

A far cry from fair: Findings from a new report on access to health care for people with disabilities

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A far cry from **FAIR**

Health-care access for
people with disabilities



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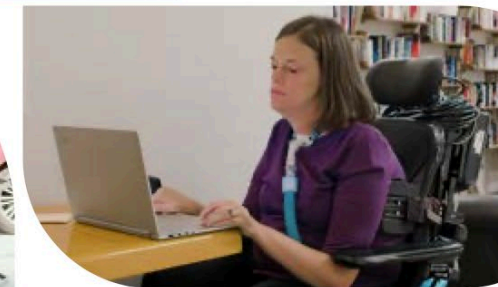
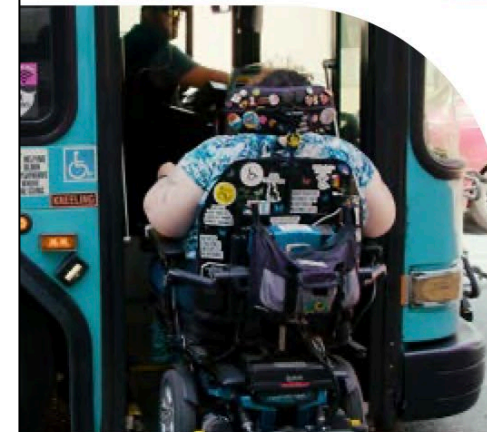
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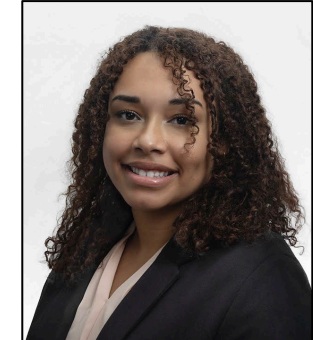
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Outline

- **Background**
- **Report creation**
- **Overview of findings**
Key barriers, compounding experiences, consequences
- **Key barriers**
- **Q&A**

Background

Impetus for the initiative



Shani Lasin

Senior Program Officer

The FISA Foundation

Report and resources:

[www.fisafoundation.org
/access-to-health-care-initiative](http://www.fisafoundation.org/access-to-health-care-initiative)

Key terminology

Health disparities: Disproportionate adverse health outcomes experienced by social factor - due to disadvantage, not disability

People with intellectual and developmental disability versus without:

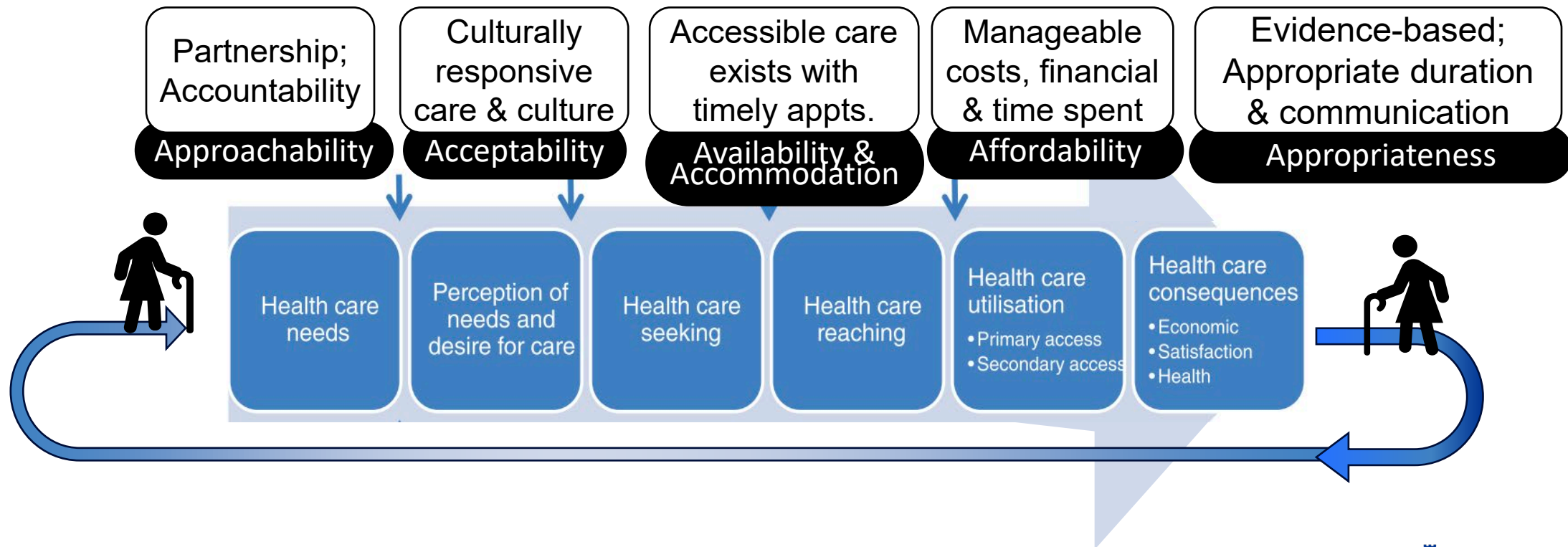
- More likely to report 'poor health' (40% vs 9%)
- Life expectancy is 20-years less in the U.S.

