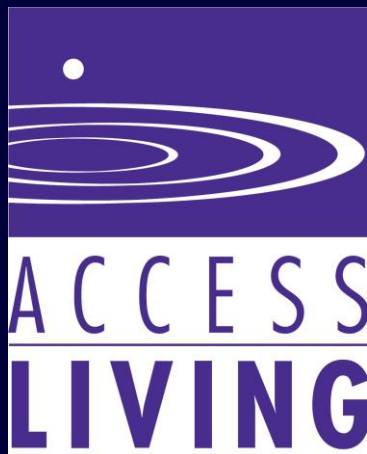


Healthcare Access for People with Disabilities

Presented by Tom Wilson & Susan Aarup

In partnership with Susan Magasi, PhD



**Program for Healthcare Justice
for People with Disabilities**

People with Disabilities Experience Significant Barriers to Healthcare



Methods

People with Disabilities Speak Out on Healthcare Disparities

- **Aim:** Understand primary care experiences of Medicaid enrollees with disabilities
- **Study Design:** Mixed methods community-based participatory research
- **Participants:** 87 Medicaid beneficiaries with disabilities from the Chicagoland area, stratified by impairment type.
- **Data Collection:** Ten focus groups stratified by impairment type.
- **Analysis:** Constructivist grounded theory.

ScreenABLE – Cancer Screening Disparities among Women with Disabilities.

- **Aim:** Understand Barriers to Cancer Screening among women with physical disabilities
- **Study Design:** Qualitative community-based participatory research
- **Participants:** Convenience sample of 40 women with physical disabilities
- **Data Collection:** Six focus groups, Oct 2013 and Jun. 2014 across IL
- **Analysis:** Constructivist grounded theory

Participants

People with Disabilities Speak Out on Healthcare Disparities

Participant Demographics (n=87)

Mean Age (Range)

48.5 (23-63) years

Gender

Male

48 (55.2%)

Race/Ethnicity

African American

46 (52.9%)

White

20 (23.0%)

Other

21 (24.1%)

Hispanic Origin

16 (18.4%)

Self-Identified Impairment Type

Cognitive

54% (n=47)

Mobility

48% (n=42)

Sensory

37% (n=32)

ScreenABLE – Cancer Screening Disparities among Women with Disabilities.

Participant Demographics (n=40)

Mean Age (Range)

50.0 (23-64) years
3 missing

Race/Ethnicity

African American

16 (40.0%)

White

18 (45.0%)

Other

1 (2.5%)

Hispanic Origin

5 (12.5%)



PEOPLE WITH DISABILITIES SPEAK
OUT ON BARRIERS TO CARE

Responsibility

It is never our fault that they don't have the training or the equipment to make it a safe clinical experience for us. Because it's all out there. The training is out there. The equipment is out there.

Dignity and Respect

They never had anybody help transfer her from her chair to the table and she was in tears because they always called up the security guard with a holster and a gun while she's in this little gown thing, which they put on her, and she just got to the point where, here she is, she's got cerebral palsy, she's got cancer, she's, you know, depressed, she doesn't want to go in for the cancer uterine exam, and yet she has to put up with the embarrassment and the humiliation.”

Responsibility

They were more concerned about trying to get me to stand up straight which won't happen, either with spinal stenosis you tend to lean forward you know the way the surgery was done that's how it left me leaning forward they keep saying you have to stand up and I said this is standing up. What else -- go ahead and break my back see if I care. But they -- they just act like they don't have a clue of what you're telling them if you say you can't, then you know figure out some other way to do it. But they only have it in their head this is the way I was trained to do it. And this is what we got to do. It doesn't work that way with everybody you know.

Lack of Provider Knowledge

My problem is some doctors, I don't know if they feel intimidated that you have a disability, you're sitting in this chair, sometimes they get scared. They don't even want to touch you.

I said, you can exam me like you exam you examine any other woman. I'm not going to break, you know.

Lack of Preventative Screening

My primary doctor used to take care of my pap smears and my breast exams but one day he got to the point where I could not get up on the table anymore. The tables are too high. So I couldn't do it. I told my doctor I couldn't do it and he was like okay and that was that. And so I went like 5 years without a pap smear or a mammogram.

Financial Barriers

You've got to have an open mind to be able to accept what I'm going through even though I might be the same disability you have and everything. But you might have a financial – a better financial situation than me so you don't even have a clue of what a person on fixed income and using public transportation and relying on just yourself, you know what I mean?

I went in there one time and I was in very, very bad pain. I wasn't able to bend down to empty out my leg bag and I asked them if they could help me do that and they said they wouldn't. I said, 'If you don't help me do that, I'm going to start having an accident on myself and I'm trying not to do that.' Their response was that they didn't have anybody to do that and I should have somebody come with me if I know that I'm going to need that kind of help and I'm in that kind of situation.

Mod: They said your history was too complicated for them to deal with?

Par: Too complicated.

Mod : Did they refer you anywhere else, or did they just show you the door?

Par: They referred me where I could go, but my ride had left, so I had to wait another 30 minutes for my ride to get back to take me over there. I said, 'man, I'll never get sick out here again.'

Mod: Like you could control that more.

Par: [Laughs] I hope I move out of that neighborhood. Can't even see you...It's ridiculous.

Attitudinal Barriers

Sometimes they just don't care. You have to be able bodied and walk so they can listen to you. If you're in a chair, they're not going to listen.

Financial Barriers

[The doctor] told them, 'take his blood pressure...and get him out of here.' And I looked at those residents. They was trying to ask me that question. I was so pissed off, tears came to my eyes. I'm not saying nothing else to nobody. *And* I was broke, and I had to go out and find somebody to give me the money to pay for my aspirin, the blood thinner. In so many words, he basically 'get a prescription and get him out of here.' I didn't like that."

Financial Barriers

The disabled people out here, we're not being treated right. We're barely surviving as it is on our income. And everything goes up all the time or you're cut on this, cut on that. Some medications you take won't be given unless at full price. They will tell you, *'Medicare won't cover it...you have to pay cash'*. Excuse me?

[Click for ScreenABLE Video](#)



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Team Members

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