

Health Equity: Access to Care

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Participants' Affiliate Organizations



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Refinement of the topic – what does “access and accessibility” mean to you?

Access to a professional who understands and can diagnose special diseases

- Provider education is not always aligned with the disease that needs to be diagnosed/treated
- Expectations placed on providers can be huge and, at times, unfair
- Personalities of providers can make people uncomfortable to advocate for themselves or others
- “Doctor as deity” can mean apprehension in securing a second opinion
- Delays in diagnosis or treatment or misdiagnosis can lead to physical harm or death

In the United States, finances can dictate care

- Insurance hurdles (like screening and tests outside of “expected” age groups) can be detrimental
- Many people must decide what they can pay for, and basic necessities (groceries, etc.) beat out necessary testing and treatment
- Inability to pay for care can be crippling to families

Some professionals are not recognized as healthcare providers

- Ex. Pharmacists are often the most trusted providers by patients, but are not recognized as a true healthcare provider

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Who are the stakeholders we can engage to help us?

Professional organizations

- Help engage and direct the patients—ex. Help pharmacists have a recognized seat at the table
- Consideration: Some providers are already overwhelmed—how do we make this easier?

Payers (U.S.-based)

- Medicare-covered items are not often an issue, but employer healthcare and exchange plans can be
- Diagnosis codes are developed by people who are not doctors or specialists, which can lead to huge problems, particularly for issues outside of the “expected” age ranges for disease or for people with rare diseases
- Patient advocates work hard to ensure that patients are educated enough to advocate for themselves with their payers, and often step in to help
 - Well-informed groups help this drastically—ex. When a center or office knows what they’re doing, they can more easily jump the hurdles and know when a second opinion can help guide the conversation
 - The power of educated advocates is huge!

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Who are the stakeholders we can engage to help us?

- Patient Advocacy Organizations
- Healthcare and medical education institutions
- Continuing education providers and accreditors
- People who work in underserved communities—help inform and get a seat at the table
- ASL interpreters and those who can assist with communication for people who need it
 - Ex. Have interpreters in medical classes to practice medical interpreting in a casual environment and also to get medical students accustomed to working with interpreters—these experiences better serve patients on both sides
- Policymakers and Department of Health and Human Services (HHS)—address access barriers like copay accumulators and enact guardrails around the use of utilization management
- **KEY POINT across all groups—Make information understandable! Are people learning the right information to seek?**

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How can we proceed?

- The complexity of this issue is really big!
- Identified one area to start focusing on: payers
- This is one of the biggest opportunity areas—what kinds of changes can we make here?
 - Share lessons learned from groups that know how to navigate
 - Ask for resources—normalize that it's ok for patients to ask!
 - Teach providers, office staff, and even patients how to interact with payers
- Let's think this one through some more and identify a path
 - Identify some more primary/secondary audiences for who we seek to influence
 - Consider where the gaps are and where things tend to fall apart
 - Keep the spirit of working together—approach the conversation without pointing fingers and with an open mind to learn and collaborate

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Resources from the Working Group

- **All Copays Count Coalition:** The All Copays Count Coalition (ACCC) was formed to provide a collaboration amongst the patient and provider community around legislative and patient education efforts on a federal and state level.
- **V for Victory Health Resource Fair:** <https://stlcopasl.wixsite.com/healthresourcefair>
- **Centers for Independent Living directory:** <https://www.ilru.org/projects/cil-net/cil-center-and-association-directory>
- **Meds on Cue:** Medication administration training in ASL <http://rxtips.medsoncue.com/asl>
- ***Signing Black in America:*** recommended so we may better understand how to serve the Black Deaf community
 - Website: <https://www.talkingblackinamerica.org/signing-black-in-america/>
 - YouTube documentary: <https://youtu.be/oiLltM1tJ9M>

Join Us for the Next Working Group Session

Thursday, May 13, 2021
12:00-1:30pm ET