Health care inequities: Unjust differences in access to and quality of health care services

Access to health care is the chance to be healthy

Opportunity to have health needs met through health care services

Levesque's Conceptual Framework of Access to Health Care, modified



Approach

Characterizing experiences accessing health care

National Data

Mixed-methods systematic review

- Integrated convergent design



Criteria:

- Person with disability or caregiver
- Self-report of health care access
- US-based, 2014 onward

Local Data

Semi-structured interviews

Participants: ≥ 18 yrs old,
has disability or caregiver of
person with disability



SEARCH

PubMed & CINAHL
Levesque 2013 & Souliotis 2016

SCREEN

Title & abstract: N=1,513

Full text: N = 1,278

ABSTRACT

RoB & data abstraction: N= 82

Transformation: n=
Qualitize quantitative data

SYNTHESIS

Convergent Integration & Synthesis
Best Fit Framework Synthesis of
Qualitized data + Qualitative data

Pre-screen remove: N=5621

Excluded N=235

Excluded N=1,196

- Not in US, n=111
- Pre 2014, n=111
- No access data, n=111
- Not self-report, n= 111

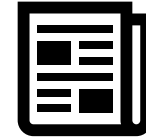
Characteristics of participants & articles



21 people interviewed

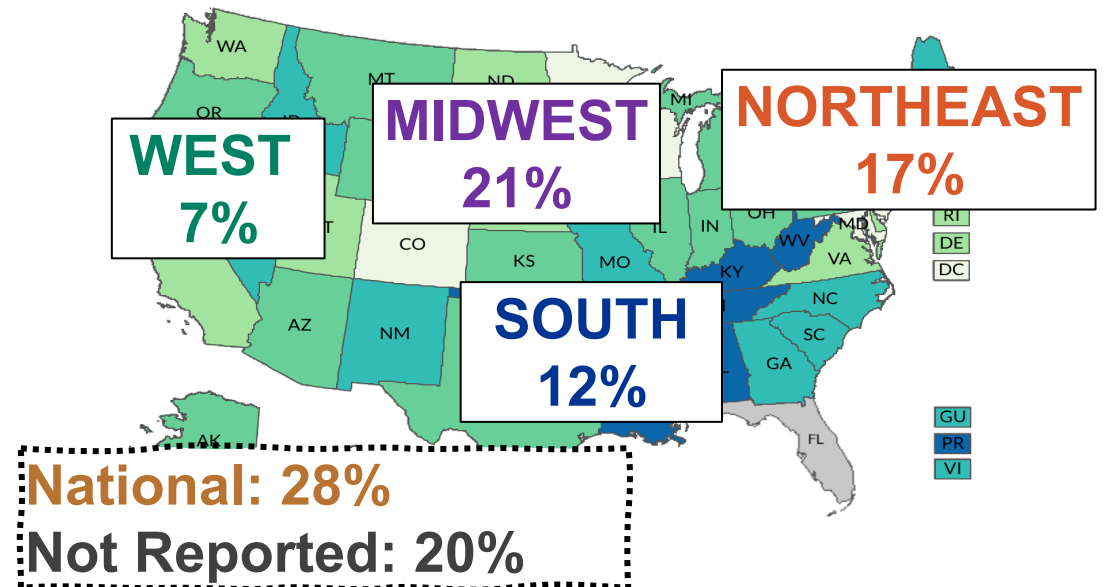
- Adult with disability (66%)

| Race | |
|------------------------------|-----------|
| White | 15 |
| Not White | 6 |
| Gender Identity | |
| Female | 16 |
| Male | 3 |
| Other | 2 |
| Primary Disability Type | |
| Physical | 17 |
| Mobility Specific | 10 |
| Intellectual & Developmental | 9 |
| Sensory | 6 |
| Vision | 4 |
| Hearing | 2 |
| Mental Health | 5 |



