically Appropriate Services in health and health care

• ACA: Section 4302, identify and assess “the number of employees of health care providers trained in disability awareness and patient care of individuals with disabilities”

• ACA: Section 4302: **Collection of disability data** across the health care system
“I think we need to add that if you are, depending on your color, the treatment you get is … provided because if you are black, or Hispanic, or Mexican, different from the White person, and sometimes even the accent, you know if you speak a different language, just because you have a different language, speech, you know, you get treated differently. And most importantly if you have a disability because it is double jeopardy itself. That kind of perception is very complex. It gives you a different kind of attitude.”