"THEY DON'T EVEN SEE US"
Intersectional Approaches to Understanding Disability in LIS

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Theory

Information Poverty (Chatman, 1996) Marginalization (Gibson & Martin, 2019)
"systematic, interactive socio-technical processes that can push and hold certain groups of people at social "margins," where their needs are persistently ignored or overlooked."

Disability
"disability as comprising individual differences (and, at times, impairments), as well as a range of socially constructed barriers"

Intersectionality (Crenshaw, 1989, 2017)
"Intersectionality is a lens through which you can see where power comes and collides, where it interlocks and intersects. It's not simply that there's a race problem here, a gender problem here, and a class or LBGTQ problem there. Many times that framework erases what happens to people who are subject to all of these things."

Methods
Thematic analysis of interviews of 12 autistic adults, and transcripts of 15 public presentations in 2019 CEDI lecture series (https://cedi.web.unc.edu/2019-cedi-lecture-series/) by adults with disabilities and family members of individuals with disabilities. The lecture series was part of a full-semester graduate level course in disability information and informatics at UNC Chapel Hill..

Findings
Present propositions of information poverty (bold black quotes), corresponding proposition from developing theory of information marginalization (dark gold preceded by arrow "→") with themes/quotes from data for 3 out of 6 propositions (24 pt. black). Takeaways related to intersectional understandings of disability are written in dark blue preceded by the symbol "∞."

Findings & Discussion

"Partially associated with class distinction" →
Institution Ignores/Perpetuates Social Inequality

∞Exacerbating inequality through over-policing, hypervisibility, invisibility for disabled people of color.

"By the time I got to college…nobody is available to help you. You're wandering. They didn't help you. They sat behind a desk. At least in grammar school and high school they knew that you needed help. In college it was fend for all, you know. You're supposed to know this already." – (Black woman, age 50+)

"everybody has been wonderfully helpful. I don't know that's anything above and beyond other than them being extraordinarily helpful. They've been patient and showed him several times -- I know they had to show him how to look up books and that type of thing" – (White woman, age 40+)

"Honestly, I don't go to the library. I don't use the resources I have because I am afraid at any minute the security person will show up." (Latina, age 30+)

∞ Gatekeeping (intentional or intentional) that reinforces racial/ethnic/gendered/ability-based segregation.

"No one has a passport all the time…Why you coming to me to tell me to use the resources – especially the ones in Spanish…but how can I get access to them if you won't give me a card?"

Engage in "Self-protective Behaviors" →
Ignores power and privilege in information systems & ignores impact in favor of intent.

∞ **Knowledge/Awareness Isn't Enough. Power Matters.**

"in February a Greenville, North Carolina dentist and department of health and human services were sued by disability rights because of discrimination with Medicare. So their legal representation is a powerhouse."

∞ **Disabled people of color make rational decisions about trusting and distrusting institutions.**

"The difference is that my parents disagreed with the physician, so I lived at home versus probably in one of the institutions"

I don't think that there is enough promotion that might reach minorities. I don't think there's enough promotion period…

"while I was there people started trusting me too and there were moments when moms would tell me certain things - whether it was about their legal situation or some problem with the father or with the mother they start trusting you. You talk to them and you give them your point of view and you listen, and the next time they know who you are and they have questions with you and you follow up on your conversation and I do know that that once I left they were asking for me. So I think if you take the time to talk to people, to know what's going on in their lives, just to ask how are you doing, are you okay, where are the kids, how are they doing in school, you build a certain level of trust."

Cost Benefit Analysis re: Information seeking →
Ignores /costs associated with information systems and personal data collection

∞ **Personal data is not free. The potential costs are high for people at intersections and margins, and we often ask them for the most information for the most basic services.**

"How you going to get a library card for your kids if they are asking you, 'I want a valid North Carolina driver's license? Some of the people cannot get one. I need a bill with your address and your name…sometimes we are unable to share a bill."

∞ **People of color are often asked to bear the cost of institutional failures and are vilified or ignored when they refuse.**

"as someone who grew up having to translate which I was happy to help my mom but there were times when I was like I'm a child, I want to go do this, or I want to go do that, but no I have to stay here because I'm trying to make this connection happen" (Latinx library worker, age 20-30)

"he didn't want to go in, and we kept asking him and saying nothing is going to happen. __ is from China and I'm Mexican, and we were like' nothing is going to happen, everything is going to be fine,' and he kind of stopped and stared at us and he said 'you don't understand, every time I go in there they look at me like I'm going to steal something'…and we went in and he just made it in and he turned around and said 'nope' and he walked out."

CEDI Lectures

Course syllabus

Gibson & Martin, 2019

INSTITUTE of Museum and Library SERVICES

Community Engaged
DISABILITY INFORMATICS
Connecting Carolina's communities with information