82 articles included

- Cross-sectional design (99%)
- Nation-wide assessment (28%)
- Health care broadly (55%)
- Developmental disability (32%)



Creating the report

Synthesis: Best-Fit Framework
synthesis of national and local data

- Mapped to Levesque framework

Themes drafted and revised
through critical reviews:

- FISA Foundation
- Disability advocates

Acknowledging Our Reviewers

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Findings

Access to health care is insufficient

Key Barriers

1. Accessibility
2. Affordability
3. Appropriateness

Consequences

Health,
relationships,
finances,
trust in system

Intersectionality

Barriers intersect
& compound

Key Barriers

1. Health-care services are rife with accessibility barriers

Environment

Building exterior & entry
Physical layout
Sensory components

Equipment

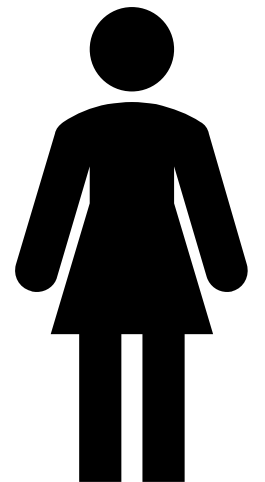
Exam tables & chairs
Scales
X-rays & mammograms
Blood pressure cuffs

Processes

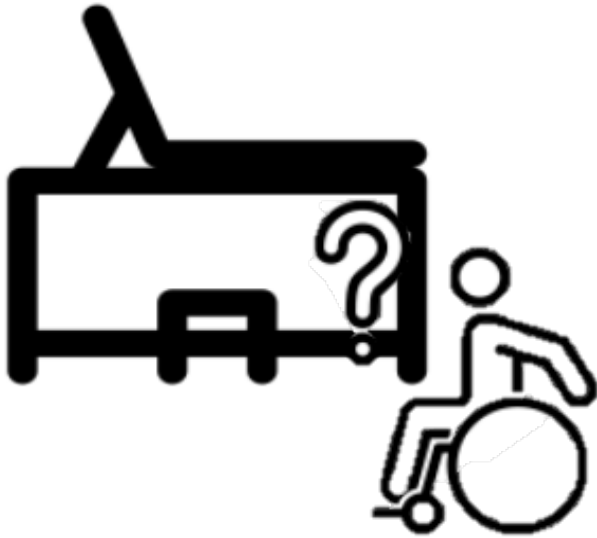
Scheduling appointment
In-take forms
Resources & information
Sharing test results

*"It should just be that every single clinic, every single space - especially pre-op where you're coming in for a procedure where you know you need to get everyone's weight - it should just be on the forefront of the mind of, 'We have a wheelchair scale that you can roll your wheelchair onto.' **It shouldn't be an afterthought.**"*

– Local participant with multiple disabilities



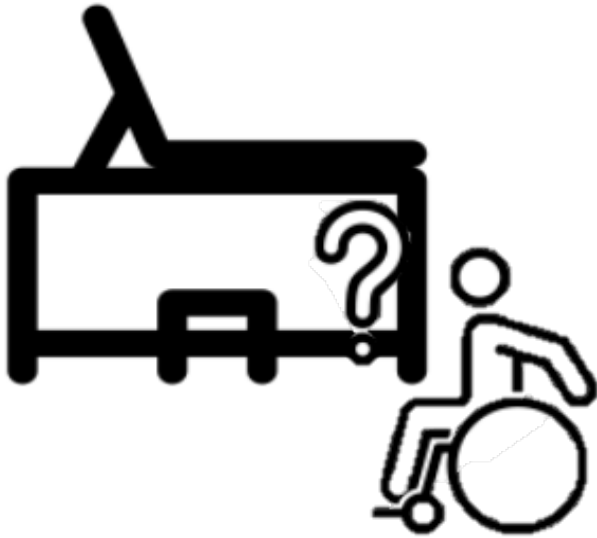
Inaccessible equipment



Across studies surveying 100 to 1,000 people:

- 60-70% report not being examined on a table
- 59% needed accessible mammogram machine
- 57% needed accommodations for difficulty with positioning of arm or shoulder

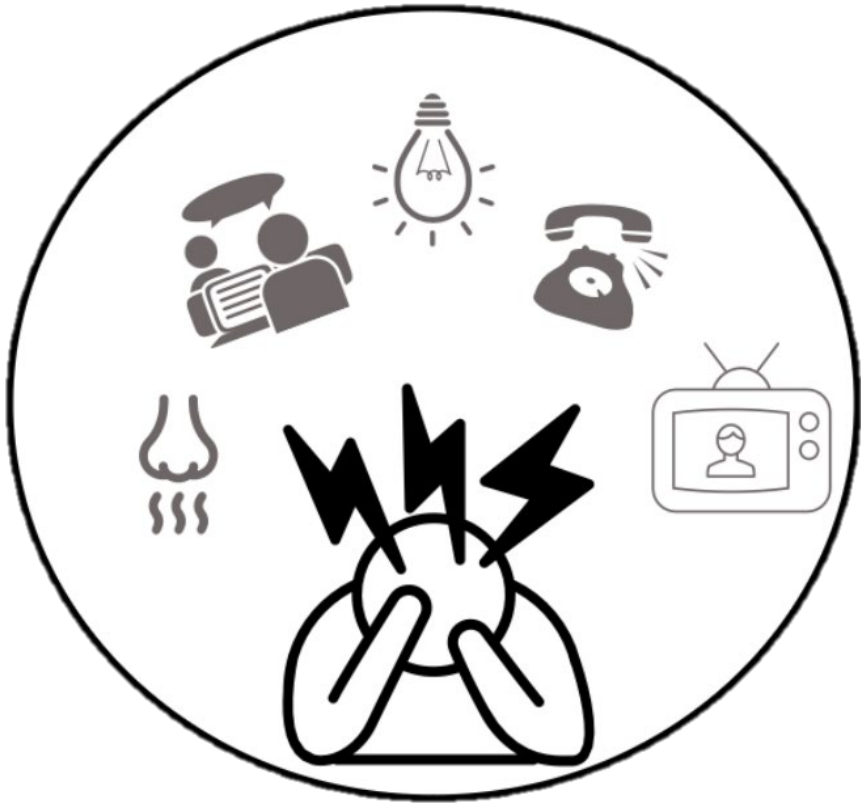
Inaccessible equipment



Kalpakjian 2020:

“[my primary care provider] doesn’t know anything about spinal cord injury and she has told me that her office...like the tables are up here and she’s like, ‘Yeah, tables don’t go up and down. **You should probably find a new primary care provider’.**”

Inaccessible environment



Environmental barriers reported included:

- Sensory components (noise, lights, crowding)
- Long distances for ramp entrance
- Hallways and exam rooms too narrow
- Objects out of reach (elevator buttons, hand sanitizer, changing gowns)
- No or inaccessible signage

Inaccessible processes



Kim 2019:

“I went to the ophthalmologist. I was given a short survey form while waiting. It was in a very small font. So, I said, Why don’t you put this in large print? You know, you are the ophthalmologist. . . . They said ‘no’.

So, I feel like I could not survive anywhere.”

Inaccessible processes



*“Some doctors require that you call them, but then I have to have a special sign language interpreter or wait for one of my kids to come home from school. And I wish there was a different way to do that. [...] while it's nice that they're willing to help me, there's got to be-- I shouldn't have to be dependent on just them. **I wish that we could make it so that we could be more independent, those of us that are deaf or hard of hearing.**”* – Local participant who is Deaf

2. Widespread *ableism* and other biases compromise care

Ableism is rooted in the belief that people with disabilities are less valuable, have lower quality of life, and are less deserving of resources.

- Biases and assumptions
- Failing to comply to best practice standards – providing suboptimal or incomplete care
- Failing to recommend age-appropriate screenings
- Disregarding reports and preferences
- Attitudes and denial of services
- Lack of disability-related knowledge and expertise

Biases and assumptions



*“... almost every doctor has always come across condescending. **It’s very rare to not have a doctor that’s condescending**, not just in the gynecological field but in other fields as well.”*

*“What I have found with disabilities and dealing with doctors [...] **a lot of people can tend to correlate that with not being so bright, talking over you, talking past you, anybody else, but you about you.**”*

“I’d rather be in pain than patronized.”

– Local participant with arthritis,
10 yrs without seeking care

Provider Expertise



“What I’ve found is that I spent so much time educating my doctors about being an amputee, because many of them even though they’ve gone to medical school, never touched one. Didn’t know how to handle it.”

- 60% of caregivers of children with Down Syndrome report being denied dental care due to disability

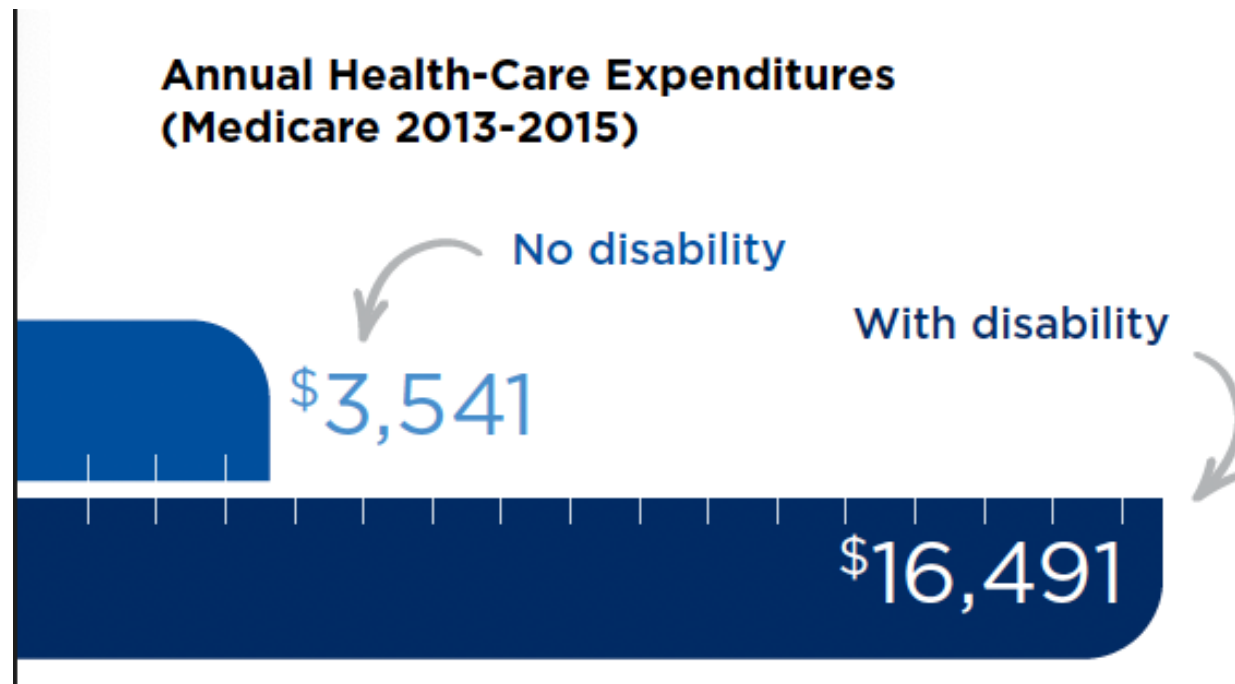
Incomplete and inappropriate care

*“She was like going down this checklist, and I remember her clicking through and going **‘well, you’re not sexually active so that’s a No.’**”*

- 40%-60% without age-appropriate tests (e.g., bone density, colonoscopy) because their physician didn’t recommend it
- 87% of caregivers of children with Down Syndrome report the dentists used physical restraints during their child’s services

3. Health care costs too much

- People with disabilities are 70% more likely to report being unable to afford having their health needs met



“When it comes to choosing groceries or co-pays, I have to choose food.” [Hall 2019]

3. Health care costs too much

Many insurance-related barriers:

- Lack of preventative coverage
- Deductibles and co-pays
- Insufficient thresholds (e.g., number of therapy sessions)
- Effort qualifying and re-qualifying
- Policies are complicated and change frequently
- Providers in-network and willing to accept your insurance

The pads on his butt, because he has almost no meat back there anymore, **he's in pain a lot**. He's uncomfortable a lot. **Those pads help** him to keep him from being uncomfortable, but they're really intended to heal bed sores. And **they keep him from getting bed sores** when we keep him protected that way. And so we've said that to the nurses and they understand, but **they said, "We can't get you another prescription for them unless you have the bed sores."** -- and they won't do it unless they come out and see him in person to prove it. And then they'll write a prescription, but then he has to go to his neurologist or his GP and get them to verify it and send in a letter to request it. And then they don't get around to doing it. So the person that came out, it goes too long. And then they got to come back out again. And we keep saying if he could have those pads on him all the time, he doesn't develop bed sores. And so it's preventive. **And they said, "We don't pay for preventive. We only pay if it's already a problem."**

3. Health care costs too much

Time spent seeking, arranging, and traveling to care is additional cost

“Sometimes I have to cancel that appointment that I waited 6-8 weeks for, at the last minute because of transportation issues. I can't ride the bus because it's too far to walk to the bus stop, and I don't have a support system here. So, the distance is way across town and hard to get to.”

“I mean there were days they [medical transportation] **just did not come** or if you went to your appointment, they leave you and **it might be four (or) five hours** before they get you and you stuck at (the) health facility.”

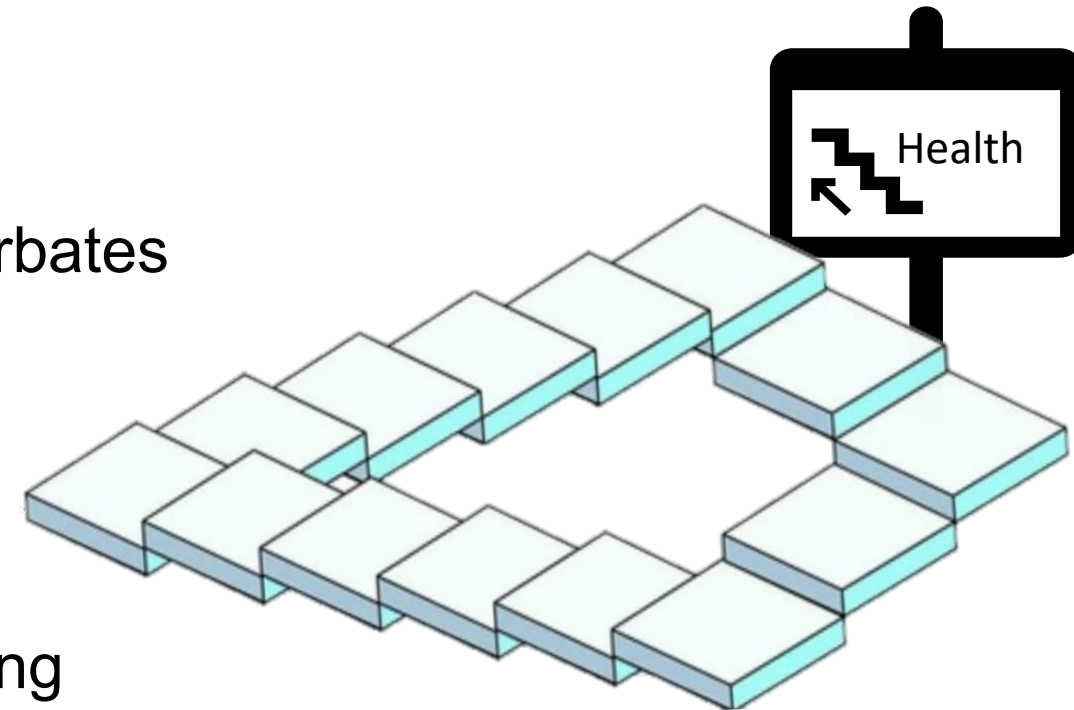
Barriers compound & have
widespread consequences

Barriers intersect and compound

Barriers create barriers

Intersection of marginalized identities exacerbates access barriers

- Hispanic ethnicity 6x longer for autism diagnosis
- People with disabilities in rural areas having longer wait times and farther commutes
- Children who are Black have 3x emergency medicine use and 30% longer wait times



Insufficient access has widespread consequences

Colorectal cancer screening
With disability: 36%
U.S. average: 62%



26% of adults with intellectual disability had no original teeth



Unmet health need with
vs without disability:
20% vs 4%



Unmet Need
Deteriorated Health
Burdened Relationships
Less Trust in System
More Costs
Impact on Career

46% women with
disability saw $2 \leq$
providers before
finding one



“I mean, there’s so many things involved, that’s really exhausting. And sometimes I have to think about, is it going to make my health worse to push myself [and] go to see this doctor who may or may not be helpful? And I mean, an appointment for me can just make me crash the rest of the day because [...] all of it is really exhausting.”

– Local participant with physical disability

Conclusion



We can & must do better



Stephani Kohli, "Walking Toward Sunshine"

Equitable access to health care needs to be a priority

- More than providing ramps

Access barriers stem from policies, systems, and individual interactions

- Question your assumptions, assess your biases

Questions?

Free copy of report available here and online:

www.fisafoundation.org/access-to-health-care-initiative

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Please see report for a full list of references and resources. Citations for slides below:

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